

Congressional Hearing Health Caucus (CHHC) transcripts:

PDF page 4.....October 2001: "To Implant or Not: A Discussion About Cochlear Implants"
PDF page 23.....February 2002: "Individuals With Disabilities Education Act (I.D.E.A.)"
PDF page 51.....July 2002: "A Discussion on the Deaf Culture"
PDF page 66.....April 2003: "Cochlear Implants Past, Present and Future"
PDF page 83.....July 2003: "A Unique Members' Forum"
PDF page 92.....October 2003: "Advances in Hearing Research"

[The transcripts and information below was retrieved from the web archives at <http://web.archive.org> on 12-15-08]

Congressional Hearing Health Caucus

The Congressional Hearing Health Caucus (CHHC) was founded in January 2001, and is a bipartisan, no-dues caucus of members of Congress committed to the support of hearing health issues. The CHHC holds luncheon briefings periodically, bringing to Congress the nation's most prominent scientists, surgeons, physicians, and business and lay leaders. Presenting the latest research, findings, and technological advances, speakers explain how this information directly contributes to the detection, intervention, prevention, and research of hearing health issues.

CHHC in July

Co-Chairs of the Caucus are Representatives Jim Walsh (R-NY), Lois Capps (D-CA), Carolyn McCarthy (D-NY), and Jim Ryun (R-KS).

Other caucus members include the following Senators:

Ben Nighthorse Campbell (R-CO)

Hillary Clinton (D-NY)

Tom Harkin (D-IA)

Daniel Inouye (D-HI)

Joseph Lieberman (D-CT)

In addition, the following Representatives have joined the caucus:

Michael Bilirakis (R-FL)

Howard L. Berman (D-CA)

Rosa DeLauro (D-CT)

Vernon Ehlers (R-MI)

Maurice Hinchey (D-NY)

Joseph Hoeffel (D-PA)

Tim V. Johnson (R-IL)

John B. Larson (D-CT)

Ileana Ros-Lehtinen (R-FL)
Betty McCollum (D-MN)
Frank Pallone, Jr. (D-NJ)
Donald M. Payne (D-NJ)
Jim Ramstad (R-MN)
Adam B. Schiff (D-CA)
Adam Smith (D-WA)
C.W. Bill Young (R-FL)

The following were members of the Caucus during their tenure in Congress:

David E. Bonior (D-MI)
Connie Morella (R-MD)

Transcripts:

October 2003: Advances in Hearing Research
July 2003: Unique Members' Forum
April 2003: Cochlear Implants Past, Present and Future
July 2002: A Discussion on the Deaf Culture
February 2002: Individuals With Disabilities Education Act (I.D.E.A.)
October 2001: To Implant or Not: A Discussion About Cochlear Implants

Purpose of the Congressional Hearing Health Caucus:

- To broaden support and knowledge of hearing health issues throughout Congress in a bipartisan manner
- To inform and educate Congress about potential and actual advances in hearing health care made by our investment in medical and biotechnological research
- To provide an educational forum for discussion and exchange of ideas on issues involving hearing health
- To maintain America's leadership in world markets through medical, audiological and otologic research and resulting biotechnology enterprises
- To help members of the Caucus develop a coalition of support with regard to policies and legislative proposals that promote hearing health nationally
- To monitor and evaluate federal programs and agencies to ensure that adequate resources are directed towards the improvement of services for all hearing health issues
- To ensure that birthing hospitals nationwide screen all newborns for hearing loss and discuss appropriate treatments with parents
- To raise awareness of the harmful effects of "toxic noise" that damage hearing
- To make quality treatment and devices accessible and affordable to all who choose to use them to alleviate hearing loss
- To fund important scientific and technological research in the areas of hearing and deafness to ensure that major breakthroughs continue

The CHHC is dedicated to providing an educational forum for discussion and exchange of ideas on issues involving hearing health. Since its inception, the CHHC and the National Campaign for Hearing Health have presented quarterly briefings on the Hill on topics ranging from community-based and educational

resources and services to hearing technology (such as hearing aids and cochlear implants) and the Individuals with Disabilities Act and its impact on children with hearing loss.

To join, or for additional information, please contact Martha Carmen (Walsh) at extension 5-3701 or Jeremy Sharp (Capps) at extension 5-3601. Together, we will succeed in making hearing health a priority so that all Americans have a chance at a lifetime of hearing health.

The National Campaign for Hearing Health was launched in March 1999 by the Deafness Research Foundation, the nation's largest voluntary health organization devoted to research and public education related to hearing loss and hearing health. For more information on the National Campaign for Hearing Health, contact Elizabeth Thorp at 202-289-5850, x1008.

=====

LINK::

<http://web.archive.org/web/20031227084009/www.hearinghealth.net/cms/index.cfm?displayArticle=49>

=====
=====
=====

"To Implant or Not: A Discussion About Cochlear Implants"

October 31, 2001

Congressional Hearing Health Caucus Presentation

Event Transcript

ELIZABETH THORP: WELCOME TO THE NATIONAL CAMPAIGN FOR HEARING HEALTH'S PRESENTATION. MY NAME IS ELIZABETH THORP AND I'M THE DIRECTOR OF THE NATIONAL CAMPAIGN FOR HEARING HEALTH.

TODAY'S PRESENTATION IS "TO IMPLANT OR NOT: A DISCUSSION ABOUT COCHLEAR IMPLANTS" AND WE'LL FOCUS ON THE TECHNOLOGICAL ADVANCES OF THE COCHLEAR IMPLANT. SPECIFICALLY OUR PRESENTERS WILL DISCUSS COCHLEAR IMPLANT TECHNOLOGY AS AN OPTION FOR INDIVIDUALS WITH SEVERE TO PROFOUND HEARING LOSS. TWO OF OUR PANELISTS WILL BE SHARING THEIR PERSONAL STORIES, EXPLAINING WHY THIS OPTION IS APPROPRIATE FOR SOME BUT NOT OTHERS.

ALTHOUGH THERE ARE APPROXIMATELY 500,000 TO 720,000 INDIVIDUALS WITH SEVERE TO PROFOUND HEARING LOSS THAT COULD BENEFIT FROM COCHLEAR IMPLANTS, THE NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS ESTIMATES THAT THERE ARE ONLY 25,000 COCHLEAR IMPLANT RECIPIENTS WORLDWIDE. TODAY WE WILL DISCUSS THE TECHNOLOGY OF COCHLEAR IMPLANTS AND THE DIVERSITY AROUND THE DEVICE.

I WOULD LIKE TO ACKNOWLEDGE THE CONGRESSIONAL HEARING HEALTH CAUCUS CO-CHAIRS: REPRESENTATIVES JIM RYUN, JIM WALSH, CAROLYN MCCARTHY, AND LOIS CAPPS, AND THANK THEM FOR ALLOWING US TO MAKE THIS PRESENTATION TODAY. I WOULD ALSO LIKE TO ACKNOWLEDGE EVELYN BILIRAKIS, WIFE OF REPRESENTATIVE MICHAEL BILIRAKIS, AND SUSAN WALTZMAN, CO-DIRECTOR OF THE NYU COCHLEAR IMPLANT CENTER. THANK YOU ALL FOR BEING HERE.

BEFORE I INTRODUCE MARTHA CARMEN, I WOULD LIKE TO GIVE REPRESENTATIVE RYUN AN OPPORTUNITY TO SAY A FEW WORDS.

REPRESENTATIVE RYUN: THANK YOU VERY MUCH FOR BEING HERE TODAY AND SUPPORTING THE CAUCUS. BECAUSE OF MY PAST WORK WITH HEARING IMPAIRED CHILDREN, I AM VERY FAMILIAR WITH COCHLEAR IMPLANTS, INCLUDING WHAT THE DEVICE DOES AND THE OPPORTUNITIES IT PRESENTS TO THOSE WHO ARE WOULD NOT BENEFIT FROM ANY OTHER KIND OF ASSISTIVE LISTENING DEVICE.

I AM AMAZED AT THE REMARKABLE PROGRESS THAT CONTINUES THROUGHOUT THE HEARING INDUSTRY IN GENERAL. AS SOMEONE WHO BENEFITS FROM THIS TECHNOLOGY WITH THE HEARING SYSTEMS I HAVE, I KNOW THAT I COULDN'T DO WHAT I DO NOW AS A CONGRESSMAN, WITHOUT THEM. IT IS REALLY A PRIVILEGE TO BE HERE AND SERVE FOR THOSE WHO ARE NOW CONTINUING THE ADVANCEMENTS AND THE PROCESS OF COCHLEAR IMPLANTS. I KNOW THIS WILL CONTINUE AS TIME GOES ON.

I ALSO WANT TO ACKNOWLEDGE MY STAFF, JAN.GRAVES, WHO KEEPS ME POSTED ON THESE DEVELOPMENTS. OUR OFFICE STANDS READY TO SERVE YOU AT ANY OPPORTUNITY. THANK YOU VERY MUCH FOR ALLOWING ME TO BE HERE.

ELIZABETH THORP: I WOULD NOW LIKE TO INTRODUCE MARTHA CARMEN OF REP. JIM WALSH'S OFFICE AND USE THIS OPPORTUNITY TO THANK HER FOR HER COMMITMENT TO THE IMPORTANT ISSUE OF HEARING HEALTH. MARTHA WILL BE MODERATING TODAY'S DISCUSSION.

MARTHA CARMEN: GOOD AFTERNOON, EVERYONE. WELCOME TO THE THIRD MEETING OF THE CONGRESSIONAL HEARING HEALTH CAUCUS. I WOULD LIKE TO ESPECIALLY THANK THE NATIONAL CAMPAIGN FOR HEARING HEALTH FOR THEIR ASSISTANCE IN PUTTING THIS FUNCTION TOGETHER TODAY. DUE TO THE DEATH OF OUR FORMER COLLEAGUE, CONGRESSMAN SOLOMON, ALL OR MOST OF THE ENTIRE NEW YORK DELEGATION IS ATTENDING THAT FUNERAL TODAY AND THEREFORE COULDN'T BE HERE.

TODAY'S DISCUSSION WILL FOCUS ON COCHLEAR IMPLANTS. WE HAVE A WELL-VERSED PANEL, FORTUNATELY, WHICH WILL DISCUSS THIS TREATMENT OPTION. COCHLEAR IMPLANTS ARE A TREATMENT MODALITY FOR DEAF AND HARD OF HEARING INDIVIDUALS, BUT THEY ARE NOT A CURE OR MAGIC PLOY.

COCHLEAR IMPLANTS, LIKE HEARING AIDS, OR ANY OTHER FORM OF TREATMENT OR COMMUNICATION, MUST BE ACCOMPANIED BY INTENSIVE FOLLOW-UP CARE. THIS FOLLOWS CONGRESSMAN WALSH'S BILL, THE WALSH BILL, ON EARLY INFANT HEARING SCREENING. WE WERE CLEAR THAT SCREENING FOR HEARING LOSS ALONE IS NOT ENOUGH. IT'S THE FOLLOW-UP CARE THAT WILL MAKE ALL THE DIFFERENCE FOR A CHILD DIAGNOSED WITH A HEARING LOSS.

OUR SPEAKERS TODAY ARE DR. ROBERT RUBEN, A PREEMINENT EAR, NOSE, AND THROAT DOCTOR IN NEW YORK. HE HAS EXTENSIVE EXPERIENCE IN OTOLARYNGOLOGY, AND OF PARTICULAR INTEREST TO THIS OFFICE IS THAT BASED ON SOME OF DR. RUBEN'S WORK CAME THE FOUNDATION OF THE NATIONAL INSTITUTES OF DEAFNESS AND OTHER COMMUNICATION DISORDERS, NIDCD, AT THE NATIONAL INSTITUTES OF HEALTH. HE WILL EXPLAIN THE SCIENCE AND MECHANICS BEHIND THE COCHLEAR IMPLANT.

KASSIE DEPAIVA IS A VERY WELL KNOWN ACTRESS FROM "ONE LIFE TO LIVE." KASSIE IS HERE WITH HER HUSBAND JIM AND THEIR FOUR-YEAR-OLD SON JQ HAS PROFOUND HEARING LOSS AND WAS FITTED WITH A COCHLEAR IMPLANT AT 18 MONTHS OF AGE. WE UNDERSTAND THAT JQ IS DOING VERY WELL, AND WE'RE VERY PLEASED. KASSIE WILL TALK ABOUT THEIR CHOICE TO IMPLANT JQ. WE APPRECIATE HER ADVOCACY.

LAST BUT CERTAINLY NOT LEAST, AND HE MAY STILL BE IN TRANSIT, IS KELBY BRICK. KELBY IS A DEAF ATTORNEY IN PRIVATE PRACTICE IN MARYLAND. KELBY FORMERLY WORKED AS LEGAL COUNSEL FOR THE NATIONAL ASSOCIATION OF THE DEAF AND IS HERE ON BEHALF OF THE CONSUMER ACTION NETWORK, A GROUP REPRESENTING THE DEAF AND HARD OF HEARING. ADDITIONALLY, HE WAS VERY INSTRUMENTAL IN HELPING ME AND CONGRESSMAN WALSH WRITE THE WALSH BILL. HE GAVE US INSIGHT INTO DEAF CULTURE, AND WE DO APPRECIATE HIS ASSISTANCE. HE AND HIS WIFE ARE EXPECTING THEIR SECOND CHILD AT ANY MOMENT NOW, SO I'M NOT SURE IF THAT'S WHY HE'S NOT HERE.

EACH SPEAKER WILL HAVE TEN MINUTES, AND THEN WE WILL HAVE A QUESTION AND ANSWER PERIOD. I ALSO WANT TO RECOGNIZE OUR INTERPRETERS AND CART PROVIDER. WE DO APPRECIATE THEIR SERVICE.

I WOULD ALSO LIKE TO RECOGNIZE CONGRESSWOMAN CAPPS, WHO JUST CAME IN, AND ASK HER TO COME SAY A FEW WORDS.

CONGRESSWOMAN CAPPS: I DON'T WANT TO INTERFERE WITH THE PRIMARY ATTRACTIONS HERE AT OUR GATHERING TODAY, BUT I WANTED TO ADD WITH MY COLLEAGUE MR. RYUN, MY SUPPORT FOR THE EFFORTS YOU ARE UNDERTAKING. I'M A SCHOOL NURSE AND NOW A MEMBER OF CONGRESS, BUT I'LL ALWAYS BE A NURSE.

MY PASSION IS TO FIND A MECHANISM WITHIN OUR FUNDING, BUT ALSO WITHIN OUR TECHNOLOGY, TO SCREEN ALL INFANTS AT BIRTH, TO IDENTIFY, AND THEN HAVE A MEANS TO PROVIDE SERVICE TO THOSE FOR WHOM THIS PROCEDURE IS APPROPRIATE. IT'S REVOLUTIONARY. I KNOW. THOSE OF YOU WHO ARE HERE KNOW HOW IMPORTANT THIS IS TO COUNTRY.

I HAVE BEEN AT THE DELIVERY END OF SERVICES, SCREENED HUNDREDS AND THOUSANDS OF SCHOOL AGE CHILDREN FOR HEARING LOSS, AND WILL ALWAYS CARRY WITH ME THE IMAGE OF MANY, MANY WHO ARE STRUGGLING TODAY TO BE STUDENTS AND FULFILL THEIR LIFE'S GOALS, BUT WHO COULD HAVE BEEN IDENTIFIED EARLY AND HAVE NOW, WITH THE TECHNOLOGY THAT WE HAVE, HAD THEIR LIVES CHANGED. SO WE NEED TO DO WHAT WE CAN HERE IN WASHINGTON, D.C.

THE FACT THAT YOU ARE HERE, ADVOCATING, IS IMPORTANT AND I'M GOING TO LISTEN CAREFULLY AND PLEDGE TO YOU THAT I WILL RESPOND. I REPRESENT THE CENTRAL COAST OF CALIFORNIA, THE 22ND DISTRICT, AND I PLEDGE TO WORK WITH YOU. CONGRATULATIONS FOR YOUR HARD EFFORTS AND THANK YOU FOR BEING HERE WITH US TODAY.

DR. ROBERT RUBEN: THANK YOU VERY MUCH. THIS IS, INDEED, FOR ME A PRIVILEGE AND A PLEASURE, ESPECIALLY WITH WHAT IS GOING ON IN THE REST OF THE WORLD. I HAVE TWO CHORES THIS MORNING: THE FIRST IS TO EXPLAIN WHAT THE COCHLEAR IMPLANT IS TO SOME OF YOU WHO MAY NOT KNOW.

THE COCHLEAR IMPLANT GOES INTO THE INNER EAR. HAIR CELLS ARE THE BUSINESS END OF HEARING. IN ALMOST ALL PEOPLE WITH

HEARING LOSS, THESE CELLS HAVE DIED OR HAVE NOT DEVELOPED, AND UNFORTUNATELY THEY DON'T COME BACK AGAIN. SO WHAT IS DONE IS A LITTLE COIL OF ELECTRODES IS PLACED INTO THIS AREA HERE (INDICATING) AND TAKES THE PLACE OF THESE AND THEN STIMULATES THESE NERVE FIBERS, WHICH THEN ALLOW THE PERSON TO HAVE PERCEPTION OF SOUND.

ESSENTIALLY THE COCHLEAR IMPLANT CONSISTS OF THE IMPLANT ITSELF, WHICH GOES INTO THE COCHLEA, A TRANSDUCER, BURIED UNDER THE SKIN, AND THEN THE OTHER PART ATTACHED BY A MAGNET TO THE HEAD, AND THIS IS ATTACHED TO A MICROPHONE. THE SPEECH IS ENCODED. THIS IS WHAT IT LOOKS LIKE (INDICATING). THIS IS THE PART THAT GOES INTO THE EAR. THIS IS BURIED IN THE MASTOID. THIS IS A MAGNET ON THE SIDE OF THE HEAD. THIS IS AN IMPORTANT PART, THE TRANSDUCER. IT ALLOWS SOUND TO BE RECEIVED AND ENCODED AND CODED SO THAT WHEN IT GOES UP THIS LITTLE AREA HERE, (INDICATING), IT CAN BE INTERPRETED BY THE CENTRAL NERVOUS SYSTEM AS MEANINGFUL SOUND AND SPEECH.

THIS IS JUST AN X-RAY OF WHAT ONE OF THESE THINGS LOOKS LIKE IN PERSON. IT HAS BEEN ONE OF THE MOST REMARKABLE ADVANCES IN ALL FIELDS OF MEDICINE. MANY OF US FELT THIS COULDN'T WORK, BUT IT HAS WORKED MAGNIFICENTLY WELL NOW, LIKE ANYTHING ELSE IN MEDICINE, IT HAS ITS STRENGTHS AND WEAKNESSES.

THE STRENGTHS ARE, FOR THE FIRST TIME, WE'RE ABLE TO ALLOW SEVERELY HEARING IMPAIRED PEOPLE TO HAVE PERCEPTION OF SOUND. WE SEE IT WITH J.Q. DEPAIVA, WHO IS HERE TODAY, AND THE MANY THOUSANDS OF PEOPLE WHO HAVE BEEN IMPLANTED. IT HAS BEEN TRULY A MIRACLE IN THEIR LIVES AND OUR LIVES AS PHYSICIANS. THE COCHLEAR IMPLANT WORKS BEST IN PEOPLE WHO HAVE ALREADY GAINED LANGUAGE. IT WORKS BEST IN, SAY, A PERSON WHO HAS LOST THEIR HEARING AS A TEENAGER OR YOUNG ADULT. IT, HOWEVER, WORKS QUITE WELL IN PRELINGUAL, AND THE EARLIER THAT YOU'RE ABLE TO IMPLANT IT, THE BETTER THE RESULTS ARE.

IT ALSO HAS TREMENDOUS ECONOMIC ADVANTAGES BOTH TO THE PATIENT AND SOCIETY. THE PATIENT IS ABLE TO MAKE A LIVING AND BE USEFUL. SEVERAL STUDIES HAVE SHOWN THAT THE COST OF THIS IS WELL COMPENSATED BY THE SAVINGS BOTH IN SPECIAL EDUCATION AND THE EMPLOYMENT OF THE PERSON AFTERWARDS. SO IT'S REALLY A WIN-WIN SITUATION.

LAST BUT NOT LEAST, A VERY PERSONAL THING, IT'S SOCIALLY AND PSYCHOLOGICALLY ADVANTAGEOUS. THE PERSON IS ABLE TO HAVE CONVERSATIONS AND IS ABLE TO JOIN THE MAJORITY OF SOCIETY.

HOWEVER, AS WITH ALL THINGS, THERE ARE WEAKNESSES. ONE IS WITH THE PRELINGUAL. THERE NEEDS TO BE EXTENSIVE EDUCATION. IF CHILDREN HAVE THIS LATER, THEY DO NOT DO AS WELL AS CHILDREN WITH NORMAL HEARING. WE, THE MEDICAL COMMUNITY, ARE WORKING TO IMPROVE THAT, BUT TO BE EMPHASIZED, THIS ISN'T LIKE PUTTING ON A PAIR OF EYEGLASSES, ESPECIALLY FOR A YOUNG CHILD. THERE NEEDS TO BE EXTENSIVE EDUCATION FOR THESE CHILDREN, AND THAT COUPLED WITH THE IMPLANT, THEN ALLOWS THEM TO BE IN THE HEARING WORLD.

ANOTHER WEAKNESS IS THE SURGICAL OPERATION. SURGERY ON SOMEBODY ELSE'S MIND OR YOURSELF IS MAJOR. THERE HAVE BEEN VERY FEW COMPLICATIONS, BUT IT IS STILL A SURGICAL OPERATION. ANOTHER WEAKNESS IS IT DESTROYS AN EAR. HOWEVER, THAT EAR WON'T BE DOING MUCH ANYWAY, HOWEVER, THERE MAY BE OTHER THINGS IN THE FUTURE THAT MAY BE ABLE TO COMPENSATE IT.

ONE OF THE WEAKNESSES IS THE ECONOMICS OF ACCESS. THEY ARE EXPENSIVE. THEY'RE EXPENSIVE NOT ONLY FOR THE DEVICE AND SURGERY, BUT THE THERAPY IS EXPENSIVE. IN SOME STATES, MEDICAID MAKES IT ACCESSIBLE TO POOR PEOPLE, AND IN OTHER STATES, IT DOES NOT. THIS IS IMPORTANT.

ANOTHER DISADVANTAGE IS DEVICE FAILURE, WHICH IS APPROXIMATELY ONE PERCENT A YEAR, WHICH IS VERY LOW. HOWEVER, THIS DOES HAPPEN.

ANOTHER DISADVANTAGE IS BECOMING OBSOLETE. THERE HAVE BEEN CHANGES WITH THE PROCESSES AND THE WAY SPEECH IS ENCODED, BUT THERE'S THE POSSIBILITY OF IMPLANTING A ONE YEAR OLD AND WHAT WILL THAT PERSON BE LIKE IN 20, 30, OR 50 YEARS. HOWEVER, THE STRENGTHS FAR OUTWEIGH THE WEAKNESSES.

TODAY, THERE ARE ABOUT 25,000 PEOPLE IMPLANTED, A LITTLE MORE THAN HALF IN ADULTS, AND A LITTLE LESS THAN HALF IN CHILDREN. THE INDUSTRY HAS A HIGHER FIGURE, HOWEVER, LET'S TAKE THE CONSERVATIVE FIGURE, WHICH IS IMPRESSIVE ENOUGH.

NOW, THE NEXT STEP. WHERE DO WE GO FROM HERE? COCHLEAR IMPLANTS ARE A FORM OF CARE. WE TAKE CARE OF PEOPLE. WE WANT SMART IMPLANTS CODED WITH VARIOUS BIOLOGICAL SUBSTANCES SO NERVE FIBERS CAN GROW INTO THEM TO WORK IN HARMONY AND SYNCHRONY WITH THE BIOLOGY. WE'LL HAVE BETTER SPEECH PROCESSES TO WORK WITH THE PERSON'S CENTRAL NERVOUS SYSTEM. HOPEFULLY WE'LL HAVE BETTER ACCESS ON THE ECONOMICS SIDE.

MOST IMPORTANTLY, ESPECIALLY FOR THE CHILDREN, WE'LL HAVE UNIVERSAL NEWBORN INFANT SCREENING WITH EARLY DETECTION SO THAT CHILDREN CAN BE IMPLANTED EARLY AND HAVE BETTER LANGUAGE, BETTER ECONOMICS, AND BETTER SOCIAL.

THE NEXT STEP IS BIOLOGICAL IMPLEMENTATION. GENETICS MAKES UP 50 TO 70 PERCENT. MOST PEOPLE IN THIS ROOM REALIZE THE GENOME PROCESS: THE PREVENTION OF NOISE TRAUMA TO PREVENT THE SEQUELAE SHOULD PREVENT MUCH HEARING LOSS. OTOTOXIC MEDICATIONS: THERE ARE MANY MEDICINES USED TODAY FOR BREAST CANCER THAT WILL ALSO CAUSE HEARING LOSS. THERE ARE NOW WAYS WORKED OUT IN THE LABORATORY TO PREVENT THE HEARING LOSS AND WILL ALSO STILL HAVE THE OTOTOXIC MEDICATION DO THE JOB IT SHOULD DO. THESE ARE THINGS ON THE DRAWING BOARD THAT ARE ALLOWING US TO DO OTHER STEPS IN THE REPLENISHMENT OF HEARING.

LAST BUT NOT LEAST, IS THE HOPE THAT IN SOME TIME WE'LL BE ABLE TO REPLENISH THE INNER EAR ITSELF. THIS IS BEING WORKED ON IN MANY LABS AROUND THE WORLD. WE AND OTHER LABS HAVE BEEN ABLE TO TURN THE SWITCH ON SO THAT MORE OF THESE CELLS WOULD GROW.

FINALLY, AND I MUST SAY IT'S A REAL PLEASURE TO BE HERE WITH THE MEN AND WOMEN IN CONGRESS WHO SPONSORED THIS, ESPECIALLY MR. WALSH, IS NEWBORN INFANT SCREENING. THIS IS SO, SO, SO IMPORTANT. THE EARLIER WE CAN FIND THE CHILDREN, THE BETTER WE'LL BE, THE BETTER OUR ABILITY TO INSTITUTE NORMAL LANGUAGE. THE COCHLEAR IMPLANT IS A MILESTONE IN THIS AND WILL MAKE THE INDIVIDUAL A MUCH MORE FULFILLING LIFE FOR SOCIETY AT LARGE. THIS BECOMES AN ECONOMIC AND SOCIAL PLUS INSTEAD OF A NEGATIVE. I THINK THAT'S IT. THAT'S MY TEN MINUTES. THANK YOU.

KASSIE DEPAIVA: HELLO. MY NAME IS KASSIE. I HAVE A SON WHO IS FOUR YEARS OLD NOW AND WAS BORN SEVERELY AND PROFOUNDLY DEAF. IT HIT US HARD. THERE WAS NOTHING IN THE YELLOW PAGES THAT SAYS, OKAY, YOU HAVE A DEAF SON, WHAT DO YOU DO. WE WERE NOT REALLY PREPARED. THE ALEXANDER GRAHAM BELL ASSOCIATION HAS A SLOGAN, A LITTLE BABY THAT SAYS, "IMAGINE NOT BEING ABLE TO HEAR." THEN UNDER IT, IT SAYS, "IMAGINE NOT BEING ABLE TO TELL ANYONE."

DEAFNESS DOESN'T HAPPEN TO AN INDIVIDUAL; IT HAPPENS TO A FAMILY. WE WERE BLESSED TO LIVE IN NEW YORK CITY WHERE IT WASN'T A MATTER OF WHEN WE WERE GOING TO GET THE IMPLANT. THAT WAS SOMETHING WE WERE DEFINITELY GOING TO DO. IT WAS WHO WAS GOING TO DO IT.

WE HAD SOME GREAT CHOICES. AT THAT POINT, JQ WAS DIAGNOSED AT A YEAR OLD. HE WAS PUT IN -- HE HAD HIGH POWERED FM HEARING AIDS UNTIL HE WAS 18 MONTHS OLD. SINCE HE WAS "TURNED ON," OUR CHILD HAS BEEN JUST A LITTLE MIRACLE BOY. IT'S LIKE HAVING A LIGHT TURNED ON IN A DARK ROOM FOR A DEAF PERSON TO BE ABLE TO HEAR. I'M GOING TO BRING HIM UP LATER TO LET YOU HEAR HIS SPEECH.

HE'S HAD 11 HOURS OF SPEECH THERAPY SINCE HE WAS A YEAR OLD. THAT SOUNDS LIKE A LOT. IT'S A LOT OF WORK FOR A LITTLE GUY. HE IS NOW IN A MAINSTREAM PRESCHOOL. WE PUT HIM IN A PRESCHOOL SITUATION AT THE CLARK SCHOOL, WHICH IS AN ORAL DEAF SCHOOL, WHEN HE WAS TWO YEARS OLD WITH FIVE OTHER STUDENTS. JQ WAS THE FIRST GRADUATE OF THE NEW YORK CLARK SCHOOL. WE FELT THAT HE WAS DOING SO WELL THAT WE WANTED HIM TO BE IN A MAINSTREAM SITUATION. THAT WAS OUR GOAL FROM THE GET GO. HE HAS DONE BEAUTIFULLY.

NOW, IS HE GETTING ALL THE INFORMATION? PROBABLY NOT. BUT IS HE PROCESSING IT? ABSOLUTELY. AND THAT IS THE IMPORTANT PART, GETTING THE INFORMATION TO A DEAF CHILD. WE HAD TO TEACH THE EDUCATORS NOT TO TALK TO THE BACK OF THE HEAD. HE RESPONDS THROUGH THE COCHLEAR IMPLANT, BUT ALSO THROUGH LIPREADING. IT TAKES EVERYTHING TO PUT THE COMPLETE PUZZLE TOGETHER, BUT JQ IS GETTING IT.

I'M HERE NOT FOR MY SON. HE'LL BE JUST FINE. I'M HERE BECAUSE SOMEBODY CAME HERE BEFORE ME TEN YEARS AGO AND HELPED

LEGISLATION GET TO WHERE IT IS TODAY FOR CHILDREN. I'M HERE FOR TEN YEARS DOWN THE ROAD FOR PARENTS THAT ARE POOR, PARENTS THAT ARE UNEDUCATED, THAT THEY CAN HAVE ACCESS TO SOMETHING THAT GIVES THEIR FAMILY HOPE AND PROMISE.

I AM REALLY EMOTIONAL ABOUT IT. NEWBORN SCREENING. FOUR YEARS AGO WHEN HE WAS BORN, HE WAS BORN IN MOUNT SINAI, ONE OF THE GREATEST HOSPITALS IN THIS COUNTRY. HE WAS NOT TESTED. YOU KNOW, A YEAR WENT BY. YOU TAKE A BABY TO THE DOCTOR EVERY WEEK FOR A MONTH, THEN EVERY MONTH FOR A YEAR. DOCTORS DIDN'T KNOW; HIS PEDIATRICIAN DIDN'T KNOW. IT WASN'T UNTIL WE WERE AROUND ANOTHER SET OF NINE-MONTH OLD TWINS WHERE WE NOTICED THESE CHILDREN WERE WATCHING DIALOGUE.

YOU KNOW, I'M A FIRST-TIME MOTHER, DIDN'T HAVE ANYTHING REALLY TO CHECK IT OUT BY. I THOUGHT MAYBE HE JUST HAD SELECTIVE HEARING LIKE MY HUSBAND. (LAUGHTER.) BUT JQ WAS DIAGNOSED DEAF.

IN THIS POLITICALLY CORRECT WORLD, WHERE YOU HAVE RESIDUAL HEARING, HEARING LOSS, IT WASN'T UNTIL WE WATCHED A FILM "DREAM SPOKEN HERE," THAT MY HUSBAND AND I SAID, GOSH, THESE PARENTS ARE DEALING WITH THE SAME SITUATION WE'RE DEALING WITH. WE BOTH SAT THERE AND WATCHED IT AND CRIED. I COULDN'T SPEAK FOR HOURS. I WHISPERED TO MY HUSBAND, OH MY GOD, JQ IS DEAF. WHY DIDN'T ANYBODY TELL ME HE WAS DEAF. THAT'S A BIG WORD. IT'S AN IMPORTANT WORD. AND THERE'S NOTHING WRONG WITH IT.

I HAD TO GRIEVE THAT AND MOURN THAT LOSS, BUT IT WASN'T HIS DREAMS BECAUSE HE CAN'T MISS WHAT HE NEVER HAD. I HAD TO MOURN IT. I'M GOING TO BRING HIM UP HERE RIGHT NOW. I WANT YOU TO HEAR HIM, IF YOU HAVE ANY QUESTIONS ABOUT THIS DEVICE BEING A MIRACLE. IT ISN'T FOR EVERYBODY.

BUT IF YOU WANT TO HELP PEOPLE, ONCE YOU PUT THE DEVICE IN, YOU DON'T SUDDENLY HEAR. I SPOKE TO A 25 YEAR OLD WITH A NUCLEUS 24 COCHLEAR IMPLANT. SHE WANTED TO BE IMPLANTED BEFORE SHE GAVE BIRTH TO HER CHILD BECAUSE SHE WANTED TO HEAR HER BABY CRY. SHE SAID IT TOOK HER TWO MONTHS TO HEAR THE DIFFERENCE BETWEEN A SCRATCH AND VOICES. SHE SAID VOICES ARE THE HARDEST THING FOR THE COCHLEAR IMPLANT TO

DECIPHER. I FOUND THAT AMAZING. JQ CAN'T TELL ME THAT RIGHT NOW.

