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AMERICAN COCHLEAR IMPLANT ALLIANCE

Engaging Families in Continuing to Improve EHDI Programs, in partnership with American Cochlear Implant Alliance

Karl R. White, PhD

National Center for Hearing Assessment and Management
Utah State University , www.infanthearing.org

The Power of Parents in Fostering Language in Deaf and Hard of Hearing Children: A Two Part Series

Why another organization in hearing health?

- Membership organization focused on cochlear implantation and access to care
- Members are audiologists, physicians, speech pathologists, educators and others on CI teams + consumers/parents, advocates, hearing aid specialists

Website designed for those in and out of CI
Highly collaborative with other organizations
Welcome your involvement!

www.acialliance.org

<https://www.facebook.com/ACIALLIANCE.ORG/>

Twitter@acialliance



American Cochlear Implant Alliance

- Mission: Advance access to the gift of hearing provided by cochlear implantation through research, advocacy and awareness
- Address factors contributing to underutilization of cochlear implants
- Improve awareness regarding candidacy and outcomes

Why this topic is critical now

- **Hearing loss in children has changed**
 - Opportunity to intervene with early identification
 - Technology routinely fit at 2 weeks of age
- **Parents are a child's best first teachers**
- **Language of the home allows integration into the fabric of the family**
 - “Language Nutrition” encouraged for all children
 - *30 Million Words* elevated awareness of talking and interacting at home for life-time achievement
 - Parents already have the tools

Listening – Language – Literacy

- High priority for ACI Alliance
- Families of children with all levels of hearing loss can foster literacy when they are comfortable talking and interacting
- Benefits for social/emotional well being
- Hearing sounds of language facilitates reading and writing



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Karl R. White, PhD

Dr. White is a Professor of Psychology at Utah State University and the founding Director of the National Center for Hearing Assessment and Management (NCHAM). Dr. White has published extensively about the issues and evidence related to implementing and improving the efficacy of Early Hearing Detection and Intervention (EHDI) programs. Projects currently underway at NCHAM are focused on developing more effective hearing screening and intervention programs through research, improving public health information systems, training and technical assistance, and information dissemination. More about NCHAM activities in these areas are available at www.infanthearing.org.

Prior to his work at NCHAM, Dr. White was the Director of Research and Development at the National Technical Institute for the Deaf, the Director of Research and Evaluation at the Center for Persons with Disabilities, and the Director of the Early Intervention Research Institute at Utah State University. From 1984 to 1985, he served as a Congressional Science Fellow with the American Association for the Advancement of Science and worked as a staff member for the Subcommittee on the Handicapped in the United States Senate where he was responsible for the staff work related to the creation of the Commission on Education of the Deaf and the Education of the Deaf Act of 1986. He also serves on many national and international advisory groups for organizations such as the World Health Organization, United States Department of Health and Human Services, March of Dimes, the American College of Medical Genetics, the National Academies of Science, Engineering, and Medicine, and the American Academy of Pediatrics.

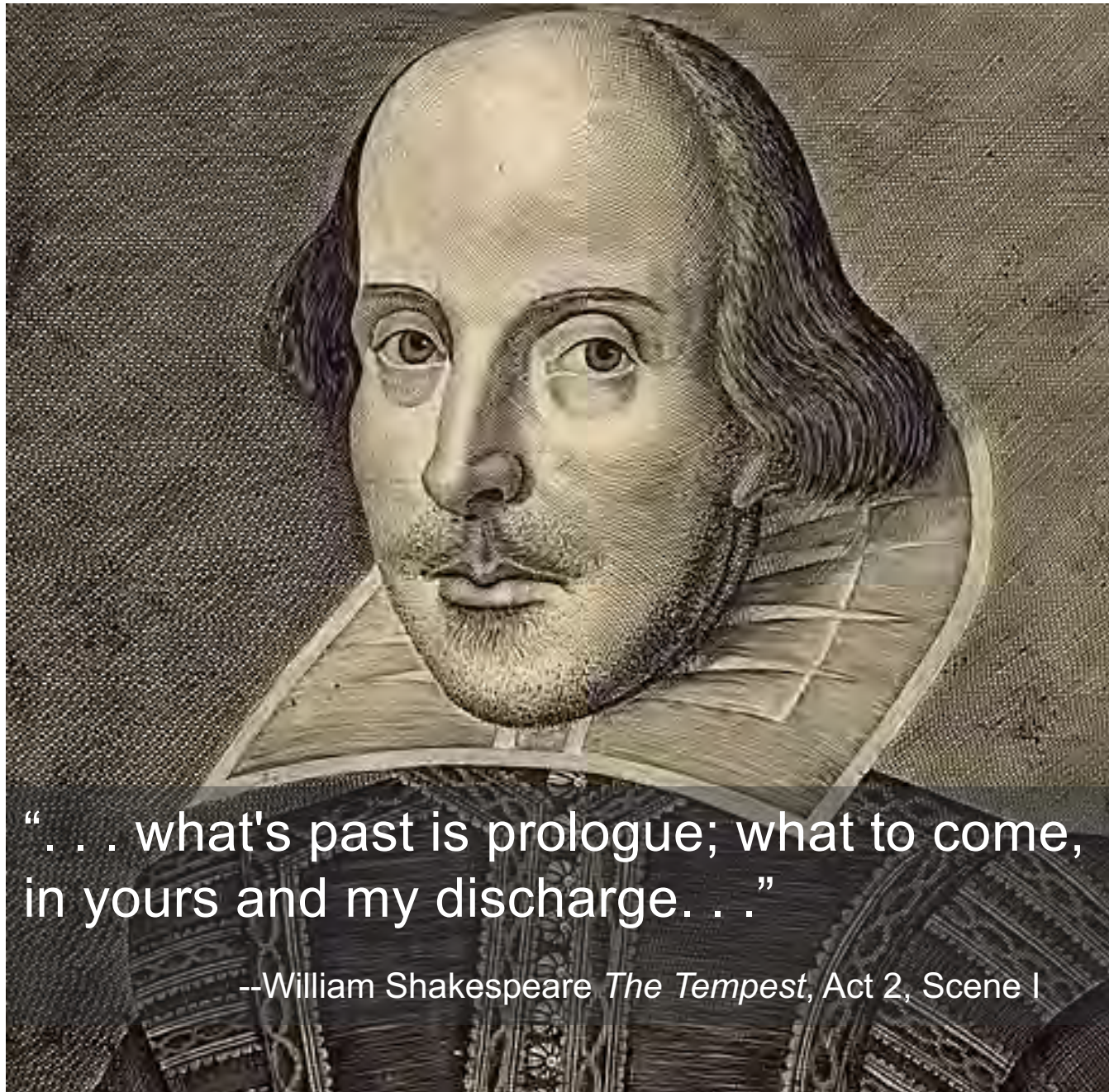
Disclosures

- **Presenter Disclosure:** Financial: Karl R. White is employed by Utah State University. He received an honorarium for this presentation. Non-financial: Karl R. White has no relevant non-financial relationships to disclose.
- **Content Disclosure:** This learning event does not focus exclusively on any specific product or service.
- **Sponsor Disclosure:** This course is presented by AudiologyOnline in partnership with the American Cochlear Implant Alliance.

Learning Outcomes

After this course, participants will be able to:

1. Describe three advances in clinical practice over the last 40 years that have contributed to earlier identification of infants and young children who are deaf or hard of hearing.
2. Identify two challenges that need to be addressed to further improve the outcomes for infants and young children who are deaf or hard of hearing.
3. Explain what various stakeholders (e.g., health care providers, public health officials, parents, and educators) can do to continue to improve outcomes for children who are deaf or hard of hearing.



“ . . . what's past is prologue; what to come,
in yours and my discharge. . . ”

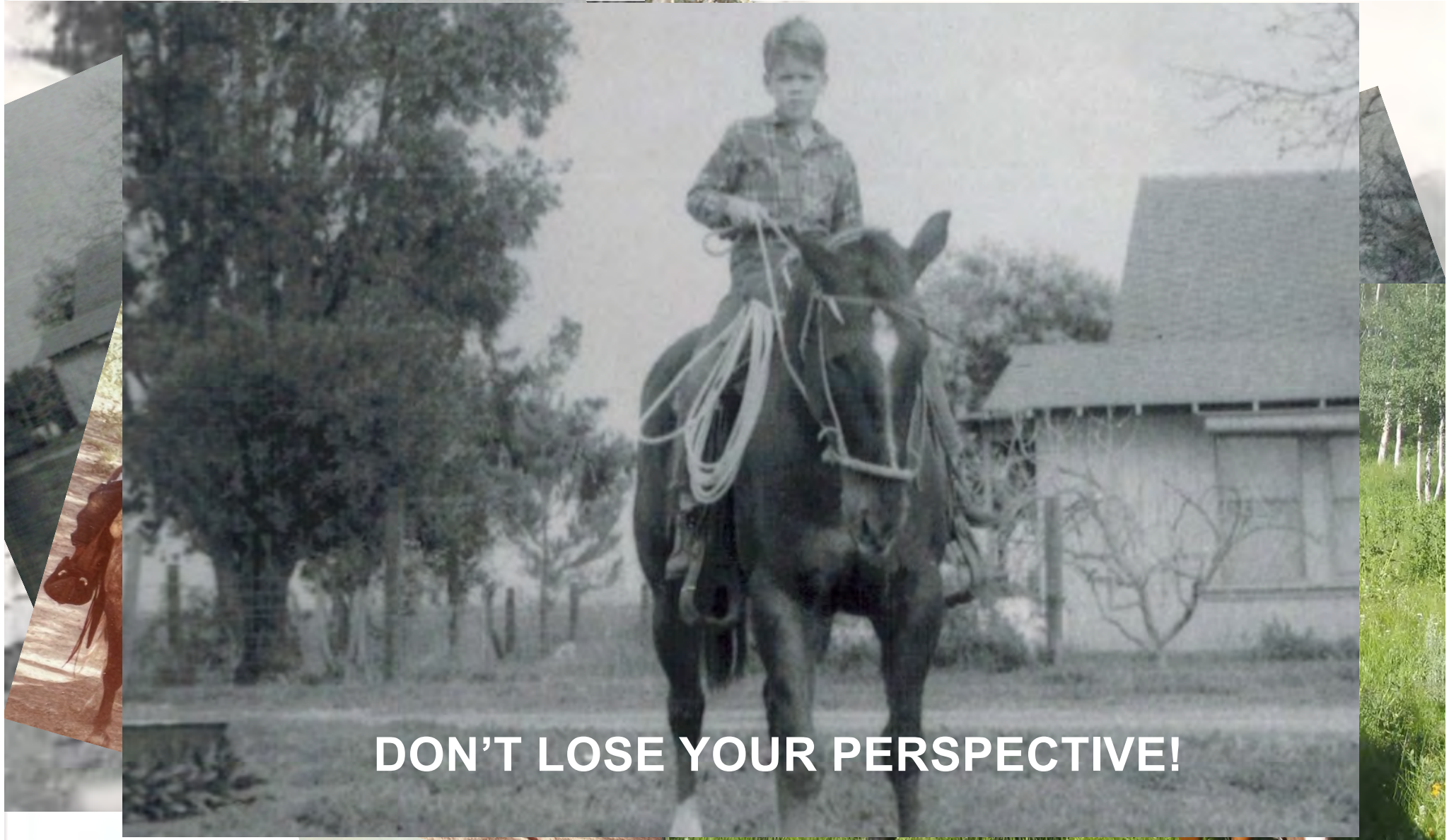
--William Shakespeare *The Tempest*, Act 2, Scene 1

**I always wondered why somebody
didn't do something about that.**

Then I realized I was somebody.

