CHILDREN WITH CMV: DON'T FORGET THE IMPORTANCE OF EARLY INTERVENTION

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STRAW POLL ON CMV

• 100 people surveyed regarding CMV

How many knew what CMV was?

Most people have never heard of CMV, but in the Utah Parent Infant Program for the Deaf , we see the effects of CMV on a regular basis

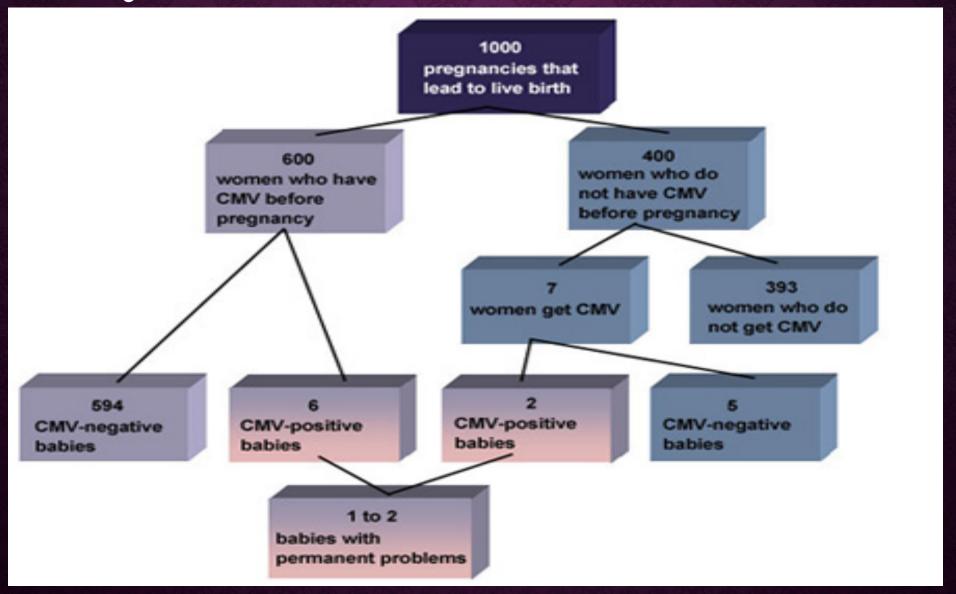
STATISTICS ABOUT CMV FROM THE CDC

- CMV is the most common viral infection that infants are born with in the United States
- About 1 in 150 children is born with congenital (present at birth) CMV infection. This
 means that in the United States, about 30,000 children are born with congenital CMV
 infection each year.
- Between 30% and 50% of women of childbearing age in the United States have never been infected with CMV
- In the United States, about 1%-4% of (1-4 of every 100) uninfected women have their first CMV infection during a pregnancy
- About 33% of (33 of every 100) women who become infected with CMV for the first time during pregnancy pass the virus to their fetuses

STATISTICS ABOUT CMV FROM THE CDC

- About 80% of (80 of every 100) babies born with congenital CMV infection never have symptoms or problems
- About 1 in 750 children in the United States is born with or develops permanent challenges due to congenital CMV infection
- In the United States, more than 5,000 children each year suffer permanent challenges caused by CMV infection

For every 1000 pregnancies that result in a live birth, about 1 to 2 babies will have permanent CMV-related challenges



Cannon MJ. Congenital cytomegalovirus (CMV) epidemiology and awareness. J Clin Virol. 2009;46 [Suppl 4]:S6-10

ONE OF THE COMMON CHALLENGES THAT RESULT FROM A CMV INFECTION IS HEARING LOSS

- We are currently serving 240 children who are deaf or hard of hearing in the Utah Parent Infant Program
- To our knowledge, 22 of those children have CMV

IMPACT OF HEARING LOSS

- The primary impact of hearing loss is on the development of language, but language affects the development of social-emotional and cognitive skills and impacts later academic success
- Any degree of hearing loss can have significant impact on the development of language
- The sooner a hearing loss is identified and entered into early intervention services, the better the child's chances of developing language skills commensurate of their hearing peers

WHAT CAN EFFECTIVE EARLY INTERVENTION DO?