THIS IS MY SON, JQ DEPAIVA. I WANT YOU TO HEAR THE QUALITY OF HIS SPEECH. SING "JOHNNIE GET A HAIRCUT."

(JQ SINGING .)

KASSIE DEPAIVA: OKAY. THAT'S ENOUGH.

I WANT TO SHOW YOU -- I'M GOING TO COVER MY MOUTH SO HE WON'T SEE ME. JIM, YOU WANT TO HOLD HIM? THIS IS MY HUSBAND JIM. HE'LL HOLD HIM. I'LL COVER MY MOUTH SO HE'S NOT LIPREADING.

I FOUND THAT WITH THE COCHLEAR IMPLANT, THE TONAL QUALITY IN HIS VOICE -- AND I HOPE I'M NOT OFFENDING ANY HARD OF HEARING OR HEARING IMPAIRED PEOPLE HERE--BUT THERE IS A QUALITY. THEY DON'T HEAR THE CONSONANTS. IF YOU SAY, HELLO, HOW ARE YOU, IT'S LIKE "OH, OW ARE YOU." JQ DOESN'T HAVE THAT, BUT I'LL SHOW YOU.

CAN YOU SAY PIZZA? SAY TELEPHONE. SAY CONGRESSMAN. SAY WASHINGTON. SAY SODA. SNAKE. BUZZ LIGHTYEAR. I'LL WHISPER OVER HERE. SAY SANTA CLAUS.

AUDIENCE: HALLOWEEN.

KASSIE DEPAIVA: SAY HALLOWEEN. SAY WITCH. GHOST. PUMPKIN. MONSTER.

DO YOU SEE THIS? AND THE DEVICE HE WEARS, I WANT TO SHOW YOU ALL. THE SURGERY IS TOUGH. IT'S HARD. WE WROTE CHRISTMAS CARDS WHILE WE WAITED. I'LL SHOW YOU THE SCAR. THEY IMPLANTED OVER HERE ON THE SIDE. HE HAS A PRETTY BIG SCAR. SEE IT? HE LOVES TO "HAVE HIS EARS ON." I SAY, "JQ, YOU WANT TO TAKE YOUR EARS OFF?" HE SAYS, "NO." OKAY. THAT'S ALL I HAVE. THANK YOU.

ELIZABETH THORP: THANK YOU SO MUCH TO THE DEPAIVAS. GOOD GOING, JQ. I LIKE MONSTERS TOO. UNFORTUNATELY KELBY HAS NOT APPEARED. WE THINK HE MIGHT BE IN THE LABOR AND DELIVERY ROOM. GRACIOUSLY DEBRA NUSSBAUM HAS DECIDED TO SPEAK ON BEHALF OF THE COCHLEAR IMPLANT EDUCATION CENTER AT GALLAUDET UNIVERSITY. DEBRA IS THE DIRECTOR THERE. IT'S THE LAURENT CLERC NATIONAL DEAF EDUCATION CENTER THERE. SHE'LL GIVE HER PERSPECTIVE. DEBRA?

DEBRA NUSSBAUM: GOOD AFTERNOON. I DIDN'T COME PREPARED TO SPEAK ON BEHALF OF THE DEAF COMMUNITY TODAY, AND I DON'T KNOW WHETHER I CAN REALLY TAKE ON THAT RESPONSIBILITY, AS A HEARING PERSON. HOWEVER, I HAVE WORKED AT GALLAUDET FOR 25 YEARS AS AN AUDIOLOGIST, AND NOW I'M CURRENTLY COORDINATING THE COCHLEAR IMPLANT EDUCATION CENTER AT THE LAURENT CLERC NATIONAL DEAF EDUCATION CENTER AT GALLAUDET.

IT'S A LOT OF RESPONSIBILITY, SETTING UP PROGRAMS NATIONALLY AND IN HOUSE, WHICH IS LOCALLY ALL THE CHILDREN IN THE D.C. METROPOLITAN AREA. WE ARE SEEING GROWING NUMBERS OF CHILDREN WITH IMPLANTS AND ALSO A HUGE DIVERSITY IN TERMS OF THE FUNCTIONING OF THESE CHILDREN WITH COCHLEAR IMPLANTS IN TERMS OF WHAT ACCESS IT WILL PROVIDE THEM.

IT PROVIDES ALL THE CHILDREN I'VE SEEN ACCESS TO SOUND. BUT AS HAS BEEN SAID TODAY, HOW THE CHILDREN ACTUALLY FUNCTION WITH THEIR IMPLANTS VARIES GREATLY. WE REALLY ARE LOOKING AT THE RANGE OF WHAT THE CHILDREN WILL BE. BUT ALSO FOR THE GROUP GETTING THE IMPLANTS OLDER, PERHAPS AUDITORY AND SPOKEN LANGUAGE WON'T BE THEIR ONLY MEANS OF COMMUNICATION.

IN BEING AT GALLAUDET, I'VE SEEN WHAT PARENTS GO THROUGH IN TERMS OF MAKING THE DECISION ABOUT WHERE THIS COCHLEAR IMPLANT WILL FIT IN FOR THEIR CHILD, BUT AS WELL FROM THE DEAF COMMUNITY PERSPECTIVE. OFTEN TIMES IT'S BEEN FELT THAT PERHAPS GALLAUDET WAS NOT THE MOST WELCOMING COMMUNITY FOR COCHLEAR IMPLANTS BECAUSE IT WAS PERHAPS A THREAT TO THE DEAF CULTURE. HOWEVER, THERE'S BEEN A GREAT CHANGE THAT I'VE SEEN PERSONALLY IN TERMS OF ACCEPTANCE OF COCHLEAR IMPLANT AS A TECHNOLOGY.

THIS TECHNOLOGY CAN PROVIDE ACCESS AND ADDITIONAL INFORMATION THAT DOES NOT NECESSARILY HAVE TO BE SEEN AS A

REPLACEMENT OF DEAF CULTURE. IT'S A TOOL THAT DEAF PERSONS CAN USE. NOT ALL DEAF PERSONS WILL MAKE THAT CHOICE TO HAVE THAT TOOL. AND THAT'S OKAY.

THERE ARE GREATER NUMBERS OF DEAF INDIVIDUALS WHO ALSO HAVE BEEN CULTURALLY DEAF THAT ARE USING SIGN LANGUAGE IN THEIR LIVES, MAKING THE DECISION. I THINK THE DEAF COMMUNITY THEMSELVES WILL CONTINUE TO ADVOCATE FOR THAT CHANGE. THAT'S WHERE WE'LL SEE THE CHANGE IN LOOKING AT THE DEAF INDIVIDUALS THEMSELVES WHO COME BACK AND SAY, I'M STILL DEAF AND I USE A COCHLEAR IMPLANT. IT DOESN'T NECESSARILY HAVE TO CHANGE THE CULTURAL PERSPECTIVES.

OTHER REASONS PEOPLE MAY NOT CHOOSE TO BE IMPLANTED, SOME PARENTS COME BACK AND SAY, MY FAMILY SAID I SHOULD HAVE HAD A COCHLEAR IMPLANT. PERHAPS FOR CHILDREN, THERE ARE OTHER REASONS MITIGATING THAT THEY CANNOT HAVE AN IMPLANT, OTHER MEDICAL CONTRADICATIONS TO THE IMPLANT ITSELF. MAYBE THEY DIDN'T HAVE QUITE ENOUGH OF THE HEARING LOSS TO BE A CANDIDATE FOR THE IMPLANT. EVERYBODY IS PUTTING ALL DEGREES OF HEARING LOSS INTO ONE CATEGORY, SO THEY HAVE TO BE AUDIOLOGICALLY ACCOUNTED FOR THE IMPLANT.

SOME FAMILIES OF OLDER CHILDREN, EVEN BEYOND THE LANGUAGE LEARNING YEARS, 7 AND UP, MAYBE EVEN 5 AND UP, FEEL LIKE MAYBE WE SHOULD TAKE ADVANTAGE OF THIS TECHNOLOGY AND HAVE IT NOW THAT MAYBE THEIR CHILDREN ARE ALREADY STRONG SIGN LANGUAGE USERS. MAYBE THERE ARE RELIGIOUS REASONS.

THERE'S A LARGE LIST OF REASONS WHY A FAMILY MAY CHOOSE NOT TO GET AN IMPLANT. I'M NOT SPEAKING FOR THE DEAF COMMUNITY. BUT JUST HAVING WORKED IN THIS ENVIRONMENT, I THINK IT IS BECOMING A MORE OPEN AND WELCOMING ENVIRONMENT TO THE TECHNOLOGY, AND I THINK WE WILL CONTINUE TO SEE THAT CHANGE AS THE TECHNOLOGY INCREASES AND THE RISKS OF THE SURGERY ARE LESS. WITH THAT, I WILL END.

MARTHA CARMEN: I WOULD LIKE TO ASK ALL SPEAKERS TO COME FORWARD AND WE'LL OPEN THE FLOOR TO QUESTIONS AND ANSWERS.

AUDIENCE: I HAVE A QUESTION FOR JQ. HAS HE SEEN BOTH TOY STORY MOVIES AND WHICH ONE IS HIS FAVORITE?

JQ: TOY STORY 2.

AUDIENCE: I HAVE A QUESTION. I'M A FATHER MYSELF OF A FOUR YEAR OLD SON WHO GETS SERVICES UNDER I.D.E.A. I WANTED TO ASK, WHEN YOU WERE DOING YOUR RESEARCH, DID YOU TAKE ADVANTAGE OF OTHER SERVICES AVAILABLE TO YOU UNDER I.D.E.A.?

KASSIE DEPAIVA: YES, I DID. I LOOKED INTO EVERYTHING. MY SON GOES TO A PRIVATE SCHOOL ONLY BECAUSE WHEN WE WERE LOOKING FOR SCHOOLS, BECAUSE HE'S JUNIOR KINDERGARTEN, I WANTED A PLACE WITH GOOD ACOUSTICS, WHICH ARE IMPORTANT.

MOST OF THESE SCHOOLS ARE IN VAULTED CHURCHES, EMPTY BASEMENTS, VERY LOUD. I WALKED DOWN AND COULDN'T HEAR MYSELF THINKING. ACOUSTICS ARE VERY IMPORTANT WHETHER YOU HAVE A HEARING AID OR HAVE A COCHLEAR IMPLANT. SO THAT'S WHY I CHOSE A PRIVATE SCHOOL.

BUT WHEN I LOOKED INTO WHAT WE ARE ENTITLED TO UNDER THE INDIVIDUALS WITH DISABILITIES ACT, JQ IS ENTITLED TO FIVE HOURS OF HAVING A HEARING TEACHER COME TO HIS SCHOOL. I WAS LIKE, OH, THANK YOU. I WANTED TO GET THE MOST I COULD GET. IT'S HARDER TO GET IN THERE AND GET MORE LATER.

WELL, A WEEK INTO IT, I GUESS THIS HEARING TEACHER DROVE EVERYBODY SO CRAZY, I GOT A CALL FROM THE HEADMASTER SAYING, WE THINK THIS IS REALLY DISRUPTING JQ'S EDUCATION. OH, REALLY. OKAY. I'M THINKING, PLEASE DON'T KICK HIM OUT. SO WE CUT BACK.

HE HAS ONE HOUR OF HEARING TEACHER A WEEK. AND HE SEEMS TO BE HOLDING HIS OWN. THAT'S AT SCHOOL. AND THEN WE HAVE A SPEECH THERAPIST WE SEE FOR FOUR HOURS OF SPEECH THERAPY A WEEK. AND SOMEONE COMES TO OUR HOME FOR INDIVIDUAL SPEECH THERAPY. IT IS AN ONGOING PROCESS. HE WILL BE ENTITLED TO THOSE SERVICES I GUESS UNTIL HE GRADUATES FROM HIGH SCHOOL. BUT YOU KNOW WHAT? I WAS SMART ENOUGH TO ASK.

WHEN THE PEOPLE WHO AREN'T AS FORTUNATE AS ME AND MAYBE DON'T HAVE THE EDUCATION, THEY DON'T KNOW HOW TO ASK. A

CHILD WITH A DISABILITY, WHETHER HEARING LOSS OR WHATEVER, THAT IS NOT THEIR NUMBER ONE PRIORITY. THE NUMBER ONE PRIORITY IS GETTING FOOD ON THE TABLE, HAVING THEIR HUSBAND GET TO WORK, MAYBE GETTING THEIR OTHER CHILDREN TO SCHOOL. YOU KNOW, IT TAKES A LOT OF EFFORT. SO THAT'S WHAT I WANT.

IF YOU CAN HELP OUT THOSE FAMILIES, REALLY, SO IT'S CHEAPER FOR THEM, SO THAT THEY HAVE ACCESS. BECAUSE I'M BLESSED. JQ IS GOING TO BE FINE. BUT HELP THOSE OTHER FAMILIES.

DR. ROBERT RUBEN: I WOULD LIKE TO RESPOND TO THAT. I SEE ANOTHER SIDE MAINLY WITH CHILDREN WITH MANY TYPES OF COMMUNICATION DISORDERS. I CAN JUST SPEAK FOR NEW YORK. WE FIND THREE OBSTACLES TO THE UTILIZATION OF THESE RESOURCES. THE FIRST OBSTACLE IS THAT PARENTS KNOW NOTHING ABOUT IT. THE SECOND IS THE SCHOOL ITSELF. MANY TIMES THE STORY THAT YOU'VE SAID--THAT'S WHAT PROMPTED ME TO CHIME IN ON THIS. MANY TIMES THE SCHOOL OFFICIALS, FOR GOOD REASONS OR BAD REASONS, WILL NOT TOLERATE AND WILL CAUSE TREMENDOUS DIFFICULTIES UNTIL EVERYBODY GIVES UP. THIRDLY, YOU ALSO HAVE THE PROBLEM OF GETTING THE APPROPRIATE SERVICES, WHICH MAY NOT EXIST EVEN THOUGH EVERYTHING ELSE IS WORKING.

THE LEGISLATION AND FUNDING IS THERE, BUT THERE IS A MAJOR DISCONNECT OF THE AWARENESS OF THE PHYSICIAN WHO MAY MAKE THE DIAGNOSIS, OF THE PARENT, OF THE SCHOOL, AND THE WILLINGNESS TO DO IT. THE IDEA OF LEAST RESTRICTIONAL EDUCATIONAL PATHWAY ARE NICE WORDS, BUT I'VE ACTUALLY BEEN TO COURT A NUMBER OF TIMES AS A WITNESS TO GET THIS GOING. SO YOUR EXPERIENCE IS TOUGH.

KASSIE DEPAIVA: IT'S TOUGH. I'M AFRAID THAT AS PARENTS WE DON'T WANT TO ROCK ANY BOATS. THERE WERE OTHER SCHOOLS THAT TURNED JQ DOWN. THEY WOULD NOT SAY IT WAS BECAUSE HE COULDN'T HEAR, BUT I KNEW THAT.

MY SON IS A BRIGHT BOY. THEY'RE NERVOUS. EDUCATORS ARE NERVOUS. THEY DON'T WANT TO BE THE ONE WHO DIDN'T MAKE HIM FIT INTO THE SYSTEM. BUT HE'S GOING TO BE FINE.

AUDIENCE: MORE OF A COMMENT THAN A QUESTION. WE HAVE SOME 50 STATES AND THEREFORE 50 DIFFERENT MEDICAL ASSISTANCE

PROGRAMS. EVERY PROGRAM OPERATES UNDER DIFFERENT RULES. THERE'S NO UNIFORMITY THROUGHOUT THE UNITED STATES. WE NEED TO DO SOMETHING TO BRING SOME OF THESE PROGRAMS INTO CONFORMITY SO THAT THOSE WHO ARE DEPENDING ON MEDICAL ASSISTANCE FOR THEIR HEARING HEALTHCARE CAN BE AFFORDED THE OPPORTUNITY TO BE ANOTHER JQ.

KASSIE DEPAIVA: I THINK YOU'RE RIGHT ABOUT THAT. WHEN WE WERE ASKING QUESTIONS TO A COCHLEAR INSTITUTE, PAT CHUTE, A WONDERFUL DOCTOR, WHO LIKE MANY OTHERS HAS HER LIFE TO THIS, HEARING HEALTH. I SAID, HOW COME CONGRESS DOESN'T DO SOMETHING ABOUT IT? SHE SAID -- AND I'M ONE TO TELL YOU BECAUSE MY MOTHER WON'T TELL YOU HERSELF WEAR ONE AND SHE'S LOSING HER HEARING.

THE MORE SEASONED PEOPLE WE HAVE HERE ARE EMBARRASSED ABOUT SAYING, I CAN'T HEAR. THERE IS A STIGMA INVOLVED WITH HEARING HEALTH AND LOSING YOUR HEARING. IF WE COULD GET OVER THAT STIGMA AND KNOW YOU'RE MISSING OUT ON YOUR GRANDCHILD'S LAUGHTER AND OTHER NUANCES, WE CAN JUST MOVE FORWARD. IF WE COULD COME TOGETHER AND KNOW THAT EVERYBODY SHOULD BE ABLE TO GET THE SAME SERVICES AND THE SAME KNOWLEDGE AND SAME INFORMATION AND SAME HEALTH, WOULDN'T THAT BE A BEAUTIFUL WORLD?

AUDIENCE: HOW MANY STATES PROVIDE MEDICAID SERVICES?

DR. ROBERT RUBEN: THAT PROVIDE COCHLEAR IMPLANTS? I DON'T KNOW.

AUDIENCE: MEDICAID IS ACTUALLY A SHARED PROGRAM BETWEEN THE FEDERAL GOVERNMENT AND THE STATES. SO THE LEVEL OF REIMBURSEMENT UNDER MEDICAID FOR COCHLEAR IMPLANTS FOR CHILDREN VARIES VERY MUCH BY THE STATE. THERE ARE SOME STATES THAT REIMBURSE 100 PERCENT. THERE ARE SOME STATES THAT REIMBURSE ONLY 20 PERCENT. AS A CONSEQUENCE, SOME COCHLEAR IMPLANT CENTERS ARE CLOSING. SOME CENTERS ARE REFUSING TO ACCEPT MEDICAID PATIENTS, WHICH MEANS THAT LOWER INCOME CHILDREN WILL NOT HAVE THE SAME ACCESS TO THIS TECHNOLOGY AS JQ. THAT'S NOT FAIR.

KASSIE DEPAIVA: NO. IT'S WRONG. IT'S JUST PLAIN OLD WRONG. AS A

MOTHER, YOU WOULD CUT YOUR ARM OFF FOR YOUR CHILD TO HEAR. YOU WOULD CUT YOUR ARM OFF SO HE DOESN'T SUFFER. IS JQ GOING TO SUFFER? NO. BUT ANY LITTLE THING THAT HAPPENS TO YOUR CHILD, YOU WANT TO MAKE A DIFFERENCE. AND THERE'S JUST NO REASON. IT IS WRONG FOR OTHER PARENTS BECAUSE THEY DON'T HAVE THE MEANS, THAT THEY CAN'T HAVE THE OPPORTUNITY.

DR. ROBERT RUBEN: LET ME PICK UP ON A LITTLE BIT OF WHAT SHE BROUGHT UP. THERE ARE THREE PARTS OF THIS. ONE, FINDING A PLACE WITH NEWBORN SCREENING. THIS VARIES BY STATE AND ALSO VARIES THE AMOUNT OF MONEY THAT WILL BE AVAILABLE TO THE HOSPITAL. THEN COMES THE IMPLEMENTATION, USE OF THE IMPLANT. AGAIN, THAT VARIES TREMENDOUSLY FROM NOTHING TO BEING GENEROUS. LASTLY, MOST IMPORTANTLY, THERE'S A COST ASSOCIATED WITH THE TRAINING AND TEACHING, AND THAT IS VERY VARIABLE AND ALMOST NONEXISTENT IN MANY PLACES.

KASSIE DEPAIVA: IT'S CALLED FOLLOW-UP. THIS COMPUTER HAS TO BE REMAPPED EVERY SIX WEEKS. HE GOES IN AND IS HOOKED UP TO A MACHINE. THAT'S CALLED A FOLLOW UP. IT STILL COSTS MONEY.

DR. ROBERT RUBEN: NOT ONLY THAT, BUT ALSO SPECIAL EDUCATION. YOU HAVE ALL THESE THINGS HAPPENING. THE FEW STUDIES IN THIS COUNTRY AND ABROAD HAVE SHOWN THAT THE ECONOMICS OF DOING THIS PROPERLY IS A NO-BRAINER, LIKE THE ADVANTAGE OF FIVE TO TEN TO ONE. THE PROBLEM THAT WE HAVE HERE IS THAT WE HAVE THE EDUCATIONAL MONEY IN ONE POCKET, HEALTH MONEY IN ANOTHER POCKET, AND SOMETHING ELSE IN ANOTHER POCKET, WHEREAS IN OTHER COMMUNITIES LIKE THE UNITED KINGDOM, THEY DRAW FROM THE SAME POCKET AND CAN SWITCH THE MONEYS AROUND AND SAVE MONEY. SO I THINK THERE'S SOME VERY INTERESTING LEGISLATIVE CHALLENGES TO TAKE THIS TECHNOLOGY THAT HAS BEEN SHOWN TO BE SO EFFICACIOUS AND APPLY IT SO THAT ALL OF OUR CITIZENS CAN UTILIZE IT.

MARTHA CARMEN: I WANT TO ADD ONE THING. IN YOUR PACKETS, THERE IS A REPORT CARD OF STATE BREAKDOWNS FOR MEDICAID REIMBURSEMENT OF COCHLEAR IMPLANTS.

AUDIENCE: I JUST WANT TO ADD TO THAT THE REPORT CARD THAT YOU HAVE IN YOUR PACKETS IS A SNAPSHOT OF A MUCH LARGER STUDY. IF ANYBODY WOULD LIKE ADDITIONAL INFORMATION, PLEASE CALL THE CONTACT PERSON IN YOUR KITS, CARRIE CLEARLY. SHE'LL

FORWARD THE FULL STUDY TO YOU.

MARTHA CARMEN: OTHER QUESTIONS FOR OUR PANELISTS?

JIM DEPAIVA: I JUST WANTED TO MAKE A QUICK COMMENT. PROBABLY ONE OF THE MOST HEART BREAKING THINGS I THINK FOR ME FOR THE PARENTS OF OTHER CHILDREN WITH THIS PROBLEM IS BECAUSE OF WHAT KASSIE AND I DO, A LOT OF PEOPLE FROM THE LOWER ECONOMIC BACKGROUND COME UP TO US ON THE STREET. THEY FEEL THEY KNOW US BECAUSE THEY SEE US ON TV EVERY DAY.

WE HAVE HAD SEVERAL PARENTS COME UP AND SAY, WE HEARD ABOUT YOUR CHILD, THIS AND THAT, WE FOUND OUT OUR CHILD IS DEAF WHEN THEY WERE FOUR, WHEN THEY WERE FIVE. FAMILIES TEND TO PUSH THESE CHILDREN AWAY AND THINK, THEY'LL START TALKING SOON, OR THEY'RE NOT PAYING ATTENTION. IT HAPPENS TIME AND TIME AGAIN. WE HAVE A HOUSE ABOUT 150 MILES FROM NEW YORK CITY. IN RURAL AREAS, IT'S MORE PREVALENT.

I THINK EARLY DETECTION IS PROBABLY THE MOST IMPORTANT THING AT THIS POINT. FOR JQ, WE WERE FORTUNATE. I PLAY THE FATHER OF A DEAF CHILD ON TV IN DENIAL ABOUT IT, AND THEY WENT THROUGH THE WHOLE PROCESS OF LEARNING ABOUT THIS. WE STILL DIDN'T FIGURE IT OUT UNTIL HE WAS ABOUT 13 MONTHS OLD. THEN WE HAD THE PEOPLE TO CALL. I CALLED UP MY TECHNICAL ADVISOR AT THE LEXINGTON SCHOOL FOR THE DEAF.

KASSIE DEPAIVA: IT WAS TOO IRONIC.

JIM DEPAIVA: THERE WAS ALL KINDS OF RED TAPE. WE WERE LUCKY. HER PEOPLE ARE LOST. THEY DON'T KNOW WHERE TO GO OR WHERE TO LOOK FOR HELP. JUST TO HAVE THESE CHILDREN WHO AREN'T SPEAKING OR HEARING, THEY'RE NOT EVEN LEARNING TO SIGN. THEY'RE LEARNING NO FORM OF COMMUNICATION. THAT I FOUND TO BE THE MOST DISTURBING THING THAT NEEDS TO BE CHANGED.

DEBRA NUSSBAUM: I THINK THE TECHNOLOGY IS WONDERFUL. THE RANGE OF OUTCOMES WILL BE VARIED AND NEEDS TO BE SEEN IN THE CONTEXT OF THE CHILD'S WHOLE EDUCATION. NOT EVERYBODY WILL HAVE THE WONDERFUL OUTCOMES YOU'VE SEEN.

KASSIE DEPAIVA: NOT EVERYBODY IS EVEN ELIGIBLE FOR THE COCHLEAR IMPLANT AS WELL. SO WE HAVE TO KEEP ALL OF THESE OTHER OPTIONS TOTALLY IN LINE.

DR. ROBERT RUBEN: ALSO, GRANTED, THE GREAT VARIETY OF THE HUMAN RACE, WE WILL ALL FINISH AT THE END LINE AT DIFFERENT TIMES. TO FIND IT EARLY DOES NOT PUT A BALL AND CHAIN AROUND THE CHILD. I THINK ALTHOUGH THERE WILL BE CHILDREN -- I SEE CHILDREN WITH MULTIPLE PROBLEMS WHERE I AM. BUT NOT TO FIND THIS REALLY PENALIZES THE CHILD.

A GROUP OF CHILDREN WHO HAVE OTHER PROBLEMS, OTHER TYPES OF COGNITIVE THINGS, IF THEY'RE NOT DIAGNOSED WITH HEARING LOSS, THEY'RE EVEN IN TROUBLE. IF THIS CHILD HAD BEEN DIAGNOSED AT FOUR OR FIVE, HIS RESULTS WOULD HAVE BEEN DIFFERENT. I TAKE CARE OF PEOPLE.

ONE DAY A MAN WALKED IN BLIND, A LAWYER. ABOUT TWO OR THREE PATIENTS LATER, IN CAME A RELATIVE OF A MEMBER OF OUR BOARD OF TRUSTEES, A SECOND COUSIN, WHO WAS DEAF. SAME TYPE OF BACKGROUND. HE HAD A MENIAL JOB. JUST TO SEE THESE TWO MEN WITHIN 15 OR 20 MINUTES, REALIZING THEY PROBABLY HAVE THE SAME GENETIC INTELLIGENT ENDOWMENT, ONE FUNCTIONS QUITE WELL BECAUSE HE HAD LANGUAGE. THE OTHER ONE, DEAF, FUNCTIONS VERY MARGINALLY AND TRAPPED INSIDE. THAT LESSON LASTED 40 YEARS.

KASSIE DEPAIVA: IT KEEPS YOU GOING, THOUGH. IT KILLS YOU. THAT MAKES ME SO SAD.

DR. ROBERT RUBEN: THIS WAS WRITTEN BEFORE YOU WERE BORN.

KASSIE DEPAIVA: IT STILL MAKES ME SAD. IT MAKES ME SO SAD. BECAUSE WE ARE LIMITED. WE ARE JUDGED. JQ WILL BE JUDGED FOR THAT. BUT WE'RE DOING EVERYTHING WE CAN TO COVER THAT AND COLOR THAT. WHETHER HE SIGNS OR WHETHER HE IS BLESSED TO BE ABLE TO HEAR THROUGH THE COCHLEAR IMPLANT, IT IS THE EDUCATION. IT IS THE FOLLOW UP. IT'S NOT JUST PUTTING ON A PAIR OF GLASSES. YOU HAVE TO LEARN TO HEAR. YOU DON'T HEAR WITH YOUR EARS; YOU HEAR WITH YOUR BRAIN. IT'S AN ONGOING PROCESS.

MARTHA CARMEN: THANK YOU. A ROUND OF APPLAUSE FOR ALL OF OUR PRESENTERS.

THANK YOU VERY MUCH FOR COMING.

REALTIME CAPTIONING PROVIDED BY COM-ACCESS, LLC.

=====

LINK::

<http://web.archive.org/web/20040104063610/www.hearinghealth.net/pages/home/transcr.html>

=====

=====

=====

February 2002: Individuals With Disabilities Education Act (I.D.E.A.)

REALTIME CAPTIONING PROVIDED BY COM-ACCESS, LLC.

REALTIME CAPTIONER: NATALIE C. PRUNTY, CSR-CA, RPR.

ELIZABETH THORP: GOOD AFTERNOON, EVERYBODY. WELCOME TO THE FOURTH CONGRESSIONAL HEARING HEALTH CAUCUS PRESENTED BY THE NATIONAL CAMPAIGN FOR HEARING HEALTH. MY NAME IS ELIZABETH THORP, AND I'M THE DIRECTOR OF THE CAMPAIGN.

BEFORE WE GET STARTED, THIS IS AN ASSISTIVE LISTENING DEVICE THAT WE'LL BE PASSING AROUND FROM SPEAKER TO SPEAKER SO THAT NATE CAN HEAR EVERYTHING THAT'S GOING ON. THIS IS ONE EXAMPLE OF ACCESSIBLE EDUCATIONAL DEVICES THAT IS EFFECTIVE IN THE CLASSROOM. SO WE'LL PRETEND THIS IS AN OLYMPIC TORCH AND PASS IT ALONG.

FIRST I WANT TO ACKNOWLEDGE THE COCHAIRS: REPRESENTATIVES JIM RYUN, JIM WALSH, CAROLYN MCCARTHY, AND LOIS CAPPS.

ALSO, I WOULD LIKE TO RECOGNIZE THE WIFE OF REPRESENTATIVE MICHAEL BILIRAKIS. THANK YOU ALL FOR BEING HERE TODAY.

TODAY'S PRESENTATION, "I.D.E.A.: A FOCUS ON CHILDREN WITH HEARING LOSS," WILL PROVIDE A CLOSER LOOK AT THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT.

ORIGINALLY, I.D.E.A. WAS CALLED THE EDUCATION FOR ALL HANDICAPPED CHILDREN ACT. IT WAS PASSED IN 1975 AND REAUTHORIZED

IN 1990 WHEN ITS NAME WAS CHANGED TO THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT.

I.D.E.A. GIVES CHILDREN WITH SPECIAL NEEDS FREE AND

APPROPRIATE EDUCATION IN THE LEAST RESTRICTIVE ENVIRONMENT. THE FOUNDATION IS THE INDIVIDUALIZED EDUCATION PROGRAM, OR IEP, WHICH IS A WRITTEN, LEGAL DOCUMENT DESCRIBING SPECIAL EDUCATION NEEDS AND SERVICES TO BE PROVIDED TO EACH STUDENT.

ALTHOUGH I.D.E.A. MAKES PROVISIONS FOR ALL CHILDREN WITH SPECIAL NEEDS, TODAY WE'LL FOCUS ON THOSE WITH HEARING LOSS.

NOW, IT GIVES ME GREAT PLEASURE TO INTRODUCE REPRESENTATIVE JIM WALSH, ONE OF THE FOUNDING COCHAIRS WHO WILL BE OUR MODERATOR TODAY AND WILL INTRODUCE OUR SPEAKERS.

THANK YOU VERY MUCH, CONGRESSMAN.

(APPLAUSE.)

JAMES WALSH: THANK YOU, LIZZY. GOOD AFTERNOON. IT'S GREAT TO SEE ALL OF YOU HERE. I'M BEGINNING TO PUT NAMES WITH FACES BETTER AND BETTER ALL THE TIME. THANK YOU FOR YOUR ADVOCACY AND YOUR SUPPORT FOR WHAT WE'VE BEEN ABLE TO ACCOMPLISH HERE. THANK YOU FOR BEING PATIENT WITH US AND WORKING WITH US.

I'M DELIGHTED TO SEE EVELYN BILIRAKIS HERE TODAY. HER HUSBAND, MIKE, IS THE CHAIRMAN OF THE HEALTH SUBCOMMITTEE OF THE COMMERCE COMMITTEE, AND HE'S BEEN A GREAT HELP TO US. SO I'M REALLY GLAD TO HAVE YOU HERE, AND MY OTHER COLLEAGUES, JIM RYUN AND LOIS CAPPS AND CAROLYN MCCARTHY, AS WELL.

TODAY WE'LL FOCUS ON I.D.E.A. WITH PARTICULAR ATTENTION TO DEAF AND HARD OF HEARING CHILDREN. I WOULD LIKE TO WELCOME AND THANK OUR PANELISTS TODAY. THEY ARE DEPUTY ASSISTANT SECRETARY LORETTA PETTY, FROM THE DEPARTMENT OF EDUCATION; PATRICIA ROTHSCHILD, COMMUNICATION DIRECTOR FOR THE LEAGUE FOR THE HARD OF HEARING IN NEW YORK CITY. SHE'S BEEN A TREMENDOUS ADVOCATE FOR FAMILIES AS THEY ENTER THE I.D.E.A. PROCESS WITH THE GOAL OF FINDING THE BEST SERVICES FOR EACH CHILD, REGARDLESS OF WHICH COMMUNICATIONS METHODOLOGY IS CHOSEN. SHE'S FROM NEW YORK CITY, BUT WE'VE BEEN TALKING AND SHE'S BEEN COMMUNICATING WITH PEOPLE IN MY PART OF THE STATE,

UPSTATE NEW YORK, AND I WAS DELIGHTED TO HEAR THAT. THANK YOU FOR THAT.