--Lily Tomlin





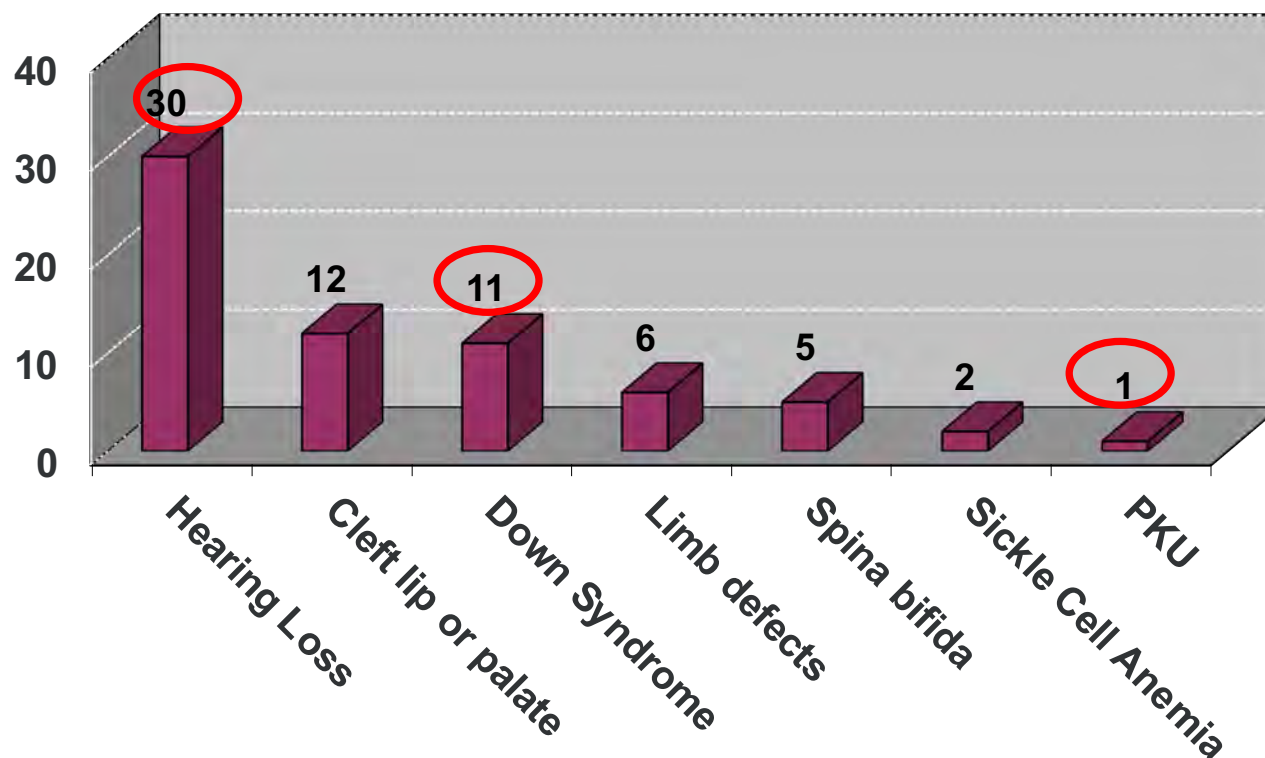
DON'T LOSE YOUR PERSPECTIVE!



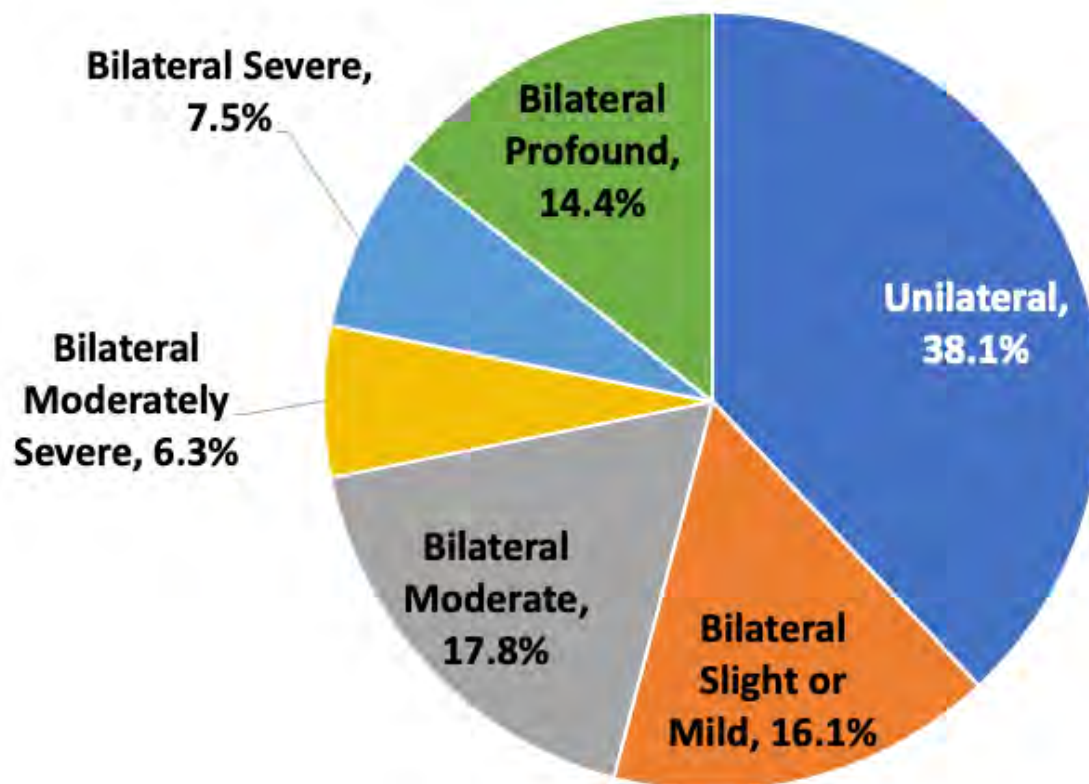
1. What's past is prologue; what to come, in yours and my discharge.
2. Why doesn't somebody do something about that? -- Each of you is a somebody!]
3. Don't lose your perspective.

- ✓ Permanent hearing loss occurs more frequently than any other condition for which we can screen at birth

Incidence per 10,000 of Congenital Defects/Diseases



Hearing Status of Children Reported to CDC by EHDI Programs (2018-2020)



Hearing Status of Parents In Gallaudet 2011-2012 Annual Survey of DHH Children and Youth

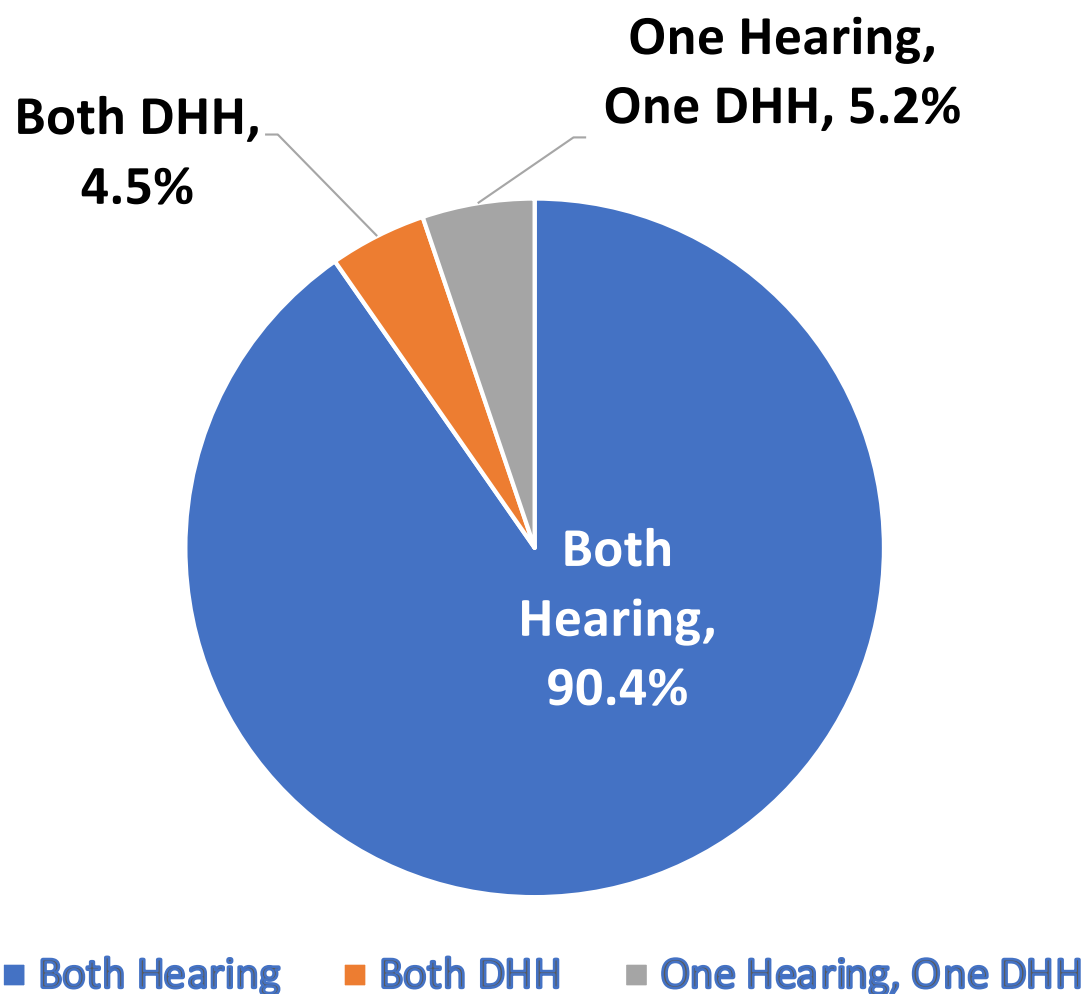


Chart 5. Family Report of Child's Primary Communication Modality

Communication Modality	Percentage of Families
Listening and Spoken Language only	49%
Sign Language only	3%
Mostly Listening and Spoken Language (supplemented by sign language, cued speech, or other)	17%
Mostly Sign Language (supplemented by listening and spoken language, cued speech, or other)	3%
Mostly Cued Speech (supplemented by listening and spoken language, or other)	12%
Equal Parts Sign Language and Listening and Spoken Language (including total communication)	14%
Other	1%



