The Two Decade Long Puzzle
One parent’s CMV journey and why awareness is KEY!

Presented by Christine Moody, M.P.H.
Michael’s mother
Executive Director
Indiana Center for Deaf and Hard of Hearing Education

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Introduction & Session Objectives

✓ Identify which important players in the system need to be aware of CMV and how their awareness can lead to parents being more prepared for the pieces of the puzzle.

✓ List and understand multiple reasons for a medical home.

✓ Explain tangible benefits of family support.

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Starting at the Beginning

Facts I knew
- Worked in hospital; uneventful pregnancy
- Over 2 wks. early; 5 lbs.13 ounces
- No complications, but Apgar’s = 4/9
- Bruising on his head/jaundice
- Seizure at ~15 hours
- Spinal tap; precautionary antibiotics through IV in head
- 5 day hospital stay (not NICU)
- Tiny VSD found at one of first checkups after birth; ECG with contrast

Looking Back
- Microcephaly
- Umbilical Cord
- Failure to thrive
- Apnea during seizure
- Ototoxic medications

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The First Medical Visits

- Pediatric Neurology - EEG - “due to the trauma of birth”
- Pediatrician - enlarged spleen/TORCH Screen - positive for CMV; no real explanation of lab results/“see a specialist”
- Pediatric Infectious Disease Specialist - “asymptomatic; PROGNOSIS EXCELLENT” / NO information
- So, I went to the library and checked out medical books! I wanted to understand. Those books terrified me, but provided some explanation of IgG, IgM and information on what to look for with a CMV diagnosis.
Watch and Wait

- Developmental delays noticed
- Observations brought to pediatrician - no clinical findings
- Changed pediatricians and referred to Pediatric Neurologist
- cCMV diagnosed; he will not walk and likely will not be aware of left side
- Pediatric Orthopedist - fitted for AFO
- Pediatric Ophthalmologist - nothing found (wears glasses now)
- Pediatric Audiologist - profound bilateral SNHL (progressed even more)
- ENT or Pediatrician - really don’t even remember this visit!
- Cat Scan - no real explanation of what this meant in terms of expectations
- Never saw the Pediatric Neurologist again; never saw a Pediatric Infectious Disease specialist again
- No one tied it all together; spokes in a wheel analogy
- No professionals ever mentioned CMV again; focused on clinical recommendations and treatment. It was like CMV went away and he became a list of problems.
Now What?

- Hearing aids by about 18 months
- Language delays
- Early intervention and therapy, therapy, therapy - no mention of CMV
- Pediatrician was for immunizations and sick appointments only
- No medical doctors ever asked about therapy, discussed potential impact of CMV or clinical expectations, much less social and academic potential
- I found support among other parents of D/HH children at a specialized pre-school, but no one was ‘CMV’ like us
- Parent support groups that included D/HH adults helped me to see the experience of others and broadened my understanding of the uniqueness of each and every journey while still giving me that sense that I was not alone.

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School Years ~
Is there an Assessment for this?

- No one provided any information on cognitive expectations related to his brain development and CMV
- Quirky behaviors and behavior difficulties surfaced for which I had no support; a new puzzle piece
- Seizures resurfaced at age 5 for first time since seizure at birth (no connection to CMV mentioned); a new puzzle piece
- Seizure medicine started; after behavior modification seemingly met with dead ends, ADD medicines tried with no success
- Experienced general lack of knowledgeable medical professionals and educational professionals; not trained for the “outliers”

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What Parents Can Do

- Set high expectations
- Roll up your sleeves
- Keep pushing forward, asking questions and adapting
- Develop collaborative relationships with professionals
- Communicate often and become an expert on your child
- Find support
- Support others; get involved
- Breathe and try to offer as many experiences as you can.

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Surgeries ~ More Puzzle Pieces

- First orthopedic surgery at age 4 was successful
- Oral surgery was required after his permanent teeth never erupted
- Next two orthopedic surgeries were completely ineffective, if not actually detrimental
- Be cautious and seek multiple opinions
- The well-meaning surgeons did not evaluate him in the context of CMV or his neurologic symptoms/cerebral palsy.
- What was the cost (and I don’t mean dollars)?
Social-Emotional Struggles

- Poor eye contact
- Impulsivity
- Easily manipulated; bullied
- Desperately wants friends and a girlfriend
- Counseling begins
- **Autism Spectrum Disorder** diagnosed at age 18! - final puzzle piece?
- Re-evaluating Part B primary eligibility and services needed beyond high school in light of ASD diagnosis
- Social ineptitude + feelings of isolation + impulsivity + ASD = addictive tendencies...still discovering pieces of the puzzle and encountering new challenges.

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Works ridiculously hard academically and never quits; requires tremendous “re-teaching”; still struggles in expressive language and literacy

Very difficult to assess with inconsistent IQ sub tests

Struggles on standardized tests

“He has unrealistic expectations!”

Pushed to change diploma track
After High School
A Word about Parent to Parent Support

- Credibility and trust
- Someone who “gets it”; commonalities cross cultural, language and socio-economic barriers
- Not alone; similar struggles
- Families learn from other families - “I can do this”
- Valuable source of resources and information; different parents have different abilities (and time) to ‘mine’ for information
- Helps put things in perspective
- Advocacy and system change; have a seat at the table

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Conclusions ~
It shouldn’t take 20 years to figure it out

- There are many points on the CMV journey where professionals have the opportunity to share information with the family. Key professionals should have a basic level of awareness about CMV including a checklist of possible symptoms. Thorough social and medical histories are vital.

- Knowing what possible things to look for or expect on the journey reduces feelings of helplessness for parents; knowledge makes parents more in control and can lead to solutions and strategies sooner. Parents need to be empowered with information.

- A medical home is crucial to manage all the spokes of the wheel and to have the big picture. Ask where parents are finding support; provide info and resources.

- A holistic approach to the child/patient is worth the time; providers need to ask questions.

- Parent to parent support is vital to the well-being of the family.

- Finally, most families say that the birth of their child is the first time they have ever heard of CMV. Basic awareness campaigns including prevention awareness is the first step.

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Any Questions?

Contact Information:
Christine Moody
ISDH, Center for Deaf and Hard of Hearing Education
cmoody@isdh.in.gov
(317) 232-5950 Office
(317) 657-6361 Cell