JOHN AND NATHAN FLANDERS ARE WITH US TODAY. MR. FLANDERS IS WITH THE ALEXANDER GRAHAM BELL FOUNDATION -- I SPENT 15 YEARS IN THE TELEPHONE BUSINESS BEFORE I CAME HERE -- BUT MORE IMPORTANTLY, TODAY HE'S HERE AS THE PARENT OF HIS SON NATHAN. NATHAN HAS SEVERE TO PROFOUND HEARING LOSS. HE AND NATHAN WILL SHARE WITH US THEIR EXPERIENCES WITH I.D.E.A. I'M SURE THOSE WILL BE VERY, VERY FORCEFUL.

NATHAN IS 8 YEARS OLD. YOU'RE PRETTY BIG FOR 8 YEARS, NATHAN. HE WILL TELL US ABOUT HIS SCHOOL EXPERIENCES, AND WE LOOK FORWARD TO HEARING FROM HIM.

DON'T BE NERVOUS AT ALL, NATHAN. WE ALL DO THIS FOR A LIVING, AND YOU'LL GET USED TO IT.

(LAUGHTER.)

LAST BUT NOT LEAST, WE'LL HEAR FROM MARK GOLDEN, WHO IS CURRENTLY ONE OF THE TWO COCHAIRS OF "COR", THE COUNCIL OF ORGANIZATIONAL REPRESENTATIVES. COR APPROACHED THE CAUCUS ABOUT HAVING A MEETING ON I.D.E.A., AND WE HAVE BEEN WORKING WITH THEM FOR SEVERAL MONTHS TO ASSEMBLE WHAT I KNOW WILL BE A VERY INFORMATIVE SESSION.

COR IS AN ORGANIZATION WITH MANY OF THE TOP LEADERS IN THE HEARING HEALTH COMMUNITY. MR. GOLDEN WILL GIVE SOME CLOSING RECOMMENDATIONS ON POSSIBLE IMPROVEMENTS TO I.D.E.A. WHEN CONGRESS ADDRESSES THE PROGRAM FOR REAUTHORIZATION THIS YEAR.

WHEN HE IS NOT ATTENDING TO COR RESPONSIBILITIES, HE WORKS FULL TIME FOR THE NATIONAL COURT REPORTERS ASSOCIATION, PEOPLE WE SPEND LOTS OF TIME WITH.

AS A STRONG SUPPORTER OF I.D.E.A. AND ONE WHO IS ENCOURAGED BY COLLEAGUES TO JOIN WITH US IN SUPPORTING FUNDING FOR

I.D.E.A., I HAVE TWO CONCERNS TO LEAVE WITH YOU: ONE, THERE ARE PARTS OF THE COUNTRY WHERE SERVICES ARE SORELY LACKING. CHILDREN IN THESE AREAS HAVE A HARD TIME ACCESSING SERVICES.

SECOND, I'M ALSO VERY CONCERNED THAT AFTER IDENTIFICATION OF HEARING LOSS, THERE STILL IS NO LINKAGE BETWEEN THE POSITIVE IDENTIFICATION AND THE I.D.E.A. SERVICES TO WHICH EACH CHILD IS ENTITLED.

WE'VE MADE GREAT PROGRESS WITH HEARING SCREENING, ALMOST TWO-THIRDS OF THE CHILDREN IN THIS NATION NOW ARE SCREENED FOR HEARING LOSS AT BIRTH. WE STILL HAVE LOTS OF KIDS TO GO YET. SOME STATES ARE BETTER THAN OTHERS. BUT WE NEED TO STOP FROM TIME TO TIME AND CELEBRATE OUR VICTORIES. IT REALLY IS A REMARKABLE VICTORY, ONE THAT IS ONGOING. WHEN WE GET EVERY CHILD IN AMERICA'S HEARING TESTED, THEN WE'LL GO FOR THE WORLD. I KNOW THE REST OF THE WORLD, WE HAVE THEIR ATTENTION NOW AND THEY'RE FEELING THE RESPONSIBILITY TO DO THESE THINGS ALSO.

EACH SPEAKER WILL HAVE 10 MINUTES TO SPEAK, FOLLOWED BY QUESTIONS AND ANSWERS. I WANT TO THANK THE PANELISTS FOR THEIR TIME, AND THE NATIONAL CAMPAIGN FOR HEARING HEALTH FOR PARTNERING WITH US IN THIS EVENT.

THANK YOU VERY MUCH.

(APPLAUSE.)

NOW WE WILL HEAR FROM ASSISTANT SECRETARY LORETTA PETTY.
LORETTA PETTY: THANK YOU.

GOOD AFTERNOON. THANK YOU FOR HAVING ME HERE THIS AFTERNOON. THIS IS MY FIRST OPPORTUNITY TO BE WITH THIS ORGANIZATION, AND ACTUALLY ONE OF MY FIRST OPPORTUNITIES TO HAVE A PUBLIC SPEAKING ENGAGEMENT SINCE JOINING THE DEPARTMENT LATE LAST YEAR, SO I APPRECIATE YOU AFFORDING ME THIS HONOR.

AS YOU KNOW, THE DEPARTMENT OF EDUCATION HAS JURISDICTION

OVER THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT. THERE IS NO WAY TO COVER ALL THE PROVISIONS OF I.D.E.A. DURING THE TIME THAT I HAVE ALLOTTED HERE TODAY, SO I'M GOING TO COVER SOME OF THE MAJOR PROVISIONS THAT I BELIEVE WILL BE OF INTEREST TO YOU.

THE BASIC PROGRAMS: TWO PARTS OF I.D.E.A. ARE PARTICULARLY SIGNIFICANT FOR OUR DISCUSSION TODAY. I WOULD LIKE TO BRIEFLY EXPLAIN THEM: PART B, ASSISTANCE FOR EDUCATION OF ALL CHILDREN WITH DISABILITIES, AND PART C, INFANTS AND TODDLERS WITH DISABILITIES.

PART B PROVIDES FEDERAL FUNDS TO STATES AND LOCAL EDUCATION AGENCIES TO ASSIST THE AGENCIES IN MAKING AVAILABLE FREE EDUCATION FOR ALL STUDENTS WITH DISABILITIES, INCLUDING THOSE WHO ARE DEAF OR HEARING IMPAIRED, AGES THREE TO 21.

PART C PROVIDES FUNDS TO ENSURE APPROPRIATE EARLY INTERVENTION SERVICES ARE AVAILABLE TO ALL INFANTS AND TODDLERS WITH DISABILITIES AGE BIRTH THROUGH THREE IN THE STATE AND TO THEIR FAMILIES.

BOTH PART B AND PART C CONTAIN WHAT ARE KNOWN AS CHILD FIND PROVISIONS, WHICH REQUIRE THAT CHILDREN WHO ARE SUSPECTED OF HAVING DISABILITIES BE IDENTIFIED, REFERRED, EVALUATED, AND, IF ELIGIBLE, SERVED. ELIGIBILITY REQUIREMENTS ARE NOT THE SAME FOR PART C AS THEY ARE FOR PART B. CHILDREN ELIGIBLE FOR SERVICES UNDER PART C ARE NOT AUTOMATICALLY ELIGIBLE FOR SERVICES UNDER PART B.

UNDER PART C, TO BE AN ELIGIBLE INFANT OR TODDLER WITH A DISABILITY MEANS THAT A CHILD IS UNDER THREE YEARS OF AGE AND NEEDS EARLY INTERVENTION SERVICES BECAUSE HE OR SHE IS EXPERIENCING DEVELOPMENTAL DELAYS AS MEASURED BY APPROPRIATE DIAGNOSTIC INSTRUMENTS AND PROCEDURES IN ONE OR MORE AREAS OF COGNITIVE DEVELOPMENT, PHYSICAL DEVELOPMENT, COMMUNICATION DEVELOPMENT, SOCIAL OR EMOTIONAL DEVELOPMENT, AND ADAPTIVE DEVELOPMENT, OR HAS A DIAGNOSED PHYSICAL OR MENTAL CONDITION WHICH HAS A HIGH PROBABILITY OF RESULTING IN DEVELOPMENTAL DELAY.

AT THE STATE'S DISCRETION, IT MAY ALSO INCLUDE AT-RISK INFANTS

AND TODDLERS. UNDER PART B, A CHILD WITH A DISABILITY MEANS A CHILD WHO HAS ONE OR MORE OF A SPECIFIED CONDITION AND WHO BY REASON OF THE CONDITION NEEDS SPECIAL EDUCATION AND RELATED SERVICES. FOR THE BROAD FEDERAL CATEGORIES, EACH STATE HAS ESTABLISHED CERTAIN CRITERIA.

PROVISION OF SERVICES. AFTER A CHILD IS ASSESSED AND DETERMINED ELIGIBLE UNDER PART B OR PART C, INDIVIDUALIZATION IS THE KEY TO SERVICES UNDER BOTH. UNDER PART C, EACH STATE MUST MAINTAIN AND IMPLEMENT A STATEWIDE COMPREHENSIVE COORDINATED MULTIDISCIPLINARY INTERAGENCY SYSTEM TO PROVIDE EARLY INTERVENTION SERVICES FOR INFANTS AND TODDLERS WITH DISABILITIES AND THEIR FAMILIES.

EACH STATEWIDE SYSTEM MUST PROVIDE AT A MINIMUM THAT FOR EACH INFANT AND TODDLER WITH A DISABILITY AND THE INFANTS OR TODDLER'S FAMILY, THEY ARE TO RECEIVE A MULTIDISCIPLINARY ASSESSMENT OF THE UNIQUE STRENGTHS AND NEEDS OF THE INFANT OR TODDLER, AND THE IDENTIFICATION OF SERVICES APPROPRIATE TO MEET SUCH NEEDS, A FAMILY DIRECTED ASSESSMENT OF RESOURCES, PRIORITIES, AND CONCERNS OF THE FAMILY, AND THE IDENTIFICATION OF SUPPORTS AND SERVICES NECESSARY TO ENHANCE THE FAMILY'S CAPACITY TO MEET THE DEVELOPMENTAL NEEDS OF THE INFANT OR TODDLER, AND A WRITTEN INDIVIDUALIZED FAMILY SERVICE PLAN, KNOWN AS "IFSP,"

DEVELOPED BY A MULTIDISCIPLINARY TEAM, INCLUDING THE PARENTS. THE CONTENTS OF THE IFSP MUST BE FULLY EXPLAINED TO THE PARENTS, AND INFORMED WRITTEN CONSENT FROM THE PARENTS MUST BE OBTAINED PRIOR TO THE PROVISION OF EARLY INTERVENTION SERVICES.

IF THE PARENT DOES NOT PROVIDE CONSENT TO A PARTICULAR EARLY INTERVENTION SERVICE, THEN THE EARLY INTERVENTION SERVICES TO WHICH CONSENT IS OBTAINED MUST BE PROVIDED.

THE IFSP MUST BE EVALUATED ONCE A YEAR, AND THE FAMILY MUST BE PROVIDED A REVIEW OF THE PLAN AT SIX-MONTH INTERVALS, OR MORE OFTEN WHERE APPROPRIATE, BASED ON THE NEEDS OF THE INFANT OR TODDLER AND THE FAMILY NEEDS.

UNDER PART B, THE PUBLIC AGENCY MUST CONDUCT A FULL INITIAL

EVALUATION IN ACCORDANCE WITH THE REQUIREMENTS OF PART B BEFORE THE INITIAL PROVISION OF SPECIAL EDUCATION AND RELATED SERVICES TO A CHILD.

AFTER THE TEST AND OTHER EVALUATION MATERIALS ARE COMPLETED, THE DETERMINATION OF WHETHER THE CHILD IS A CHILD WITH A DISABILITY UNDER PART B MUST BE MADE BY A GROUP OF QUALIFIED PROFESSIONALS AND THE PARENTS OF THE CHILD. A COPY OF THE EVALUATION REPORT AND THE DOCUMENTATION OF DETERMINATION OF ELIGIBILITY MUST BE GIVEN TO THE PARENT. IN MAKING A DETERMINATION OF ELIGIBILITY, A CHILD MUST NOT BE DETERMINED TO BE A CHILD WITH A DISABILITY IF THE DETERMINING FACTOR IS LACK OF INSTRUCTION IN READING OR MATH OR LIMITED ENGLISH PROFICIENCY.

IF A CHILD IS DETERMINED ELIGIBLE UNDER PART B OF I.D.E.A., THE CHILD'S INDIVIDUALIZED EDUCATION PROGRAM TEAM, THE IEP TEAM, THAT INCLUDES THE PARENTS, MUST MEET TO DEVELOP AN INDIVIDUALIZED EDUCATION PROGRAM FOR THE CHILD.

THE "IEP", THE INDIVIDUALIZED EDUCATION PROGRAM, MUST INCLUDE, AMONG OTHER COMPONENTS, A STATEMENT OF THE CHILD'S PRESENT LEVELS OF EDUCATIONAL PERFORMANCE, HOW THE CHILD'S DISABILITY AFFECTS THE CHILD'S INVOLVEMENT AND PROGRESS IN THE GENERAL CURRICULUM, SUCH AS THE SAME CURRICULUM FOR A NONDISABLED CHILD, A STATE OF ANNUAL MEASURABLE GOALS INCLUDING BENCHMARKS RELATED TO MEETING THE CHILD'S NEEDS THAT RESULT FROM THE CHILD'S DISABILITY TO ENABLE THE CHILD TO BE INVOLVED IN AND PROGRESS IN THE GENERAL CURRICULUM, AND MEETING EACH OF THE CHILD'S OTHER NEEDS THAT RESULT IN THE CHILD'S DISABILITY OR FROM THE CHILD'S DISABILITY.

A STATEMENT OF THE SPECIAL EDUCATION AND RELATED SERVICES AND SUPPLEMENTARY AIDS AND SERVICES TO BE PROVIDED TO THE CHILD OR ON BEHALF OF THE CHILD, AND A STATEMENT OF THE PROGRAM MODIFICATION OR SUPPORTS FOR SCHOOL PERSONNEL THAT WILL BE PROVIDED FOR THE CHILD TO ADVANCE APPROPRIATELY TOWARD ATTAINING THE ANNUAL GOALS TO BE INVOLVED AND PROGRESS IN THE GENERAL CURRICULUM, AND TO PARTICIPATE IN EXTRACURRICULAR AND OTHER NONACADEMIC ACTIVITIES, AND TO BE EDUCATED AND PARTICIPATE WITH OTHER CHILDREN WITH DISABILITIES AND NONDISABLED CHILDREN IN EDUCATION AND EXTRACURRICULAR ACTIVITIES.

IN DEVELOPING EACH CHILD'S IEP, THE IEP TEAM MUST CONSIDER THE STRENGTHS OF THE CHILD, THE CONCERN OF THE PARENT FOR ENHANCING THE EDUCATION OF THE CHILD, AND THE RESULTS OF THE INITIAL EVALUATION OR MOST RECENT EVALUATION OF THE CHILD.

SPECIAL FACTORS. I.D.E.A. '97 ADDED A NUMBER OF SPECIAL FACTORS THAT MUST BE ADDRESSED. ALL SPECIAL FACTORS ARE IMPORTANT IN IEP DEVELOPMENT. TODAY I WILL MENTION ONLY TWO THAT ARE OF PARTICULAR SIGNIFICANCE FOR CHILDREN WHO ARE DEAF OR HEARING IMPAIRED. THE IEP TEAM MUST CONSIDER THE COMMUNICATION NEEDS OF THE CHILD, AND IN THE CASE OF A CHILD WHO IS DEAF OR HARD OF HEARING, CONSIDER THE CHILD'S LANGUAGE AND COMMUNICATION NEEDS, OPPORTUNITIES FOR DIRECT COMMUNICATION WITH PEERS AND PROFESSIONAL PERSONNEL IN THE CHILD'S LANGUAGE AND COMMUNICATION MODE, ACADEMIC LEVEL AND FULL RANGE OF NEEDS, INCLUDING OPPORTUNITIES FOR DIRECT INSTRUCTION IN THE CHILD'S LANGUAGE AND COMMUNICATION MODE. CONSIDER WHETHER THE CHILD NEEDS ASSISTIVE TECHNOLOGY AND SERVICES.

IF, IN CONSIDERING THESE AND OTHER FACTORS, THE IEP TEAM DETERMINES A CHILD NEEDS A PARTICULAR DEVICE OR SERVICE, INCLUDING ANY INTERVENTION ACCOMMODATION OR OTHER PROGRAM MODIFICATION, IN ORDER FOR THE CHILD TO RECEIVE THE FREE, APPROPRIATE PUBLIC EDUCATION, THE IEP TEAM MUST INCLUDE A STATEMENT TO THAT EFFECT IN THE CHILD'S IEP.

THE PARENT MUST GIVE INFORMED CONSENT PRIOR TO THE PROVISION OF SPECIAL EDUCATION AND RELATED SERVICES. A CHILD'S IEP TEAM MUST REVIEW THE IEP PERIODICALLY, NOT LESS THAN ANNUALLY, TO DETERMINE WHETHER THE ANNUAL GOALS FOR THE CHILD ARE BEING ACHIEVED, AND MUST REVISE THE IEP AS APPROPRIATE TO ADDRESS ANY LACK OF EXPECTED PROGRESS TOWARD THE ANNUAL GOALS AND IN THE GENERAL CURRICULUM WHERE APPROPRIATE, THE RESULTS OF ANY REEVALUATION, INFORMATION ABOUT THE CHILD PROVIDED TO OR BY THE PARENTS, THE CHILD'S ANTICIPATED NEEDS, OR OTHER MATTERS THE IEP TEAM DETERMINES APPROPRIATE.

THE EDUCATIONAL ENVIRONMENT. TO THE MAXIMUM EXTENT APPROPRIATE, CHILDREN WITH DISABILITIES MUST BE EDUCATED WITH OTHER CHILDREN. REMOVING CHILDREN FROM THE REGULAR

EDUCATIONAL ENVIRONMENT OCCURS ONLY IF THE NATURE OR SEVERITY OF THE DISABILITY IS SUCH THAT EDUCATION IN REGULAR CLASSES WITH THE USE OF SUPPLEMENTARY AIDS AND SERVICES CANNOT BE ACHIEVED SATISFACTORILY.

EACH PUBLIC AGENCY MUST HAVE AVAILABLE A CONTINUUM OF ALTERNATIVE PLACEMENTS TO MEET THE NEEDS OF CHILDREN WITH DISABILITIES OR SPECIAL EDUCATION AND RELATED SERVICES. IN DETERMINING THE EDUCATIONAL PLACEMENT OF A CHILD WITH A DISABILITY, THE PLACEMENT DECISION IS MADE BY A GROUP OF PERSONS, INCLUDING THE CHILD'S PARENTS AND OTHER PERSONS KNOWLEDGEABLE ABOUT THE CHILD, THE MEANING OF THE EVALUATION DATA, AND THE PLACEMENT OPTIONS, AND IS MADE IN CONFORMITY WITH THE LEAST RESTRICTIVE PROVISIONS.

THE CHILD'S PLACEMENT MUST BE DETERMINED ANNUALLY BASED ON THE CHILD'S IEP AND AS CLOSE TO THE CHILD'S HOME AS POSSIBLE. IN SELECTING THE LEAST RESTRICTIVE ENVIRONMENT, CONSIDERATION MUST BE GIVEN TO ANY HARMFUL EFFECT ON THE CHILD OR THE QUALITY OF SERVICES HE OR SHE NEEDS.

DUE PROCESS: GENERALLY PARENTS AND SCHOOL DISTRICTS AGREE ON THE SERVICES AND PLACEMENT FOR THE CHILD. HOWEVER, IN THE FEW CASES WHERE AGREEMENT CAN'T BE REACHED, PROCEDURAL SAFEGUARDS MUST BE AVAILABLE. UNDER BOTH PART B AND C, WHEN PARENTS DISAGREE WITH THE PUBLIC AGENCY REGARDING AREAS SPECIFIED IN THE STATUTE, SUCH AS THEIR CHILD'S IFSP OR IEP, THEY CAN REQUEST A DUE PROCESS HEARING.

MEDIATION MUST BE MADE AVAILABLE WHEN A DUE PROCESS HEARING IS REQUESTED. MANY STATES OFFER MEDIATION MUCH EARLIER AND LESSEN THE LIKELIHOOD OF ADVERSARIAL RELATIONSHIPS DEVELOPING.

ALTHOUGH I'VE HARDLY GONE OVER SOME OF THE PROVISIONS OF PART B AND C OF I.D.E.A., I THINK IT'S CLEAR THE LAW APPLIES TO CHILDREN WITH A NUMBER OF DISABILITIES, INCLUDING CHILDREN WITH HEARING LOSS. IT FOCUSES ON THE INDIVIDUAL NEEDS OF THE ELIGIBLE CHILD. THIS ENSURES THAT ALL CHILDREN WITH DISABILITIES HAVE AVAILABLE TO THEM SERVICES DESIGNED TO MEET THEIR INDIVIDUAL NEEDS.

DOES THE LAW WORK AS IT SHOULD FOR EVERY SINGLE CHILD? IT HAS PLAYED A MAJOR ROLE IN THE LIVES OF COUNTLESS CHILDREN AND THEIR FAMILIES. AS RECENTLY AS 1970, SCHOOLS IN AMERICA EDUCATED ONLY ONE IN FIVE CHILDREN WITH DISABILITIES. MANY STATES HAD LAWS EXCLUDING CERTAIN STUDENTS INCLUDING THOSE WHO WERE BLIND, DEAF, OR EMOTIONALLY DISTURBED OR MENTALLY RETARDED. I.D.E.A. IS A LAW THAT HAS AND MUST CONTINUE TO MAKE A DIFFERENCE IN THE LIVES OF OUR NATION'S CHILDREN.

I LOOK FORWARD TO WORKING WITH YOU IN THE FUTURE. THANK YOU.

(APPLAUSE.)

PATRICIA ROTHSCHILD: GOOD AFTERNOON. MY NAME IS PAT ROTHSCHILD. ON BEHALF OF THE COUNCIL OF ORGANIZATIONAL REPRESENTATIVES AND MY FELLOW PANELISTS, I THANK YOU MOST SINCERELY FOR THE OPPORTUNITY TO MEET WITH YOU AND SPEAK WITH YOU THIS AFTERNOON REGARDING THE VITAL ISSUES SURROUNDING THE REAUTHORIZATION OF THE I.D.E.A..

I HAVE BEEN A SPEECH LANGUAGE PATHOLOGIST WORKING WITH CHILDREN AND ADULTS WITH HEARING LOSS FOR MANY MORE YEARS THAN I WOULD LIKE TO ADMIT.

I AM THE DIRECTOR OF THE COMMUNICATION DEPARTMENT AT THE LEAGUE FOR THE HARD OF HEARING IN NEW YORK CITY, WHICH IS PERHAPS THE OLDEST PROGRAM, PRIVATE, NOT FOR PROFIT, REHABILITATION SOCIAL SERVICES ORGANIZATION IN THE UNITED STATES. WE WERE ESTABLISHED IN 1910. THE LEAGUE AND PARTICULARLY OUR CHILDREN'S PROGRAMS ENJOY AN INTERNATIONALLY RENOWNED REPUTATION FOR EXCELLENCE AND INNOVATION.

WHEN I EMBARKED UPON MY CAREER IN SPEECH LANGUAGE PATHOLOGY WORKING WITH CHILDREN WHO WERE DEAF OR HARD OF HEARING, IT WAS JUST ABOUT THE TIME THAT PUBLIC LAW 94-142, THE EDUCATION FOR ALL HANDICAPPED CHILDREN'S ACT, WAS IMPLEMENTED. AT THAT TIME, I NAIVELY APPROACHED MY WORK WITH A TOTALLY OPEN MIND AND FOUND THAT MY FAR MORE EXPERIENCED COLLEAGUES WERE FAR MORE AMBIVALENT THAN I WAS. IT WAS

CONFUSING. THEY WERE ELATED, BECAUSE AT THAT TIME, THEY WANTED TO PROVIDE THE BEST EDUCATIONAL PROGRAM FOR THE CHILDREN WHO WERE IN THEIR CHARGE. THEY REALLY WANTED TO DO A GOOD JOB.

THE MIND SET, HOWEVER, WAS THAT VERY MUCH OF ONE SIZE FITS ALL. THEIR APPREHENSIONS SPRANG FROM BEING INTIMIDATED BY THAT MANDATE, THE MANDATE CONTAINED IN THAT LAW THAT EACH CHILD'S SPECIFIC NEEDS WERE REQUIRED TO BE CONSIDERED AND MET. LEAST RESTRICTIVE ENVIRONMENT FOR THEM AUTOMATICALLY AND ERRONEOUSLY TRANSLATED INTO MAINSTREAMING OR REGULAR EDUCATIONAL PLACEMENT.

THE UNCERTAINTY OF THE IMPACT OF THIS LAW WAS THREATENING AT THAT TIME ADMINISTRATORS, ESPECIALLY OF SEGREGATED PROGRAMS WHERE REDUCTION IN STUDENT NUMBERS WOULD MEAN REDUCTION IN FUNDING, JOBS, AND PRESTIGE FOR THEIR PROGRAMS. IMPLEMENTATION OF PL 94-142 AND ALL OF ITS MODIFICATIONS AS IT HAS EVOLVED INTO THE I.D.E.A. AS WE KNOW IT TODAY HAS PROFOUNDLY CHANGED THE LIVES OF CHILDREN WHO ARE DEAF OR HARD OF HEARING, THEIR FAMILIES, AND ALL OF US. THE LANDSCAPE OF SCHOOLS AND PUBLIC EDUCATION HAS BEEN CHANGED FOREVER. I CAN REPORT THAT FIRSTHAND.

THE GOAL OF ASSURING THAT STUDENTS WHO ARE DEAF OR HARD OF HEARING HAVE ACCESS TO PUBLIC EDUCATION HAS LARGELY BEEN ACHIEVED. THE I.D.E.A. IS A BOLD, ASSERTIVE, AND SWEEPING PIECE OF LEGISLATION. ITS PROVISIONS MANDATE A FREE, APPROPRIATE PUBLIC EDUCATION IN THE LEAST RESTRICTIVE ENVIRONMENT, TRUE, NOT APOLOGETIC, ACCESS TO CURRICULUM, AND IDENTIFICATION AND INTERVENTION AT THE VERY YOUNGEST AGE IMAGINABLE.

WITH THESE PROVISIONS IN THE VANGUARD, SPECIAL EDUCATION PROFESSIONALS, SCHOOL DISTRICT ADMINISTRATORS, AND PARENTS HAVE JOINED RANKS IN AN EMPOWERED TEAM TO SCULP INDIVIDUAL PROGRAMS TO MEET THE INDIVIDUAL NEEDS OF INDIVIDUAL CHILDREN.

FOR THE MOST PART, WE ARE FEELING COMFORTABLE THAT THE ONE SIZE FITS ALL MENTALITY NO LONGER HOLDS WATER IN DEAF EDUCATION. AS A RESULT, LARGE NUMBERS OF THESE CHILDREN ARE THRIVING, LEARNING, AND ACHIEVING PREVIOUSLY UNHEARD OF LEVELS OF EDUCATIONAL PROFICIENCY AND SUCCESS.

A WONDERFUL COMPELLING BIPRODUCT OF THIS INITIATIVE IS THAT ALL STUDENTS TODAY ARE LEARNING FIRSTHAND IN THEIR VERY CLASSROOMS TO UNDERSTAND AND TO EXPAND THEIR CONCEPT OF NORMALCY, AS WELL AS ACCEPTING THEIR DIFFERENCES FROM THEIR PEERS. WORKING WITH OTHER CHILDREN WITHOUT DISABILITIES SIDE BY SIDE IN THE CLASSROOMS, THEY INTERNALIZE RESPECT, COOPERATION, AND APPRECIATION OF THE WORTH OF EACH INDIVIDUAL.

PLACING CHILDREN IN SPECIAL SCHOOLS FOR THE DEAF AFFORDS THEM THE OPPORTUNITY TO NURTURE AND FLOURISH IN AN ENVIRONMENT OF SHARED LANGUAGE, EXPERIENCE, ROLE MODELS, AND CAMARADERIE. CHILDREN WHO ARE DEAF OR HARD OF HEARING HAVE GAINED GREATER ACCEPTANCE AND HAVE BECOME MORE KNOWLEDGEABLE AND EMPOWERED. THEY ARE CONFIDENT ABOUT THEIR ABILITY TO PLAY A MEANINGFUL ROLE IN THE FULL RANGE OF SOCIETAL ACTIVITIES.

I.D.E.A. HAS CREATED A GENERATION WHAT TRULY HAS THE CHANCE TO ACCEPT INDIVIDUALS ACROSS THE SPECTRUM AS EQUALS IN SPITE OF DIFFERENCES.

WHAT A BETTER WORLD WE WILL GROW FOR ALL OF US. EVERYONE IN THIS ROOM SHOULD CONGRATULATE HERSELF FOR HER PART IN THIS PROCESS, AT THE SAME TIME THAT WE ALL COMMIT TO MOVE FORWARD WITH THE IMPORTANT WORK THAT INDEED STILL NEEDS TO BE DONE.

AT THIS JUNCTURE, WE MUST ALL RESOLVE THAT THE SPIRIT AND LETTER OF THIS LAW REMAINS STRONG AND TRUE, AND THAT I.D.E.A. BE FULLY FUNDED AND IMPLEMENTED. 90 PERCENT OF PARENTS OF CHILDREN WITH HEARING LOSS DO NOT THEMSELVES HAVE HEARING LOSS, NOR DO OTHER MEMBERS OF THEIR FAMILY. WHEN THEY FIRST LEARN OF THEIR CHILD'S DEAFNESS, THEY ARE OFTEN STUNNED AND VERY VULNERABLE. I.D.E.A., THROUGH EXPERT AND OBJECTIVE PROFESSIONALS, NOT GENERALISTS, MUST PROVIDE A FORUM FOR PARENT SUPPORT FROM THAT MOMENT OF IDENTIFICATION AND THROUGHOUT THE TREACHEROUS YEARS OF THEIR CHILDREN'S EDUCATION.

FROM THE ONSET, PARENTS MUST LEARN ABOUT COMMUNICATION AND EDUCATION OPTIONS. WHAT LEVEL OF COMMITMENT IS REQUIRED

FOR SUCCESS? WHAT ROLES MUST THEY THEMSELVES ABSOLUTELY PLAY IN THEIR CHILD'S EDUCATION? PARENTS ARE OUR ALLIES AND PARTNERS, AND I.D.E.A. MUST ENSURE AND ENGENDER THEIR NEEDS.

THE AVAILABILITY OF THESE COMMUNICATION AND EDUCATIONAL OPTIONS CANNOT CONTINUE TO BE RESTRICTED BY COMMUNITY AND GEOGRAPHICAL BOUNDARIES OR BY ARBITRARY FUNDING ALLOCATIONS. INFORMATION AND SUPPORT CAN BE AMASSED THROUGH THE GLOBAL NETWORK OF COMMUNICATION, DISTANCE LEARNING, THE TECHNOLOGY SUPER HIGHWAY. MEANS CAN AND MUST BE DEVELOPED TO ESTABLISH A VARIETY OF FEASIBLE PROGRAMS LOCALLY. LIMITING CHOICES BECAUSE OF LIMITED AVAILABILITY NEED NOT AND CANNOT BE PERPETUATED. THIS CONTINUES TO BE A CHALLENGE TO BE ADDRESSED THROUGH IMPLEMENTATION AND ENFORCEMENT OF I.D.E.A.. IN ORDER TO MAINTAIN AND FURTHER EDUCATIONAL INITIATIVES, TEACHERS AND RELATED SERVICES PROFESSIONALS MUST BE PREPARED TO MEET THE NEEDS OF ALL STUDENTS IN THE CLASSROOMS OF TODAY.

WE ARE ALL TOO AWARE OF THE SHORTAGE OF QUALIFIED, WELL PREPARED, CREATIVE, RESPONSIBLE TEACHERS THROUGHOUT OUR COUNTRY. THIS PROBLEM IS GREATLY MAGNIFIED FOR THOSE WHO WORK WITH STUDENTS WHO ARE DEAF OR HARD OF HEARING.

BUSINESS AS USUAL IN TEACHER PREPARATION PROGRAMS IS NOT ACCEPTABLE. FOR MANY, THAT MODEL HAS PERPETUATED MEDIOCRITY, INFERIOR LITERACY AND ACADEMIC COMPETENCY AMONG CHILDREN WHO ARE DEAF OR HARD OF HEARING, NO MATTER WHAT THEIR COMMUNICATION MODALITY. WE MUST ENSURE THAT DEAF AND HARD OF HEARING YOUNG ADULTS WILL NOT COME TO THE END OF THEIR SECONDARY EDUCATION WITH INCREDIBLY LOW ACHIEVEMENT IN LANGUAGE AND ACADEMICS IN SPITE OF THEIR POTENTIAL. TO DO THIS, WE MUST ENSURE THAT TEACHERS AND ALL SCHOOL STAFF CAN COMMUNICATE FULLY AND EFFECTIVELY WITH THEIR STUDENTS, WHATEVER THE COMMUNICATION MODE.