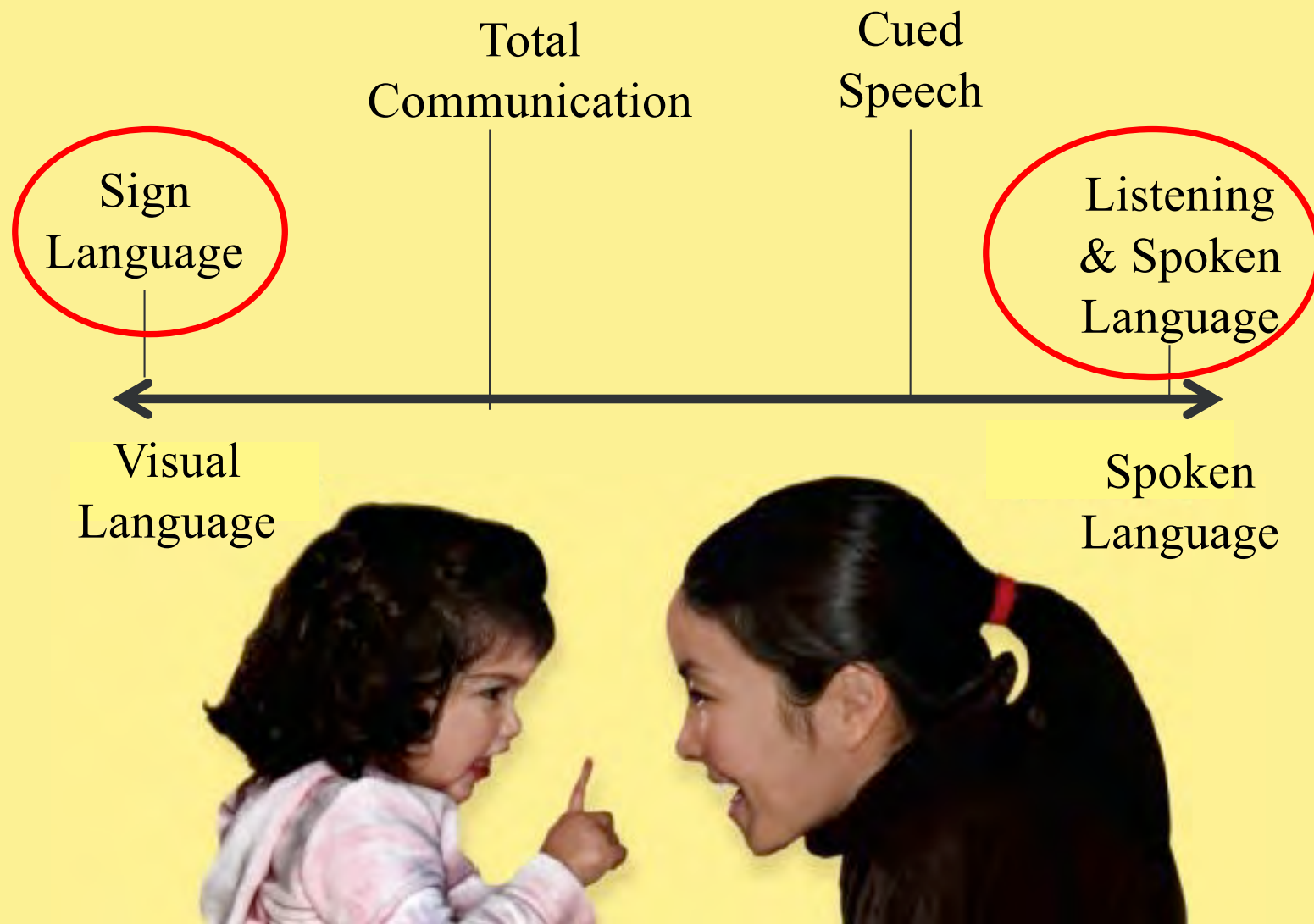
**N=303 families of 2-6 year-old
DHH children from 10 states** (CO, GA,
IA, LA, MA, MN MT, NV, SC, VT)

Behl D and White KR. (2018). Early Intervention for Children Who are Deaf or Hard of Hearing: Systematic Analysis of Program Strrrengths, Hurdles, Opportunities, and Trends. Utah State University. Accessed April 2024 at <http://www.infanthearing.org/ei-snapshot/>

**Blindness separates people from things.
Deafness separates people from people.**

--- Helen Keller











Audio and picture courtesy of Susan Nittrouer, University of Florida



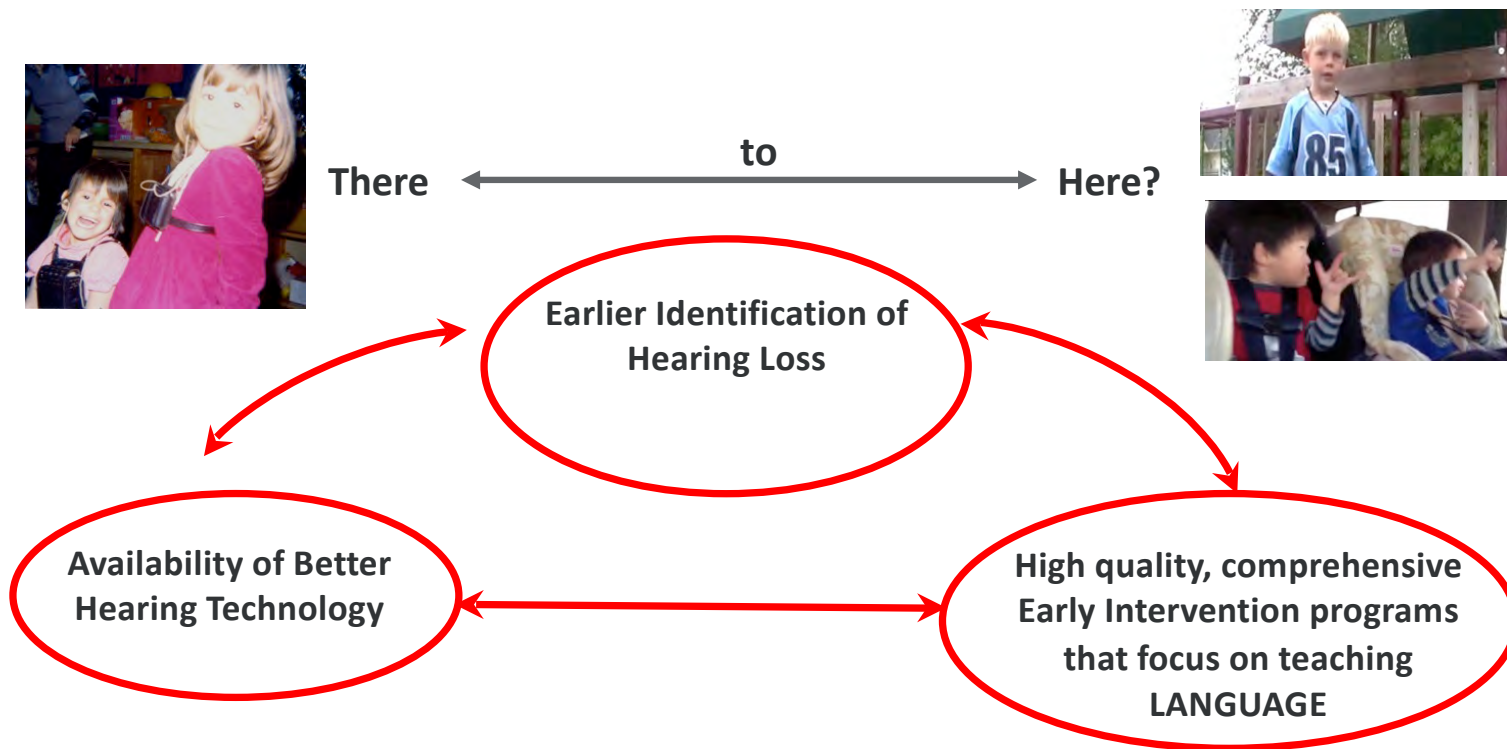


**Spring is my favorite season.
The sun shines bright. The
flowers begin to grow. I
like spring.**





What enabled us to move from



From 1988-1993, Utah State University conducted the first large-scale systematic evaluation of universal newborn hearing screening.



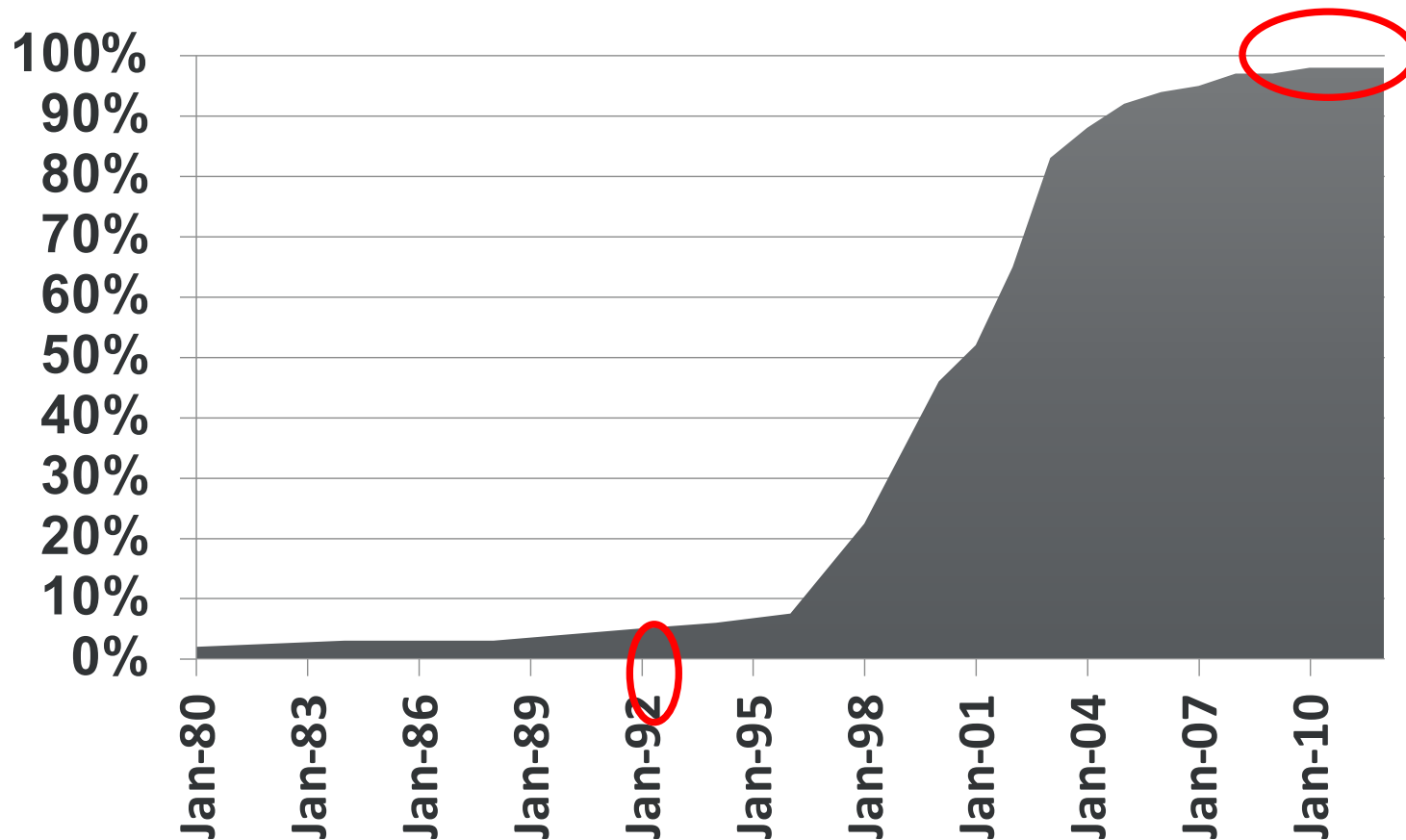
White KR, Vohr BR, & Behrens TR. (1993). Universal newborn hearing screening using transient evoked otoacoustic emissions: Results of the Rhode Island Hearing Assessment Project. *Seminars in Hearing*, 14(1), 18-29.

