Cytomegalovirus (CMV) and Hearing Loss

Sara Menlove Doutre
Utah State University, Logan, UT
May 22, 2019
Life can only be understood backwards; but it must be lived forwards.

Soren Kierkegaard

About Me

- Special education and early intervention consultant
- Advocate
- CMV Mom
- Founder of the National CMV Foundation
- Ph.D. Candidate in Sociobehavioral Epidemiology, Utah State University
Cytomegalovirus
What is CMV?

• CMV is Common
• CMV is Serious
• CMV is Preventable
CMV is Common

- 1 in 200 babies is born with CMV
- 1 in 1000 babies is disabled by CMV

CMV is the most common infection infants are born with. CMV causes more cases of congenital disease than the combination of 19 currently screened conditions in most American states.

(CDC, 2008; Impact of expanded newborn screening, 2006)
<table>
<thead>
<tr>
<th>Condition</th>
<th>Awareness (%)</th>
<th>U.S. Annual Incidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congenital Cytomegalovirus (CMV)</td>
<td>0</td>
<td>8,000</td>
</tr>
<tr>
<td>Congenital Toxoplasmosis</td>
<td>75</td>
<td>4,000</td>
</tr>
<tr>
<td>Congenital Rubella Syndrome</td>
<td>50</td>
<td>2,000</td>
</tr>
<tr>
<td>Beta Strep (Group B Strep)</td>
<td>25</td>
<td>0</td>
</tr>
<tr>
<td>Parvovirus B19 (Fifth Disease)</td>
<td>25</td>
<td>0</td>
</tr>
<tr>
<td>Fetal Alcohol Syndrome</td>
<td>50</td>
<td>0</td>
</tr>
<tr>
<td>Spina Bifida</td>
<td>75</td>
<td>0</td>
</tr>
<tr>
<td>Sudden Infant Death Syndrome (SIDS)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

**CMV is Serious**

CMV causes disabilities including **hearing loss**, cerebral palsy, seizures, and other developmental disabilities.

<table>
<thead>
<tr>
<th>Born symptomatic</th>
<th>Born asymptomatic</th>
</tr>
</thead>
</table>
| **Death**  
Miscarriage, stillbirth, infant or child loss | **Hearing loss**  
Hearing aids, Cochlear implants, Communication and learning issues, Mild vision disorders |
| **Medically fragile**  
Cerebral palsy, Seizures, Failure to Thrive, Hearing loss, Vision loss | None  
No visible delays or impairments |
| **Multiple impairments**  
Cerebral palsy, Vision loss, Hearing loss | **Developmental delays**  
Cognitive delays, Learning issues, Feeding and sleeping issues, Vision loss, Hearing loss |
| Severe | Moderate |
| Moderate | Mild |
CMV is Preventable

• A pregnant woman has to have an active CMV infection to transmit CMV to her unborn baby.

• Many women transmit CMV to unborn babies during a reactivation or infection despite having had CMV in the past.
• CMV lives in bodily fluids like urine and saliva.
• It can live in crackers or bread crust for up to six hours.

(Cannon, 2014)
We can’t prevent what we don’t know about
• CMV is the leading non-genetic cause of childhood hearing loss.
• CMV accounts for approximately 25% of SNHL in children.
• About 15% of infants with congenital CMV will not have symptoms at birth but later develop hearing loss.
• The AAP recommends hearing tests at least every six months.

Congenital CMV has been labeled as one of the *Neglected Infections of Poverty* in the United States as it is poorly known by the US public-health community, it has a disproportionate impact on the health of the poorest Americans, and it promotes poverty via its negative impact on child development and pregnancy outcomes.

Bristow et al. 2011
International Consensus - 2015

• Consensus group convened at international CMV conference in Brisbane, Australia in 2015

• “...consideration should be given to universal neonatal cytomegalovirus screening to enable early detection of congenital cytomegalovirus-infected infants, facilitating early detection and intervention for sensorineural hearing loss and developmental delay where appropriate (level 2b evidence).”

• “The consensus recommendations from the group were that the diagnosis of congenital cytomegalovirus infection in neonates should include real-time PCR of saliva, urine, or both, as soon as possible after birth but within the first 3 weeks of life, with saliva as the preferred sample (level 2b evidence).”

Summary of State Mandates

In the United States, legislation has effectively passed in 12 states, with additional states in progress.

Summary of Complete Legislative Mandates

Education
- Nine states require the state to educate the public and professionals about congenital CMV: Hawaii, Idaho, Illinois, Iowa, New York, Oregon, Texas, Utah.
- Tennessee requires healthcare providers to educate women of childbearing age.
- Only Utah has legislation that is accompanied by ongoing funding ($70,000 per year). Idaho has proposed $15,000 per year.

Screening
- Five states (Connecticut, Iowa, New York, Utah, and Virginia) require each newborn that fails the newborn hearing screening to be tested for congenital CMV.
- Illinois requires that a CMV test be offered to the parents of every child who fails the newborn hearing screening.
Our purpose is to prevent CMV infection in women of childbearing age by:

- Empowering women, parents, families, and local community networks through grassroots engagement to facilitate conversation and champion the cause.

- Delivering consistent, clear messaging, and evidence-based data that aids in prevention, educates the public, and increases its understanding of congenital CMV.

- Influencing CMV research priorities regarding CMV prevention, treatment, and intervention.

- Advocating for a CMV vaccine.
National CMV Foundation by the Numbers:

- 5 Years Young
- 6 Co-Founders
- 9 Board of Directors
- 2 Staff Members
- 60 Active Volunteers
- 50 States with CMV Champions
- 19K Social Media Followers
- 25K Average Monthly Unique Visitors

Our Dollars at Work:

- $75K to Early Career Research Funding
- $160K in Public Health Awareness Activities and Grants
2019 Campaign Teaser

Awareness: Updates

The threat of CMVirus is invisible to most. So let's make it as plain as day in the every day ways it gets transmitted. Seeing the threat, is believing the threat.
Mom, why didn’t you know the facts? Why didn’t you protect me from CMV?

Daisy, age 8
What can you do?

• Talk to women of childbearing age about CMV
• Encourage parents whose children’s cause of hearing loss is unknown to have them tested for CMV
• Advocate for awareness and screening

• June is CMV Awareness Month

• What else?
For questions or to request materials, please visit our website