UNIVERSITIES MUST PREPARE TEACHERS OF THE DEAF TO TRULY EMBODY THE SPIRIT OF I.D.E.A.. THESE PROGRAMS MUST PROVIDE FUTURE TEACHERS WITH COMPREHENSIVE AND UNBIASSED INFORMATION ABOUT ALL OPTIONS IN DEAF EDUCATION. TEACHERS MUST EXPECT AND REACH FOR HIGHER LEVELS OF ACADEMIC ACHIEVEMENT FROM THEIR STUDENTS. THIS IS ESPECIALLY URGENT IN LIGHT OF THE DRAMATIC IMPACT OF EARLY IDENTIFICATION AND ADVANCES IN TECHNOLOGY. THEY MUST UNDERSTAND AND BE

INVIGORATED BY THE CHALLENGE AND POTENTIAL, A NEW MODEL FOR PROVISION OF EDUCATIONAL SERVICES, INCLUDING TEAM TEACHING, TEACHING IN INTEGRATED INCLUSIVE CLASSROOMS, CONSULTANT TEACHER MODELS, AND PARTNERING WITH THE DEAF STUDENT HIMSELF AS A PUSH AND SUPPORT AND A PULL-OUT RESOURCE. THIS MODEL MUST BECOME THE NORM. CREDENTIAL AND PERFORMANCE CRITERIA MUST BE ESTABLISHED AND MONITORED TO ENSURE KNOWLEDGE AND SKILLS REGARDING SIGN LANGUAGE, THE TECHNOLOGY OF AMPLIFICATION, INCORPORATING SIGN LANGUAGE INTERPRETATION IN THE EDUCATIONAL PROCESS, COCHLEAR IMPLANTS, CART, VIDEO REMOTE INTERPRETING, AND INNOVATIVE TELECOMMUNICATION OPTIONS.

LET US NOW MOVE FORWARD, ASPIRING TO EXCELLENCE AND INNOVATION, AND COMMITTED TO ACCOMPLISHING THIS IMPORTANT WORK WITHIN OUR OWN INDIVIDUAL ROLES AND WITHIN OUR COMMUNITIES, FOR STUDENTS, FOR THEIR FAMILIES, AND FOR US ALL.

THANK YOU.

(APPLAUSE.)

NATHAN FLANDERS: HELLO. MY NAME IS NATHAN FLANDERS. I'M 8 YEARS OLD. I'M FROM CONNECTICUT AND I'M IN THIRD GRADE. IN SCHOOL, I LEARN LOTS OF THINGS LIKE MATH, SCIENCE, ART, MUSIC. MY FAVORITE SUBJECT IS ROCKS. I LIKE STUDYING ROCKS AND VOLCANOES. I DON'T LIKE STUDYING VOLCANOES VERY MUCH, BUT I LIKE THE ROCKS.

IN MY READING GROUP, WE READ LONG BOOKS AND THINK OF QUESTIONS ABOUT THE BOOK. RIGHT NOW WE'RE READING "CHARLIE AND THE CHOCOLATE FACTORY," WHICH I ALREADY READ TWO YEARS AGO.

I HELPED MAKE A WEB PAGE FOR MY CLASS.

THIS YEAR WE ARE STUDYING THE OLYMPICS. IF YOU GO TO THE WEBSITE, YOU CAN SEE WE ARE KEEPING TRACK OF THE MEDALS FOR OUR COUNTRIES. MY COUNTRY IS CANADA.

AT RECESS, I USUALLY GO PLAY FOOTBALL WITH MY FRIENDS. I CAN HEAR THEM FINE. I'M THE ONLY KID IN MY SCHOOL WITH A HEARING AID. MY TEACHER WEARS A MICROPHONE THAT LETS ME HEAR IN CLASS. SHE PASSES IT AROUND WHEN WE HAVE DISCUSSIONS.

EVERY DAY WE HAVE DIFFERENT CLASSES, AND I CARRY THE MICROPHONE TO EACH TEACHER. THERE ARE GOOD THINGS AND BAD THINGS ABOUT HEARING AIDS. SOME BAD THINGS THAT I DON'T LIKE ARE YOU HAVE TO FOOL A LOT WITH THE EQUIPMENT. WHEN THE F.M. MICROPHONE BREAKS, IT'S HARD FOR ME TO HEAR IN SCHOOL, PLUS I HAVE TO WORK HARDER IN SCHOOL.

SOME GOOD THINGS ARE THAT LOTS OF KIDS ADMIRE IT. I ONCE WAS PLAYING FOOTBALL AND THE TEACHER WAS WEARING THE MICROPHONE AND FORGOT TO TURN IT OFF AND SHE WAS PLAYING FOR THE OTHER TEAM AND I COULD HEAR THEIR PLAYS.

(LAUGHTER.)

(APPLAUSE.)

JOHN FLANDERS: THANK YOU FOR THIS OPPORTUNITY TO TALK FOR A FEW MINUTES ABOUT I.D.E.A. AND HOW IT LOOKS FROM THE POINT OF VIEW OF A FAMILY WITH A CHILD WHO IS DEAF OR HARD OF HEARING.

I DON'T THINK THERE'S ANY QUESTION THAT NATHAN IS AN EXCELLENT EXAMPLE OF WHAT A CHILD WITH PROFOUND HEARING LOSS CAN DO IN SCHOOL WITH THE APPROPRIATE SUPPORT. HE IS IN A MAINSTREAM CLASSROOM, GETS GOOD GRADES, AND FOR MOST OF THE TIME IS JUST ONE OF THE KIDS.

NATE WAS NOT BORN DEAF. TWO WEEKS AFTER HIS THIRD BIRTHDAY HE CONTRACTED MENINGITIS. HEARING LOSS IS COMMON RESULT OF THIS DISEASE. NATE WAS NO EXCEPTION.

IN THE HOSPITAL AND IMMEDIATELY AFTER WE TOOK HIM HOME, WE TRIED TO DETERMINE IF HE HAD LOST ANY HEARING. THE DAY HE

CAME HOME FROM THE HOSPITAL I REMEMBER HIM SAYING HE WAS STILL SICK, BUT AT THREE HE DIDN'T HAVE THE WORDS OR AWARENESS TO TELL US WHAT WAS REALLY WRONG.

ALTHOUGH HE HAD LOST HIS HEARING, HE APPARENTLY LEARNED TO READ LIPS VERY QUICKLY, BECAUSE HE CONTINUED TO TALK AND ANSWER US APPROPRIATELY WHEN HE COULD SEE US TALKING. WHEN WE FINALLY LEARNED THE DIAGNOSIS, THAT HE COULDN'T HEAR ANYTHING MUCH SOFTER THAN THE SOUND OF A LAWNMOWER, WE WERE FLOORED.

WE HAD NO IDEA WHAT TO DO. BUT WE WERE LUCKY. WE WERE IMMEDIATELY SENT TO A GOOD AUDIOLOGIST IN CONNECTICUT. HE EVALUATED THE LOSS AND RECOMMENDED APPROPRIATE HEARING AIDS. WE CONTACTED OUR LOCAL SCHOOL DISTRICT, WHICH WAS QUICK TO DIRECT US TO THE EDUCATIONAL OPTIONS AVAILABLE TO US. WE ARE FORTUNATE TO LIVE IN CENTRAL CONNECTICUT WHERE THERE IS A RANGE OF OPPORTUNITIES FOR CHILDREN WITH HEARING LOSS.

WE WERE ABLE TO CONSIDER THE AMERICAN SCHOOL FOR THE DEAF, THE OLDEST SUCH SCHOOL IN THE COUNTRY, WHICH FOCUSES ON SIGN LANGUAGE, AS WELL AS A REGIONAL PROGRAM WHICH OFFERS SEVERAL ALTERNATIVES FOR DEAF CHILDREN.

RIGHT FROM THE START, HE HAS BEEN A VERY VERBAL CHILD. HE WAS UNUSUALLY ARTICULATE FOR A THREE YEAR OLD AND THEREFORE WAS ABLE TO GET GOOD RESULTS FROM A HEARING AID, SO WE WERE DRAWN TO ORAL APPROACHES AND CHOSE A PROGRAM CALLED AUDITORY VERBAL THERAPY.

AUDITORY VERBAL THERAPY FOCUSES ON TEACHING A CHILD TO MAXIMIZE THE INFORMATION HE GETS THROUGH HIS HEARING WITHOUT RELYING ON VISUAL CUES LIKE SIGNING OR LIPREADING OR CUES. WE GOT OFF TO A GOOD START, AND THE RESULTS HAVE BEEN EXCELLENT, BUT WE'VE HAD CHALLENGES.

HE ATTENDS PRIVATE SCHOOL, NOT BECAUSE OF SPECIAL SERVICES, BUT BECAUSE OUR LOCAL SCHOOL DISTRICT HAS 800 CHILDREN IN A SCHOOL DESIGNED FOR 500. OVERCROWDED AND BAD ACOUSTICS ARE JUST SOME OF THE PROBLEMS HE WOULD HAVE HAD TO DEAL WITH. HE NEEDS SMALL CLASSROOMS WITH SMALL CLASS SIZES.

HE RECEIVES PRIMARILY INDIRECT SERVICES. AN ITINERANT TEACHER FOR THE DEAF COMES INTO HIS CLASSROOM PERIODICALLY TO GIVE HIS TEACHER ADVICE ON ACCOMMODATION TECHNIQUES.

OUR LOCAL BOARD OF EDUCATION PROVIDES THE ASSISTIVE LISTENING DEVICE THAT YOU'VE SEEN US HANDLE SO WELL UP HERE. THEY ALSO PROVIDE AN ANNUAL AUDIOLOGICAL CHECK, REPAIR SERVICE FOR HIS HEARING AIDS, AND LONER AIDS FOR WHEN HIS AID BREAKS DOWN. IN ADDITION, THEY GIVE US A VERY SMALL AMOUNT OF MONEY TO HELP OFFSET THE SPEECH THERAPY THAT MY WIFE AND I PROVIDE.

EACH YEAR WE HAVE TO WORK VERY HARD TO MAINTAIN THESE VERY FEW SERVICES. IN THE PAST YEAR, EVEN HARDER, TO TRY TO INCREASE AND ADD THE SPEECH AND LANGUAGE SERVICES THAT HE'S GETTING NOW. OVER THE PAST SIX YEARS, WE'VE HAD TO FIGHT AT EACH IEP, AND ONE YEAR FILED FOR A DUE PROCESS HEARING, ALTHOUGH WE'VE BEEN FORTUNATE TO COME TO A NEGOTIATED AGREEMENT EVERY YEAR.

I DIDN'T COME HERE WITH THE INTENTION OF COMPLAINING ABOUT THE SPECIAL EDUCATION PROCESS IN OUR PARTICULAR CASE. WE'VE BEEN FORTUNATE. ANNE AND I ARE BOTH PROFESSIONALS WITH THE RESOURCES, KNOWLEDGE, CONNECTIONS, AND SOME MONEY TO BE ABLE TO UNDERSTAND AND ADVOCATE FOR THE NEEDS OF OUR CHILD. NONETHELESS, WE DREAD EACH YEAR'S IEP. WE SPEND THE SPRING WONDERING WHAT PART OF THE SERVICES THEY'LL WANT TO CUT AND WHY. BEFORE THE MEETING, WE LITERALLY SPEND WEEKS CONSULTING WITH HIS EXPERTS TO DETERMINE WHAT APPROPRIATE SERVICES HE NEEDS.

THREE YEARS AGO, AS AN EXAMPLE, THE SCHOOL PROPOSED THAT BECAUSE HE WAS MEETING HIS GOALS AND HAD AGE-APPROPRIATE LANGUAGE, THAT HE MIGHT NOT QUALIFY AT ALL AS A CHILD WITH A DISABILITY. WE SPEND A LOT OF TIME WITH THE PROFESSIONALS BECAUSE WE KNOW THAT EVEN WITH A PRETTY GOOD SCHOOL SYSTEM AND A SYMPATHETIC SPECIAL ED DIRECTOR, THE FOCUS ON HIS INDIVIDUAL NEEDS IS BLURRED BY THE DISTRICT'S NUMBER ONE PRIORITY OF CONTROLLING COSTS. THIS MEANS PARTICULARLY FOR A CHILD WHO IS BENEFITING FROM THE PROCESS AND NOT SUFFERING GROSS ACADEMIC IMPAIRMENTS, THAT THERE'S A REAL PUSH TO TAKE AWAY THE SUPPORTS THAT MAKE THIS PROGRESS POSSIBLE.

FROM A PARENT'S PERSPECTIVE, IT OFTEN LOOKS LIKE THE SCHOOL WILL ONLY HELP YOUR CHILD IF HE'S FAILING. LET HIM CATCH UP, MOVE ALONG WITH HIS CLASS, AND IT'S LIKE HIS DISABILITY DISAPPEARS. HE'S PASSING; HE DOESN'T NEED ANY HELP. CALL US BACK WHEN HE GETS A COUPLE OF F'S.

BUT FOR ALL THAT, WE'VE BEEN LUCKY. I WANTED TO FOCUS ON NATE AND HOW WE KNOW THAT MUCH OF HIS SUCCESS IS JUST PURE DUMB LUCK. THERE IS NO QUESTION THAT IF WE HAD LIVED IN ALMOST ANY OTHER PART OF THE COUNTRY, HE WOULD NOT BE DOING AS WELL AS HE IS NOW.

WHEN WE DISCOVERED HIS HEARING LOSS, WE HAD ALMOST IMMEDIATELY A NUMBER OF RESOURCES TO START. THERE WERE AUDIOLOGISTS IN PRIVATE PRACTICE EMPLOYED BY THE HOSPITAL WHERE HE WAS, AND THE SCHOOL SYSTEM THAT WAS ABLE TO DIAGNOSE HIS LOSS AND PRESCRIBE A HEARING AID. WE HAD THE ABILITY TO COME UP WITH THE INCOME THAT THOSE HEARING AIDS COST.

THEN WE HAD OPTIONS. WE HAD EASY ACCESS TO PROGRAMS THAT OFFERED BOTH ASL AND ORAL APPROACHES. AS IMPORTANT, WE HAD PEOPLE WHO WERE WILLING TO TALK TO US CANDIDLY ABOUT OUR OPTIONS. WE HAD A SCHOOL THAT DIRECTED US BUT DIDN'T TRY TO DICTATE WHICH OPTION TO CHOOSE. AND FINALLY, WHEN WE DID CHOOSE, THERE WAS ACTUALLY A PROFESSIONAL THERE, ABLE TO PROVIDE THE SERVICES THAT HE NEEDED.

I CAN TELL YOU HOW RARE EACH OF THOSE IS, PARTICULARLY THE LAST ONE. BECAUSE OF HIS DISABILITY, I DECIDED TO CHANGE MY CAREER. I MOVED FROM MY FAMILY'S INSURANCE AGENCY TO BECOME AN ADVOCATE FOR CHILDREN WHO ARE DEAF AND HARD OF HEARING. I GET TO SEE HOW THE SYSTEM WORKS NOT ONLY FOR OUR FAMILY BUT FOR FAMILIES ALL ACROSS THE COUNTRY.

I'LL GIVE YOU AN EXAMPLE OF HOW THINGS CAN WORK. WHEN WE DECIDED THAT AUDITORY VERBAL WAS THE APPROPRIATE CHOICE FOR US, THERE WAS ONE CERTIFIED AV THERAPIST IN THE ENTIRE STATE OF CONNECTICUT. TODAY THERE ARE TWO. IN THE PAST FEW WEEKS I'VE TALKED TO PARENTS IN MIAMI, FLORIDA, WHERE THERE IS ONE, AND THE DETROIT AREA, WHERE THERE IS ALSO ONE. THOSE ARE

AREAS WITH OVER 2 MILLION PEOPLE APIECE.

SHORTLY AFTER NATE BEGAN HIS TRAINING, A COUPLE OTHER CHILDREN BEGAN THE PROGRAM AND WENT INTO AV. THE FACT IS, IF HIS ILLNESS OCCURRED IN MAY INSTEAD OF MARCH, IT'S LIKELY THERE WOULDN'T HAVE BEEN ROOM FOR HIM. HE WOULD HAVE BEEN CLOSED OUT OF THAT OPTION, AND THAT THERAPIST GENERALLY HAS A 6- TO 12-MONTH WAITING LIST.

LET ME STOP HERE, BUT I WANT TO ADD THAT I DON'T ENVY ANY OF YOU WHO WILL BE TRYING TO WORK ON CREATING A REAUTHORIZED, STRENGTHENED VERSION OF I.D.E.A.. I KNOW IT'S EASY FOR ME TO TELL YOU WHAT I THINK YOU SHOULD DO. I DON'T HAVE TO MAKE SOMETHING THAT WORKS IN THE FACE OF CONFLICTS AND PRESSURES THAT YOU WILL HAVE TO. AFTER FOUR YEARS AS AN ELECTED OFFICIAL MYSELF, I KNOW WHAT FUN THAT CAN BE.

BUT I DID WANT TO ASK YOU, WHEN YOU TRY TO WORK THIS PROCESS, PLEASE PAY PARTICULAR SERIOUS ATTENTION TO WHAT THE PARENTS HAVE TO SAY. WHEN A CHILD FAILS, ULTIMATELY ALL OF US PAY THE BILL. BUT THE FACT IS THAT THE PARENTS PAY THIS BILL EVERY DAY. THEY'RE THE FIRST ONES TO PAY FINANCIALLY, EMOTIONALLY, AND IN TERMS OF THE DREAMS OF THEIR CHILDREN.

THIS LAW HAS LITERALLY BROUGHT HOPE TO MILLIONS OF FAMILIES ACROSS AMERICA WHO ARE COUNTING ON YOU TO HELP MAKE THAT HOPE REAL.

(APPLAUSE.)

MARK GOLDEN: I THINK THOSE CONCERNS ABOUT NATHAN'S PUBLIC SPEAKING HAVE BEEN PUT TO REST.

GOOD AFTERNOON. I'M MARK GOLDEN. ON BEHALF OF TIMOTHY CREAGAN AND THE OTHERS WHO MAKE UP COR (COUNCIL OF ORGANIZATIONAL REPRESENTATIVES ON NATIONAL ISSUES CONCERNING THE DEAF AND HARD OF HEARING), I WANT TO THANK THE CONGRESSIONAL HEARING HEALTH CAUCUS FOR PUTTING THIS PANEL TOGETHER TO TALK

REAUTHORIZATION OF I.D.E.A. IS A MAJOR PRIORITY FOR COR. FIRST LET ME EXPLAIN MORE ACCURATELY WHO COR IS. THE COUNCIL OF ORGANIZATIONAL REPRESENTATIVES WORKS ON NATIONAL ISSUES OF PEOPLE WHO ARE DEAF OR HARD OF HEARING IS THE PROSAIC AND CUMBERSOME TITLE FOR A VERY SIMPLE AND POWERFUL I.D.E.A.. COR IS A VOLUNTARY ORGANIZATION COMMITTED TO IMPROVING THE LIVES OF DEAF AND HARD OF HEARING PEOPLE.

WE HAVE ORGANIZATIONS PROVIDING SUPPORT INCLUDING TECHNOLOGICAL, TELECOMMUNICATIONS ACCESS SERVICES, EDUCATION PROGRAMS, PARENT INFORMATION AND REFERRAL, SUPPORT GROUPS AND SELF-HELP PROGRAMS, MEDICAL, AUDIOLOGICAL, SPEECH LANGUAGE PATHOLOGY ASSESSMENT AND REHABILITATION SERVICES, INFORMATION ON ASSISTIVE DEVICES AND TECHNOLOGY, AND GENERAL INFORMATION ABOUT OTHER SERVICES FOR THE DEAF AND HARD OF HEARING CONSUMER.

COR'S MEMBERSHIP DOES NOT ADHERE TO ANY ONE SINGLE APPROACH OR FOCUS TO THESE ISSUES. RATHER WE REPRESENT THE FULL ARRAY OF HEARING HEALTH AND ACCESS OPTIONS AND WORK TOGETHER FOR A COMMON GOAL OF PROMOTING AWARENESS OF THE NEEDS OF INDIVIDUALS WHO ARE DEAF AND HARD OF HEARING AND IMPROVING ACCESS.

WE HAVE OPERATED IN THIS WAY FOR NEARLY 15 YEARS. COLLECTIVELY, COR ORGANIZATIONS ESTIMATE 70,000 INDIVIDUALS DEDICATED TO ADVANCING THE LIVES OF DEAF AND HARD OF HEARING.

OUR PLATFORM CONSISTS OF THREE PLANKS THAT STATES, IN PART, THERE IS AN URGENT AND SUBSTANTIAL NEED, ONE, TO ENHANCE THE DEVELOPMENT OF INFANTS, TODDLERS, AND CHILDREN WHO ARE DEAF AND HARD OF HEARING AND TO MAXIMIZE THEIR POTENTIAL FOR ACADEMIC ACHIEVEMENT; TWO, TO ENHANCE THE INDEPENDENCE AND EMPLOYABILITY OF PEOPLE WHO ARE DEAF AND HARD OF HEARING TO MAXIMIZE THEIR

POTENTIAL TO BE PRODUCTIVE CITIZENS; AND THREE, TO ENHANCE THE CAPACITY OF FAMILIES AND SCHOOLS TO MEET THE NEEDS OF CHILDREN WHO ARE DEAF AND HARD OF HEARING.

THAT STATEMENT FORMED THE BASIS OF COR. THE I.D.E.A. HAS BEEN

THE BASIS FOR MAJOR ADVANCES AND ACCOMPLISHMENTS IN THAT PLAN'S GOALS. IN ORDER FOR I.D.E.A. TO CONTINUE TO EFFECTIVELY MEET THE NEEDS OF DEAF AND HARD OF HEARING CHILDREN, WE THINK CONGRESS MUST ADDRESS FOUR AREAS: FIRST, FUNDING. FEDERAL FUNDING OF PART B

FOR UP TO 40 PERCENT OF THE AVERAGE PER PUPIL EXPENDITURE IN PUBLIC, ELEMENTARY, AND SECONDARY SCHOOLS IN THE UNITED STATES IS NECESSARY. REAUTHORIZATION AND INCREASED FUNDING FOR PARTS C AND D ARE ALSO REQUIRED.

SECOND, EARLY IDENTIFICATION AND EARLY INTERVENTION. NEEDS IN THIS AREA INCLUDE IMPLEMENTATION OF UNIVERSAL NEWBORN SCREENING AND EARLY INTERVENTION, AND ESTABLISHING PROGRAMS FOR DEAF AND HARD OF HEARING CHILDREN WHERE NO SUCH PROGRAMS CURRENTLY EXIST, AS WELL AS COMMUNICATION WITH PARENTS REGARDING THE FULL ARRAY OF OPTIONS AVAILABLE TO BE THEM FOLLOWING THAT EARLY IDENTIFICATION OF HEARING LOSS.

IN SHORT, A LINK IS NEEDED BETWEEN THE DETECTION OF HEARING LOSS AND APPROPRIATE FOLLOW-UP IN BOTH MEDICAL AND EDUCATIONAL TERMS. THAT MEANS A LINK BETWEEN DETECTION AND THE I.D.E.A. SYSTEM SO NO DEAF OR HARD OF HEARING CHILD FALLS THROUGH THE CRACKS OR IS LEFT BEHIND IN THE UNITED STATES OF AMERICA'S EDUCATION SYSTEM.

THIRD, THE ISSUE OF COMMUNICATION ACCESS. THERE IS A NEED TO ENSURE DIRECT AND UNINHIBITED LANGUAGE AND COMMUNICATION ACCESS THROUGH AWARENESS OF VISUALLY ORIENTED LANGUAGE MODES AND COMMUNICATION STRATEGIES SUCH AS SIGN LANGUAGE AND CART, BOTH YOU SEE DEMONSTRATED HERE TODAY, AND OF MODES SUCH AS AUDITORY VERBAL, ORAL, AND OTHER AUDITORY APPROACHES.

ASSURANCES ARE NEEDED THAT ALL STUDENTS WHO ARE DEAF OR HARD OF HEARING WILL, AS APPROPRIATE TO THEIR INDIVIDUALIZED EDUCATION PLAN, HAVE ACCESS TO INTERPRETERS, ASSISTIVE LISTENING TECHNOLOGIES SUCH AS F.M. SYSTEMS, CART, AND OTHER ALTERNATIVE MODES OF EDUCATION.

FOR CHILDREN WHO CHOOSE TO USE VISUAL COMMUNICATION MODES,

OPPORTUNITIES NEED TO BE MADE FOR INTERACTION WITH PEERS WHO SHARE THEIR LANGUAGE PREFERENCES WITH INTERPRETERS AND TECHNOLOGICAL AIDS AS NEEDED.

FOR STUDENTS USING AUDITORY MODES, PROVISIONS NEED TO BE MADE THAT AN APPROPRIATE PHYSICAL ENVIRONMENT AND APPROPRIATE DEVICES ARE PROVIDED AS NEEDED. FOR ALL STUDENTS, PROVISIONS NEED TO BE MADE BETWEEN STUDENTS, THEIR TEACHERS, AND PROFESSIONAL PERSONNEL.

FOURTH AND FINAL AREA IS PERSONNEL. THERE IS A NEED FOR AN ADEQUATE SUPPLY OF APPROPRIATELY TRAINED AND FULLY QUALIFIED TEACHERS OF CHILDREN WHO ARE DEAF AND HARD OF HEARING, EDUCATIONAL ADMINISTRATORS, INTERPRETERS, CART PROVIDERS, SPEECH LANGUAGE PATHOLOGY PROFESSIONALS, SOCIAL WORKERS, COUNSELORS, ET CETERA. ALSO CRITICAL IS THESE INDIVIDUALS IS TRAINING IN INTERACTING EFFECTIVELY GIVEN THE DIVERSE BACKGROUNDS AND CULTURES OF DEAF AND HARD OF HEARING CHILDREN, AND CONTINUING EDUCATION TO MAINTAIN THOSE SKILLS.

QUALITY STANDARDS ARE NEEDED FOR INTERPRETERS, CART PROVIDERS, TEACHERS, COUNSELORS, AND OTHER PERSONNEL. BUT STANDARDS ARE NOT ENOUGH IF THE EDUCATION SYSTEM DOES NOT PROVIDE APPROPRIATE INCENTIVES TO RECRUIT AND MAINTAIN THE MOST QUALIFIED PERSONNEL FOR THE CHILDREN WHO NEED THEM.

RECRUITMENT OF TEACHERS AND RELATED PERSONNEL WHO ARE THEMSELVES DEAF AND HARD OF HEARING ARE ESPECIALLY NEEDED. EFFORTS MUST BE MADE TO ACHIEVE BETTER GENERAL AWARENESS OF LANGUAGE OPTIONS, INCLUDING ASL AND ENGLISH, AND MODES OF COMMUNICATION SUCH AS SIGN LANGUAGE OR APPROACHES THAT ALLOW ACCESS TO SPOKEN LANGUAGES, AND THE USE OF TECHNOLOGY TOOLS TO PROMOTE LANGUAGE ACQUISITION AND DEVELOPMENT WITH CHILDREN WHO ARE HARD OF HEARING.

IN CLOSING, THE ACCOMPLISHMENTS AND BENEFITS OF I.D.E.A. ARE MANY AND SHOULD BE A SOURCE OF GREAT PRIDE FOR THE CONGRESS AND HEARING HEALTH CAUCUS. THE REAUTHORIZATION OF PARTS C AND D AND CONTINUED COMMITMENT AND FUNDING OF ALL TITLES OF THE ACT SHOULD BE AN IMPORTANT PART OF THE CONGRESS' AGENDA FOR THE COMING SESSION. COR LOOKS FORWARD TO WORKING WITH CONGRESS TO ACHIEVE OUR COMMON

GOALS.

THANK YOU FOR YOUR ATTENTION AND TO THE CONGRESSIONAL HEARING HEALTH CAUCUS FOR THEIR SUPPORT AND FOR HEARING OUR ISSUES AND FOR THE OPPORTUNITY TO SHARE OUR VIEWS TODAY. THANK YOU VERY MUCH.

(APPLAUSE.)

ELIZABETH THORP: THANK YOU VERY MUCH TO ALL OF OUR SPEAKERS TODAY ON THIS IMPORTANT ISSUE. WE DO HAVE TIME FOR SOME Q AND A. CONGRESSMAN WALSH HAS HAD TO LEAVE FOR AN APPOINTMENT, SO MARTHA CARMEN FROM HIS OFFICE WILL BE FACILITATING THE QUESTION AND ANSWER SESSION.

(APPLAUSE.)

MARTHA CARMEN: THANK YOU, EVERYBODY. ANY QUESTIONS FOR OUR PANELISTS?

AUDIENCE: ONE PART UNDER I.D.E.A. REAUTHORIZATION IS CHANGING THE FUNDING FORMULA FOR VOLUNTEERING PRIVATE SCHOOL PLACEMENT. AS MR. FLANDERS INDICATED, HIS CHILD GOES TO A PRIVATE SCHOOL, AND UNDER THE LATEST VERSION OF I.D.E.A., IT HAS MADE IT VERY DIFFICULT FOR PARENTS TO RECEIVE SERVICES IN SOME COMMUNITIES FOR VOLUNTARY PRIVATE SCHOOL PLACEMENTS.

LORETTA PETTY: I CAN ANSWER THIS QUESTION. I THINK SEVERAL OF US HAVE MULTIPLE ANSWERS OR DIFFERENT ANSWERS. AS FAR AS THE DEPARTMENT OF EDUCATION, WE ARE IN THE EARLY STAGES OF THE REAUTHORIZATION OF I.D.E.A. -- I'M SORRY, NATE. WE ARE IN THE EARLY STAGES OF THE REAUTHORIZATION OF I.D.E.A., AND WE HAVE HAD A NUMBER OF FORUMS ACROSS THE NATION TO RECEIVE INPUT FROM PARENTS, PROVIDERS, ADMINISTRATORS, ET CETERA. AND THAT IS ONE OF THE ISSUES WE HAVE HEARD AT THE FORUM. WE WILL BE CONSIDERING ALL OF THE ISSUES THAT WE HAVE HEARD AT THE FORUM, THAT WE'VE RECEIVED DURING THE NOTICE FOR PUBLIC COMMENT IN THE FEDERAL REGISTER, AND OTHERS. CERTAINLY IF YOU HAVE COMMENTS TODAY, WE WILL BE CONSIDERING ALL OF THOSE AS WE MOVE FORWARD WITH THE REAUTHORIZATION OF I.D.E.A..

THANK YOU.

JOHN FLANDERS: I'M GOING TO STEP OUT OF MY PARENT ROLE HERE AND INTO MY ADVOCATE ROLE, BECAUSE THERE IS AN ISSUE HERE THAT CONCERNS US VERY MUCH. THAT IS WITH THE TREND TOWARDS PRIVATE SCHOOL VOUCHERS IN THIS COUNTRY. THE COURTS HAVE GENERALLY RULED THAT EVEN IF A PUBLIC SCHOOL IS PAYING FOR YOUR ATTENDANCE AT A PRIVATE SCHOOL, IT IS A VOLUNTARY PLACEMENT IN A PRIVATE SCHOOL. SO WHEN YOU GET A VOUCHER AND TAKE ADVANTAGE OF IT, AS FAR AS WE CAN TELL UNDER THE CURRENT LAW, YOU'RE VOLUNTARILY OUT OF SPECIAL EDUCATION AND PERHAPS WAIVING YOUR RIGHTS ON THAT, DEPENDING ON WHERE YOU ARE.

THAT'S AN ISSUE OF VERY SERIOUS CONCERN TO US. IT NEEDS TO BE ADDRESSED IF THIS TREND IS GOING TO CONTINUE.

AUDIENCE: I HAVE A QUESTION THAT'S DIRECTED AT MISS PETTY. I'M FROM COCHLEAR AMERICA. WE SERVE SOME OF OUR FAMILIES TO ASSIST WITH THE REAUTHORIZATION FAMILIES. ONE OF THE ISSUES THAT CAME UP REPEATEDLY IS THE GAP BETWEEN PART C AND B, A CHILD TURNS THREE BUT THEY DON'T START SCHOOL UNTIL THEY'RE AT LEAST FOUR OR FIVE. SO A NUMBER OF PARENTS INDICATED THAT MY CHILD TURNED THREE AND EVERYTHING STOPPED.

AS AN ORGANIZATION THAT'S PROMOTING APPROPRIATE REHABILITATION FOR CHILDREN AND SEEING KIDS NOW IMPLANTED AT 12 MONTHS OF AGE, THEY NEED AT LEAST TWO OR THREE YEARS OF ONGOING THERAPY. THAT'S A REALLY SERIOUS GAP FOR FAMILIES. SO I'M WONDERING IF THERE'S ANY CONSIDERATION ABOUT EXTENDING PART C AT LEAST ONE MORE YEAR UNTIL THE CHILD'S FOURTH BIRTHDAY.

LORETTA PETTY: ACTUALLY, IF I MAY, DR. REYNOLDS IS HERE WITH THE OFFICE OF SPECIAL EDUCATION PROGRAM. SHE IS WITH OUR POLICY DIVISION AND CERTAINLY HAS THE BACKGROUND IN I.D.E.A.. DO YOU MIND ANSWERING THIS QUESTION?

DR. REYNOLDS: AS I UNDERSTOOD DONNA'S QUESTION, SHE WAS SAYING THAT WHEN CHILDREN TURN THREE, THEY WERE NOT GETTING

SERVICE. THERE'S TWO THINGS HAPPENING THERE. I WOULD ASK DONNA IF YOU KNOW A SPECIFIC SITUATION, YOU LET US KNOW, BECAUSE WE MIGHT BE ABLE TO HELP.

FIRST OF ALL, THE REQUIREMENTS UNDER PART C FOR ELIGIBILITY ARE DIFFERENT THAN UNDER PART B. A CHILD UNDER PART C WILL NOT AUTOMATICALLY BE ELIGIBLE UNDER B. THAT HAS COME UP. WE WILL BE CONSIDERING THAT COMMENT THAT WE RECEIVED JUST LIKE WE WILL OTHER COMMENTS DURING THE REAUTHORIZATION PROCESS.