In March 1993 an NIH Consensus Panel on Early Identification of Hearing Impairment in Infants and young Children concluded that:

- The average age of diagnosis of hearing loss remains constant at about 2 ½ years of age.
- All infants should be screened for hearing loss.
- [Screening] will be accomplished most efficiently prior to discharge from the well-baby nursery.
- Identification of hearing loss must be seen as imperative for all infants

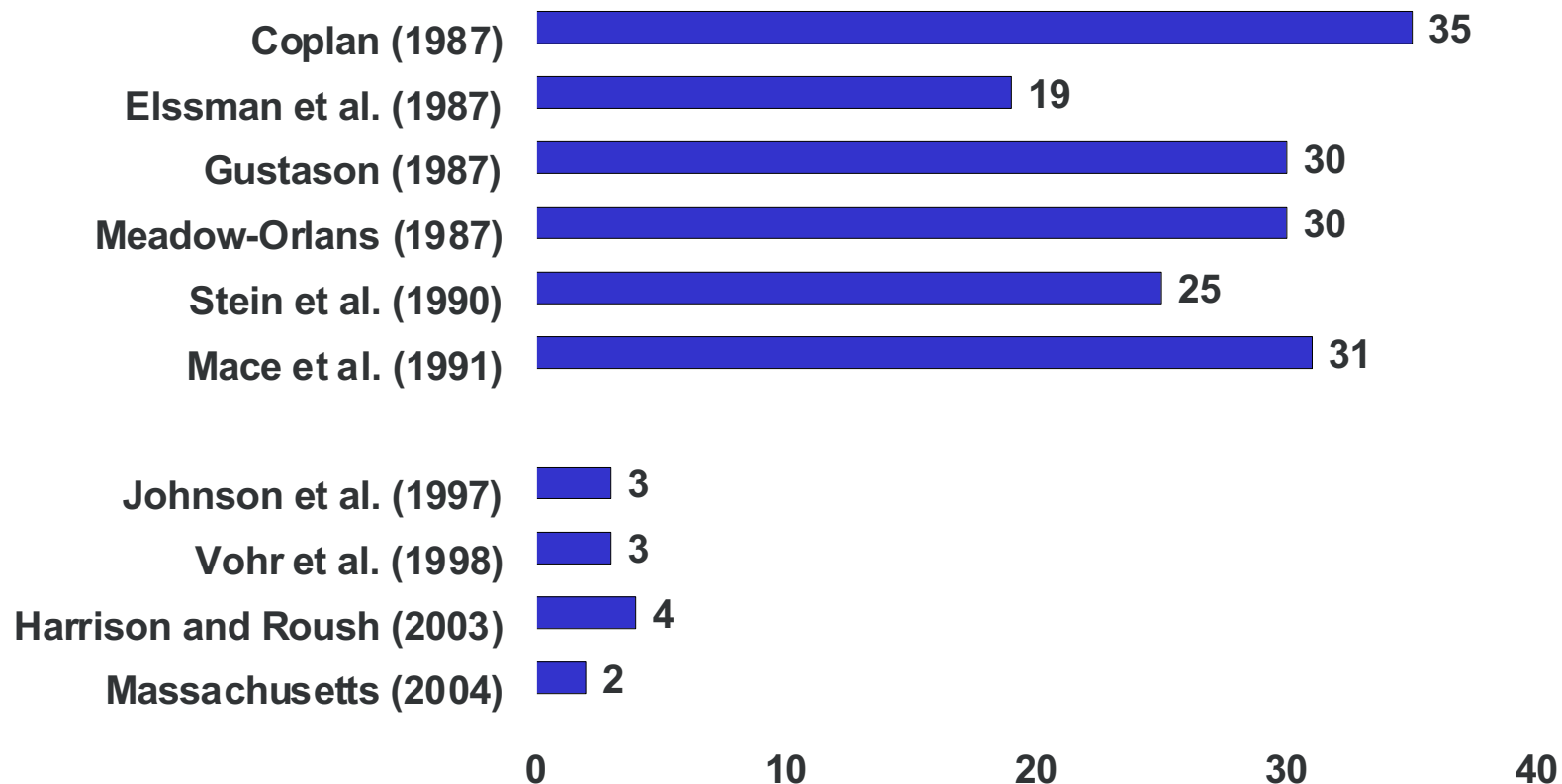
Summary of the NIH consensus statement on early identification of hearing impairment in infants and young children. Md Med J. 1994 Feb;43(2):171-2. PMID: 8208077.

Percentage of Newborns Screened for Hearing in the United States

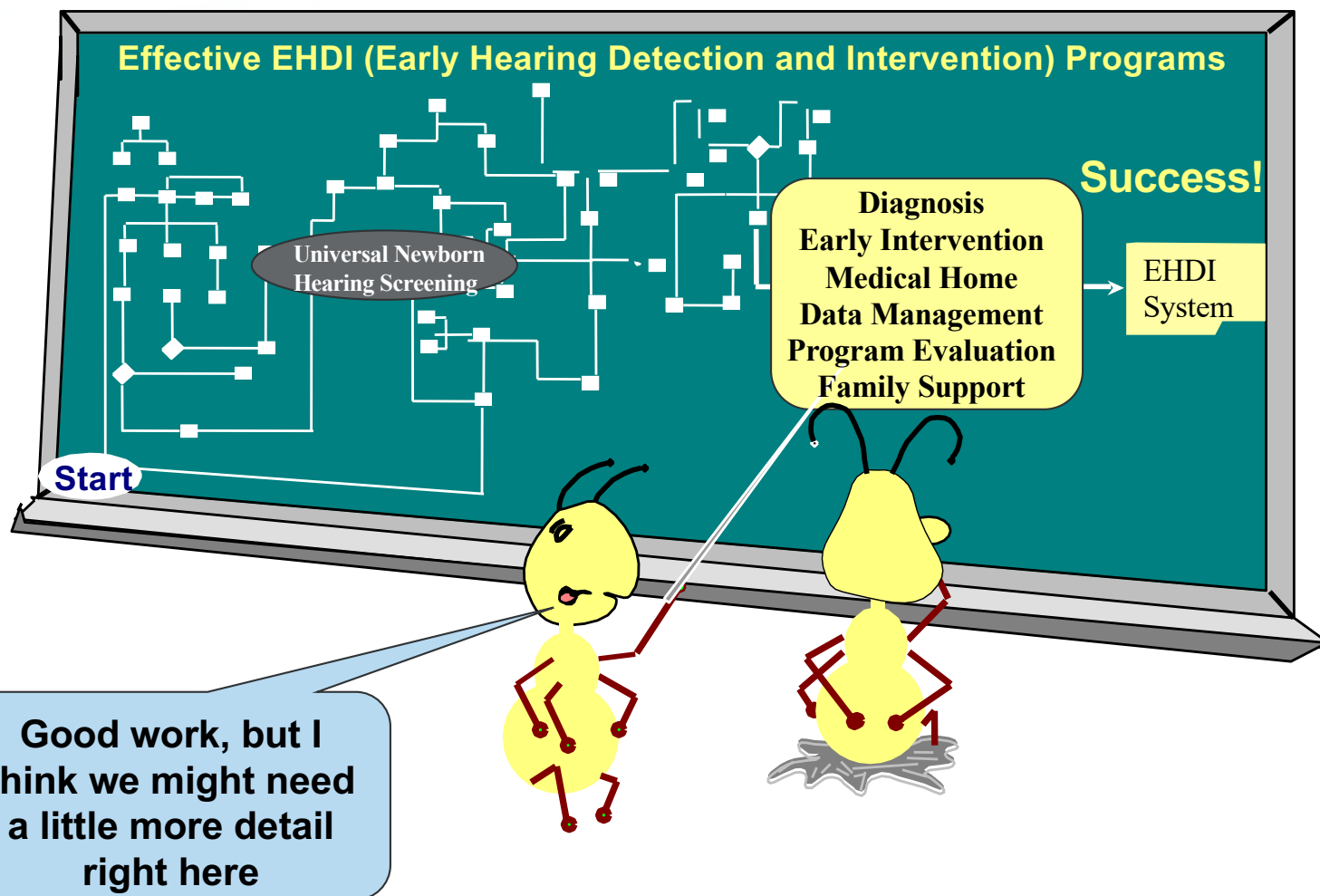




Age in Months at Which Permanent Hearing Loss Was Diagnosed



White KR, Forsman I, Eichwald J, Munoz K (2010). The evolution of early hearing detection and intervention programs in the United States. *Semin Perinatol.* 34(2):170-9.

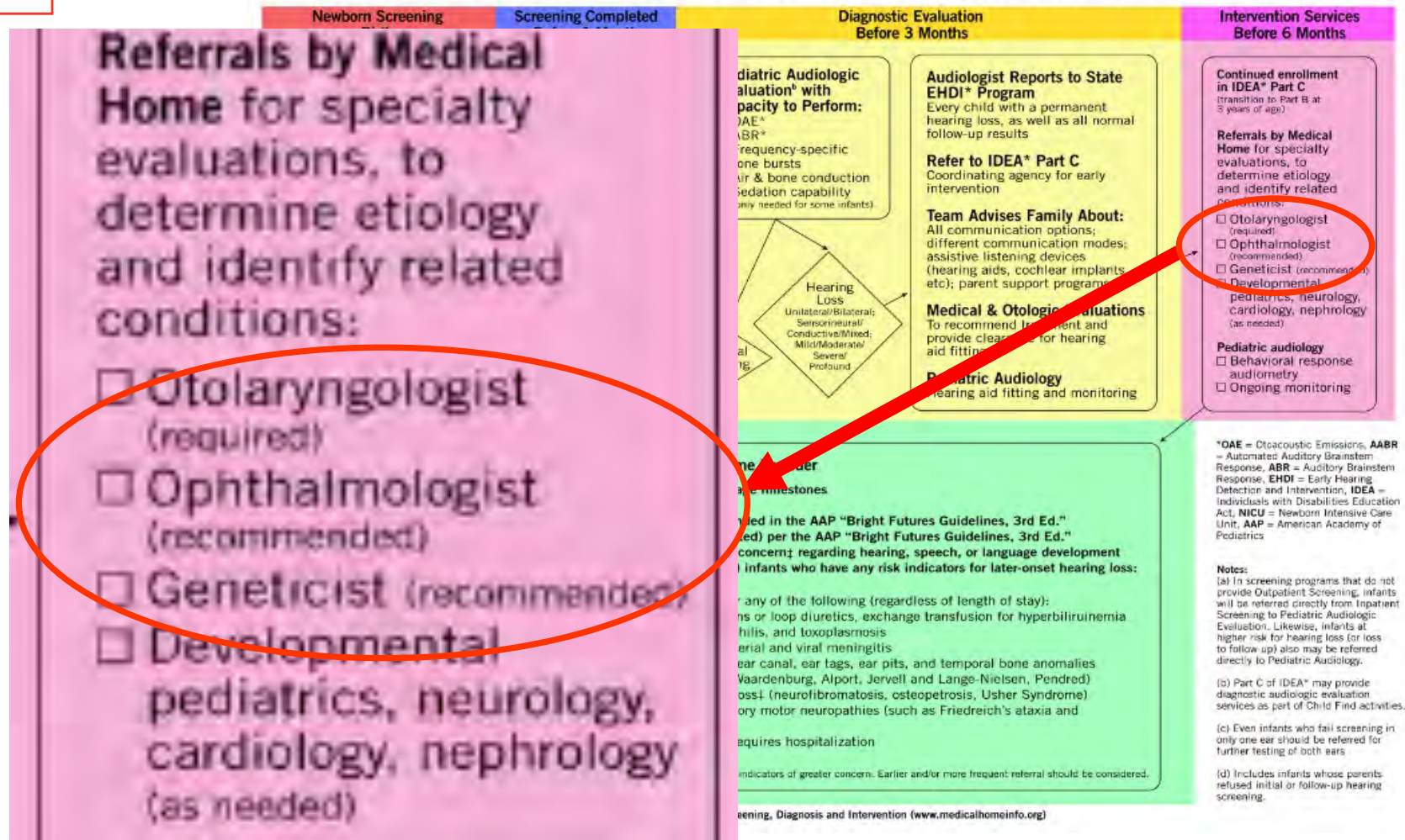




1. What's past is prologue; what to come, in yours and my discharge.
2. Why doesn't somebody do something about that? -- [Each of you is a somebody!]
3. Don't lose your perspective.