Children who were identified early (before 6 months of age), were appropriately amplified, and began EFFECTIVE early intervention <u>BEFORE</u> six months of age had significantly better:

Receptive Language Skills

Expressive Language Skills

Personal-Social Skills

✓ Speech Production



Children with normal cognitive development whose hearing losses were identified before age 6 months had language development within the normal range at age 3, and also at

The impact of identification by age 6 months is present regardless of gender, presence of a secondary disability, source at testing (12-36)



hinaga-Itano, Sedey, Coulter & Mehl, 1998

Children with mild, moderate, severe, and profound sensory neural losses demonstrated this effect of early identification by 6 months of age.

Children educated predominantly through spoken language or signed language or those children educated through a combination of sign and/or spoken language evidenced this effect of identification by 6 months of age.

THE CHALLENGE...

- Babies with congenital CMV often pass their first newborn hearing screening, or will at least pass on one ear with a refer on the other
- Parents may not be as concerned if their child passes newborn hearing screening in at least one ear and may not be motivated to do follow-up testing
- Many children with congenital CMV will have a progressive hearing loss that may not be detected until the child is 18 months 2 years of age
- These children often do not have the benefit of early intervention services in the first months of life, and as a result typically have significant language delays
- Children with CMV will often have additional learning challenges in addition to hearing loss and would benefit from early intervention early

HOW THE UTAH PIP PROGRAM IS ADDRESSING THIS CONCERN

Broaden eligibility for program services

A CHILD QUALIFIES FOR UTAH PIP DHH IF ANY OF THE FOLLOWING CONDITIONS EXIST:

- A documented sensorineural or conductive hearing loss of greater than 20 dB in either or both ears
- Inconsistency in test results including Otoacoustic Emission Testing (OAE), Auditory Brainstem Response (ABR) and/or booth testing
- A documented Auditory Neuropathy Spectrum Disorder diagnosis
- Failed Otoacoustic Emission Tests (OAE) under the following conditions:
 - a. Two failed OAEs for children less than one year of age, including the failed newborn OAE.
 - b. Two failed OAEs for children ages two years and above, if the child is enrolled in a BWEIP with delays in the area of communication
- At least three documented ear infections or episodes of middle ear fluid within a three to six month period

HOW THE UTAH PIP PROGRAM IS ADDRESSING THIS CONCERN

- Broaden eligibility for program services
- Partner with the Health Department, Pediatric Audiologists and Pediatricians to ensure babies who are referred for additional audiological testing after their first OAE and are identified with CMV are enrolled in PIP Early Intervention services as soon as they are identified
- Provide additional training to PIP staff regarding the effects of CMV and potential learning challenges for children with CMV in order to more effectively serve children and families
- Partner with the Early Intervention Agencies under Baby Watch to ensure that babies with CMV who are deaf or hard of hearing plus additional disabilities receive services that address all of their child's and family's needs
- Provide a broad range of services within PIP to address communication needs

UTAH PIP DHH PROVIDES:

- Weekly home visits to families where information is provided to families based upon the child's and family's needs
- Deaf Mentor services for families who feel an ASL/English
- Listening Time services weekly to help children develop listening skills
- Support to families through parent groups and parent-to-parent contact
- Toddler Groups for children 18-36 months of age

TO MAKE A REFERRAL TO THE PARENT INFANT PROGRAM FOR THE DHH

- Go to our PIP web page at http://classic.usdb.org/pip/deafpip/default.aspx
- Scroll down and on the right side of the website you will see PIP Referral Form that you can click on
- Complete the referral form and fax it via secured fax to 801-629-4777

THANK YOU FOR YOUR TIME!