HOWEVER, IF YOU HAVE A CHILD THAT TURNS THREE OR FOUR, WHENEVER THEY TURN THREE, IF THEY'RE ELIGIBLE UNDER PART B, THEY'RE SUPPOSED TO BE, WHEN THEY REACH THEIR THIRD BIRTHDAY, AT THAT TIME THEY SHOULD HAVE ALREADY HAD AN IEP MEETING AND EVERYTHING TAKEN PLACE. IF YOU KNOW OF CHILDREN WHO HAVE BEEN DETERMINED ELIGIBLE AT THREE BUT AREN'T GETTING SERVICE, WE NEED TO KNOW ABOUT IT. BUT YOU MAY HAVE SOME CHILDREN THAT WERE IN THE EARLY INTERVENTION PROGRAM THAT WON'T BE ELIGIBLE AT THREE, FOUR, OR FIVE UNDER PART B BECAUSE THEIR ELIGIBILITY REQUIREMENTS ARE DIFFERENT.

AUDIENCE: I THINK IT'S AN ISSUE, THE TRANSITION NOT OCCURRING THE WAY IT SHOULD. THESE ARE KIDS WITH SEVERE TO PROFOUND HEARING LOSS WITH COCHLEAR IMPLANTS WHO WOULD BE ELIGIBLE.

DR. REYNOLDS: DONNA WAS SAYING THAT THERE WERE CHILDREN WHO HAD COCHLEAR IMPLANTS AND OTHER SEVERE HEARING LOSS THAT WOULD BE ELIGIBLE UNDER PART B. IN THOSE CASES WHERE YOU HAVE A CHILD THAT IS ELIGIBLE AND THEY'RE NOT GETTING SERVICES, THEN WE NEED TO KNOW ABOUT IT BECAUSE AS WE MONITOR, WE HAVE FOUND SOME OF THAT, AND WE DO TRY TO MAKE THOSE CORRECTIONS. WE NEED TO KNOW ABOUT IT WHEN THAT HAPPENS.

PATRICIA ROTHSCHILD: I JUST WANTED TO ADD THAT MY EXPERIENCE CERTAINLY IS YES, THERE'S A DIFFERENCE IN ELIGIBILITY REQUIREMENT, BUT WE HAVE ALWAYS BEEN ABLE TO BE MAKE A VERY STRONG CASE THAT WHERE HEARING LOSS IS THE DISABILITY, THE NATURE OF HEARING LOSS IS THAT IT'S NOT GOING TO GO AWAY, ESPECIALLY A CHILD WITH A PROFOUND HEARING LOSS WITH A COCHLEAR IMPLANT. THE ELIGIBILITY SHOULD NOT BE AN ISSUE WHEN THE CHILD TRANSITIONS FROM PART B TO PART C. THE TRANSITION PROCESS IS A DIFFICULT ONE. THE NATURAL SETTING FOR A

PROVISION OF SERVICES IS INTERPRETED DIFFERENTLY. BUT IT CERTAINLY IS MY CLEAR UNDERSTANDING AND EXPERIENCE THAT IT SHOULD NOT BE AN ISSUE FOR SERVICES TO CONTINUE, AND IF IT IS, THE FAMILY NEEDS A STRONG ADVOCATE TO GET THE RIGHT EVALUATIONS THAT PROVE THE NATURE OF THE NEEDS, AND THEN TO FIND THOSE SERVICES. THERE SHOULD BE NO REASON WHY SERVICES SHOULD BE INTERRUPTED FROM MY UNDERSTANDING OF THE LAW.

MARTHA CARMEN: THANK YOU.

KELBY BRICK: I'M KELBY BRICK. MY QUESTION IS FOR MS. PETTY. YOU MENTIONED THE SPECIAL FACTORS CLAUSE OF I.D.E.A. AS BEING A VERY IMPORTANT CLAUSE WHICH SAYS THAT SCHOOL DISTRICTS AND THE IEP TEAMS MUST CONSIDER THE COMMUNICATION NEEDS OF DEAF AND HARD OF HEARING STUDENTS. IS THERE ANY DISCUSSION WITHIN THE DEPARTMENT TO STRENGTHEN THAT PART? BECAUSE RIGHT NOW, MANY IEP TEAMS INTERPRET THAT CLAUSE AS RAISE THE ISSUE, MENTION IT, AND THEN SAY, NOW WE'VE CONSIDERED IT, AND BE DONE WITH IT. THERE ARE NO REQUIREMENTS THAT THOSE SPECIAL NEEDS HAVE TO BE ADDRESSED, JUST THAT THEY HAVE TO BE CONSIDERED.

LORETTA PETTY: I UNDERSTAND THERE IS THE REQUIREMENT IN THE REGULATION. ARE YOU FAMILIAR WITH THAT? WE CAN PROVIDE THAT TO YOU, IF THAT WOULD BE HELPFUL. WOULD YOU LIKE THAT?

KELBY BRICK: I AM AN ATTORNEY WHO HAS REPRESENTED PARENTS IN THE IEP TEAM, AND SCHOOL DISTRICTS INTERPRET THAT AS, JUST CONSIDER IT. BUT THEY SAY, WE DON'T ACTUALLY HAVE TO ADDRESS IT; ALL WE HAVE TO DO IS JUST MENTION IT.

LORETTA PETTY: IF YOUR QUESTION MORE GENERALLY GOES TO WILL WE BE CONSIDERING IT DURING THE REAUTHORIZATION AS WE MOVE FORWARD, I WOULD GO BACK REALLY TO THE RESPONSE I MENTIONED EARLIER WITH THE FIRST QUESTION, THAT CERTAINLY TODAY, AND IF YOU ALL WANT TO TAKE A FEW MINUTES TO SHARE COMMENTS WITH ME, I WOULD BE HAPPY TO TAKE THEM BACK TO THE DEPARTMENT SO THAT WHEN WE MOVE FORWARD IN THE REAUTHORIZATION, WE CAN CONSIDER THESE COMMENTS AS WE HAVE FOR THOSE IN THE PUBLIC FORUMS, AS WELL AS THE ONES WE HAVE RECEIVED FROM THE NOTICE IN THE FEDERAL REGISTER. SO IF YOU HAVE SOME INFORMATION YOU WOULD LIKE TO SHARE EITHER NOW OR CERTAINLY SEND ME, I WOULD BE HAPPY TO SHARE THAT WITH THE STAFF TOO.

THANK YOU.

AUDIENCE: OKAY. I AM EILEEN BRISKIN FROM THE MARYLAND SPEECH AND HEARING ASSOCIATION. I'M SORRY TO DIRECT ALL THIS TO YOU. HOWEVER, I HAVE BEEN IN FORUMS SUCH AS THESE WHERE THE SUPERINTENDENT OF SPECIAL EDUCATION FOR A LOCAL EDUCATIONAL AGENCY STATED THAT IT WAS -- THAT UNDER I.D.E.A., THEY WERE ONLY REQUIRED TO PROVIDE ADEQUATE INTERVENTION AND NOT OPTIMAL INTERVENTION. AND I WOULD LIKE TO KNOW WHETHER OR NOT THAT IS THE APPROPRIATE INTERPRETATION FROM THE POINT OF VIEW OF THE DEPARTMENT OF EDUCATION.

CERTAINLY YOU WOULDN'T WANT THAT KIND OF ATTITUDE FOR ALL OTHER CHILDREN IN THE SCHOOL SYSTEM. YOU WOULD WANT THEM ALWAYS TO HAVE OPTIMAL EDUCATION. SO I WOULD LIKE TO KNOW HOW I.D.E.A. CAN BE INTERPRETED THIS WAY BY A LOCAL EDUCATION AGENCY.

DR. REYNOLDS: ACTUALLY, WHAT THE LAW CALLS FOR IS A FREE, APPROPRIATE EDUCATION. THE APPROPRIATENESS IS DETERMINED BY THE CHILD'S IEP TEAM. THERE ARE A NUMBER OF COURT CASES AS THE ATTORNEY OVER HERE CAN ATTEST TO, WHERE THERE HAS BEEN SOME CONVERSATION OF THE JUDGE OR DETERMINATION OF THE JUDGE WHAT THAT IS. BUT THE LAW TALKS ABOUT APPROPRIATE EDUCATION. SOME STATE LAWS HAVE OTHER WORDING LIKE MAXIMUM, FEASIBLE, AND WORDS OF THAT SORT, BUT I.D.E.A. HAS THE WORD "APPROPRIATE," AND THE IEP TEAM MAKES THOSE DETERMINATIONS.

MARTHA CARMEN: OKAY. THANK YOU ALL. WE HAVE TIME FOR ONE MORE QUESTION.

AUDIENCE: OKAY. I GUESS MY STATEMENT IS A COMMENT/QUESTION. YOU HAVE TWO CHOICES. FORCE STATES TO COMPLY, SUCH AS THE ATTORNEY WAS SAYING. AGAIN AND AGAIN, THE IEP PROCESS IS A STRUGGLE BETWEEN PARENTS AND PROFESSIONALS. SO EITHER THE LANGUAGE IN I.D.E.A. REAUTHORIZATION, IF THAT COULD BE MADE MORE CLEAR SO THAT THE LOCAL SYSTEMS UNDERSTAND, MAYBE BEING ABLE TO ASSOCIATE WITH PEERS, MAYBE HAVING TEACHERS THAT ARE QUALIFIED AND SO FORTH, SUCH AS WE'RE DOING IN MASSACHUSETTS, OR IF YOU INCREASE THE FUNDING OF I.D.E.A., WHICH I UNDERSTAND IS BEING CONSIDERED, THEN THAT WOULD BE A THREAT. I HOPE YOU WILL CONSIDER THAT.

MARTHA CARMEN: ANY COMMENTS FOR THAT?

LORETTA PETTY: MY ONLY COMMENT REALLY IS HE ASKED THAT WE CONSIDER HIS STATEMENT AS PART OF THE CONSIDERATIONS DURING REAUTHORIZATION, AND CERTAINLY WE WILL. THANK YOU.

MARTHA CARMEN: OKAY. ON BEHALF OF REPRESENTATIVES WALSH, CAPPS, RYUN, AND MCCARTHY, I THANK THE PANELISTS AND THANK YOU ALL FOR COMING TODAY.

(APPLAUSE.)

=====

LINK::

<http://web.archive.org/web/20031227084009/www.hearinghealth.net/pages/home/caucus.htm>

=====
=====
=====

A Discussion on the Deaf Culture

July 2002 Caucus Transcript

CONGRESSIONAL HEARING HEALTH CAUCUS PRESENTS:

A Discussion on the Deaf Culture

Wednesday, July 17, 2002

Rayburn House Office Building

MS. GRECO: Good afternoon, and welcome to the 5th Congressional Hearing Health Caucus presented by the National Campaign for Hearing Health. Please continue to enjoy your lunch. We will begin.

My name is Susan Greco and I'm the executive director of the Deafness Research Foundation. The Deafness Research Foundation sponsors the National Campaign for Hearing Health and is the nation's largest organization devoted to advocacy and research to hearing loss and health. Since 1958 DRF has been the leading source of private funding for hearing science awarding approximately 1800 grants totaling over 22 million dollars.

First I would like to acknowledge co-chairs, Representatives Jim Ryun, Jim Walsh, Carolyn McCarthy and Lois Capps. Today we have with us Representative Walsh, who will be speaking. And hopefully some of the other representatives will join us throughout the course of the luncheon.

Today's presentation, a discussion on the deaf culture, will provide a closer look at the lives, challenges and accomplishments of deaf and hard of hearing individuals. Deafness is one of the most prevalent, chronic health conditions in the United States. According to the National Institutes of Health, approximately 28 million Americans suffer from some form of hearing loss. One in 300 babies are born profoundly deaf. That is why this is such an important caucus panel. It is meant to illustrate the challenges that deaf and hard of hearing people face in terms of better integrating into a hearing society, access to education, communications and transportation as well as Civil Rights. DRF, being the largest private funder of hearing science, we advocate for access to incredible hearing technology available such as the Cochlear implants.

In the past few years it appears the line evidently dividing the culture and those who choose hearing have blurred. These two options do not have to be mutually exclusive anymore. Evidence of this adjustment is the Cochlear implant center at Gallaudet University as well as increased collaborations between deaf and hearing health organizations, especially with respect to mandatory infant hearing screening, also known as the early hearing detection and intervention. We are very anxious to learn more from each other and continue to work together to put

hearing health and access issues for deaf and hard of hearing individuals on the national agenda.

Now it gives me great pleasure to introduce Representative Jim Walsh, one of the founding co-chairs, who will be our moderator today, and he will introduce his fellow members as they enter. Thank you, very much, Congressman. We are glad to have you here and thank you for attending today.

MR. WALSH: Thank you, Susan. Good afternoon. It is great to have you all here today. We have had a number of these hearing health caucus meetings and they grow larger each time and more substantive each time. I think that is something we can be very proud of. The National Campaign for Hearing Health has been our caucus partner and I appreciate all their hard work in assembling these events. So thank you Susan and Lizzy, who have been a great help.

Today we are hosting a Capitol Hill first. This panel of distinguished speakers will educate us in issues facing the deaf and hard of hearing in a predominantly hearing world. I know of no other time that such a presentation has been made to Congress and I am pleased that we are breaking new ground here today. Our first speaker, Dr. Ben Bahan, Professor and Director of Deaf Studies at Gallaudet University and a prolific author on deaf studies and American Sign Language, he will open remarks on deaf culture.

Next, we will have Dr. Roslyn Rosen, also of Gallaudet University, a Professor of the Graduate of Administration and Supervision, as well as executive director of Council on Education of the Deaf. Dr. Rosen will discuss the Special Education needs of deaf children in the classroom.

Following her we will here from Claudia Gordon, a staff attorney at the National Association of the Deaf. She will discuss progress in the area of Civil Rights and what needs to be done in the future for the deaf and hard of hearing community.

And last, we will hear from Kelby Brick, also an attorney in private practice in Maryland, who has been with us at a number of these caucus meetings in the past. He is a legislative representative for Consumer Action Network. Kelby, who I have known for several years now, was instrumental in helping me write the language for the Newborn Infant Hearing Screening and Intervention Act, something I like to refer to as the Walsh Bill, which was signed into law in 1999. Kelby will speak on barriers to transportation. This panel will discuss the challenges faced by the deaf and hard of hearing community and offer solutions to these problems.

For those of us not regularly involved in issues facing the deaf and hard of hearing, we often take our hearing for granted. I remember -- and I probably mentioned this before -- when I visited Gallaudet University, we played a congressional basketball game against each other, Republicans against the Democrats. And after the game was over we have a reception at the administration building, beautiful hall there. And I remember crossing the

campus, losing my direction and stopping to ask someone if they could tell me which way to go. And, of course, they couldn't hear what I was saying. And I realized that I was a very distinct minority in this campus. And I felt a little like when I was a Peace Corps volunteer in Nepal, an English speaker trying to speak their language. And it is a wonderful way to gain empathy with people, to put yourself in their shoes for a little while. So you all understand that far better than most would. But I think these meetings go a long way toward understanding differences between the hearing and non-hearing community. This panel of professionals has incorporated other techniques to accommodate for the hearing loss and have succeeded even under some less than desirable conditions when visual cues are not posted or updated in a timely manner. I invite you to sit back and learn from this group, which will be followed by a question and answer period.

Dr. Bahan, you're the first speaker. Thank you.

DR. BAHAN: I would like to give you a little background about myself before I proceed with my comments. I was born hearing and I became deaf at the age of four. My parents are deaf and they grew up learning to speech read and lip-read and speak rather than to learn to sign. They both learned to sign later in life. So I had the opportunity to learn both sign and oral method. I have two children and I'm married to a deaf woman and both of my children are deaf. I guess I'm trying to establish who I am here and when I came into the deaf community I noticed there were a variety of different deaf persons. Some deaf persons became -- became deaf later in life, maybe at the age of seven or maybe at the age of 70. Some grew up signing and some group up in an oral environment. So there was a whole range of people that I met who are deaf. And I had to look at the needs of those people as well and they are equally diverse.

But one thing that we have in common all across the deaf community, regardless of where, when and how we lost our hearing or became deaf, we have become visual people. We have an increased dependency upon our vision. This is one thing that I want you to consider, that we are a visual people. One thing very unique about the deaf community and deaf culture, the community has been constructing over years a history of solutions, solutions to dealing with navigating the hearing world. Unfortunately, many times people in hearing society ignore the solutions that the deaf community has come up with. We have solutions and yet they seem to be pushed to the side. One thing I learned from my father that I would like to pass on to you, maybe you might benefit from these solutions, as I have, always maintain eye contact. It is very important. That is one basic solution. When leaving a room, always look back, just to check before you leave. Some very simple solutions that might alleviate some communication problems later.

Deaf people function in the world just as hearing people do. We learn how to read the world. My father taught me that. By "real the world," I have to explain what I mean. We have to look at others, and we have to look at other animals as well, because animals and people respond to sound. That means something is

happening. For example, I have a dog at home. My wife walks down the stair, my dog's ears perk up. I can know when someone is coming down the stairs by my dog. So I learn to read the world to compensate for my loss of hearing. The information is out there. It provides solutions; I just have to learn to read that. Communication, when you put language into the mix and you consider American Sign Language that has been developing throughout the years, has its own grammar and syntax and a huge community of users here in America. The community who shares a language and shares a visual need -- need for visual information, needs to make its way in the hearing world. And we encounter barriers in that every day.

Let me give you an example. I took my son, who is now four years old, four and a half years old, I have to emphasize the half part, as you well know, I went to a vacuum cleaner store to have my vacuum cleaner repaired. My son and I were sitting on the couch waiting for the customer service person to come out. We were just talking with each other. And we saw a very small vacuum there. And I thought, wow. My son thought it would be perfect for him because it was his size and he could play with it. And I said it is not to be played for, probably it is used for vacuuming small space. And the woman in the store came up to us as I was describing this to my son and he said, "I'm sure I can use it, dad. I know I can."

And while we were discussing this, the woman was looking at us and she finally turned to me and said, "Can he talk?" And I looked at her and said, "Well, we have been talking for a long time."

"No, no, no, no. Can we talk?"

And I thought, "Well, we have been talking. You don't get it."

"No, no, no. Can he talk?" And I looked at her and I understood what she meant, can he speak, can he use his mouth to perform utterances that become language. "Not yet," is what I told her, "but he will."

She had a look on her face with such pity. She walked off to the back, shaking her head sadly. And I looked to my son and he looked at me and said, "What is going on?" And I explained to him what was going on. "I told her we were talking with each other but she thought it was not as good as speaking."

He looked at me and said, "Can she sign?" And I looked at him and said, "No." And he looked at me and said, "Oh, poor lady." And he shook his head sadly.

Our community and our culture already have solutions. We have a way of life. We have a way of handling and navigating the world. And sometimes our ideas are not included in general society and we have to try to make fit there and a bridge -- and we have to bridge the gap. Now, these conflicts don't have to be there and these barriers don't have to be there. They can be worked out. If hearing people learned how to see, maybe they can benefit as well. Now, certainly if that person can benefit from hearing, but the chances of that are

much less. Thank you, very much.

MR. WALSH: Thank you, very much. Our next speaker is Dr. Roslyn Rosen. And she will discuss Special Education needs of deaf children.

DR. ROSEN: Thank you. I'm honored to be here to present to you this afternoon. My thanks to the committee and to the caucus for addressing this important issue.

My name is Roz Rosen. I wear several hats. I am a daughter, wife and mother of deaf people. I'm also a professor at Gallaudet University. I started as a teacher in the classroom before becoming an administrator. I have also served as the president of the National Association of the Deaf. Currently I'm a board member of the World Federation for the Deaf and Executive Director of the Council on Education for the Deaf, as well as a very proud grandmother.

My presentation will focus on deaf children and education options for deaf and hard of hearing children. I was born in the great State of New York to a deaf family and I can remember my first vision was of waving hands – sign language. That was the communication that my family used when I grew up. I noticed that other people didn't sign and I wondered what was wrong with them. This is the same story that Ben shared with you. I pitied those poor hearing people. I wondered what was wrong with them and I felt sorry for them because they weren't able to make the beautiful pictures in the air by waving hands like my family could.

I went to school in New York where I learned the basic academic subjects in a program with other deaf students. I had wonderful teachers. I attended Gallaudet University for my BA and MA degrees, and later I got my doctorate degree from Catholic University, here in Washington DC. So I have experienced various modes of education throughout my own life. I would like to begin by commending Congressman Walsh for sponsoring and helping to pass the bill on infant hearing screenings for early identification and educational intervention.

It is very important because the first step is always with the family of deaf children. The earlier the child is identified as having a hearing loss the better. However, the second important factor is the partnership that family has with the professionals and with the deaf community, as well as educators. And the deaf community has been working towards that partnership between the deaf community and the hearing families. There are all sorts of projects and studies that have been done. A couple of years ago I conducted a national survey of deaf adults who are leaders in the community asking their opinions about early identification and intervention and what their hopes and fears were with regards to those initiatives. And there were over 200 responses, which is a very good response rate. And the primary indication we got from their responses was the concern that there would be early identification but a lack of partnership between the hearing families and the deaf community. That is where education must

begin.

If we look at children's needs, educationally and socially, one of the initial needs is that the family accept the child as part of the diversity that is important, so very important in today's society. Whatever means and methods the family decides to choose as their preferences for communication, and there are certainly several available, and regardless of the means of communication, the child needs a role model; the child needs to be exposed to other deaf people in life. Many people are interested in sign language. They think it is beautiful or useful. Every year about 30,000 to 50,000 hearing people enroll in a sign language class in this country. Many hearing high school and colleges are offering sign language as an elective course nowadays, leading to good career opportunities. Offering sign language training is very important. It is also important not only to make it available to hearing people, but to deaf children and deaf students. Sign language adds to, not subtracts from, a deaf child's language growth. It has a multiplier effect.

I want to talk a little bit about the needs of children related to education. I could show you volumes of papers, reports, studies and surveys that have been reported. I brought just a few today with me to show you. Congress funded National Council on Education for the Deaf to study issues and recommendations; a significant report was published in 1988, which I have with me here today for you to see. There have been other reports since then. There was a report on inclusion and the effectiveness, or lack there of, of inclusion programs. There is a report on principles of education for deaf children. Communication must be the basis, must be the driving factor. Congress has funded a special research and study project to develop guidelines on education services for deaf and hard of hearing children. There is another publication here the National Council on Disabilities published a Back to School Civil Rights book which mentions we already have the laws but they need to be interpreted more effectively. We need them to be enforced, which means they need to be funded as well. I am glad President Bush and Congress is in support of increased funding for IDEA, both Parts B and C must be included there. Ninety percent of deaf children are born to parents who are hearing. There is a conflict right there in terms of like language and communication. The parents look at their deaf baby and may feel like they have a child from Mars, in terms of their first thoughts – “how will we communicate with him/her?!!”

Seventy percent of the school programs around the country that provide educational programs to deaf students in fact have only one or two deaf or hard of hearing children in the school system. That means there are many deaf children growing up very isolated, without role models and oftentimes without true peers. Again, the key is early identification and intervention and the provision of contacts and role models. I served on a panel in the heart of the U.S., in Kansas, where we talked about deaf education and a bilingual, bicultural education model. One question came from a mother in the back of the room who said she had two hearing boys and a deaf toddler. She was worried about the toddler, and what would happen to her when she grew up. Who would take

care of her? Would she be able to care for herself? I responded, "Are you equally worried about your other two children?" She said, "No, I'm sure they will be fine. But my daughter is deaf." That disconnect was telling to me. I said, "Rest assured, your daughter will not want to live with you for the rest of her life, just as your sons won't. She will learn how to communicate and she will be able to succeed and be independent and happy. You need be able to communicate with her. Read books and make sure she grows up as a well-rounded person. The mother responded with a great smile, "I am so glad to hear that!! I am so glad to meet you, a deaf adult who is doing well." Without that kind of exposure and knowledge, what can hearing parents expect for their own deaf children?

President Bush is advocating an initiative "No Child Left Behind". Before that we had America 2000 and Goals 2000 and various other initiatives. All of which come down to one simple line: Children must be able to start school ready to learn; they must graduate from school on grade level. I commend the initiatives and the support they are getting, but we need to consider specifically how we are going to get there. The National Association of the Deaf has published position papers and working various subcommittees here on the Hill to make sure IDEA is interpreted correctly to provide the most appropriate placement and environment for the deaf child, though consideration of that child's individual needs through the Individual Education Program, the IEP. What does that mean for a deaf child? Deaf children are already isolated too often in the inclusive mainstream settings. We need to consider the environment where the child is for their education. We need to make sure the environment is appropriate. When we consider the least restrictive environment, we need to consider what that means in terms of academic and social development for the child. There needs to be a critical mass of peers who function on the same grade and language level in order that the child can communicate with their peers. The process and the environment must be child-centered. IDEA was amended in 1997 to look at the Natural Environment for deaf children, in addition to instructional issues, which are both, critically important. I would like to spend just a moment on the three A's, as I call them, required for a quality education. Access, accountability, that is, accountability for results, and achievement. That is basically what the Special Education Commission report came out with. I think it came out just this month. So what does that mean? Well, again, it indicates the importance of people, such as ourselves, being involved in understanding this process. When we look at the issue of interpreters, we must understand the critical need for qualified interpreters for authentic access. Let me share with you a story about an interpreter and a situation that, unfortunately, that many parents face. This anecdote is not unusual, unfortunately, and indicates the need for further work, training and funds. A woman who worked at Kmart -- and I certainly don't mean any offense to Kmart, but this happened to be where she worked -- She was a cashier and had taken one or two sign language classes. There happened to be a deaf child with a hearing mother who came to the store and the cashier recognized that and signed a bit to the child. The mother was thrilled to find this cashier who knew sign language and she said, "My daughter is in a mainstream setting and they can't find an interpreter. Can you be a interpreter work in the school system with her?" The clerk explained she only

had basic signing skill. She had no training to be a sign language interpreter. The mother was so desperate she convinced the young woman to take a position with the school system where she then served as a so-called interpreter. This anecdote led to us in the deaf community to coin the phrase "a Kmart interpreter," meaning this woman was not qualified, but too often we find interpreters at this level without training, without credentials, without the basic qualifications getting into the system and interpreting for our children.

Many of us are getting older, although not all of us, just those of us who are part of the baby boom who are looking towards retirement in the next few years. However this is a huge number of people who will be leaving the field. We expect an exodus leaving the field of education. One of the things we must consider is recruiting and retaining many new professionals to work with deaf students. They will need training and to be certified. The system must be accountable for the results. That means personnel must be qualified and capable as well as personnel must be available to serve as role models for deaf children. Deaf children also need deaf teachers.

Achievement depends on those partnerships that I mentioned previously. We are now working on a national agenda with various organizations of and by deaf people to identify what we would like to see accomplished with education of deaf and hard of hearing children. The bottom line is certainly equality for all. I would like for us to look at the concept of "habilitation" rather than rehabilitation. Instead of analyzing costs to educate a deaf child, please keep in mind the tremendous costs of rehabilitation and welfare if the child is not appropriately educated in the first place. That is the thrust of my message this morning. Thank you.

MR. WALSH: Thank you, Dr. Rosen. She was not kidding about the piles of studies. She came equipped. As I mentioned earlier, our next speaker will be Claudia Gordon, who is a staff attorney with the National Association for the Deaf. Kelby Brick will follow her. I am going to leave now so I will introduce them briefly again both and they can follow after each other.

Claudia Gordon will discuss progress in the area of Civil Rights and what needs to be done in the future with the deaf and hard of hearing community. And Kelby will speak in areas of transportation. First, Claudia Gordon.

MS. GORDON: Good afternoon representative Jim Walsh, Martha J. Carmen and distinguished members of the congressional hearing health caucus. Thank you for inviting me to participate on this panel. I am a staff attorney at the national association of the deaf law center. The national association of the deaf is the nation's oldest and largest consumer organization whose mission is to promote, protect, and preserve the rights and quality of life of deaf and hard of hearing people in the United States of America. The national association of the deaf law center has been at the forefront of the civil rights movement for over two decades creating and enforcing rights to ensure equal access for people who are deaf and hard of hearing.

While I will speak about civil rights law and the need for enforcement, I also wish to provide you with some information about my personal background because of the interrelationship with disability civil rights laws. I grew up in Jamaica, West Indies, where 'rights for people with disabilities' is a foreign term. Equal access, inclusion and integration of people with disabilities into mainstream society are still a far cry from becoming anything close to reality. I lost my hearing at the age of 8. In spite of the fact that I was a bright pupil prior to my deafness, my deafness became a reason for my family to determine that I was no longer educable thus kept me home from school to perform domestic chores. Thanks to my mother who scrub floors and wash other peoples laundry to earn enough money to get me to this country so I could have better opportunities. I thank and applaud this country for enacting laws such as the Rehabilitation Act of 1973, the individuals with disabilities education act, the Americans with Disabilities Act and the Telecommunication Act - - that clear the path leading to my success and the success of countless of other deaf and hard of hearing individuals. My point is, perception of deaf and hard of hearing people as being defective, incapable and burdensome to society whose defect must be cured does have severe consequences to the individual and to society. I, we -panelists- are living proof that if enough doors are jarred open, support given and the right tools and opportunities are made available, deaf and hard of hearing people can and will become independent self sufficient individuals making significant contributions to society. Thanks to the civil rights laws safeguarding the rights and access of people with disabilities. So much progress have been made as a result. Yet, much more is left to be done especially by way of adequate and effective enforcement of already existing laws.

The NAD law center know first hand the severity of the problem plaguing the u.s. department of justice, civil rights division - disability rights section. Investigations can sink a claim. In many cases the experience of our clients had with DOJ has felt like a second experience of discrimination rather than a vindication or even fair review. We have not had one positive result arising out of a DOJ complaint in the past ten years. We don't know if the problem is the investigators or if it is that DOJ is simply overwhelmed. We don't always expect to win, but our client's cases are important and should be reviewed fairly and in a timely manner. DOJ has not met with any of our clients regarding complaints we filed or they filed, yet often times, the respondents are interviewed either orally or in writing. Years pass after filing without any correspondence from DOJ. Statutes of limitation pass and still DOJ has not investigated.

Notably, there are cultural nuances that DOJ, EEOC and other departments must take into consideration when dealing with cases involving deaf individuals. They should be afforded an opportunity to explain their story of what happen in a language comfortable to them. If given an opportunity at all, they are most likely asked to communicate in writing - take for example one of our client who filed DOJ complaint against a doctor who refused to provide a qualify sign language interpreter and instead insisted on communicating in writing. DOJ sent this deaf complainant a letter demanding that he explain in writing why he cannot

communicate in writing. These sentiments echo true for other enforcement agencies as well, the EEOC, dept. Of ed., HUD, DOT all causing an erosion of confidence in the process. For actual enjoyment of the rights promulgated under ADA, 504, idea, etc., and because leadership and attention to enhancing the civil rights enforcement from the administration and congress are critical to improving the enforcing of laws that are designed to correct discriminatory practice, we propose the following recommendations:

- Adequate funding of enforcement agencies. Disability rights section of DOJ is wholly under funded a 2001 research showed that EEOC has had only one budget increase to speak of in the past 20 or so years. Yet, under title I of ADA if you feel you've been discriminated against by an employer because of a disability, you are to first file a complaint with EEOC then a lawsuit. The perception is that EEOC has never been funded well in the first place in order to do a thorough investigation of discrimination complaint yet receive no additional resource with the passage of ADA.
- Ensure quality and adequate staff available to perform the necessary task for efficient enforcement. [intake, investigative and mid-management]
- Allocate resources to training of staff. Those who work to improve compliance must be up-to-date with judicial policy development and be able to apply the law consistent with its interpretation.
- Take a leadership role in identifying the implication of recent Supreme Court decisions that have limited the force of ADA. What do these decision mean for the future of section 504 as well as the ADA itself which was once hailed as the most significant civil rights law ever enacted for people with disabilities. Congress should take necessary steps to curtail further erosion of ADA.
- Establish compliance standards that if not met, would result in a compliance review. Recipient of federal funding are still very not making their programs, services and activities accessible in spite of their 504 obligations. Hence the problem with DOJ as earlier described hamper vigorous enforcement and sanctions.
- Outreach to hard to reach consumer groups. Language barrier still keep many deaf and hard of hearing individuals especially those who are ALS members of other minority groups, in the dark as far as their rights under the various civil rights laws are concerned. Funds must be made available for outreach efforts to such communities and outreach must be provided in language accessible to such communities.
- The NAD law center welcome an opportunity to address our specific concerns with the department of justice regarding deaf and hard of hearing community. Certainly, we would appreciate the opportunity to be involved in developing solutions.

Thanks again Rep. Walsh - for the opportunity to speak this afternoon. It's an honor and a privilege.

MR. BRICK: Good afternoon, everyone. My name is Kelby Brick. I'm an attorney in private practice. I'm also a legislative consultant with the Consumer Action Network, known as CAN, which is the national group representing constituent groups of deaf and hard of hearing people. We already have gotten an overview of various issues and groups in the deaf and hard of hearing community who make up that community, the richness and diversity of that community. You have heard a bit about the importance of education and how that has the biggest impact on the ability to succeed. You have heard a little bit about Civil Rights and I would like to take it a step further and talk specifically about transportation issues. I would like to tell you a story. A friend of mine went to Dulles Airport and arrived a bit early and was planning on taking a flight to Southwest Virginia, which would have been a pretty short flight, less than an hour. He went to the gate and informed the gate attendant that he was deaf and that he was there for boarding and he was directed to have a seat and wait for boarding. At about the time the flight was to take off, he saw everybody else in the gate get up and leave. Now, if you remember Ben Bahan mentioned we are a visual people and we depend upon visual cues; he called it reading the world. My friend saw everyone else get up and leave so he figured it was time to board the plane and he had his ticket, he got in line, he took his seat. After a while, once they were airborne, he looked out the window and noticed water. There was water on the right side of the plane. In fact, it was the ocean. And he thought to himself, "I was heading to Southwest Virginia; there should be no water on the side of the plane and if there were, it would be on the left side, not right side." And he began to wonder of. After a few minutes he got a bit worried. He called the flight attendant over and asked, "Is this not the right ticket for this flight?" The flight attendant said, "Oh, my goodness, this flight is going to New York." Well, to make a long story short, instead of the less-than-hour-long flight that my friend expected -- a town in Southwestern Virginia, he ended in being in various flights in the next 12 hours that landed not only in New York but also took him to Cincinnati. Apparently what had happened is there were technical problems at the one gate so they moved his flight to a different gate and were boarding his flight from an entirely different gate. The flight was postponed but there was no information to alert him to that fact. Not only did the gate attendant not alert him, but also in addition there was no visual information. All he got for it was a coupon for a free glass of wine. A deaf/blind person I knew who travels a lot and from time to time when he goes to the gate he will still is told by the gate attendant, "I'm sorry, you can't fly."