1

Early Hearing Detection and Intervention (EHDI) Guidelines for Pediatric Medical Home Providers



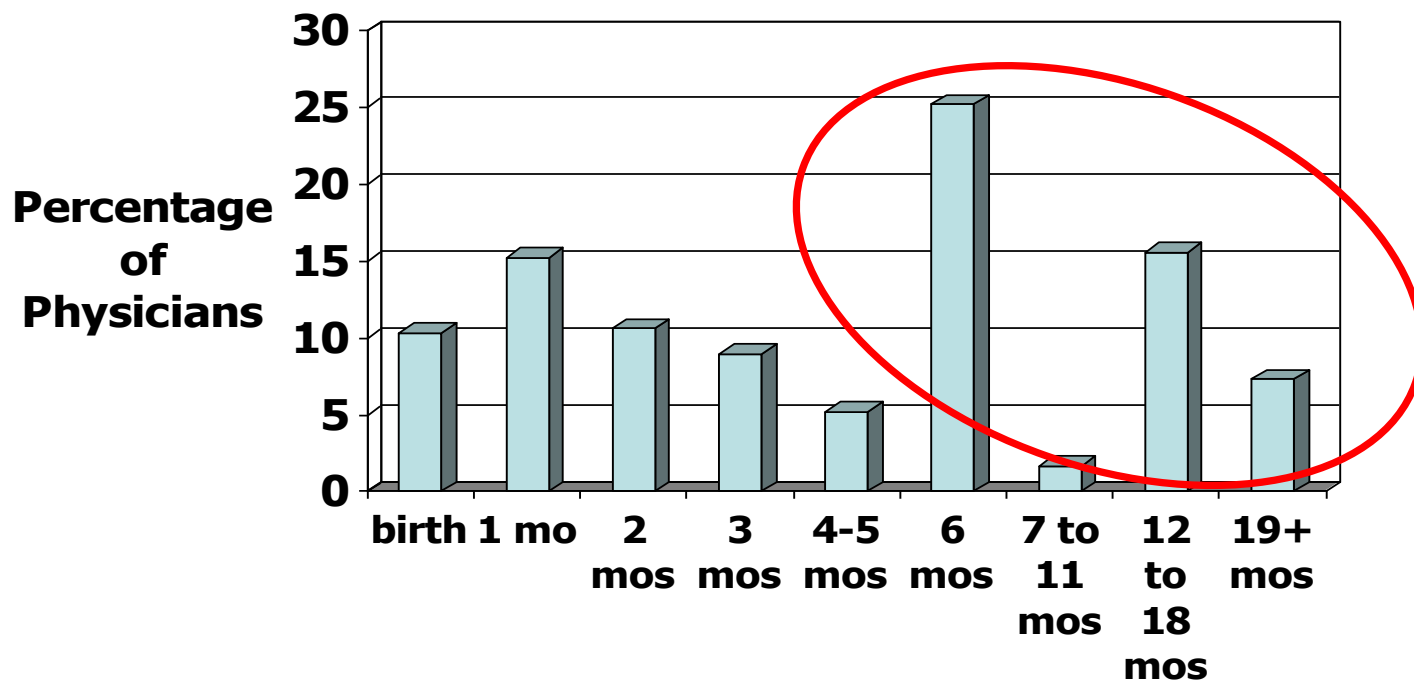
Educating Primary Health Care Providers About Early Identification of Hearing Loss

Assume a newborn for whom you are caring is diagnosed with a moderate to profound bilateral hearing loss. If no other indications are present, to which specialists would you refer the baby?:

	Always or Often
Ophthalmological evaluation	0.6%
Genetic evaluation	8.9%
Otolaryngological evaluation	75.6%

Responses of 1975 physicians in 21 states

When can an infant be fit with hearing aids?



Moeller MP, White KR, & Shisler L (2006). Primary care physicians' knowledge, attitudes and practices related to newborn hearing screening. *Pediatrics*. 118, 1357-1370.

2

Question: What percentage of children who are DHH at 5 years of age were born DHH?

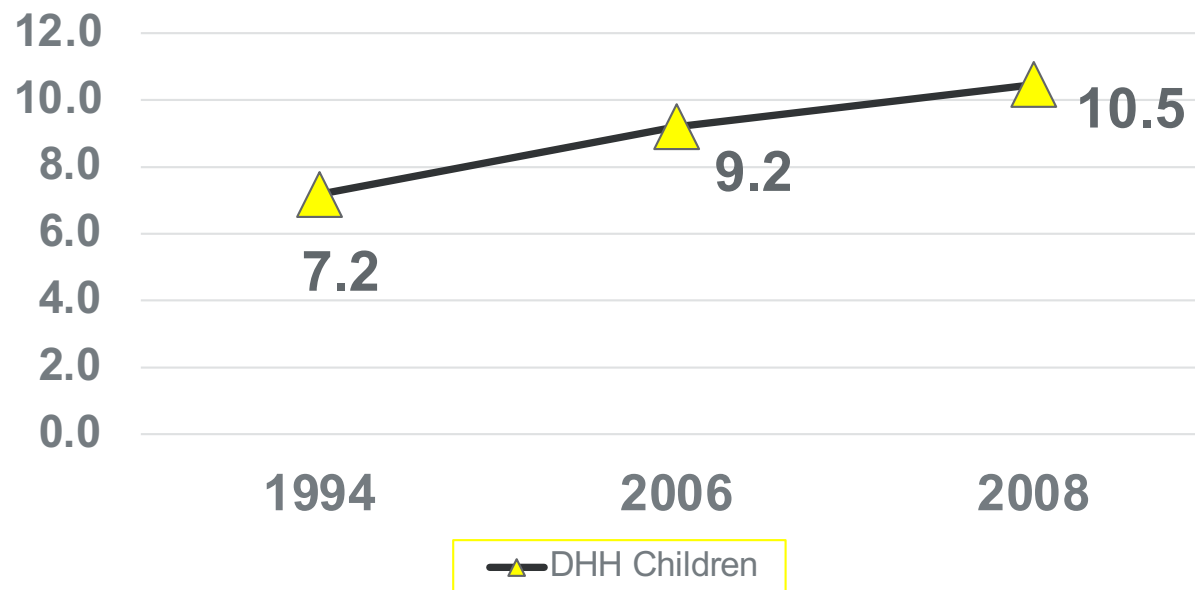
Answer: 50%



Twice as many children become DHH after birth as are born DHH!

2

Children per 1,000 with moderate or worse permanent hearing loss



**National Health and Nutrition Examination Survey (NHANES)
for 6-19 year-olds based on audiometric examination**

Barrett TS, White KR. (2016). Prevalence and trends of childhood hearing loss based on federally-funded national surveys: 1994–2013. *Journal of Early Hearing Detection and Intervention*, 1(2), 8-16. DOI: 10.15142/T3P88B.

What's Our Safety Net?

Hearing Screening for 0-3 Year Old Children

Study #1 (Early Head Start Programs)

- 4,519 young children screened
- 257 (6%) needed medical follow-up
- 100 (2.2%) with fluctuating conductive hearing loss
- 7 (1.6 per 1,000) with permanent hearing loss
 - 4 passed newborn hearing screening
 - 2 were not screened as newborns
 - 1 failed newborn hearing screening but didn't follow-up



What's Our Safety Net? (continued)

Hearing Screening for 0-3 Year Old Children

Study #2 (Federally Qualified Health Centers)

- 1,965 young children screened
- 75% of children required <10 minutes
- 102 children (5.2%) with fluctuating conductive hearing loss
- 5 children (2.5 per 1,000) with permanent hearing loss



Study #3 (Federally Qualified Health Centers)

- 846 young children screened
- 3 children (3.5 per 1,000) with permanent hearing loss



Bhatia P, Mintz S, Hecht BF, Deavenport A, Kup AA. Early identification of young children in Federally Qualified Health Centers. *J Dev Behav Pediatr.* 2013;34(1):15-21. doi: 10.1097/DBP.0b013e318279899c

Foust T, Eiserman W, Shisler L, Geroso A. Using otoacoustic emissions to screen young children for hearing loss in primary care settings. *Pediatrics.* 2013 Jul;132(1):118-23. doi: 10.1542/peds.2012-3868.



www.kidshearing.org
Helping you implement evidence-based hearing screening practices

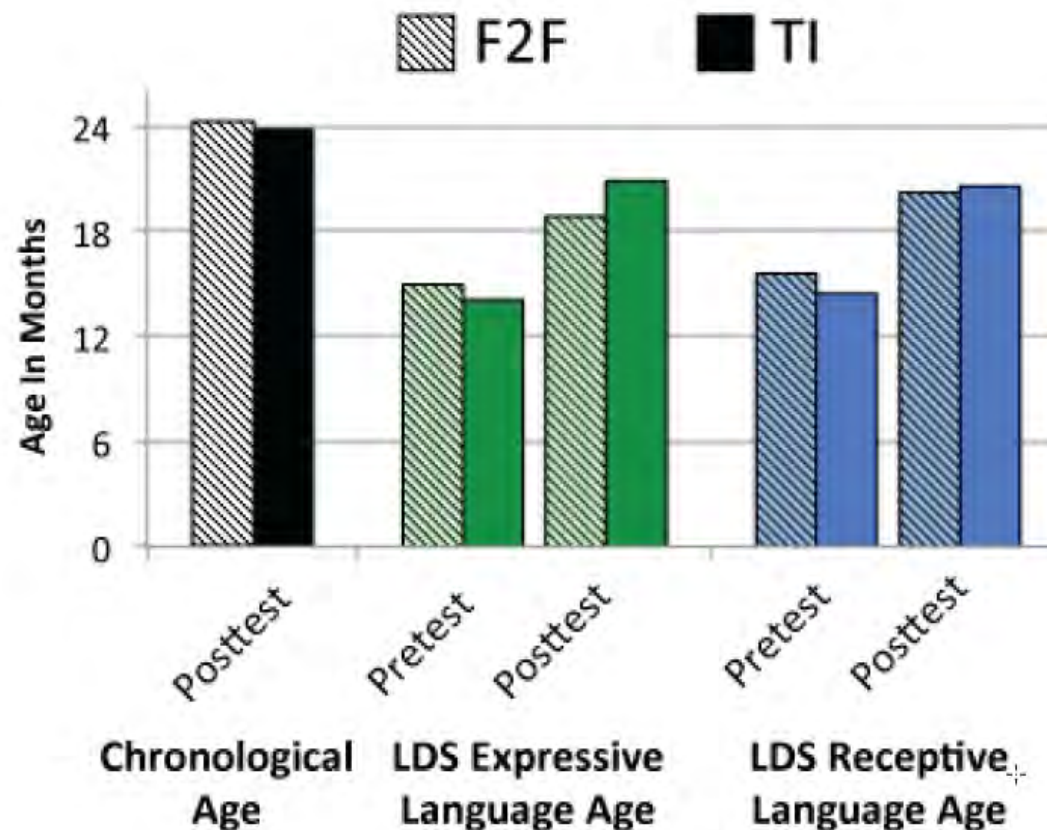
Early Head Start – Head Start – Early Intervention – Preschools – Home Visiting – Schools – Health Care

3





Comparison of 27 children randomly assigned to face-to-face (F2F) services or tele-intervention (TI) services



Blaiser KM, Behl D, Callow-Heusser C, **White KR**. (2013). Measuring costs and outcomes of tele-intervention when serving families of children who are deaf/hard-of-hearing. *International Journal of Telehabilitation*, 5(2), 3-10. doi: 10.5195/ijt.2013.6129.