"I have my ticket."

"I'm sorry you have to have someone with you to accompany you."

"Wait a minute. I have my ticket. All I need is someone to guide me to my seat. I do have someone meeting me at the end of my flight and I need someone to guide me to my seat."

And too often he still hears, "I'm sorry, you still won't be able to fly."

Many hard of hearing and deaf people commute or fly regularly and we are usually able to take flights where there are movies shown, but they are not captioned. So the in-flight entertainment is not accessible to deaf people. There are plenty of other anecdotes I could share this morning that boil down to the problem there is legislation requires access, the Air Carrier Access Act is in existence but the law is only as strong as the enforcement provides. And right now that provides almost no enforcement. There have been studies and recommendations, which have been long-standing, looking at issues of Civil Rights for the deaf community, which have not yet been addressed. Right now people who are discriminated against have no right of private action by the airline industry. We are hoping that time, staffing and funding will be provided to follow through on these issues but it hasn't happened yet.

We worked with the Department of Transportation to identify improvements that can be made. The Air Carriers Access Act needs to be amended to provide for attorney's fees. Without attorney's fees individuals find it hard to get representation on a pro bono basis for some of these issues. Other Civil Rights legislation does include attorney's fees. The Civil Rights Act of 1964 and others provides for punitive damages, attorney's fees, right for private action. These things currently don't apply to the Air Carrier Access Act. We need to clarify that with an amendment. And that is not just -- for air transportation.

More and more people commute by rail or on buses. Just a few months ago a person thought she was at the right stop but it was dark. She got off only to realize she had gotten off at the wrong stop and the train already pulled from the station. There were no visual cues. The only information was over a loud speaker on the train. And she had no access to that information, no access. Throughout the transportation industry, we have transportation providers telling us, "I'm sorry, it is not our responsibility. We are to provide access. As long as you can get in we have met our needs." What does access mean? It is not just the traditional need that we have today on getting on to the plane. But people who have hearing loss, people who can't hear for other reasons because of noisy environments, what we need to improve access in the transportation industry is visual cues, visual signage to ensure access for issues in America for the transportation services. There are some laws out there currently, but right now there is not sufficient means of enforcement.

The few people in government who are responsible for enforcing these laws are not being effective. They don't have the power to pursue issues these laws provide. When we begin to look at enforcement, we will be able to pursue our goals of having equal opportunity for everyone in America and pursuing the life, liberty and happiness that are due. Thank you.

SPEAKER: Good afternoon. I work for Congressman Walsh. As you know, he had to leave for another commitment. We will have a question and answer period now. We will run that for about 15 or 20 minutes. Before we do so, I would like to recognize two people. One is Kari Fantasia, National Campaign for Hearing Health. She was helpful in putting together this program. And Jan Graves who was also helpful in putting together the program. So I wanted to make sure you were aware of them. In addition the transcript of today's event will be available on the National Campaign's website, which is HearingHealth.Net, will be available in two weeks. I would like to ask our panelists to come up front to field questions from the audience.

MODERATOR: Do we have anybody for questions for our panel here? In the back.

PARTICIPANT: I was wondering if anybody could speak to the issue of Cochlear implants.

MR. BRICK: I'm sorry. Who was speaking? Can you raise your hand?

PARTICIPANT: Sorry. If someone could speak to the issue of Cochlear implants and I was reading in your literature that there was some barriers to access to Cochlear implants. If you had any ideas on what Congress could do to improve access to Cochlear implants?

DR. ROSEN: I don't know what the barriers might be to access to Cochlear implants. Maybe someone else can speak to that specifically. The National Association for the Deaf has produced a position paper available at our web site, NAD.ORG. And the position paper indicates that the parents need certainly to have the right to choose what approach they will use for the hearing health of their child. But the child must have access to visual information, whether that is sign language, whether that is some other means of communication. But too often we find the socioeconomic status of deaf people are lower than average. Just recently there was a study done showing very few people of color get Cochlear implants relative to the majority population. Issues of insurance programs and various health benefits being available to people come into play there. Deaf people would like insurance companies also to cover hearing aids, which too often today is not being done. I feel strongly that hearing aids have become more and more sophisticated with digital technologies and are less invasive than other means of medical technology. It is a good question. I would start there.

MODERATOR: Any other questions?

PARTICIPANT: Pardon me. This is for Mr. Brick. My Senator is on the Senate

Committee for Congress Science and Transportation. Spoke to the need of an amendment to the aviation -- access to aviation. I believe it was. Do you have -- does the group have any sample legislation or sample amendment that they would specifically like to be seen and have any of the Senators on the Senate side, have they already taken up this issue or any other legislator have specific legislation written up, something that can be shown to my senator?

MR. BRICK: I am glad you asked. No legislation has been introduced that specifically addresses this area. However, we have been in touch with various legislators and we do have some sample language that I would be more than happy to share with you. I would happy to meet after the Q and A session and exchange business cards.

MODERATOR: Other questions?

PARTICIPANT: I'm going to use the interpreter. I heard you talking about many laws that we have that should be benefiting people with hearing loss. What recommendations do you have for people with hearing loss and for members of Congress to make those laws more effective?

MR. BRICK: I'm sorry. I want to clarify your question. Can you help me understand it better?

PARTICIPANT: We already have laws but they are not working. What can we do to make them more successful for us?

MS. GORDON: I touched on the need for increased funding for enforcement issues in part of my presentation. Too often we find that various federal agencies that have oversight and enforcement responsibility suffer from a tremendous backlog. In my experience that the NAD will file a complaint and sometimes it takes years before the client even gets a letter acknowledging receipt of complaint. I'm not talking about investigation; I'm talking about acknowledging receipt of their complaint. Justice delayed is justice denied. So first we look at funding and then specifically oversight responsibility, training of the staff that are tasked with enforcement, ensuring standardized enforcement. As well as appropriate interpretation of the laws and keeping the staff up to date to be aware of new rulings, new policies, regulations, outreach to members of the disability community to make sure they are aware of their rights. Kelby, do you have anything to add?

MR. BRICK: I think we can summarize it in four different areas; funding, funding for enforcement by the government agency that is responsible for that, language that would permit enforcement of those laws, language allowing private action by individuals and then legislation that would overturn recent decisions handed down by the Supreme Court that limits the scope of the Americans with Disabilities Act.

MODERATOR: Okay. Is there another question from the audience? Okay.

Well, thank you very much for coming. We appreciate your attendance and I want to thank our panelists for an outstanding job.

=====

LINK::

<http://web.archive.org/web/20040303214556/www.hearinghealth.net/cms/index.cfm?displayArticle=88>

=====
=====
=====

CONGRESSIONAL HEARING HEALTH CAUCUS PRESENTS:
Cochlear Implants Past, Present and Future
Wednesday, April 30, 2003
Rayburn House Office Building

Ms. Greco: Thank you very much for coming here to the National Campaign for Hearing Health's Congressional Hearing Health Caucus. My name is Susan Greco and I am the Executive Director of the Deafness Research Foundation. The Deafness Research Foundation sponsors the National Campaign for Hearing Health and is the nation's largest voluntary health organization devoted to research and public education related to hearing loss and hearing health.

Founded in 1958, DRF has been the leading source of private grants for hearing-related research in the United States. These grants have led to significant accomplishments. In fact, DRF funded one of the first investigations which led to the development of the cochlear implant and continues to support projects related to cochlear implant technology.

I would like to acknowledge the American Academy of Audiology for their co-sponsorship of the Caucus forum. I would also like to acknowledge the Congressional Hearing Health Caucus co-chairs: Representatives Jim Walsh, Jim Ryun, Carolyn McCarthy and Lois Capps, and thank them all for allowing the National Campaign for Hearing Health to make this presentation. Mr. Ryun came in briefly earlier to wish us his best. He apologized for not being able to stay longer, but he had joined us briefly. And I see that Ms. Capps is joining us today and welcoming you to the Congressional Hearing Health Caucus.

Today's presentation, entitled Cochlear Implants Past, Present and Future, will focus on the technological advances and reimbursement issues surrounding the cochlear implant. Specifically, our presenters will discuss cochlear implant technology as an option for individuals with severe-to-profound hearing loss. Although there are approximately 500,000 to 725,000 Americans with severe-to-profound hearing loss that could benefit from cochlear implants, the National Institute on Deafness and Other Communication Disorders estimates that there are only 59,000 cochlear implant recipients worldwide.

This afternoon we are going to hear from two Manufacturers of cochlear implants and discuss the technology, accessibility and benefits of the cochlear implant. And now it gives me great pleasure to introduce Representative Jim Walsh, one of the Congressional Hearing Health Caucus founding co-chairs, who will be our moderator today and will introduce his fellow members. Thank you Congressman.

Representative Walsh: Good afternoon. Welcome. It's great to have everybody here. This, I think will be a very interesting meeting for all of us. It's certainly

something that we need to learn more about, as it relates to federal policy. I'm delighted to see Lois Capps here. Jim Ryun, as was mentioned, was here earlier and hopefully he had a chance to speak with you.

Anyway, this is a very exciting place to work, as you all know. Susan, thank you for the kind introduction, and I'm pleased to be here to discuss the significant advances of biomedical engineering, specifically cochlear implants. First I'd like to thank the Deafness Research Foundation and the National Campaign for Hearing Health, as well as the American Academy of Audiology for sponsoring the luncheon. I would like to thank and recognize my co-chairs, Representative Ryun, Representative Capps and Representative McCarthy, who I don't believe is here. They have all been very active in this Congressional Hearing Health Caucus.

I'd also like to thank our special guests today, Alfred Mann who is, I see, with us today and also Donna Sorkin. Donna is here. Hi, Donna, good to see you. I'd also like to acknowledge for the record and for those who know her, Martha Carmen, from my office, who was instrumental in putting this together, had a car accident the other day. She is in the hospital, but she is okay and she expects to go home tomorrow. So if you'd like to contact her, we have her address and it is in my office. You can send her a note or give her a phone call. I think she'd appreciate that. Anyway, she is here in spirit for us and she has done so much to make this happen.

Breakthroughs in hearing research over the last ten years led to increases in early hearing detection and intervention as a result of legislation and advocacy efforts by organizations such as the National Campaign for Hearing Health and others here today. These developments have allowed for the identification of more children who may benefit from cochlear implants during recent years. I became involved with hearing health over a decade ago when I received a letter from a constituent regarding the prevalence of hearing loss and related educational and developmental issues. In 1989, when I began working in Congress to create this program, only three percent of all babies in the U.S. were being screened and there were only three hospital-based screening programs in the entire country.

In 1999, ten years later, we passed federal legislation that I sponsored, creating the Newborn and Infant Screening and Intervention Program. The bill created a program through the U.S. Department of Health and Human Services to assist states in establishing programs to detect and diagnose hearing loss in every newborn and to appropriate treatment and intervention for those diagnosed with hearing loss. Since the program's inception, approximately 69 percent of all newborns are now being screened through programs in approximately 2,200 hospitals and 22 states and the District of Columbia.

Significantly, when we met last year there were people from five or six other countries who were coming to learn about this program and what they could do in a global effort. So it's really exciting to see and you are all very much a part of

this, and we very much appreciate it. The program's creation states that voluntarily implemented statewide programs are eligible to tap into resources to support the operations. One in every thousand infants born in the U.S. today has a severe or profound hearing problem. Cochlear implants, coupled with intensive post implementation therapy, can help young children to acquire speech, language and developmental and social skills. The best age for implementation is still being debated, but most children who receive implants are between 2 and 6 years old. Earlier implementation seems to perform better.

According to the Food and Drug Administration, 2002 data, I think Susan just alluded to this, more than 59,000 individuals received cochlear implants worldwide based on estimates of prevalence of hearing loss. In the U.S. alone there are between 200,000 and 500,000 additional cochlear implant candidates.

Before I introduce our first speaker, I'd like to ask Lois Capps if she'd like to come up and weigh in on this very important issue. Thank you.

Representative Capps: Thank you all for being here, coming to where I now work. I feel like this is a collegial setting for me as a member of Congress, But going way back to all the years I was a school nurse in a local school district, I didn't have to be talked into joining the Hearing Health Caucus. The Hearing Health Caucus is a natural extension of my previous work with children and their hearing needs; the screening, the interests of providing access to treatments and care.

Hearing loss affects 28 million people in the United States, and of this number we know 12,000 are newborns. Screening is the key and as one who was mandated to screen, as schools are now, from kindergarten on, we realize we are missing a whole age group, and the ways of filling in those gaps is really important.

I want to also pay recognition to Mr. and Mrs. Mann and to call you our national treasures. There are other technological advances made by other companies, but the fact that all through the years, and now it's Bionics in various mutations and aspects, you have continued to pursue this effort. It is just the best of what we have in this country, in the way of creativity and ingenuity, and if we are able to harness that, hopefully we can take your advances, make them available to more people and work for our goal, which is to reduce the number of people living with hearing loss, and to help those that are to live normal lives starting at a very early age. I know there are many other people here too, with many skills to offer, but because you are not actually in my congressional district, but you are close enough, by that I consider this a partnership that is really important.

But back to early diagnosis, which is really a key to how we can get a handle on this situation. So many opportunities are possible when early diagnosis can happen. Last year, 69 percent of all newborns were screened for hearing loss. This year, 80 percent. Now that is the right direction and we should just keep going in that direction until it is 100 percent. I know that is what this caucus is

about and I praise you my colleague, Mr. Walsh, for your leadership and perseverance in making sure this can happen.

We also need to continue with our efforts toward technological advances to address these known deficits in hearing. Cochlear implants are an important innovation, as we have been hearing about them and will be hearing about them this afternoon. The demand for cochlear implants increases by 20 percent a year. But our reimbursement rates don't keep up, and that is the important challenge of your presence, being here today and motivating us to do something about this. I believe our reimbursement rates are too low to make it more accessible or accessible enough for our population. Medicare and Medicaid reimburse about 40 to 50 percent of the costs and usually that translates into what insurers will also reimburse. Many people think that this is an insurmountable barrier, and that is a real deprivation on the life of that newborn who has been screened and who would be appropriate to receive a cochlear implant. So we need to do our part, I believe, and raise the reimbursement rates so that access to implants can be there for every individual for whom it could make such a difference in their lives. Actually, we would recoup the investment very early on and this is what we are committed to. I salute my colleagues, representatives Jim Ryun, Jim Walsh, Adam Schiff, and Senator Harkin. The leadership is there. Your motivation is inspiring us and we'll continue to do the good work on your behalf, so thank you very much for introducing me.

Representative Walsh: Thank you very much for your continuing involvement in health care, and especially this issue, which has brought us all together. One of the remarkable things about working in Washington is the people that you meet and the ideas that you come across. I've heard it sort of caustically said, "Washington is Hollywood for ugly people." I would prefer to think that Washington is the Wall Street for policy ideas. You come across great ideas here, and they obviously spring from great people.

One of the really neat people I've met since I have been in Washington now is Alfred Mann, and his wife who is a great, great activist also. Al is CEO of Advanced Bionics Corporation since 1994. Advanced Bionics is a manufacturer and distributor of cochlear implants for the restoration of hearing, and is introducing a broad range of neural stimulation systems. He also serves as chairman of the board and chairman of the executive committee of Mankind Corporation, a diversified pharmaceutical company focused on the development of novel therapeutics and drug delivery technologies. Since 1998, Mr. Mann has served as a trustee for the University of Southern California, and is a member of the board of overseers of the CAC, University of Southern California School of Medicine.

Mr. Mann has also served as the chairman of the Southern California Biomedical Council, a nonprofit association dedicated to fostering the biomedical industry in the Los Angeles area. Mr. Mann holds a B.A. and M.S. in physics from the University of California. He is a former rocket scientist and holds an honorary doctorate degree from the University of Southern California. The Johns Hopkins

University and Western University have also given him honorary doctorate degrees. Mr. Mann is a member of the National Academy of Engineering and received numerous honors, including Father of the Year from Juvenile Diabetes Foundation 1998, Fellow of the American Institute of Medical and Biological Engineering in 2000, and Business Person of the Year award from Los Angeles Business Journal in 2003. So without any further ado, I'd like to introduce to you, Alfred Mann. Al.

Mr. Mann: Thank you, Jim. Thank you, Lois and thanks to all of you for joining us today. What I'd like, I was asked to talk about mostly, was some of the reimbursement problems that we have in this industry which really are a challenge to us, because if there were ever any therapy that made sense and made such a difference in people's lives and, frankly, saves money, it is really this one. So I'm going to talk a little bit about just a very brief overview of a little technology, and since we couldn't provide any slides for you or any PowerPoint, I've handed out, and I hope you all have copies of, the PowerPoint fliers.

Advanced Bionics is, principally, today the only U.S. company manufacturing cochlear implants, and we also are developing and introducing a whole series of neural stimulators for, for example, continuing urging incontinence, for spinal cords, for treating pain and one of the other interesting things we are doing is developing a visual prosthesis for blind people. As we said a few years ago, if we could really create good quality hearing for people, shouldn't we try to also help the blind people? And we have now implanted our third first generation device and interestingly enough, these people are seeing. The third patient we just turned on a few weeks ago, and we put in front of her a knife, a fork, a spoon, a plate and a cup, and we asked her what she saw. And she said, "a knife, a fork, and a spoon, a plate, and a cup, oh, that is a plastic cup," she said. Isn't that neat? So, today we are here to talk, really, about cochlear implants and what they can do. If you will look, one of the charts you have shows a comparison of a group of 47 people who were just selected, people who are severely or profoundly hearing-impaired, and what, for these people, hearing aids can do and what cochlear implants can do. If you look at that, it doesn't take very much to see that these devices do a great deal and we've made enormous progress.

But first let me say what a cochlear implant consists of today. First of all, there is a microphone they usually wear in the ear level thing behind the ear. That is where you have a microphone. It sends the information to a circuit in this device that processes the sound and then sends it, conducts it, to a little transmitter that is worn right nearby, and transmits the sound through the skin to an implanted device which then conducts the energy to a series of electrodes placed in the inner ear or the cochlea. And it tends to simulate sound. Now I've read in many journals, and sometimes very respected journals, who speak of cochlear implants, and they say they don't really produce sound. They produce some kind of queues that help people with lip-reading or whatever. I've got to tell you that information is a decade or decade-and-a-half obsolete. It is not true. Today, we are producing pretty good quality hearing, and with a recent system that our company's introduced, people are hearing music and enjoying music.

Last Friday night, here in Union Station, there was a meeting here in town of cochlear implants, and we brought in one of our patients, one of our better patients. This fellow is a 50-year-old guy who used to be a professional singer and guitarist, not a star, but a guy who earned a living at it. When he went deaf he lost his career. We implanted him. He was there at this meeting, at this party, and he and two others from our company were playing music for us. This fellow was playing his guitar and singing, and when somebody is off key, he corrects them. Don't tell me he doesn't hear. That guy hears and hears well. And in our laboratory we have been able to take 9 people with advanced processing capability; these 9 people were all able to distinguish individual musical notes. If you can do that, you are hearing more than some queues to understand communication.

We are providing hearing, and this hearing is getting better and better and better. So what we do, though, is we apply this to people who have central neural loss. These are people whose hair cells in their inner ear have been lost through either disease or congenitally or from loud sound, and these people no longer have good hearing. So what we do is provide this information through these devices, through restored hearing. We electrically stimulate the auditory nerve, whereas today in a normal person the hair cells essentially mechanically stimulate the auditory nerve. This is the only device today, which can really restore any kind of a human sense. But these systems are complex; they are very sophisticated, with a lot of research involved, but in the past, 80 percent of our patients have been able to talk on the telephone. That number today is probably closer to 90 percent. We don't have any study, but it is amazing what these people can do. It's a lot more than just communicating, it is really hearing. And as we provide more and more data to our patients, they are doing more and more, and they are enjoying life. And it is not just enjoying life, because these people can be employed, they can pay taxes, and all of these things.

Now Michael Dorman, who is an expert in audiology at Arizona State University, Michael Dorman made an interesting observation. He gave a speech at a meeting last week, gave a couple of them actually, and I'm going to address both of them because, in one of them, he talked about how the tests that we use today don't really evaluate hearing; they only evaluate speech. Unfortunately there is no way of measuring the quality of hearing, and that is unfortunate. But he was trying to show how these systems have gotten better. One of the things he observed is that the tests we use, even for speech communication, are so out of date. They were done over, you know, a decade ago. And today not just the Advanced Bionics system, but the other systems, the Nucleus System and Med-el System, all produce so much data for the patient that the people are topping out. They are doing testing all at the very high levels, so he is now generating tests which are more difficult so that it can sort of spread out the data and compare how they do.

The other thing, the test and trial that he talked about, was something that was really fascinating, because you mentioned the fact that -- you want to do it

earlier. And everybody has known this, but there has not been a lot of quantitative data to support it. But he gave a paper in which they lifted a certain characteristic of the brain response and he looked at this for normal people. He plotted it as a function of age and then he showed what happens to people who are implanted over the age of 7, between the age of 3½ and 7, and before 3½, and it was fascinating. Because those people implanted over 7, they were almost all outside of the normal range. And in the 3½ to 7 group, about 40 percent were in the normal range. In the under 3½ age group, they were all but 1, I think it was 1 or 2, within the normal range. And there were about two-dozen people in that group. So this was the first quantitative data that I have seen that really shows that you want to do it early. We ought to be trying to do it for children as quickly as we can in the 1 to 2 age range if we can.

Now in the handout you have, there is a graph that shows what these people say about what they're hearing. I've got to tell you, this is an old slide, which doesn't show what we are doing now, which is even far better. This just shows about the quality of speech, and whether it is more natural, and so forth and so on. The units today are really doing a very good job. Now if we can restore good quality hearing, why can't we use this, why can't we implant it in all these people?

The biggest challenge we have is, one, education, because most people don't know about it. What they do know about it is so obsolete because they are thinking about the early units that didn't provide very good speech. But there is a distribution of the people who are profoundly hearing impaired, and you see that about half the people who are profoundly hearing impaired are under the age of 65, so these are people who are either children or of working age. And unfortunately, as you will see in one of the slides, most of these people are not covered by insurance, or many of them, and in many cases it is because if the person is hearing impaired he can't even be employed or he doesn't have any access to insurance, or the insurance companies don't want to include these kinds of people because it is expensive taking care of a person. And so the cost, the overall cost on the average, for lifetime cost to take care of a deaf person without a cochlear implant was \$237,000 in 1998, so it is over \$300,000 today. That includes people who are 80 and 90 years old.

If you want to look at what happens with children, if you implant these devices in children, you save over one million dollars of lifetime expense for that child. If you do it through the age of 17, you still save almost a million dollars, \$919,000. Those numbers are really quite conservative numbers. If we were to pay for these things, really pay for them, we would actually save money. So why don't we? It doesn't really make any sense. We, in fact, dictate in the federal government, we demand and direct the states that they must be willing to send the child to a school for the deaf. School for the deaf costs, K through 12, depending on where you are, from a quarter of a million to a half a million dollars a year, over and above what it costs to send that child to a regular school. If you put a cochlear implant in a child under 3 years old, that child is almost always able to be mainstreamed to go through regular school. Yes it costs \$40,000, \$45,000 to do the implant, and take care of the audiology, and another \$15 or

\$20,000 over the school years to take care of that child. So it costs maybe \$65,000. But you save several hundred thousand dollars of schooling costs, and then it goes on, becomes a wage earner, usually a professional, because these people try harder because they know they are disadvantaged, and they pay taxes, and it saves our country a million dollars.

What kind of sense is this that we are doing? This is insane. That is really my feeling about it. And I get really, very upset over it because it seems to me if there was anything that deserved to be supported by our government, it is cochlear implants. Now, the cost of utility compares any standard you use to measure cost utility, cochlear implants come out best of any other medical therapy. We really need to do it. What do we pay today? We just went through a review, and there is no DRG, Diabetes Related Group, for cochlear implants. They are talking about doing one, but there hasn't been one, and so cochlear implants in the hospital were implanted with a major head and neck surgery and paid, as you said, about 40 percent of the costs. So then what happened is the doctor learned how to do it at outpatient surgery centers, and there it was handled under the other different program, and with that arrangement, the standard cost was about \$19,200. And there was a pass-through that they arranged. It was about another \$3,000, so the hospitals were getting about \$22,000. If you looked at the cost of the device, it is around \$22,000 to \$25,000, depending on some details of what you use for this particular patient. And the out of pocket costs, just materials, not overhead, not any mark-up or anything else is another \$4,000 or so.

The real average direct cost to the hospital is about \$27,500. Now, if it is going to cost that, and they only get \$19,000, because that is what happened last year, they reduced the cost to \$19,174, that means for every implant that the hospital makes, they lose cash out of pocket, \$8,300, and that doesn't cover their overhead either. So if you added that, it would be a lot more. Now, this compression of prices doesn't make any sense. So that if a hospital does 25 implants a year, they lose over \$200,000 of cash.

What does that mean? A lot of hospitals are refusing to do them; some hospitals with programs have discontinued them. UCLA, major center in Los Angeles, no longer implants cochlear implants because it can't make it make sense. So they're rationing implants in some places and other hospitals are refusing to start. If you save \$297,000 on a patient, and you do 1,000 patients, then you are saving \$297 million and what does it cost? If you just implanted another 1,000 patients, if you raise the price to \$27,500 for example, don't pay them overhead, at least don't have them pay money out of their pocket. If you did that, then the cost to the additional cost, if you did 1,000 additional patients plus the other \$8,300 for all the other people, the total cost to our country would be \$43 million. \$43 million subtracted from \$297,000, means we would save \$253.5 million a year in this country if we covered them at \$27,500. So it doesn't make much sense to me. That gives you an almost 7 time return on investment. I mean nobody, no business ever does that, and it is a unique opportunity for our country.

Now, you can say, "Well why can't we reduce the price of these things?" Nobody is making -- nobody is getting rich on making these things. The companies aren't. Advanced Bionics has yet to make a single dollar profit on cochlear implants. We do it because it is important, and hopefully one day it will become profitable. But we don't make a single dollar when we do it. So it seems to me the hospitals maybe don't need to make a single dollar, but they sure as hell don't need to lose \$8,300 when they do it. This is something that returns great rewards to society. We need to do it; it is something that ought to be a major -- it ought to be a major thrust of our government to do it. I have been trying to propose that we cover these things under the Disabilities Act. And we pay the full cost under Medicare, at least for kids, because for kids the financial argument is clear. If you want to talk about doing them for people who are working age, that also pays. And maybe you don't pay for people under Medicare so much, but that is another issue. The bottom line is we need to do this. It makes sense. Thank you.

Representative Walsh: Thank you very much. As always, fascinating. Mr. Mann was also involved in development of the insulin pump, is that not correct? And he could talk forever about this new concept of cancer vaccines he is involved with. He's made a tremendous mark on all of our lives. We have been joined by Congressman Berman of California, and Congressman Schiff also of California. Our next speaker is Donna Sorkin. I'd like to give either or both of those gentlemen opportunity to say hello. If you don't have anything prepared, don't feel obligated, but Adam.

Representative Schiff: Thank you Mr. Chairman. It's a pleasure to join you today, and the co-chairs of the Hearing Health Caucus, as well as my friends from the National Campaign for Hearing Health, in discussing some of the ongoing advancements in cochlear implant technology. And I want to thank my friend Al Mann for joining us this afternoon and sharing your experience on the technology advancements in cochlear implant technology, as well as the barriers to accessing this technology.

As you know, over 28 million Americans have some degree of hearing loss, and for many of those Americans, mostly children, cochlear implant technology is the ability to provide incredibly improved healthcare, hearing health. Over 25 thousand Americans already benefited from cochlear implants, with the demand for the devices increasing every year, but it is still estimated over half a million Americans would benefit from this technology. A reasonable person would wonder why there is such a profound gap between those benefiting from the technology and those who have been able to avail themselves of it. While I'm sure many of those reasons will be explored today and already have, a lack of awareness, philosophical objections, limited health insurance coverage among them, I'd like to speak to one roadblock in particular that I have been working to address legislatively. And that is the major barrier to patients receiving cochlear implants opposed by low reimbursement rates by both Medicare and Medicaid. According to a recent study, hospitals lose \$6,000 each time they purchase

cochlear implant devices and, in fact, the UCLA Audiology Clinic shut down its entire cochlear implant program due to low reimbursement rates. According to Hear Us, cochlear implant centers will lose approximately \$7.7 million in 4 years if Medicare and Medicaid reimbursement rates do not improve.

Working with the National Campaign for Hearing Health and other stake-holder groups, I began drafting legislation to increase Medicare and Medicaid reimbursement rates for cochlear implants, require coverage for linguistically deaf children and waive the 24-month waiting period for Medicare coverage for individuals identified as cochlear implant candidates. While we haven't yet introduced legislation this session, we are continuing to work on it with the expectation of introducing it during the 108th Congress.

As both children and adults continue to make the choice to utilize this wonderful technology, it is our responsibility to assure that they have appropriate access to it. And Mr. Chairman, I want to thank you again for your leadership on this, and Mr. Mann, Mrs. Mann, thank you as well. Thank you very much.

Representative Walsh: Mr. Berman shakes his head, no thank you. Great to have you here. Thanks for your leadership. That leaves the floor for an old friend of the legislative arena, Donna Sorkin. Donna is Vice-President for Consumer Affairs at Cochlear America. In that capacity, she leads a range of activities at Cochlear aimed at the broad life needs of the cochlear implant community, including appropriate educational options for children, early intervention, accessibility for people with hearing loss, and insurance reimbursement. Donna was Executive Director of Self Help for Hard of Hearing People from 1993 to 1999, she served as Executive Director at AG Bell Association, which is where I got to know her, from 1999 to 2000. She was also appointed by President Clinton to the U.S. Access Board in 1994, and was reappointed to a second term in 1998. She also served on National Institutes of Deafness, at the National Institute of Health Advisory Board, and has advised numerous U.S. businesses on accessibility for people with disabilities. She has been an enthusiastic cochlear implant user since 1992. Donna also participated in helping my office draft the Walsh and Green hearing-screening bill in 1999 for which I am eternally grateful. Donna.

Ms. Sorkin: Thank you for that very lovely introduction Congressman Walsh. Our President, James Jiller, cannot be with us today; he had a prior commitment, but he did really want to thank you and all the other sponsors for this, for holding an event on cochlear implants. I'm going to spend my time talking about what happens after a child is implanted because as extraordinary as this technology is, and Mr. Mann did a marvelous job of explaining it, what comes after in terms of the rehab is really just as important as the technology itself. Some people would maintain it is even more important. And I want to just put some context on the Medicaid issue that people have been talking about because in many states, Medicaid reimburses even lower than Medicare. What clinics sometimes will do is they manage this cost by putting children on waiting lists. And so we have kids waiting 6 months, 8 months, a year, to get a cochlear implant if they are a

Medicaid recipient. So just keep that in mind, as I take you through the importance of all of these issues.

As Congressman Walsh mentioned, and others, Congresswoman Capps, universal newborn screening means now we are screening 80 to 85 percent of all babies, and that is huge difference from where we were just a few years ago. It wasn't that long ago that the average age of identification was 2½ years of age. And so now we are -- we know babies are deaf at a very early age, days of life, and we know that early intervention prior to 6 months of age has a huge difference in terms of how a child does with language acquisition, regardless of the modality, regardless of whether the child is using a cochlear implant, hearing aids, sign language, whatever. Getting to that child before 6 months of age makes a huge difference. And in the past, when we find these children at 2½ and the parents are making choices about what modality to pursue for a child who is deaf or hard of hearing, it really took a lot of resources for parents to choose the oral option, because if a child had very little residual hearing it was hard work. It took a lot of therapy and a lot of rehab and really, to tell you the truth, the children who were oral years ago, who were deaf, came from families that had money. They had the access to resources that they needed to provide their child with the queues they needed to listen and speak.

What is so extraordinary about cochlear implants is it opens up the ability to access spoken language to any child, regardless of their family's income, regardless of the family's educational background, no matter where they live. This is a technology that makes it possible for any child to learn, to listen, and speak, if they have the supports that they are able to follow up, and the educational supports they need to excel with the device. And that is what I really want to talk about some more.

Currently, in the United States, 19,000 children under 18 years of age have a cochlear implant, out of an eligible population of 45,000. So that is about a 19 percent penetration rate. We are growing at about 20 percent a year, as Mr. Mann said, so the projection is that within a few years probably, by 2006 maybe 2007, if this rate of growth continues, probably half of eligible children will have cochlear implants. That is a big change from where we are today. I bet some of you didn't realize 19 percent of eligible kids had implants. But just think, in a few years, we are going to be up to 50 percent. And half of the surgeries today, half of the cochlear implant surgeries, are for children, even though it's a much smaller population.