EHDI Tele-health Resource Guide

www.infanthearing.org



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Last Modified: 03/17/2022

EHDI/ UNHS Resources

- Virtual Site Visit
- Just In Time Family Resource Guide
- Quality Improvement
- Newborn Hearing Screening Training Curriculum
- EHDI Consultants
- Interagency Collaboration, Data Sharing, and Privacy Issues
- Slideshow Presentations
- Educational & Training Videos
- NCHAM Materials
- EHDI Learning Center
- Telehealth
 - Tele-Intervention Courses
 - Tele-intervention Guide
 - TeleAudiology Guide

Telehealth and EHDI Systems

What is "Telehealth"

Telehealth is the use of electronic information and telecommunications technologies to support long-distance clinical health care, patient and professional health-related education, public health and health administration. <https://www.hrsa.gov/rural-health/telehealth/index.html>

What are some examples of Telehealth technologies?

Technologies used in telehealth typically are: videoconferencing, the Internet, store-and-forward imaging, streaming media, and terrestrial and wireless communications.

What is "Telepractice?"

Telepractice encompasses a broader range of services. Groups such as the [American Speech-Language-Hearing Association \(ASHA\)](#) define telepractice as "the application of



4

What is Congenital Cytomegalovirus (cCMV)? (And why should you care?)

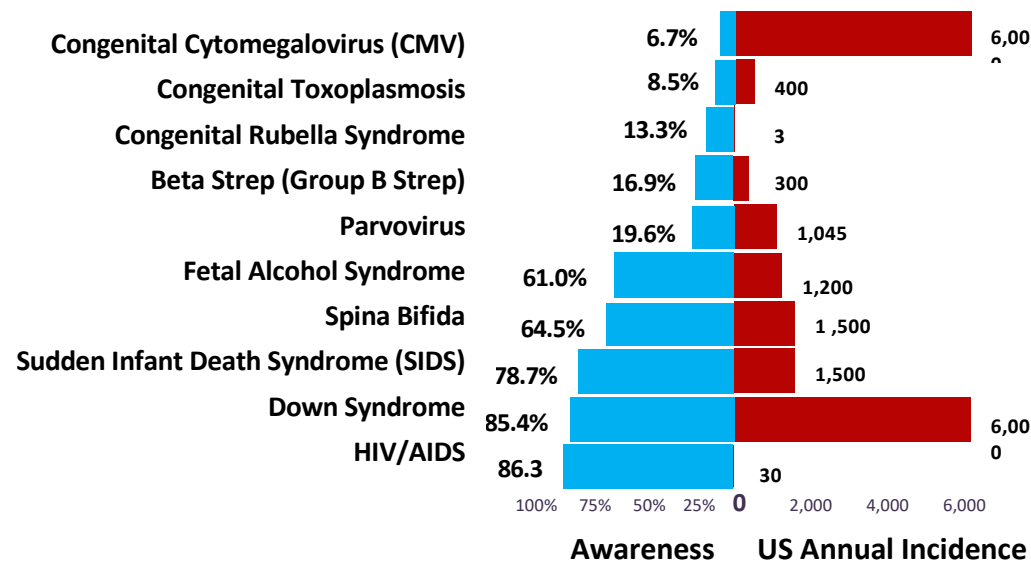
1 OF 200 CHILDREN ARE BORN WITH
CYTOMEGALOVIRUS (CMV) ~20,000
children each year in the USA

1 OF EVERY 5 CHILDREN BORN WITH CMV
WILL DEVELOP PERMANENT PROBLEMS

EVEN THOUGH IT'S THE MOST COMMON
VIRAL CAUSE OF DEVELOPMENTAL
DISABILITIES IN CHILDREN --
MOST PEOPLE ARE UNAWARE OF
PROBLEMS CAUSED BY CMV.



Awareness of Adults in the US of Childhood Conditions compared to Prevalence of Disability Due to Each Condition



Data from 2016 Health Styles™ survey

Doutré SM, Barrett TS, Greenlee J, White KR. (2016). Losing ground: Awareness of congenital cytomegalovirus in the United States. *Journal of Early Hearing Detection and Intervention*, 1(2), 39-48. DOI: 10.15142/T32G62.

- Of ~20,000 babies born each year with CMV:
 - 400 will die
 - 3,600 will be deaf or hard of hearing
 - 1,100 will have cerebral palsy
 - 570 will have vision impairment
- 4 x as many babies who fail newborn hearing screening have congenital CMV as in the general population.
- 43% of infants and young children with cCMV related hearing loss pass the newborn hearing screen*

*Fowler, K. B., McCollister, F. P., Sabo, D. L., Shoup, A. G., Owen, K. E., Woodruff, J. L., Cox, E., Mohamed, L. S., Choo, D. I., Boppana, S. B., & CHIMES Study (2017). A Targeted Approach for Congenital Cytomegalovirus Screening Within Newborn Hearing Screening. *Pediatrics*, 139(2), e20162128. <https://doi.org/10.1542/peds.2016-212>

Meet Daisy

- Born March 9, 2011
- Enlarged ventricles
- MRI at two days old
- Failed newborn hearing screening
- Incomplete ABR at 13 days
- Hospitalized at 6 weeks, again at 5 months





- Unilateral mild hearing loss @ 15 months
- CMV diagnosis
- Profoundly deaf @ 20 months
- Bilateral cochlear implant surgery @ 21 months

Meet Daisy's Team



Enrolled Copy

H.B. 81

CYTOMEGALOVIRUS PUBLIC HEALTH INITIATIVE

2013 GENERAL SESSION

STATE OF UTAH

Chief Sponsor: Ronda Rudd Menlove

Senate Sponsor: Curtis S. Bramble

LONG TITLE

General Description:

This bill amends the Utah Health Code and directs the Department of Health to establish a public education program regarding the impact and danger of congenital cytomegalovirus (CMV) infection and the methods of prevention of CMV infection.

Highlighted Provisions:

This bill:

- directs the Department of Health to create a public education program to inform pregnant women and women who may become pregnant about the occurrence of CMV, the transmission of CMV, the birth defects that CMV can cause, methods of diagnosis, and available preventative measures;
- requires the Department of Health to provide this information to:
 - licensed child care programs and their employees;
 - health care facilities licensed pursuant to Title 26, Chapter 21, the Health Care Facility Licensing and Inspection Act;
 - child care programs administered by educational institutions regulated by the boards of education of this state, private education institutions that provide education in lieu of that provided by the public education system, or by parochial education institutions;
 - child care programs administered by public or private institutions of higher education, if the care is provided in connection with a course of study or program, relating to the education or study of children, that is provided to students of the institution of higher education;

Signed into law March 22, 2013

H.B. 81 (2013) – Utah Cytomegalovirus Public Health Initiative

1. Directs the Department of Health to create a public education program to inform pregnant women and women who may become pregnant about the occurrence of CMV, the transmission of CMV, the birth defects that CMV can cause, methods of diagnosis, and available preventative measures;

H.B. 81 (2013) – Utah Cytomegalovirus Public Health Initiative

2. Requires the Department of Health to provide this information to:
 - Licensed child care programs and their employees;
 - Health care facilities
 - Child care programs
 - School nurses
 - Health educators
 - Health care providers offering care to pregnant women and infants

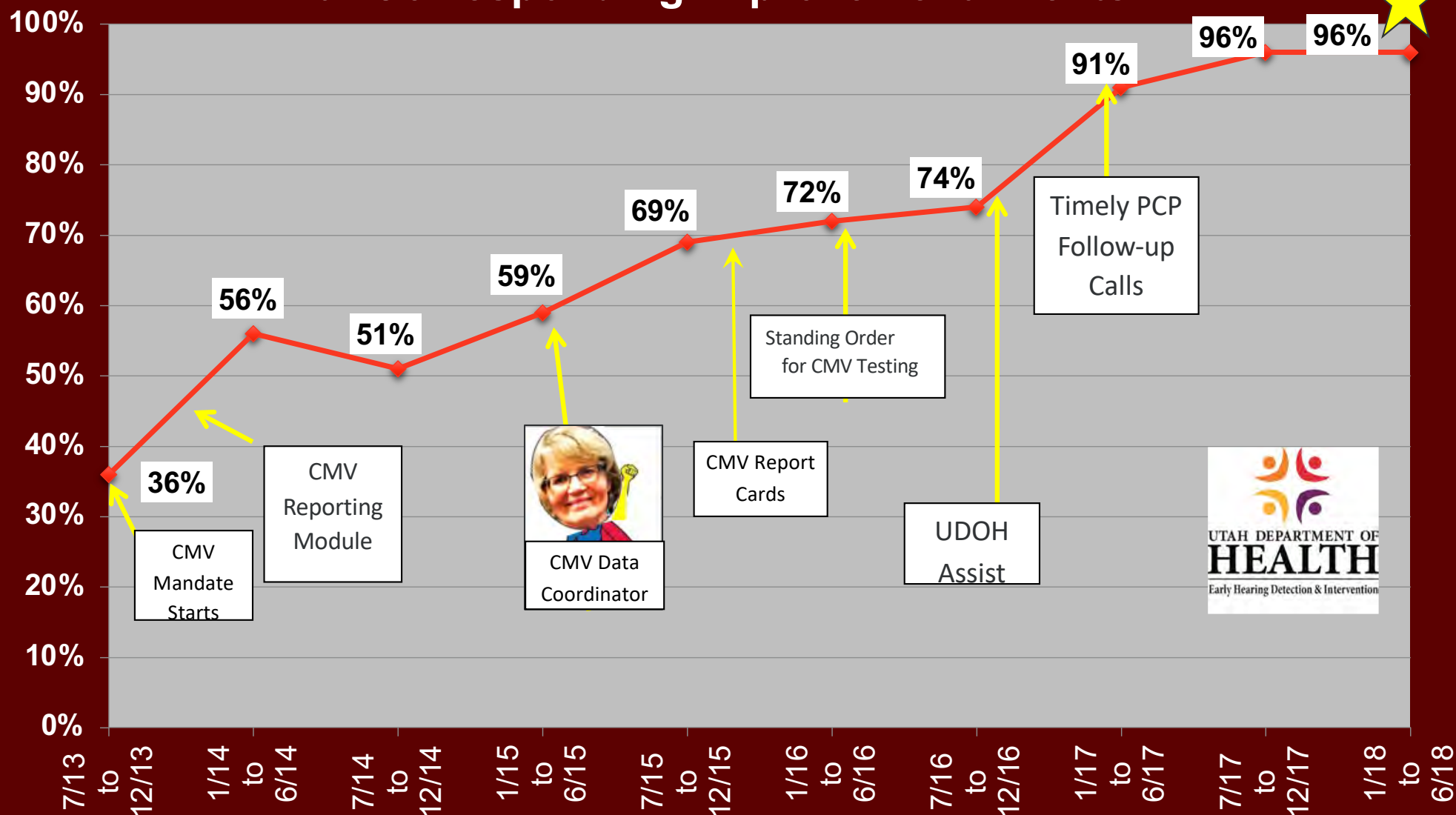
H.B. 81 (2013) – Utah Cytomegalovirus Public Health Initiative

3. Directs medical practitioners to test infants, who fail the newborn hearing screening test(s), for CMV and inform the parents of those infants about the possible birth defects that CMV can cause and the available treatment methods
4. Directs the Department of Health to notify medical practitioners of the CMV testing requirements

- ✓ **4 x as many babies who fail newborn hearing screening have congenital CMV as in the general population.**
- ✓ **43% of infants and young children with cCMV related hearing loss pass the newborn hearing screen**

Fowler, K. B., McCollister, F. P., Sabo, D. L., Shoup, A. G., Owen, K. E., Woodruff, J. L., Cox, E., Mohamed, L. S., Choo, D. I., Boppana, S. B., & CHIMES Study (2017). A Targeted Approach for Congenital Cytomegalovirus Screening Within Newborn Hearing Screening. *Pediatrics*, 139(2), e20162128. <https://doi.org/10.1542/peds.2016-212>

Percent of Eligible Babies Tested for CMV With Corresponding Improvement Events





Do **U** know about the risks of cytomegalovirus during pregnancy?

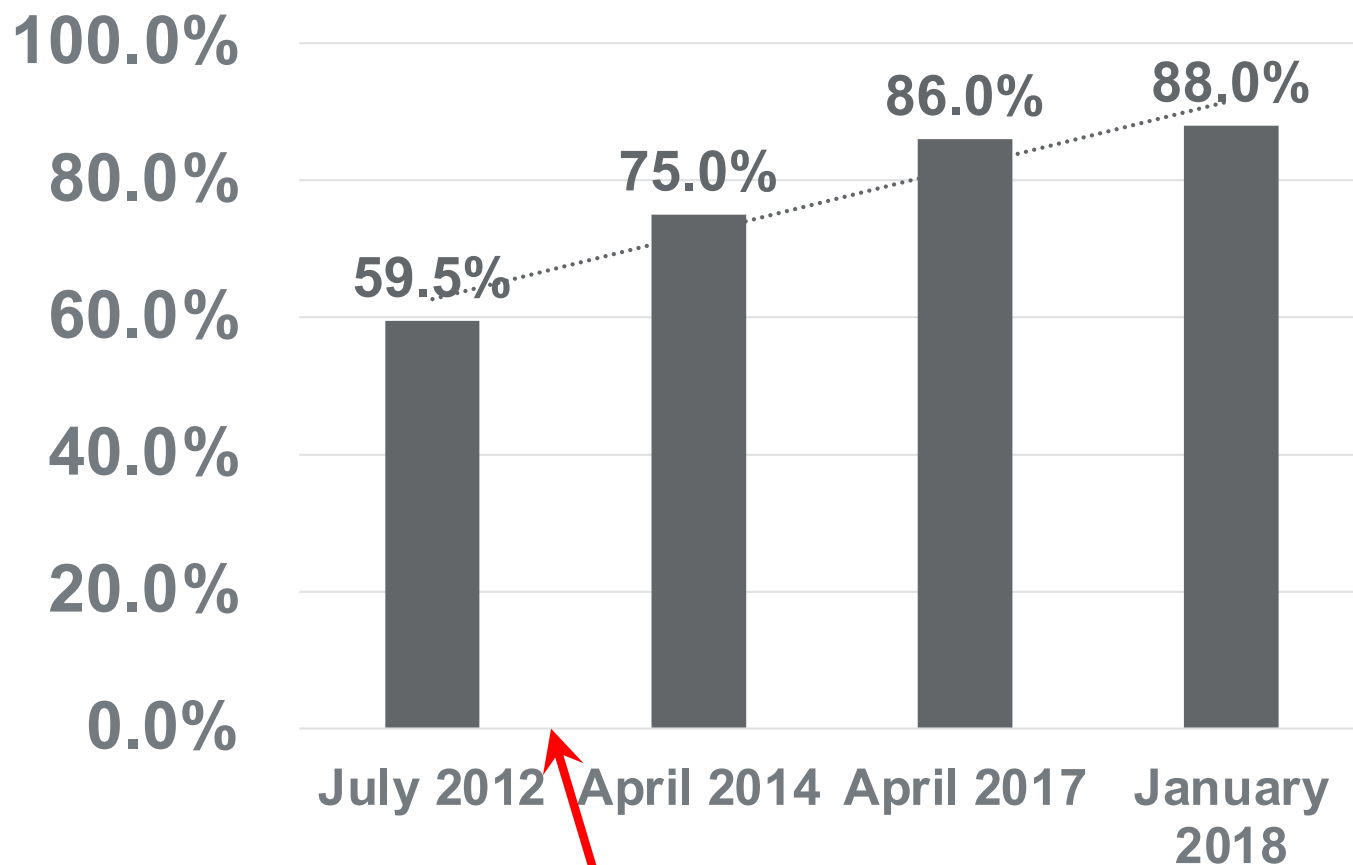
1 of every 5 children born with cytomegalovirus (CMV) will have permanent disabilities.

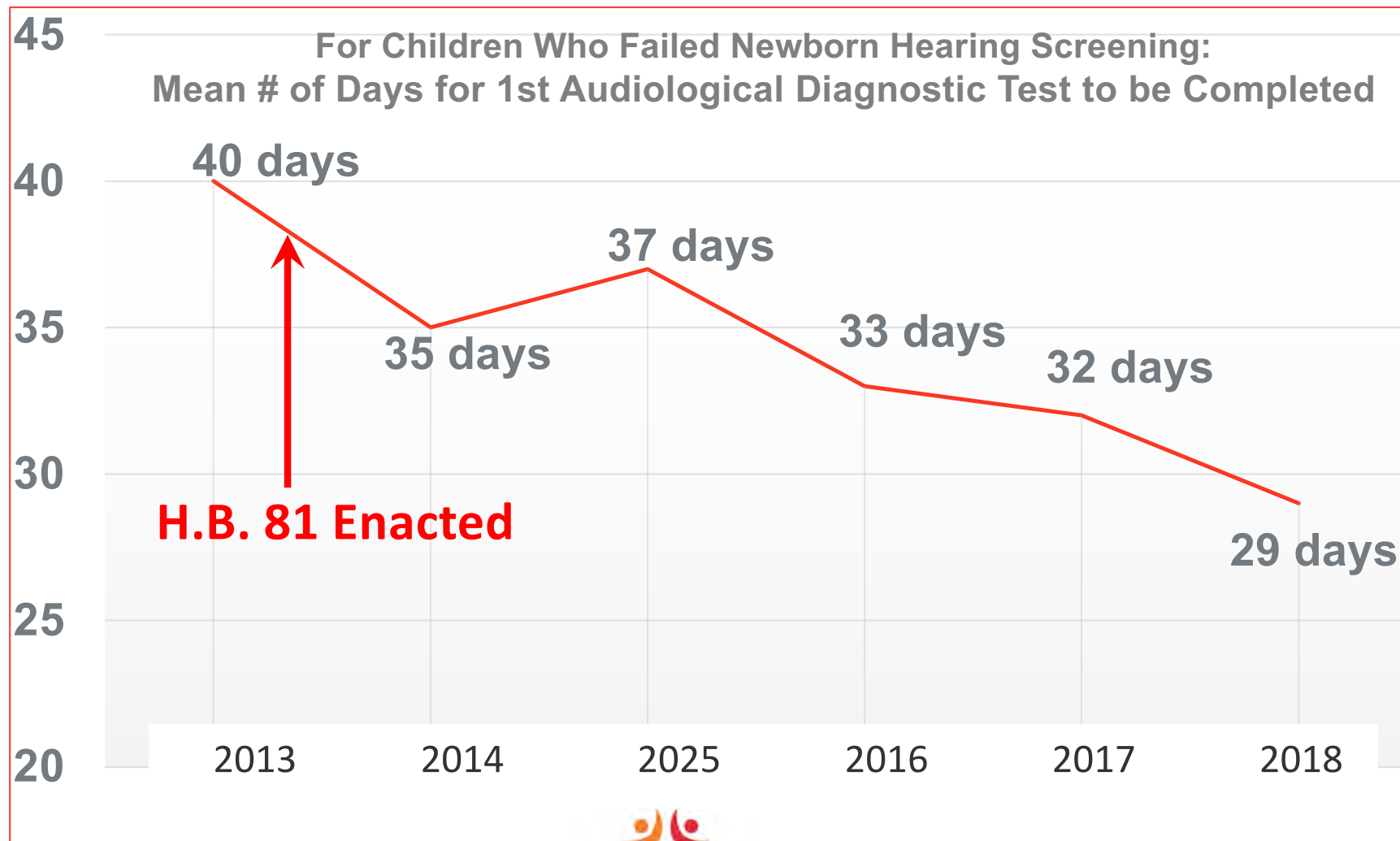
Learn more at:
health.utah.gov/cmV

Know the facts. Protect your baby.