Another trend: the age and outcomes for children is declining. The age of implantation is declining. It used to be very early implantation for a child would be 3 or 4 years of age. Now we implant children routinely at 12 months of age. 18 months is very common age of implantation. And what we are finding is if a child is implanted at or near 2 years of age, within a few years, if that child has appropriate rehab, we are talking about speech language pathology, services, appropriate audiology services, therapy, et cetera, that child will be at or near normal language, after a few years, if they are implanted early and they have

that appropriate follow-up.

One of the issues we find that parents tell us is that too often during the early intervention phase, and that is part “c” of IDEA. Everybody familiar with IDEA in the room? It is going to the floor today or tomorrow, but IDEA has a component in it whereby children who have disabilities are to be provided with early intervention services. And very often, parents are not provided with information on the range of options available to a deaf child. In fact, we recently surveyed parents of children with cochlear implants, and asked them to characterize the nature of early intervention services that they had received for their child, as being comprehensive, providing information on all options, somewhat biased and focused on one option, or very biased and focused on one option, and 59 percent of those parents indicated that the information that they received was either very biased or somewhat biased on one option. So parents during that period are often not getting the information they need. Fewer than half of them, and these are parents of deaf children, were being told about the option of a cochlear implant. So this is a program that is federally funded that currently is not giving parents information that they need to make choices.

A third trend has to do with where these kids are, what kinds of educational settings they are in, and what kind of language they are using. The majority of children with cochlear implants under the age of 13 are using spoken language alone, and that is 58 percent. And they're in public or private mainstream settings. That is 67 percent. 36 percent of the kids are using total communication, which is a combination of sign language and audition, and so there is variability and as a society we need to support children regardless of what their modality is. We need to provide them with whatever that child needs to excel in the educational setting. There is more understanding of cochlear implants than there has been in the past, fortunately, but it is still the case, we hear this from families all the time, that by and large, educators are unaware of the needs of a child with a cochlear implant. And further, the growth of professional therapists to work with these children has not been what it needs to be, and very often parents are unable to access those services I went through -- either through early intervention or in educational settings.

A fourth trend has to do with broader interest in cochlear implants and expanded candidacy. A few years ago we changed the candidacy criteria and made it possible for children who had less than a profound loss to receive a cochlear implant. So now, at age 2 if a child has been appropriately fitted with hearing aids, if they are not progressing with language, they are a candidate with a severe to profound hearing loss. Under age 2, it is just with a profound loss. So what we are seeing is more kids that had more residual hearing, more language coming into a cochlear implant, and they do extremely well with implants.

The other change that we're seeing in implants is greater interest by older children who started out using American Sign Language, have seen other deaf kids using cochlear implants, and they have come in and said they want cochlear implants. So this is an interesting trend that I don't think any of us would have

predicted years ago. These children will do differently. They can benefit if they are given appropriate rehab. They will not learn to listen and speak the same way that a child who is implanted early can, but they can also make some significant benefit with the technology. They can learn some audition and some speech, but people have to go into implantation with an older child with appropriate expectations.

Some of the challenges remaining: kids need support and schools vary very much in their responsiveness. In this area of the world, in the Washington, D.C. area where I live, there are a couple of school districts that do a really good job at providing for the needs of kids with cochlear implants. Some of you from the Washington area may be familiar with Fairfax County and Montgomery County, both of which have really nice public programs for kids with hearing loss. But it's very variable and we often hear from families that have actually had to move to get access to appropriate services for their child. Lots of stories of moms who have moved with their kids and the father stays where the job is, in order to be able to access an appropriate school system. I don't think that is fair. I think that the law says we are supposed to look at the unique needs of the child. IDEA is supposed to require school districts to respond to whatever a child needs to excel in that setting. And that is happening to a variable extent. There are some school districts that do an excellent job at it. I would like to see everybody doing an excellent job on it. We asked parents if they had difficulty getting services. This was part of a survey that we did last year. The majority said they got the services that they needed, but 29 percent said that they did not get the services that they needed. So almost one-third of parents in public school settings are having difficulty. I have more here.

I think one of the things that is also very interesting is where the children are in terms of school settings. 57 Percent of kids with cochlear implants are in public mainstream schools and another 10 percent are in private schools, so combined that is 67 percent of children that are in mainstream settings, and Mr. Mann made a number of comments related to the cost effectiveness of this technology. And if you look at the cost of educating a child even with services in a mainstream setting, it is considerably less than putting them into a confined setting, or a state school. I think those options should always be there for families, so a family could choose whatever option they have. But as a society, certainly we ought to support a choice that is more cost effective in the long-term.

So some key survey messages related to cochlear implants and educational issues: there is variability in terms of where children are and what their language modality is. We found early intervention providers provide biased information to families. Right now, that information source really has not caught up to where we are with the technology. So the technology has changed. Kids are doing well with it, but as institutions have not changed appropriately, parents are still having difficulty accessing services. And from a public policy context, by the year 2006 just to go back, remember I said 50 percent of these kids in just a few years are going to have cochlear implants. We have seen the impact that early

implantation can have, so it's very important that parents do get information early so they can make choices for their children. We don't think, as companies, we don't think we should ever go in and tell a family that their child should have a cochlear implant. What we do feel is a family should have sufficient information so that they can make choices about an option that they want to make, and not have to ask 3 or 4 years later, "Why didn't anyone ever tell me about this option?" And we hear that all the time.

So I think there are some key public policy issues related to education that I hope you all will think about, particularly since IDEA is being considered on the floor this week and certainly some of these issues are very important now, and will continue to be important in the years ahead. Thank you very much.

Representative Walsh: Thank you, Donna. I think that presents a really broad, and at the same time focused, discussion of the issues from the technology to a discussion of the culture of deafness historically and the transition that people who have been involved in that over the years are now experiencing. There are dramatic changes occurring. I see Congressman Rohrabacher is here today. Dana told me he'd try to stop by. I'd like to give the folks who sat through these discussions the opportunity to ask questions, so if Donna and AI would make themselves available, we'll give you the opportunity to ask questions or comments or provide advice. So who would like to -- let me see. Oh, there are some additional acknowledgments I'd like to make: Dr. Susan Waltzman, Professor and Co-Director of the New York University Cochlear Implant Center at the NYU School of Medicine. We are delighted to have you here with us here today also. All right anyone who would like to address questions either to Donna or to AI, please feel free. Yes.

Question: I'd like to just comment on the age of implantation from my own experience. I have a 16-year-old son who was born profoundly deaf and until the age of 10 wore hearing aids, and he was educated in an oral setting and he also developed extremely good lip-reading skills, really remarkable, in fact. So we felt pretty comfortable getting him a cochlear implant even though we didn't do it until he was 10 years old. Well, he has been just fine. I mean he had adjusted to it within days. He adjusted to it. His lip-reading skills enabled him to. I think have a real-time kind of therapy and so it was just in no time that he was being successful, so I just wanted to add that because age does not necessarily provide a detriment.

Mr. Mann: It is quite remarkable. There are people who are in their later years who have been supposedly diagnosed as pre-lingually deaf, who are able to establish language. The reason for the early age of implant is that when you are born, you have a plastic mind that needs to be trained. The programming, the software programming of your mind is done in your early years. If for example, one of you had a child or a grandchild who is like 5 years old and you take him to China, that child is going to learn Chinese; it would be pretty tough for you to learn Chinese. It would take you longer, and that is really, I think, what we are seeing, that people can learn and they can learn to speak, and they can learn to

hear, and they do quite well, even if they are at a later age. But it takes a more intensive program to bring them along.

As Donna said, not all of the kids in school today can be mainstreamed because, largely because, they weren't implanted early enough. I mean unless you have serious neural damage, I mean sensory damage to the auditory nerve, most of these kids can be mainstreamed today. But the earlier the better. But that doesn't mean you shouldn't do them when the child is 10. Even if he can't learn speech, just being able to get environmental queues and so forth, even that is important.

You know, those of us who have our senses and our faculties, we can't comprehend what these senses mean to people. I mean I can't. I'll tell you that I was shocked last year, because I told you earlier that we had created a visual prosthesis for blind people. And it was a first generation device. We had no intention of commercializing it because it really doesn't provide great sight and someone said, "No, no, you don't understand what is important to a blind person." I mean, just to be able to tell night from day so they regain their circadian rhythm, we can't comprehend what is important to them. I have seen a number of cases where even if you can't provide great hearing, it would be helpful. But I'm telling you that with the technology that is evolving today, we are going to provide not just communication skills, we are going to provide sound, sound with good quality, and reasonable fidelity, and that is going to change a lot of lives.

Ms. Sorkin: I want to just add to that when I was implanted in 1992, I was considered an ideal candidate, because I was an adult who had had a fair amount of hearing as a child, and had lost my hearing relatively recently. And at the time, we weren't doing very many kids; we were doing maybe 20 percent of children. And what has happened over time, is we have realized that people who have had an early and significant exposure to spoken language, like your son, who have been amplified consistently, can do well with cochlear implants at a later age. I was really talking about kids who were primarily sign users, who were not amplified as your son was. Recently, most of you know Heather Whitestone McCollum, in 1995 received a cochlear implant. Heather had been deaf for 28 years and she had not used a hearing aid in 1 year. She had used a hearing aid on 1 side only and she chose to be implanted on her unaided ear so it's taken her some time. But because she was wired for sound, because her mind worked in an oral mode, she really is beginning to get some extraordinary benefit from her cochlear implant. So we are in fact now implanting oral deaf adults who have been deaf for many years, but who used hearing aids early on, and used spoken language. It is better if they are younger but they can also get important benefits.

Representative Walsh: Anyone else? Yes.

Question: Yes, can you say anything about what manufacturers are doing to minimize the risk of meningitis?

Mr. Mann: First, let me say that meningitis is a risk of the general population. The implantation of any foreign object in a body provides a nest for bacterial accumulation and you can have a somewhat increased risk. The risk of meningitis in the worst case is very small. There are very few and, in fact, in the cases that were reported, there appear to be somewhat procedural as well as the device in the particular cases that were where the focus was.

Actually, our company, in order to provide the very best sound, was trying to get the electrodes right up against the auditory nerve, so we put a little piece of silicone rubber-like, spaghetti-like thing behind the electrode array. We called it a 'positioner' and that forced the electrode up against the auditory nerve, and it was postulated that if a person -- if a surgeon didn't seal it properly at the hole, where you make a little hole in the bone next to the cochlea, where you put the electrodes into the cochlea, if you add 2 pieces coming out, it was harder to seal it and maybe that was what led to a somewhat increased incidence.

The bottom line is that everybody who gets any device, in fact, all children are now recommended by the CDC to be vaccinated against meningitis. And, remember that most of the people, I shouldn't say most, but a large portion of the people who get cochlear implants have lost their hearing through meningitis. Many of these children or people have a predisposition towards meningitis because you have these bacteria in you all the time, or most of the time. And they're in your nasal cavity, and you have a Eustachian tube that goes up the inner ear. If it goes up the inner ear, maybe there is an increase. There has been no solid evidence as to what caused it. But there was a concern, so our company immediately took the position they were off the market because we felt if it is possible for this to cause an increase in meningitis risk, it was a wise thing to remove it. But the numbers are small and everybody seems very comfortable, and we just recommend, in fact our company will pay for, the vaccination if it is not available otherwise.

Representative Walsh: Anyone else? All right, well, I'd like to thank both of our guest speakers today. I'd like to offer them a nice warm applause, and thank them.

Question: Just a little bit more: what is the next generation? You touched on it just briefly. Current cochlear implant users, what is the next step in 5 To 10 years?

Mr. Mann: Where will we be in 5 or 10 years? I would expect in 5 years or so, we will see cochlear implants that will have a far more than 16 or 20 electrodes that are stimulated. We are able to, in our laboratories, demonstrate 150 channels for example. There are all sorts of things that will happen. We are getting better at developing processing techniques that will simulate speech and, as I said, we have shown in 9 adults selected, they were generally good performers with our current system. We were able to show that they could distinguish individual musical notes. Now that says that they are getting a lot more Than just communication skills. They are getting some degree of fidelity of sound. So I

would think that in 5 years you will see, first of all, a device that will be fully implanted, nothing outside other than to maybe recharge the batteries occasionally. And it will produce a quality of sound that may not be as good as you or I, and perhaps we won't be able to sing as well as some of the professionals, but probably better than my eldest son.

Representative Walsh: He is a great guy to ask about what is going to happen in 5 or 10 years because he is working on those things right now. Again, thanks to the people from Deafness Research Foundation, Lizzie Thorpe, National Campaign for Hearing Health. To all of you members for their interest in this, and these are the kinds of things we anticipate we would have to worry about once we got the legislation passed. Legislation is passed, it is being implemented, and people are being tested. Now we have to do next step. So we really appreciate your support. Thank you all very much.

=====

LINK::

<http://web.archive.org/web/20040104062927/www.hearinghealth.net/cms/index.cfm?displayArticle=98>

=====
=====
=====

July 2003 Caucus Transcript

The Congressional Hearing Health Caucus Presents
A Unique Members' Forum
Tuesday, July 22, 2003
Canon House Office Building

MS. GRECO: I'm the Executive Director of the Deafness Research Foundation. The Deafness Research Foundation sponsors the National Campaign for Hearing Health and is the nation's largest and oldest voluntary health organization devoted to research and public education relating to hearing loss and hearing health. We are very proud to cosponsor today's members' forum along with Cochlear Americas. First I would like to acknowledge the Congressional Hearing Health Caucus co-chairs: Representatives Jim Walsh, Jim Ryun, Carolyn McCarthy and Lois Capps. We are very lucky to have Mrs. McCarthy and Mr. Ryun here and we hope the other co-chairs will take time out of their busy schedules today and swing by and join us at the caucus luncheon. For now I would like to introduce Mrs. McCarthy and invite her to the podium to say a few words about her interaction in the Congressional Hearing Health Caucus and the reason she is involved with us. And we appreciate her attendance today. Mrs. McCarthy.

MS. McCARTHY: Thank you, very much. Number one, I want to say thank you to all of you for doing the grassroots work you all do. Because the more you meet with members of Congress to educate them on the different issues we are fighting for, the better off we who are fighting for you will have more support. Again, I thank all of you.

You know, the last couple of years I started off with a little bit of a hearing problem and it was nothing compared to what we are dealing with on a daily basis for those profoundly deaf. It took me almost a year and a half to finally find a doctor who actually found out why I was losing my hearing. And the simple thing was apparently there is something wrong with my sinuses. And without the medication I was almost totally deaf in my left ear, which started off 2 years ago when I landed in an aircraft carrier. Apparently I did damage and went to a number of doctors and it was not until I went to the hospital for a real work-up that they obviously found out. Now I'm on medication. Unfortunately, when I get on a plane I still lose my hearing for a little while.

That is not complaining. That is education. I consider myself a very well informed consumer. I knew something was wrong and I was going to doctor after doctor.

And this was not my imagination. When I was asking my staff to speak a little bit louder or I noticed the TV had to be on a little bit louder, I figured, okay, I have got a problem. But to take 2 years to find the answer is 2 years too long. The doctors here should have picked it up and sent me immediately to the specialist who I had asked for. By the way, in the beginning I asked for an ear, nose and throat specialist. But besides that, your work is going to be a little bit harder. You know, we are under terrible budget constraints right now and we see cuts being made at NIH, which is certainly the research arm that we need, because we have to have more scientific information. I sit on the Education Committee, and we keep fighting to make sure our children have the best education. And yet, those children that have hearing implants, they are not getting the help. We are spending more money in the long run to make sure they get a good education. So these are the things that we have to look at. So when you are out there lobbying, please remind people that we need to increase the money for NIH so we can do the research. This is something that we can beat.

You know, we have come a long way, from when I first joined the caucus, on making sure that newborn babies get their tests, which is, what, \$35? Think about that, \$35. Yet in some states we still have a problem. Here is where a penny-wise and a pound-foolish surely comes into life play. We can save hundreds of thousands of dollars. If you think about that in a lifelong trip of getting the help that someone needs, isn't \$35 worth it? So we have to convince more and more members to get on to this. We have to convince more and more members of the committees to make sure we can do this in every state, and bring it up to 100 percent. I think that is the most important thing.

Thank you very much for the work you all are doing. We will continue with Jim and Mr. Walsh on fighting for all of you because we believe in it. You don't join a caucus just to join a caucus. You join a caucus because you believe in what you are fighting for.

And obviously each and every one of you believes what you are fighting for and I thank you for being advocates. Thank you and have a great day.

MS. GRECO: The leadership of people like Representative McCarthy is very inspiring to us, and we are very fortunate to have her here today to share her personal experience with hearing loss and to show us how important it is that we continue to do all that we can for those who have hearing loss and to detect hearing loss early so that intervention can be taken as appropriate. So without further ado, I would like to move on with the program and explain to you, first of all, how this members' forum came about. This was an idea that comes from Jim Ryun, to share his personal experiences with hearing loss so as to educate his peers and his staff, the people on Capitol Hill, and those of you who are interested in hearing loss and issues concerning hearing health. This is something very close to him, which he will explain to us in a few moments. This is something that

Mrs. McCarthy already did; she shared with us her own personal experience with

hearing loss. We do hope this will inspire you and inspire your bosses, as appropriate, to continue to help us and join the Congressional Hearing Health Caucus.

So I would like to, without further ado, introduce Mr. Ryun. You know Mr. Ryun as the fourth term Representative of the Second District in Kansas. He is one of the founders of the Hearing Health Caucus. He won the Olympics for running. But he recently started his educational program called "Sounds of Success" with the Resound Hearing Aid Company aimed at helping hearing aid children fulfill their potential. Mr. Ryun will share with us his personal experience with hearing loss and why this issue is very near and dear to him. Mr. Ryun.

REPRESENTATIVE RYUN: I too wish to extend my thanks to all of you being here. I think most of you came for more than just a free lunch. Probably your boss said come or you had an interest. But I do appreciate you being here today because this is a subject very dear to me and very important. And simply because at the age of 5, because of a very high fever, I lost nearly half of my hearing.

I went to school making sure I was well positioned in the classroom, near someone who had good notes I could copy, or would always ask the teacher afterwards what exactly I might have missed. It is the kind of thing that plagued me through the years. I know as the years went along I had different testing along the way and my hearing loss was static; just a one-time thing. Fortunately for me, my speech was formed before losing my hearing. That is why sometimes people ask, "How could you have a 50 percent loss of hearing and have good speech?" Because generally people with that much hearing loss don't speak well because they can't hear themselves. It is one of those unique situations that through the years developed. I learned to adjust. I even tried in junior high to learn how to lip read. I must say I was totally unsuccessful with it. I continued to struggle along, hoping some day I could find help.

I think part of the message I want to express to you today, and I will continue to tell you more about my story, is the fact that it is very important that you have the right kind of help. I say that through all of those years, nearly 30 years, I wasn't fitted with hearing aids until my 40s. I had gone the normal route through an ear, nose and throat specialist, who examined me and said, "You do have loss of hearing, but the bad news there is no assistance for you." That is because up to the early 90s most of the time hearing aids amplified everything. So if you walked in a room, you might hear my voice but if a glass fell in the back you would hear that too, because the amplification didn't have discrimination. And that was very frustrating. So people would wear it for a period of time and put it in the drawer.

As the years went along and I eventually married my wife Anne, my wonderful wife Anne became my hearing aid. She would tell me what the children said. And those who are married and have children, it is not as good to hear it the second time. You want to hear it when it is spontaneous. That was a frustration

I carried on with.

In the early 90s someone suggested, "You need to see an audiologist." I learned what is the difference between an ear, nose and throat doctor and audiologist. What I came to appreciate is the fact that they are the people who have the training to be able to make sure, if you have a hearing aid, that it is well fit for you, that it is adjusted. That is the biggest part of the problem I see facing those who have lost hearing and want to be able to hear once again; they often take a route that leads them to someone who will fit them with a hearing aid that doesn't combine the kind of assistance that allows them to hear the quality of life that is available because of the hearing system. So my message is, make sure you go to the right trained person. I send people to audiologists today. In fact, I discriminate more. I send them to an audiologist who has experience, who has the ability to fit the hearing system in your ear, not just put them in your ear, but are willing to have you come back and make sure if you need to have something turned down a little bit, they will fix that. The hearing aids available today now have thousands of options because of the computer chips. They can lower background noise, increase high frequency to low frequency.

All the advancements that have taken place in the last few years are so significant is what I find, even with members on the Hill. And perhaps some of your bosses are this way, or some of us have seen some of our colleagues. They will put the hearing aid in during the hearing and they will take it out as they leave because they want to make sure they hear everything. But the frustration is that they haven't been fit properly. So I like to run around and point them out to audiologists here or back in their hometown that can genuinely help them. The other part of that is that generally when you have slow loss of hearing, and you start wearing a hearing aid, you feel like "I didn't know I sounded that way." It is getting used to the way your voice sounds because through the years it has been incremental loss. One day you tell everybody to turn up the radio. My experience is when I was first fit with the hearing systems, I went to the car and the first thing I did was turn down the radio because all of a sudden I could hear things. I was out in Kansas mowing the grass, I heard a sound and I said, "That sounds like geese." I looked up and there were the geese. They went over the house before but I had never heard them. Having a well-fitted system is critical.

Now, let me just wrap it up a little because I know others will speak. A couple of things we have done: I talked to my staff and hearing aids are expensive. And any system worth its salt is going to cost something. Some of these systems just don't work. They may amplify everything in the world, but you find most people put it in the drawer. We addressed that through hearing aid assistance tax credit. So if you are interested you can find out about that particular bill.

I want to introduce, back by the telephone, Jan Graves. Jan is the one who help put it together- the tax credit up to \$500. Now, \$500 is not going to cover the entire new system, but at least it gets people a foot in the door, the camel's nose under the tent. So, perhaps, they will experience what is available to them. So we are making that particular tax credit available to them. I have also worked on

the Hearing Health Accessibility Act, which will simply say that Medicare patients can go directly to the audiologist instead of having to stop at the physician's office. This is because 80 to 90 percent of those that have a hearing loss don't need to see the physician, but the audiologist. So they can generally get the kind of help that will assist them.

One more closing point: You mentioned a moment ago a program I did called "Sounds of Success." It was something I did with the Resound Hearing Aid Company, traveling around the country working with young children. They need encouragement and a pat on the back. They needed to know just because they couldn't hear everything, the future is bright for them because things are changing. Cochlear implants, hearing aid advancements, and the technology continue to move forward. I was able to do that and work with young children. I have to say, it was one of the more exciting programs I was involved in prior to entering office because you can actually see in their eyes when all of a sudden they can hear the changes that have taken place. We help people with hearing. We offer them a future that often goes away as the years go along.

So I want to encourage you to keep doing what you are doing. Keep spreading the word. Keep educating people about the technologies, the advancements that continue, and the tax credits that are available. Thank you, very much. God bless you.

MS. GRECO: Thank you, Mr. Ryun. We appreciate your inspirational words. At this time we would now like to introduce a woman who works for Congressman Frank Pallone's office. Nancy Fatemi is from the office here and would like to share how resourceful she and her family had to be when they learned about their son's deafness years ago and their decisions to use cutting-edge technology to have his sense of hearing restored. Nancy.

MS. FATEMI: Thank you, Susan. My son is 16. He has a cochlear implant. He was born deaf and it has been a long 16 years in dealing with the situation. Fortunately, things are looking bright and they continue to look brighter every day with the technology that is being developed and is now available.

I will speak for a minute to the idea of responsive education, public education. Almost every parent of a deaf child, meaning a child that is born deaf, has very similar experiences. It is really amazing when I talk about how similar the experiences are. I first suspected my son was deaf at about 6 months of age because he was not responding to me when I walked in the room. And then I thought, well, maybe he is not just alert to it or doesn't care. So then I would test, you know, he would be in the bathtub and I would knock against the side of the tub and he would turn and look at me. And I thought everything was okay. Of course he was responding to the vibration in the tub, not to my voice. So we took him to an otolaryngologist in Washington. And he brought the child in and we sat down. He just observed him for a few minutes and then he said, "There is no way this child is deaf. I know. You don't have to worry. Come back in 6 months if you are still concerned." He said, "I have a lot of experience and I

dated a woman who is deaf for 6 months." 'Oh, good to know about these things.' So for 6 months we let it go. And then finally I thought, 'no, this is -- something is seriously wrong here.' So I went to a different pediatrician, and he, Dr. Pillsbury, he knew what to do, and he sent us right away to Children's Hospital. And my son had appropriate testing done. And it was determined right off the bat that he was deaf. Exact level was not determined until we went for the audiological tests. So this was about 11 months of age. And then he was fitted for hearing aids. But they were loaner hearing aids. It took another 6 months to get the correct, proper hearing aids. And the loaners would go off and on.

If I had to do it again, I would do it differently. But at the time this was the way we were advised to go. So we lost about 6 very, very valuable months because of bad advice. And, you know, perhaps had I been more alert and had we all known a little bit more, even at that time, which was 1987, I would immediately have gotten hearing aids on him; I would have pressed to have testing done immediately. And this shows the importance of early detection. And these things are not going to happen so much anymore. But because my son lost a good 14 months of sound, even if it is inadequate sound, at least it is sound and the normal connections can be made. It is based on speaking, and language is developed. And if it is absent during that period of time, you really lose an important window for later technology that might come along, for learning; it has a tremendous impact. So that was something. Fortunately things have worked out well, but we are still working to make up that 1 lost year.

Then the second example of that -- and I must say that I had the most wonderful people in the world working with my son. So I'm just citing two bad examples. So it is not the rule but the exceptions, and the exception can have a big impact sometimes.

So the second thing: my son got the hearing aids on. We enrolled him in an oral program. Many of you know, there are three different tacks you can take: the sign language, the cued speech, and the oral. We chose oral for two reasons. My son was excellent at lip reading. He could understand us even when he was in the crib before the hearing aids were on. He was responding appropriately to questions like, 'where is your pacifier?' and he would find it. So he developed an incredible lip reading skill that made us take advantage of this approach. We also wanted him to be able to take advantage of any technology in the future. So, for our son, that was the right choice, we think. There are so many advantages to other approaches and -- for instance, oftentimes the children who are raised using sign language, actually have better language ability, not necessarily speech ability, but language ability. So there are advantages, and there may be some social advantages to that approach because the biggest problem we have with my son is with socializing. Because even though he is tall and handsome and athletic and speaks pretty well and most people can understand him, it is very tough in high school because he doesn't understand what boys are saying in the cafeteria and so on.

Anyway, the second example of what I would call bad advice was when he was about 9 years old. We had a new principal of the oral training care center where he was in school. She had come from a background that was not particularly open to new technology. When we brought up the idea of a cochlear implant, she said, "Oh, do you want to have a big hole drilled in your son's skull?" So that put us off for about a year. And also the fact that the technology in 1990s was not advanced as it is now. So it was a little bit riskier, but I do wish we had made a decision a few years earlier because my son, when he did go for the cochlear implant, was 10 years old. For an older child it is risky to put in the cochlear implant. But fortunately, because he was always wearing his hearing aids and he had good lip reading skills, again, he adapted to it immediately. So that was a little bad advice that delayed again something that we should have done. Eventually, because of wonderful people like Dr. Berlin, who is an amazing audiologist in LSU, and Dr. Epstein, who was head of AG Bell here in Washington, because of their encouragement we went ahead with it when my son was 10. So he has the cochlear implant and it is just wonderful. He had surgery done at Johns Hopkins when he was first turned on to speak. I was the one who said the first words to him and he would first hear clearly, and when I spoke to him he looked at me and he started to cry. He wouldn't stop crying because he had never heard my voice clearly. And it didn't sound like mom. But it only took a little while, and with all the wonderful support he has had up until today, it has just been the best decision we could have possibly made. But it is not for everyone. The parents just have to research, and it still requires a lot of work on behalf of the parents, and the decision has to be made. For us, we chose the cochlear implant because, number one, really: safety. If he is out riding his bike or something, I want him to be able to hear a car approaching or somebody yelling, "Watch out!" That is the number one reason I made that choice and it is hard to argue with that. The second one is that most of the world does hear and speak. And that is why we felt it is best for him. But everyone has to make their own decision on that. So that is my story.

MS. GRECO: Well, that was a different perspective from a parent who had dealt with finding out about her child's deafness in an early age and the resourcefulness that Nancy and her family had. We thank you very much, Nancy, for sharing that with us. Now what I would like to do is move on with the program to our final speaker, which is Donna Sorkin of Cochlear Americas. Cochlear Americas has co-sponsored today's luncheon with us along with the National Campaign for Hearing Health. I would like to have Donna speak for a few moments and then what we will do is a little bit unusual in the typical format that we present at the caucus events. What we will do is we will close today's caucus with a video presentation. The video is shared by a Hill staffer. Her name is Ginnie Kontnik. She is the Chief of Staff for Senator Ben Nighthorse Campbell of Colorado. Ginnie was supposed to be here today, however, she could not make it out to Washington from her Colorado office due to a minor emergency. However, she did share this video called "Spencer's Crossing" that was done by PBS. It runs approximately 20 to 25 minutes. We would invite everybody, after Donna Sorkin's remarks, to please feel free to stay and enjoy the film about Spencer who has hearing loss and hearing aid and is a young,

vibrant teenager who has done incredible things in his life, even as a teenager. I hope you will feel inspired by Ginnie's family story. Now I would like to invite Donna Sorkin, the Vice President of Consumer Affairs of Cochlear Americas, to join us. Donna, herself, has personal experiences with hearing loss, but as a representative of Cochlear Americas, I would personally like to tell you that the company is a global leader in cochlear implants. 50,000 recipients in more than 70 countries around the world have a device made by Cochlear Corporation. They are committed to ongoing research and market development with the aim of bringing the gift of hearing to people who cannot benefit from hearing aid. Without further ado, Donna.

MS. SORKIN: Thank you, Susan. We are really delighted to have had the opportunity to sponsor the luncheon today and to hear personal perspectives that our speakers have with hearing loss. There were some nice themes, I think, that went through all of the 3 speakers. And I thought I would just sum them up.

The first is that people really do need good information about their options at the earliest possible time. And unfortunately, that still is not the case. Professionals and educators and pediatricians and all those involved in the process really do need to give people the very best possible information, so that they can make choices about what they want to do.

The other thing that really is important is technology. Mr. Ryun spoke about that. And I know from personal experience that technology has just made dramatic strides, whether you are talking about hearing aids or cochlear implants. It is really very different than it was.

And the other thing I think is very important is that people need to be very open and have attitudes about hearing loss that allow us to pursue options in a variety of ways. Thirty years ago my father, who worked for the federal government, retired on a medical disability. At the time, my sister and I thought that he was retiring because he had had a heart attack and he couldn't keep his blood pressure down. And my dad was using hearing aids at the time. But he never spoke about the issues that he had. And one of those issues was that part of his job – my dad worked for the Department of Defense -- was to come to Congress periodically and lobby for the Defense Department's budget. All of you have been in the big hearing rooms here on Capitol Hill. And that was pre-ADA. So there were not assistive listening devices, and there wasn't captioning, and he wore hearing aids, but it was not enough to overcome the problems of a listening environment. So my dad retired on disability at age 52. And it was not until long after his death, when I went to be evaluated for a cochlear implant, that my mother admitted to me that the reason for my father's medical retirement was, in fact, his hearing loss. And looking at his audiograms today, my dad could have benefited from technology. He could have benefited from better technology than what he was using. He could have used an FM system or other assistive listening devices. He would not have been, at least at his age, a candidate for a cochlear implant as I was. But it is an interesting personal perspective to see how much things have improved for all of us with technology, with societal

changes, and with laws like the ADA. And there are just many more opportunities than there were before.

So, anyway, thank you very much, everyone, for being here and for your interest in these topics. And I will stop at this point as we have a great video to watch. This is a neat kid and I think you will enjoy this. Thank you, very much.

MS. GRECO: While we are setting up the video, I want to send out thanks to Jan Graves of Representative Ryun's office for helping to organize this day, and April Parreco from the National Campaign for Hearing Health for her help and the logistical planning of today.

We hope that you continue to enjoy lunch and the fabulous brownies on the table in front of you. The transcripts of today's Congressional Hearing Health Caucus, along with any past caucus events, is available on our website, which is www.hearinghealth.net. Feel free to stay as long as you like, but "Spencer's Crossing" I think you will find very enjoyable. Thank you.

(Video Plays)

MS. GRECO: Thank you all, very much, for joining us today for the Congressional Hearing Health Caucus. We hope this was, between the speakers who joined us today and the film, "Spencer's Crossing", something you will go back to your offices and feel as though you can, as staffers on Capitol Hill, help to affect change when it comes to hearing related issues. Again, many thanks to Congressman Ryun, to Congresswoman McCarthy and to Jan Graves of Mr. Ryun's staff. We hope to see you in September when the caucus forum will be about research. Thank you very much, and good day.

=====

LINK::

<http://web.archive.org/web/20040104024412/www.hearinghealth.net/cms/index.cfm?displayArticle=109>

=====
=====
=====

October 2003 Caucus Transcript

THE CONGRESSIONAL HEARING HEALTH CAUCUS PRESENTS:
Advances in Hearing Research
Wednesday, October 15, 2003
Rayburn House Office Building

MS. GRECO: Good afternoon everyone, and welcome. We are going to begin the Congressional Hearing Health Caucus discussion so please continue to eat. Help yourself to refreshments. I would like to welcome you. I am Susan Greco, the Executive Director of the Deafness Research Foundation. The Deafness Research Foundation sponsors the National Campaign for Hearing Health and is the nation's largest and oldest voluntary health organization devoted to research and public education related to hearing loss and health. We are proud to cosponsor today's discussion along with the National Institute on Deafness and Other Communications Disorders, NIDCD.