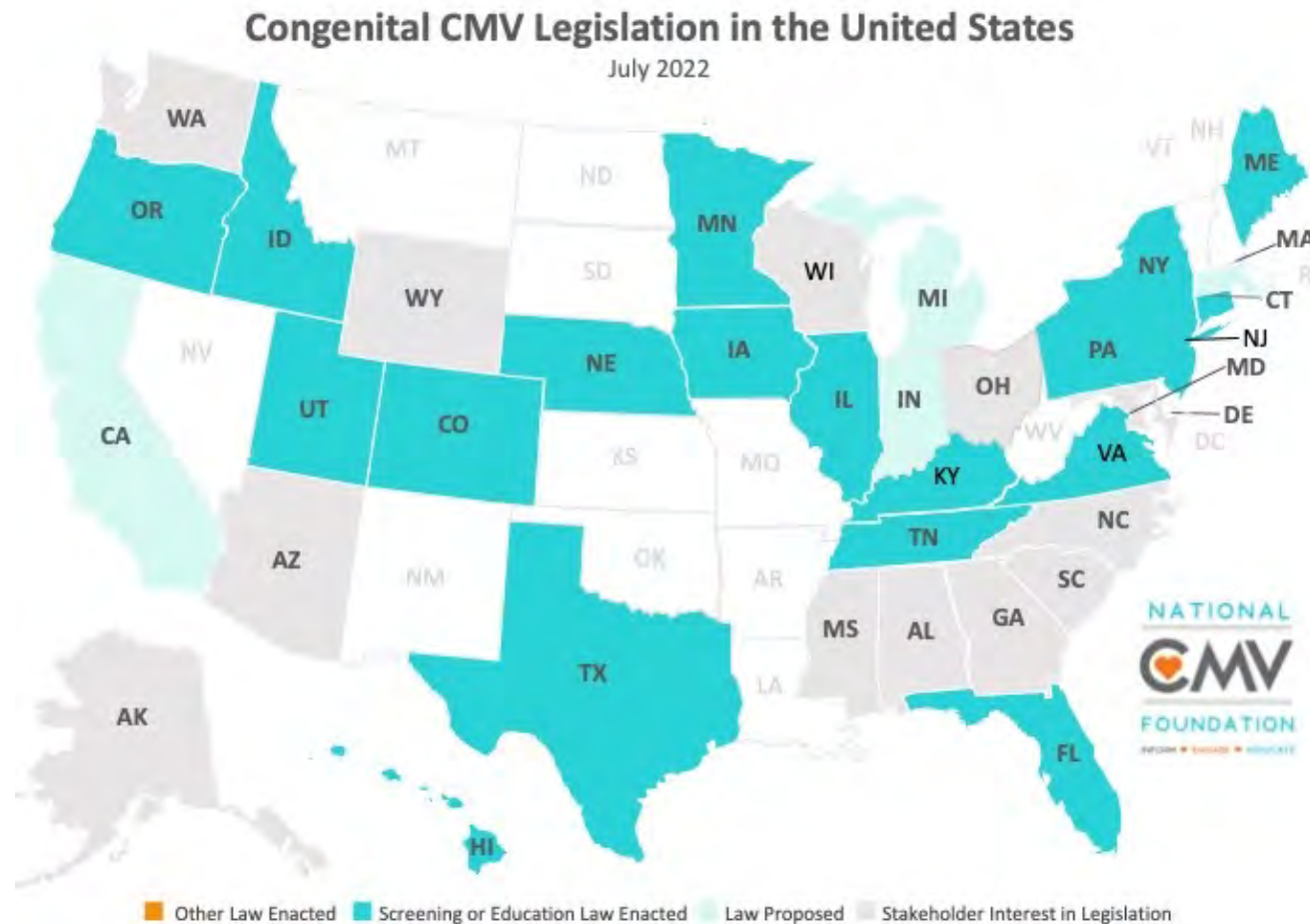


Completion of Audiological Diagnostic Testing by 3 Months





Impact Beyond Utah



© National CMV Foundation, <http://www.nationalcmv.org/>

The Power of Parent Advocacy

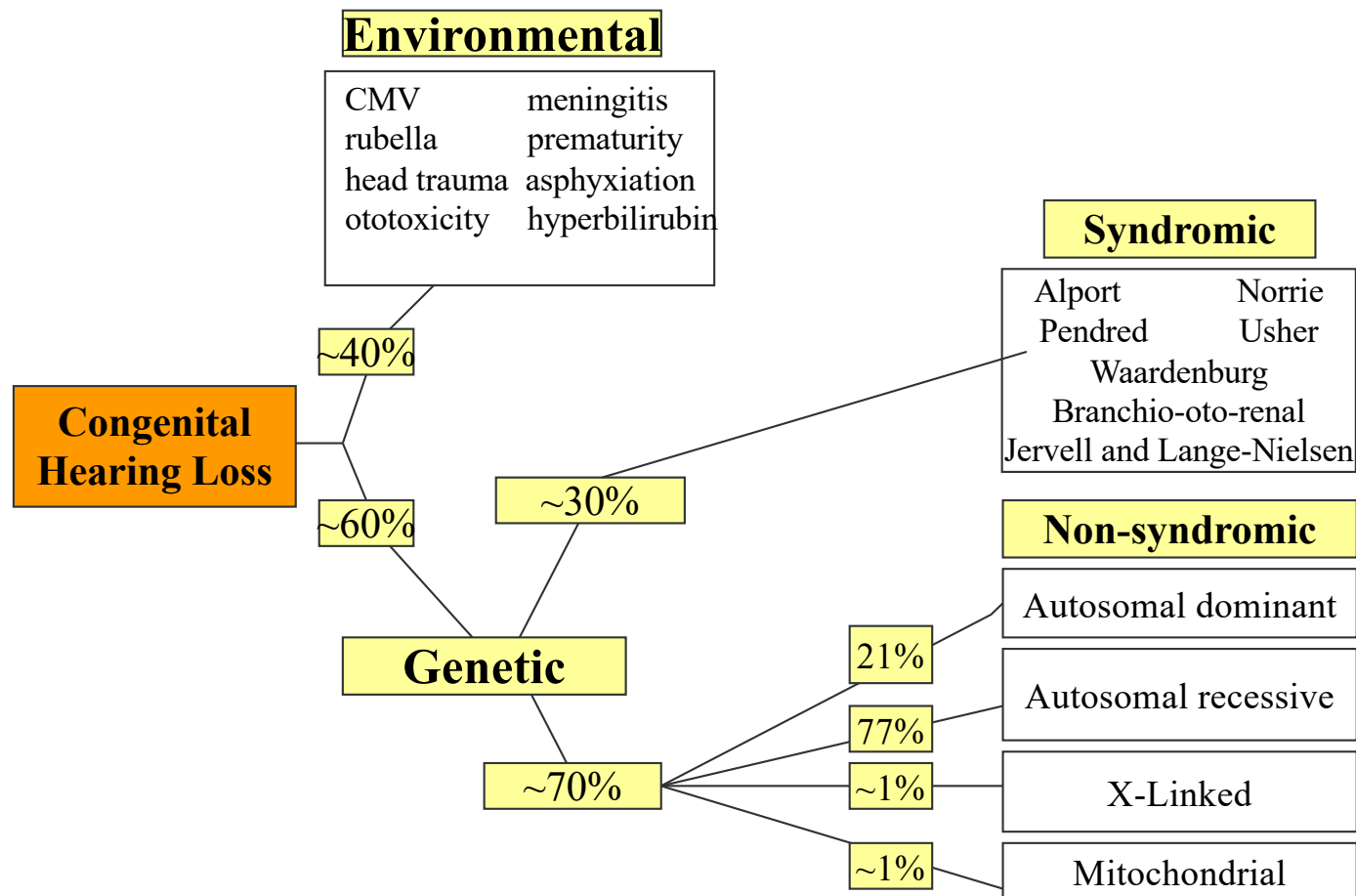
Utah's Congenital Cytomegalovirus Public Health Initiative



5

Advances in Genetic Screening

What Causes Hearing Loss?



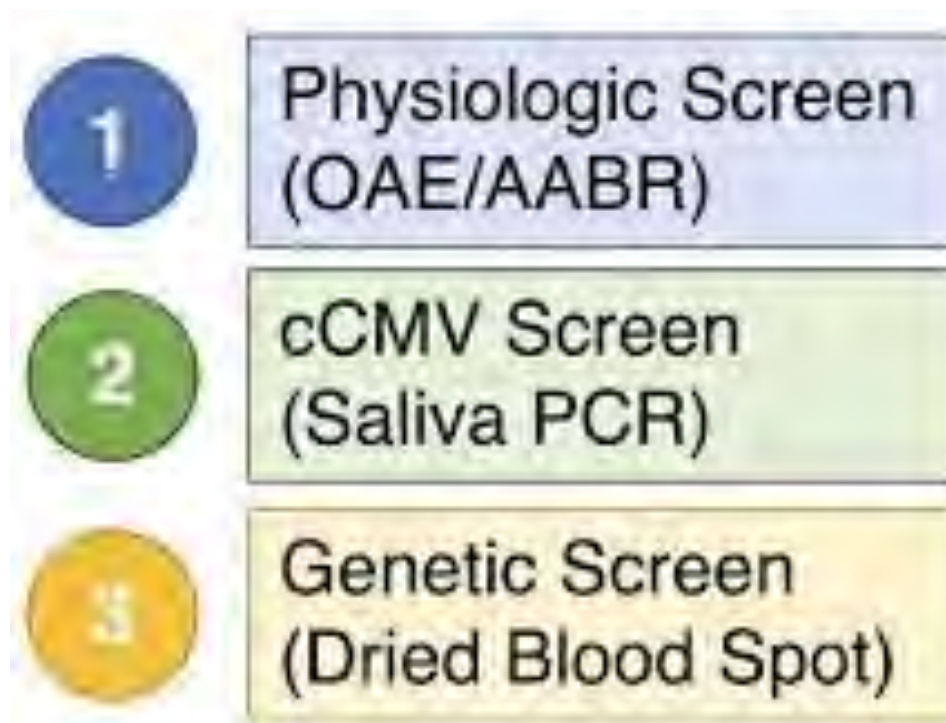


Benefits of Genetic Testing for DHH Children

- Avoid unnecessary (and often costly) tests such as temporal bone imaging, electroretinograms, and electrocardiograms
- Dispel misinformation and offer emotional support by allaying parental guilt
- Anticipate potential health problems
 - Identify children who are at risk for antibiotic induced deafness (ototoxicity).
 - Monitoring for myopia and early retinal detachment for Stickler syndrome
 - Identify kidney problems in branchiootorenal syndrome
 - Vitamin A therapy may be beneficial in slowing retinal degeneration in child with Usher syndrome
 - Treatment of children with Jervell and Lange-Nielsen syndrome can minimize cardiac complications
- Determine the chances of hearing loss in subsequent children



A Possibility for Comprehensive Newborn Hearing Screening



Shearer AE, Shen J, Amr S, Morton CC, Smith RJ. 2019. A proposal for comprehensive newborn hearing screening to improve identification of deaf and hard-of-hearing children. *Genetics in Medicine*. 21(11). 2614-2630.



“Genetic screening complements newborn hearing screening by improving the detection of infants at risk of hereditary hearing loss and ototoxicity.”

- 239,636 infants received concurrent hearing and genetic screening.
- Among those who passed hearing screening, genetic screening identified additional 41 with hearing loss and 570 at risk for ototoxicity.

Guo et al., (2020). Concurrent hearing and genetic screening in a general newborn population. *Human Genetics*. 139: 521-530.

“Incorporating genetic screening improves the effectiveness of newborn hearing screening programs by ... identifying additional children who may benefit from early intervention, and informing ... relatives of increased susceptibility to ototoxicity.”

- ~1.2 million newborns screened for hearing and 20 hearing-loss-related genetic variants.
- Genetic screening detected 13% more infants with hearing loss than hearing screening alone and 2,638 newborns predisposed to preventable ototoxicity.

Wang, et al., (2019). Nationwide population genetic screening improves outcomes of newborn screening for hearing loss in China. *Genetics in Medicine*. 21:2231-2238.

Breaking News!

- European Society of Gene and Cell Therapy (October 2023)
 - Positive results using gene therapy for profound genetic hearing loss due to mutations of the otoferlin gene.
- New York Times (January 2024)
- “Ground breaking study...gene therapy allows an 11-year old boy to hear for the first time.”
- *Lancet journal* (January 2024)
 - “...we found that a single injection of AAV1-hOTOF resulted in robust hearing recovery in five of six children with autosomal recessive deafness 9, and in improved speech perception in those who had hearing recovery.”
- *Molecular Therapy journal* (April 2024)
 - “Otoferlin gene therapy restores hearing in deaf children...the data are compelling and astonishing and indelibly celebrate the ways gene therapy can change lives.”



1. What's past is prologue; what to come, in yours and my discharge.
2. Why doesn't somebody do something about that? -- [Each of you is a somebody!]
3. Don't lose your perspective.

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2024 EHDl Conference

2024 EHDl Conference Videos

- Opening Plenary: These Roots Run Deep
- Plenary 2: A New Era of Early Detection - The Race to Newborn Genomic Sequencing and Where EHDl Fits In
- Closing Plenary: Courage Plus Dreams Equals Success: A Call to Support Children who are Deaf/Hard of Hearing Plus



Events and News

Upcoming Events & Webinars

- 2024 EHDl Conference | March 17-19, 2024 | Denver, Colorado
- More Events & Webinars...

Past Events & Webinars

- Introduction to Evidence-based Hearing Screening Practices for Children Age 0-5
- Intermediate Hearing Screening Webinar: Building on

The National Center for Hearing Assessment and Management (NCHAM) at Utah State University provides support to Early Hearing Detection and Intervention (EHDl) programs throughout the United States. NCHAM helps EHDl programs ensure that children who are deaf or hard of hearing (DHH) are identified through newborn, infant, and early childhood hearing screening and receive the diagnostic and early intervention services they need. To achieve these aims, NCHAM provides programs and professionals with:

- Technical assistance
- Training
- Access to information about evidence-based practices
- Partnership opportunities with national EHDl systems of care organizations and other key stakeholders, including those that represent and/or serve families with children who are DHH.

Check out these resources!

The Core of EHDl Tutorials



Newcomer to EHDl?

Learn about some of the basic elements of the system and access resources to expand your knowledge and skills.



EarWorm Podcast



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Podcast

*Dialogues on Hearing Health
You Can't Stop Thinking About*

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Thank You!

Karl R. White, PhD

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