First, I would like to acknowledge the co-chairs, Representatives Jim Walsh, Jim Ryun, Carolyn McCarthy and Lois Capps. I understand several representatives may be coming by today so we will accommodate them. They of course sometimes jump in and out. So, we do hope they will be able to make it and we will notify you upon their arrival. The founding co-chairs of the Congressional Hearing Health Caucus had the vision to establish the Caucus in 2001, in support of the 28 million Americans who are deaf and hard of hearing. We are also very pleased to note the fact that this luncheon is brought to you again by the National Institute on Deafness and Other Communication Disorders in partnership with us today. We are very lucky to have their support and partnership in this matter. And their involvement is purely to present to you topics that have to do with research and the funding of research in the United States today. It is an opportunity for us to understand that research is not only important, but continued funding for research in hearing is something very vital. You will see there are so many advancements occurring in America and the world that we can't stop here. We have to continue to grow the research pot.

Hearing loss is one of the most prevalent health conditions in the United States. As I said, approximately 28 million Americans have some kind of hearing loss, including 1 in 300 babies who are born with significant hearing loss each year. It is very important we formed the Congressional Hearing Health Caucus. As you can see with those with the legislative offices, this really does represent a huge portion of your constituency. I know many of you are familiar faces and you are

back here at the many different Congressional Hearing Health Caucus events, and we hope it makes an impact when you brief your congressman, your bosses, and your senators on these issues.

With no further ado, I would like to begin the program by introducing Dr. James Battey. He earned his medical degree and Ph.D. from Stanford University and came to the NIH in 1983. Through the years, he has contributed a great deal of knowledge, time, and tremendous hard work to a variety of institutes within the NIH, from the National Cancer Institute, to National Institute of Neurological Disorders and Stroke, to his current work with the NIDCD. He was appointed Chief of the Laboratory of Molecular Biology in 1996 and Director of NIDCD in 1998. He is presently the Chair of the NIH Stem Cell Task Force, which is a team of leading scientists at NIH whose objective is to meet and seek advice from scientific leaders in stem cell research to further advance the field. Now, I would like to introduce Dr. Battey. The way we will run the program is that Dr. Battey will introduce each speaker and move forward with the program and close around 1:30 today. So enjoy your lunch. Dr. Battey.

DR. BATTEY: Thank you very much, Sue. It is a pleasure to be here. Before I begin my remarks, I would like to say a word about Susan Greco. She serves on the National Advisory Council, which is a group of distinguished scientists, advocates and other interested parties who help us determine priority for funding. She plays an indispensable role and I would like to thank her. The Deafness Research Foundation is extraordinary. They've funded over 2000 research grants in their history. That provided the seed money that launched the programs of many leading researchers in the country. And I think Dr. Friedman will have a word to say about that when he begins his presentation. We have a wonderful partnership with them and their role is absolutely critical. They will often provide funds for a research project at a point in time where it may be difficult for a scientist to acquire federal funds because of lack of a preliminary data or other limitation to obtain an NIH grant. And very often, the NIH steps in only after proof of principal has been established by money provided by the Deafness Research Foundation.

At the NIDCD, National Institute on Deafness and other Communications Disorders, the mission is to fund research and research training in the normal and disorder processes of hearing, balance, smell, taste, voice, speech and language. We do this by funding nearly a thousand research grants and contracts in extramural academic sites as well as funding close to 20 investigators in our intramural laboratories here in Bethesda/Rockville area. It is indeed an enormous privilege to be able to support this wonderful research. We absolutely couldn't do it without the generous unswerving support of the American people and the Congress, and we very much appreciate that support.

We have three speakers for you today; two of which are supported by NIDCD on extramural grants. One of them is an intramural scientist and supported by the roughly 8 percent of our budget that is dedicated to your intramural laboratories. I think when you grasp the excitement of the advances that these scientists are

shepherding and bringing forward, you will understand why the money that has been provided so generously by the Congress and American people is, in fact, being very well spent. With that, I will not make any further remarks and introduce Dr. Thomas Friedman, who is chief of the Laboratory of Molecular Genetics at the National Institutes of Health. Tom.

DR. FRIEDMAN: Thanks. It is going to take a minute to just get the computer up here. Good. So thank you for inviting me. I want to give you a very brief overview of human hereditary hearing loss. There are now hundreds of different genes, each one when mutated, can cause deafness or deafness combined with an additional disorder, which is called syndrome deafness. So what I would like to do is tell you a little bit about those genes in a matter of a couple of minutes. So the way we are going to work this, is I am going to give you some background on hereditary hearing loss and I will tell you a little bit about how hearing happens with slides. And the next thing I'm going to do is give you a brief introduction to genetics, and then I want to tell you about two genes: we have been working on both of them, but my lab identified one and other groups in the world identified the others. What I would like to do is put all this together in one example and then summarize what I had to say. So let's get started.

First of all, as mentioned, about 1 in 1000 children are born with a significant hearing loss and for perhaps 50 percent, maybe a little bit more, it is the result of an inherited defect. By the time we are 70 or 80, about half of us will have a significant hearing loss. And this is a significantly understudied area, which is hearing loss in the elderly.

There are basically two origins of hearing loss. They are actually related. One is the non-hereditary cause, such as infection, ototoxic drugs, noise, and trauma. The genetic background influences even the susceptibility of environmental agents. The hereditary causes are divided into syndrome deafness and non-syndrome deafness. That is deafness all by itself and the syndrome form of deafness is where there are other organ systems involved, such as deafness and also a widening of space between the eyes. So there are many forms of syndrome deafness, perhaps 400 different syndromes. I would like to give you an example of each, as soon as I tell you a little bit about how hearing happens on this next set of slides.

So sound waves enter the external ear canal and vibrate the tympanic membrane. There are three ossicles, 3 little bones in the middle of the ear that transmit that vibration into the inner ear or cochlea, which is fluid-filled. What we will do now is look at a cross-section of the cochlea. It looks like it has three chambers, however the lower and upper are connected and fluid-filled, and the sound waves are traveling through the fluid. What is happening is the Organ of Corti, the third chamber, is being vibrated.

What I want to do now is focus in on the Organ of Corti. As you can see, as we get smaller and smaller, the structures get more and more delicate. Moreover, we don't know the molecular equivalence; we don't know the genes involved in

most of these structures, in forming them and maintaining them. We know some of them. Well, the business end of this is the inner hair cell, which transmits these vibrations to the brain. And what happens is these little extensions of the cells are moved by an angle -- maybe 1 degree is all it takes to open a channel that depolarizes this cell. There are other cells involved in the process: the outer hair cells and they are actually amplifiers. And I'm not going to talk about that. So on to... an inner and outer hair cell are the structures called stereocilia, and these are extensions from the single cell and filled with a protein called actin. What is happening is the sound wave traveling through the solution is bending the stereocilia ever so slightly and stretching the links, and in the process of stretching them, apparently opening a channel, a stretch activated channel. This just illustrates the channel opening, potassium, which is bathing the cell, rushing in, depolarizing the cell and sending an electrical signal to the brain, which is receiving the very complex signals and making sense of the sound, which itself is a process we don't fully understand.

So you can imagine several things. One, there must be many, many genes involved because this is a very complex structure. And, number two, it is very delicate, so it is easily damaged. Okay.

Now the bit about genetics: I want to remind you that there are basically two forms of inheritance. There are others, but there are dominant form and recessive and maternal. Others I won't tell you about. Here we have a person who is affected and he is darkened in and square. Circles indicate females; she is unaffected. This is a dominant mutation so it only takes one to cause the disorder. Since this man got one chromosome from mom and one from dad, maybe he inherited this chromosome from his mother or father, and half of his children are going to receive the chromosome. So half of the children from this marriage are going to be effected, if they received that. This is in contrast to recessive inheritance, where the parents may be a carrier of the mutation, but they are unaffected. Each of them has a mutation and there is a one in four chance that their children are going to receive both mutated chromosomes. It is 50/50 here, so $\frac{3}{4}$ of the children are going to be unaffected because they either didn't receive the mutation at all or received one copy. They are called carriers. And they are carriers just like their parents. Okay, enough of genetics.

So there are 23 chromosomes. These are the ones found in a normal male. In 1996, not a single gene hereditary deafness had been identified. Many had been mapped but none identified. But by 2003, 54 genes in total have been mapped and identified; mutations in any of these can cause non-syndrome deafness. When we started our work and our contribution to these genes in the early 1980s, it was the Deafness Research Foundation that provided the seed money that allowed us to get the project off the ground and then successfully obtain an NIH grant. So I want to thank them for that.

So what I want to do is tell you about two genes in order to give you a feeling for this area. One is called GJB 2. You have probably heard it mentioned by a different name, but that is the official name. The other one is PCDH 15, and that

is a gene that we identified. Mutations in this gene are pretty interesting and I will tell you very briefly about it. So why has there been such rapid progress in understanding hereditary deafness in a matter of a few years? It is the combined efforts and focus of a number of resources and individuals. First of all, the publicly available DNA sequence for the human genome rat, fish, bird and others under the rubric of the Human Genome Project have provided data that have accelerated the rate of gene discovery many fold; innovative instrumentation software, much of it developed in this country; the leadership and resources of federal and non-federal agencies; and the collaboration and competition between scientists. There are many groups that we collaborate with and we may compete with them on other projects. I think this has accelerated the rate of discovery. We all want to get there first.

At any rate let me tell you about GJB 2. It was discovered and mapped by a group in Paris, France and identified by a group in England. And mutations in this group account for 30 to 60 percent of non-syndrome deafness in Europe, southern Europe, and this country. There are about 50 different mutations of this gene identified. But there are only a few of them that are very common. One is called 35delG. And I won't bore you with the details. They account for the majority of the deafness in Europe and United States. There is another mutation that accounts for 60 percent of the deafness in the Ashkenazi Jewish population. The carrier mutation is 1 in 25, about 4 percent. It is important you know the ethnic background of your patients or your subject.

This little drawing illustrates the function of this gene called GJB 2. It forms channels between cells. So this is one cell, this is another cell, and these cells are communicating by passage of small molecules or ions through this channel. There are many different channels like this, in fact, there is a whole family of them, and this is just one of them. We often think of cells as autonomous entities but they are actually communicating with each other. Okay. That is one example.

The second example is Usher syndrome. This is a dual deficit disorder that is devastating. It is characterized by bilateral congenital deafness. The children are often born profoundly deaf. By the time they are 10 or 12 years old, they begin to lose night vision; they indicate they don't see the stars any more. And they also have late walking onset, often around 2 or 2 ½ years old. This is a retina from an individual with Usher syndrome Type 1. And what you will notice are these black spots, which are not normally present. They are pigmented spots and eventually the entire retina will be covered by the pigmented spot, thus the name retinitis pigmentosa. Let me tell you it affects 1 in 10,000 individuals. There are seven different Type 1 Usher genes mapped, and of those, five are identified. We have cloned them and know what these genes produce. So there are still two that have been mapped that we have not yet identified. What I want to do is tell you about one of them.

And so now, I want to put together everything I have told you very briefly. So this is a family that Dr. Andrew Griffith, who is an otolaryngologist in our institute, and

I first started studying. They have two children that were profoundly deaf and late walking. And it looks like it is recessive. After extensive discussion with the family, we learned there was a branch of the family, that they didn't want us to know about, that had two individuals in their 40s that have Usher syndrome. But they were convinced that this is not what their children had. However, these children were not carrying a mutation in the GJB 2 gene. Although the father was a carrier, the two children had no normal GJB 2. By technologies, which I won't discuss, we identified the mutation that was segregating in this little family, and it is called R245X and it is in the gene called PCDH 15, which we had shown previously to be a cause of Usher syndrome Type 1. So the two individuals with Usher syndrome are—and so are these two children. They will eventually lose their sight if we are not clever and figure out an intervention or strategy for slowing down the rate of loss of vision.

So to summarize what I have told you and some other points I would like to make, there are many genes that can cause hearing loss. There are multiple mutations of each of these deafness genes and some are very rare. That is, you will only find them in a single family in Bali or Pakistan or the United States. But some are quite common, and when they are common you can develop molecular techniques to identify them quickly, and they are part of the repertoire of information that genetic counselors use to advise parents. Children who have deafness alone, a pre-lingually deaf child with Usher syndrome is likely to be initially diagnosed with deafness alone. And children with early onset deafness not due to mutation of GJB 2 should have an early examination. A cochlear implant can restore a significant degree of hearing loss with individuals with those mutations in GJB 2. And we now know from two patients, who have this form of Ushers with R245X that they too respond favorably to a cochlear implant. You will hear more about that. But it is a bionic device that stimulates the cochlea rather than through hair cells directly. It is a very clever device. The identification of genes that cause deafness gives new insight to how hearing happens. As I showed you in the little cartoons, we don't know much about the molecular events in the transduction of sound. Identification of these mutated genes that cause deafness or loss of vision will provide new therapeutic strategies. I am overly confident about that, I know. But I'm sure in my lifetime we will have some breakthroughs.

Improved diagnostic accuracy and genetic counseling will be possible through more complete understanding of the genes that cause deafness. An increased understanding of the function of deafness genes has already facilitated better health care for hearing impaired individuals. And new insight into the reasons for progressive losses in the elderly should lead to prevention. I wanted to point out some of the work is not our own, but of other scientists elsewhere, and for some of the work I did present it was Zubair Ahmed and others. And our collaborations at Johnson and Johnson, Sackler School of Medicine in Tel Aviv, and Center for Excellence in Molecular Biology in Lahore, Pakistan. So thank you very much.

DR. BATTEY: Thank you for a wonderful presentation on our progress for understanding deafness. Well-known to everyone in this audience, I will reiterate

that there are roughly 30,000 genes in the human genome, and to narrow it down to a single base pair chain is an extraordinarily task. Dr. Friedman's laboratory has played a part in identification of over ¼ of the genes that have been identified in hereditary deafness. So it is one of the leading laboratories in the world in this effort. And we are proud to provide support for his efforts. It is money very well spent.

The second speaker is Dr. Ronald Hoy. He is David and Dorothy Merksamer Professor of the Department of Neurobiology and Behavior at Cornell University. He has identified some remarkable new mechanisms that allow us to hear sounds in a directional manner from one particular direction. He has studied a fascinating animal model that is able to do this, even though his ears are extremely close together. And based on this discovery, and the work on this animal model, he is working together in multidisciplinary partnerships with engineers and others to potentially translate this new understanding into a better hearing aid. Ron.

DR. HOY: Excuse me while I get familiar with this computer. Ladies and gentlemen of the Congressional Hearing Health Caucus, and guests, I'm honored to be here today. I am going to tell you about research we hope to translate into improved hearing aids. Hearing aid technology is very advanced and fully in step with the digital aids, nonetheless there is always room for improvement and new technologies. So here is some well known—I got this out of a textbook. Actually, I drew up the list from two sources: from some magazines and text and from my mom, who has been wearing a hearing aid.

So one problem is that the ability to hear directional sounds varies and it is very expensive. In fact, directionality is only a part of the most expensive hearing aids at this point. And mom tells me they are very expensive. They are up to 2 to \$3,000 for digital ones. This is the most common complaint of anybody wearing a hearing aid. Hearing a conversation in a crowded, noisy room is very difficult with a hearing aid. This one is strictly from mom: they can be bulky and uncomfortable, where she wants to take it out all the time. So our new designs and technology are able to address these problems, and that is what I will talk about a little bit today. All right.

Well, I have to confess that my involvement in the work that follows was not initially motivated by concerns about hearing aid technology, but by curiosity about how animals hear. However, new breakthroughs in technology often come from studying nature. That is how my work started and that is how I'm going to begin this presentation.

So many animals use acoustic signals for communication, including the crickets I study, as well as frogs, birds and mammals you are much more familiar with. Male crickets seem to attract female crickets for mating. Female crickets have ears to hear and hone in. But female crickets are not the only insects that find the cricket sound attractive. It turns out there are a couple of species of flies that do too. Flies are not noted for their ability to hear and that led to why, where and

how questions about fly hearing: How do flies here hear? Where are their ears, and how do they work? The why of fly hearing was initially puzzling. Virtually all flies are deaf. However, the *Ormia* flies have ears because they are parasites of crickets, which they find by hearing and honing in. So these flies are found throughout the Sun Belt; I studied them in Florida, Texas and Hawaii. The next slide answers the why question of parasitism. It turns out that the *Ormia* must deposit its larvae on a host to complete the reproductive cycle. In short, if she can't hear, she can't produce. I apologize for showing you this at lunch. Let me go back. So these are the larvae; they are 1/3 millimeter around. The female deposits on the male host. In a week, they complete the development - they burrow out and kill the cricket. So infestation is always lethal. All right. While that is my answer to the why of parasitism. Let's turn to the why and how of fly hearing.

As soon as my colleagues Daniel and Ron started to work on *Ormia*, it was obvious the ears were very unusual, even for a bug. Anatomically you can't see the ears; you have to remove the head, which is what we have done here. This reveals the ears sitting on its chest, if insects had a chest. At any rate, here is one eardrum, the eardrum on the left, eardrum on the right. And the fly's special trick is that the two eardrums are actually connected anatomically together and the movements occur about a pivot point, rather like a seesaw. Another point I want to make is that these flies are very small, so the ears are even smaller - a millimeter, or millimeter and a half from the edge of one eardrum to the edge of the other. As we progressed in our studies, we found out that *Ormia* ears are unlike any other ears in the animal kingdom, and this seemed like kind of a neat thing. Okay. As part of studying how ears work, we needed to know how well they perform. So to find out, we brought these flies into the lab and we gave them a hearing test. So here is the deal here. Here is the fly. You will see it moving around in a second. This is the runway and we have speakers on the left and on the right, only one speaker is active at any given time. So we alternate the cricket sound played between speakers. So let me show you how...

From the right... left... right... left... right... left... right....

I think you get the idea. Could have made a fortune with this thing at circuses at the turn of the century. The previous century. Data like these convinced us that flies have amazing ears for cricket sounds. I hope you are convinced too. That may be entertaining, but that is obviously not why I'm here. Research collaborators, particularly Ron Miles, are translating our basic research of fly ears into novel designs for a directionally sensitive hearing aid microphone. What the fly did was invent a new kind of biologically directionally sensitive ear so the question is: Can Ron and his group copy, or "biomimic", the anatomy of the fly's ear in a directional hearing aid microphone? To do this we still needed to know how flies work in great detail. So Ron and his group of collaborators from Cornell have worked out the mathematics and mechanics of this. It is really more complicated than I care to go into, so I will show you a video. The work caught the attention of American Scientific Frontiers Television and they produced a video narrated by Alan Alda.

(Video Plays)

“These ears are connected together. Connected together like a teeter-totter, it is able not only to pivot in the center the whole thing can also flap like a bird. When a sound arrives, say, from the left, the pitching and flapping combine to exaggerate the motion on the left and suppression on the right. Giving a signal big enough for the fly’s brain to pick up. A simple mechanical trick.”

DR. HOY: So the question is, can that simple, mechanical trick be implemented as a device? Well, Ron’s engineering group built a one-millimeter long microphone. He did it at Cornell’s nanofabrication facilities. So it is pretty good as a silicone chip goes; it is a pretty good model. This is the left eardrum. Here is the right eardrum, speaking in fly terms, and here is the central pivot point. And these struts give the device incredible strength. Ron calculates it can be dropped off a two-story building and not break. Robustness is an important feature because it is so delicate. It is one thing to build a silicone device that looks like a fly’s ear. It is another to work like it is a biological counterpart. Does it do so? Fortunately it does. The silicone prototype exhibits both the teeter–totter and flapping modes of vibration while stimulated by directional sound just like fly ears. It is proof of principle and a very important step to the next stage. What I’m going to show you in motion now is the performance of the silicon model. First, you will see the teeter–totter mode and then you will see the flapping mode that was displayed in the video. Here is the teeter-totter mode and now the flapping mode. Of course, it is very important that both are replicated; this is proof of concept and it is obvious that the design is going to go well.

Well, while the engineering phase of our project is still in its early days, I’m pleased to report it is very promising and proceeding very well. Ron put together this collaboration with five different labs across the country. And we are very hopeful there will be a device soon. Now the potential application of an Ormia-inspired silicon microphone is related to the second slide that I put up in the beginning of the talk. I made, obviously, a major point about the directional sensitivity of Ormia’s ear as well as silicon analog. So why is directionality desirable in hearing aids? Well, in essence, a listener could focus his or her most sensitive hearing zone to the area right in front of the person wearing the aid, while suppressing sounds from the side and in the back. So this directionally selective focus would obviously make conversing with a person in front of you in a noisy room much easier because extraneous sounds, such the television set or traffic noise or the other conversation (for example, visualize a cocktail party), could be suppressed, and that is certainly one of the goals of directional hearing aids.

Many kinds of directional hearing aids are currently available. There are some, we believe, advantages to the one modeled on Ormia’s ears. In particular, we believe that these nanofabricated silicon microphones will certainly be small, in the order of a millimeter. We’ve already shown they are highly directional. By

highly directional, this fly has the same acuity, left, right, as we humans do. So it is as acute as any animal known because we are the most directionally acute animals. In addition, there is acuity in the elevational plane, up and down. So by compounding these devices on a hearing aid chip, we are hoping to put a sharp focus of sensitive hearing. And because it is in nanofab, we are hoping it will be very cheap to manufacture.

While hearing aids and cochlear implants, that you will hear about from Rich, are certainly important aspect of maintaining hearing health in America, prosthesis is by no mean the whole story. Age related hearing aids, as you just heard from Tom, has its origins from a number of ways. But the age related hearing loss can come from degeneration of hair cells in the inner ear. And if that happens, no hearing aid, no matter how advanced, is going to do much good. So, in addition, we need advances in molecular cell biology particularly in the area of genomics, proteomics, and molecular biology. So both in prosthesis and cell biology.

I will end with this. Here is my interesting moral of my story. I never dreamed in the middle 1990s when the burning question was how Ormia and her honing in on cricket sound would lead to hearing aid research. But it has and I find it stimulating work. Glad to take questions at the end of the session. Thank you for your time and attention.

DR. BATTEY: Ron, thank you very much. I think that is a stellar example of how work on an animal model can lead to whole new paradigm shifts in how we might ultimately use that understanding to provide better prosthesis or in other cases, better treatments. The final speaker in the session is Dr. Richard Miyamoto. He was a pioneer in this effort and working on cochlear implants before there was widespread believe in the auditory community that this would provide benefits to people. He had funding from NIH for many, many years. We're delighting to support his work. He is the Arilla Spence Devault Professor at Indiana State University. And I might add the work is featured in Dr. Zerhouni's testimony last year, an example where NIH has clearly made a difference. So I am very much looking forward to hearing Richard tell his story.

DR. MIYAMOTO: Thank you very much. I'm pleased to be here at this Hearing Health Caucus. I would like to acknowledge Dr. Devault. You may know him. He is the Chair at Indiana University and took an interest in our cochlear implant project. He was the Medical Director of the Department of State here in Washington, and held the rank of Ambassador throughout his career. He was a graduate of Indiana University, and decided to make his research contributions to our university. So I was put in an endowed chair when I was an Assistant Professor, which is unusual. But he wanted me in it and the Dean was not going to turn down all the money, so he launched the project. I met several of you in the room early on. I was a representative of Lions and they were early supporters before we had funding. I mentioned sorority—but private support has been actually crucial in all of the research efforts that eventually lead to NIH funding, and our cosponsor Deafness Research Foundation has been crucial in launching so many of the careers of our young investigators in otolaryngology

and related fields. So I thank Susan and her group for that effort.

We heard Dr. Friedman's very excellent description of what happens in the ear. We have here a diagram of the ear. What we are talking about with cochlear implants are abnormalities within the cochlea itself. So this portion of the ear makes the complex transition of mechanical energy into the electrical signals that go up the auditory nerve. When I started our research efforts in cochlear implants, most of the scientific community felt it was not going to be possible with an implanted device to impart enough information to make this meaningful to our patients. It was a fellow, Bill House, who was the one who launched the first critical trial, which is when we started our work at Indiana University. You think about it - there are about 30,000 nerve fibers that support the inner ear. And we have this little wire to put in there. Well, this just doesn't add up; there is no way patients are going to get enough information to make this all worthwhile. I saw early investigations and I said this really does need to be explored. We launched our critical trial at Indiana University. This is my first patient who received her cochlear implant in 1979 and I was asked to be part of the clinical trial at that point, only about 6 months out of my fellowship. So I was a very young investigator in that initial group. I figured in this particular project I'm everybody's equal because nobody knows anything. And that is about where we were.

This is Virginia Law. She was actually the mother-in-law of one of my residents at the time and she came up from Florida. It is a picture from her. I started learning what deafness was all about from people like Virginia. She had a progressive loss, had gradually gone deaf. What really motivated her was that Dan and Sue were going to have a baby that year and she said, "If you can do one thing for me out of this project, my life will be complete. I want to hear my grandbaby cry." I started thinking about all the levels of hearing; just being in contact with your environment was really crucial. And we started looking at this and I said, "We need to explore this." So we launched into this clinical trial really without much support from the basic hearing scientists, thinking it wouldn't go very far. People like Virginia drove the project because they kept coming back with reports saying, "You can't quit. This is changing my life." At that time, we just had the single channel implant but it helped her speech reading skills. And through all my work at FDA here, we basically had to demonstrate two things. We had to demonstrate, first of all, safety, that there weren't going to be adverse influences by putting these little electric currents in the ear with a surgical procedure. That did not take us too long because the operation is not technically that difficult. If you do ear surgery, I guess you have to start there. It didn't add a lot of surgical complexity. Once the safety issues were then addressed, we had to show there was enough benefit to make it all worthwhile. During this time, our private support was absolutely crucial.

During my time making these reports, NIH took an interest in what we were doing and encouraged me to submit our first grant. My focus for this research funded since 1987 was to see what the import of implants were going to be in the pediatric age group. We started looking at young children. We had to establish many of

our own tests. In the early 1980s, there was not much interest in studying young children, mainly because progress was so slow. You have to be a patient person to document what was going on. We didn't have many interventions. First of all, we just had a look at anatomic issues. This is a temporal bone of an infant. You can see here what is lacking. There is not much of a mastoid process present. We knew dimensions were going to be small along with growth of the ear we had to take this into the account. This is a temporal bone at age 1 year. You can see we have a mastoid process and entrance. By looking at these types anatomical studies, we determined by probably age one -- we could do an implant. The first studies were down to the age of two because the children were very difficult to assess.

I think the key factor when we started looking at anatomic issues was the cochlea, which is located right here. It is already in adult configuration when it is born. In fact, in the first trimester the cochlea is adult size. We did have to account for about a centimeter and a half for skull growth. The way we deal with that is put a little loop of the redundant in the mastoid. I have been doing pediatric implants since 1983. That is 20 years. We have not had any pull out because of skull growth. I think the basic anatomy issues had to be addressed, but it really didn't present a major obstacle.

As far as the surgery is concerned, we have to take into account that the dimension of a mastoid procedure is about the same as adults. We do a mastoidectomy and do a small opening - this is facial recess that gives us a view of if middle ear and round window. Once we get to this point in the infant, it is the same as an adult because the cochlea is in its adult configuration. This is one of the electrodes, this is a nucleus electrode, and we actually have all three of the companies in our research program. I think the key thing I wanted to show here - you see the band of electrodes and all the corporations have come up with a similar strategy of having multiple stimulation sites so you can move the signal around to get high and low frequency information. The low frequencies are coded up near the cochlear apex and the higher frequencies down toward the base here. But by separating the channels, we can get frequency information. We found from single channel studies, timing information comes through very accurately. You can reproduce loudness by making the signal larger and smaller. What was lacking early on was frequency information. With more complex devices available, we are able to get good frequency information.

So we had to really think about how we were going to assess these children and think about how to test for these types of issues because we didn't have measures. That is part of what we worked out. Also about half of my children, the first part of the first FDA had ossification of their cochlea because the deafness was caused by meningitis. This was an ossified cochlea. We had to deal with that early on. We can deal with that surgically. You can tell the difference between new bone and other bone because it is softer with different color. So we can create channels to implant the electrode. This shows a partly ossified cochlea. Many children had this situation, where we had to drill through the ossification, brake through the channels and do the insertion. The

corporations did help us out later on. They came out with special electrodes that allowed us to make a straight opening in the cochlea; we can put one in the basil turn and get all our electrode bands in place. I think a lot of corporations worked with the developers of the implants so that a lot of the engineering people entered into the scene and added a tremendous amount. I gained an understanding when I was doing many of the FDA reports; the FDA brought in their electrode people. And one of the things we had to learn from the early devices - these devices need to be there. And the little children will hopefully have the device for a lifetime. So they have to be sealed and mechanically very stable. So there are just a number of issues that we learned a little bit about trial and error early on. We now have very stable devices. The failure rate is very low and we are putting in devices we think will last a lifetime.

I want to acknowledge the people that drive our research program. Most of our research at Indiana University has been behavioral research. See what happens with the young children that receive implants. The team includes audiologists, educators, and parents. We have on our team biomedical engineers, linguists, and psychologists. I think one of the most exciting things I have seen during the last 25 years involved in the study is the importance of teams of researchers pooling their talents and making this project go. We were all doing our own thing sort of in isolation before. This is a perfect example of what teamwork can accomplish with a research team. I think if you look all across the projects funded by NIH, you are seeing this happen at every level. It has become so complex that the leading teams are going to be teams of researchers. There will be some triple people that can do everything in their area. But for the most part, advanced research is going to come from related disciplines figuring how to work together and creating new entities.

Just to show you a couple of data slides. This was one of the important things that came out of early observations. If we demonstrate the worth of cochlear implants, we have to do longitudinal studies. If you think about it, babies are acquiring information for quite some time before it transfers into speech and language skills; we are seeing the same thing with implants patient. They had to detect the sounds and attach to the sounds, and turn them into learning concepts. These are just longitudinal scores going out 3 ½ years. And we had, in the early days, come up with our own measure to standardize the results in the young children because there weren't many measures that were available to us. I think the key here is that these speech perception tests—and this is pretty much across the board—play out over a long period of time. I think, thanks to the NIDCD, we have been able to track a large group of patients. We now have over 850 implant patients at our center. And we have not lost track of too many of them just because of our ability to track them through our NIH funding.

Another thing we found is that there is quite a difference between the perceptual advances we see and the speech production that comes afterwards. There is often delay. That kind of makes sense. You have to have it in your head before it comes out of your mouth. So we have several wings to our research. Some just study perceptual abilities of children and also—I'm only clinician. We did not

have a speech scientist but at the outset I got the idea that something good was going happen with the group of children that would be reflected in their vocal production. We started doing our implants. We took voice recordings of the kids. When the kids came in we took a speech sample. I had banks of tapes mounted on the wall there and I thought sooner or later something was going to come out of this. I could hear big changes in their speech productions. I said now I have got it and I just have to find someone to do something with the tapes. Mary Jo turned my banks of tapes—she knew how to analyze the voices. From that point on, we had real credibility among the speech scientists because we could describe things in terms of what they could understand and were meaningful. I think critical observations are crucial to decide what your next research direction is going to be. This is another thing that came out. We carefully analyze all the phonetic information and the people that know how to listen to these tapes we could extract the vowel and consonant scores. This was spread over a time sequence here. By having all these tapes put together, we could follow the progress of the kids and see what phonetic elements emerged first. We found it wasn't that much different in many normal children. As you know, cochlear implants do not pass on every bit of information a normal ear has to deal with, so there were differences and the trends were very obvious.

I think the most exciting part of research is what is happening to actual functional language and this is the ultimate byproduct. This has turned into a language that is useful to the children. What we found out early on was that there were very few studies that really tracked language in young, deaf children. So we did a very detailed long-term study of children with hearing aids. This is a slide that is kind of summarizing some of this. We have tracked language age with chronological age using a language score from a test called the Reynell Development Language Scales (RDLS). A widely used standardized language score. The horizontal axis is chronological age. So if your language age and chronological age are working in tandem, a normal child should be right along the diagonal. Doing a progression analysis among 100 deaf children who wear a hearing aid, we found that there is half of what the normal is, maybe less than half. You can see here the children would get more and more in line as time went on. We superimposed a group of young implemented children. You can see these lines now show something that is very interesting. The slope parallels a normal hearing child. So even though they started later, they were acquiring language at nearly normal rates. So you can see here, we have got a line that is parallel to what we would expect. You didn't have to be a rocket scientist to figure this out. I figured if they were going to learn at the same rate, if you start earlier before they got so far behind, you would have a much different situation. So what we have been doing with our work is just inching downward in the age of implantation, thinking that if children could access the key speech features they need at a very young age, they are going to develop speech and language concepts as regular children. This is not always the case, but it is quite frequently.

Now we were gathering earlier, and I met some of the people who were very involved in the newborn screening efforts around the country. This is very

exciting. I think for the deafness found in children very early, we now have interventions that we can offer. That wasn't the case before. It was very frustrating just to find the deaf children. As an otolaryngologist, it was very discouraging. With the implant, this is all different. This is a young mother who called me. She is actually from Augusta, Georgia, but I think the people who were involved with newborn hearing would like to get this call. She said, "I have a youngster who failed his newborn screen - no acoustic emission or auditory brain stem response. He has a gene for deafness and needs a cochlear implant." I said, "How old is he?" She said, "He is 3 months old and ready to go." Well, it is a little bit young. Actually, at that time the FDA just lowered our age limit to 18 months. It has now gone down one. But pa

=====

[Remaining text of speech was not posted]

LINK::

<http://web.archive.org/web/20040104024637/www.hearinghealth.net/cms/index.cfm?displayArticle=111>

=====
=====
=====

See:

http://saveourdeafschools.org/congressional_hearing_health_caucus_transcripts.pdf