CMV Is a Greater Threat to Infants Than Zika, but Far Less Often Discussed

By Catherine Saint Louis

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Laura Sweet had no idea that she had contracted a virus that would leave her daughter, Jane, deaf by her first birthday.

During her second pregnancy, doctors had warned her against alcohol and changing kitty litter. They had said to avoid sushi and cold cuts. But nobody — not her obstetrician, nor her midwife — mentioned cytomegalovirus.

Only after a frustrating search lasting months did doctors discover that the girl had been infected in utero. The infection and the emotional ordeal that followed, she thinks, could have been prevented — for the Sweet family and thousands of others every year.

"It's tough to play the what-if game," said Ms. Sweet, 37, a consultant for an education nonprofit in Cumberland, Me. "You can drive yourself crazy with that."

The world has been galvanized by the Zika epidemic spreading through the Americas, which has left more than 2,000 infants with severe brain damage. But for pregnant women and their infants in the United States, cytomegalovirus, or CMV, is the far greater viral threat.

Every year, 20,000 to 40,000 infants are born with CMV. At least 20 percent — up to 8,000 — have or develop permanent disabilities, such as hearing loss, microcephaly, intellectual deficits and vision abnormalities. There is no vaccine or standard treatment.

But there are now hints that some newborns may benefit from antiviral drugs, a finding that has reinvigorated the debate over whether they should be routinely screened for the infection.

CMV is the most common congenital viral infection and the leading nongenetic cause of deafness in children. Roughly 400 children die from it annually. By contrast, roughly 900 pregnant women in the continental United States have contracted the Zika virus.

"Everyone and their brother knows about Zika, but it's very rare in the U.S.," said Dr. Mark R. Schleiss, the director of pediatric infectious diseases at the University of Michelotte Metallingenous! | CMChelotte Hork Cimes han Zika, b...

CMV should be every bit as urgent a priority as Zika, he argues. Health officials called for a vaccine decades ago, and there still isn't one, partly because of a lack of public awareness about CMV, Dr. Schleiss said.

CMV is a hardy member of the herpes family, and it is transmitted by contact with saliva and urine — often from diaper-wearing children to adults. Pregnant women often get it from toddlers, especially those in day care who share drool-drenched toys.

"Toddlers are hot zones for CMV," said Dr. Gail Demmler-Harrison, a pediatric infectious disease specialist at Baylor College of Medicine in Houston. It is difficult for mothers to protect themselves from a virus carried by the children they care for.

Nearly one in three children is infected by age 5, and more than half of adults by 40.

CMV takes up permanent residence in the body and can cause illness again after being dormant. Like the Zika virus, it causes mild flulike symptoms, or none — but can be devastating to a fetus.

Had she known any of that while pregnant, Ms. Sweet might have reduced her chances of contracting CMV with diligent hand-washing, especially after diaper changes, and not sharing utensils or food with her son, Henry, then 2 and in day care.

"If there was awareness about CMV, at least women working in day care and women with toddlers could potentially modify some behavior," Ms. Sweet said.

But surprisingly few women are warned about this infection. Less than half of obstetrician-gynecologists tell pregnant patients how to avoid CMV, according to federal survey.

By contrast, doctors and public health officials have advised American women to take every imaginable precaution against Zika.



Erica Steadman, 30, helping Evelyn, her daughter, get ready for school. In the United States every year, 20,000 to 40,000 infants are born with the CMV virus, with varying

effects. Whitten Sabbatini for The New York Times

Rebekah McGill, a speech language pathologist in Greeneville, Tenn., gave birth to a stillborn daughter, Elise, at almost 39 weeks, later discovering that CMV was the likely reason. Ms. McGill was inconsolable — and angry that she had never been warned about the virus during any of her four pregnancies.

"Sometimes, I wonder if our daughter would still be alive if I had only known," she said.

A Debate About Discussing

The American College of Obstetricians and Gynecologists used to encourage counseling for pregnant women on how to avoid CMV. But last year, the college reversed course, saying, "Patient instruction remains unproven as a method to reduce the risk of congenital CMV infection."

Some experts argue that because there is no vaccine or proven treatment, there is no point in worrying expecting women about the virus. Instead, Dr. Christopher Zahn, the vice president for practice at ACOG, said doctors must focus on conditions with proven interventions and let patients dictate the discussion.

"There are so many topics to cover during pregnancy that this is often driven by what patients are most worried about," he said.

But pregnant women don't worry about CMV only because they don't know about it, some researchers say. They argue that it is high time to carry out education campaigns and infant screening for the infection, arguing that it smacks of paternalism to do otherwise.

Dr. Demmler-Harrison, the infectious disease specialist, said she was "livid" about ACOG's decision.

"I am baffled why obstetricians do not feel it is important or even worthy to educate pregnant women about CMV," she said. "It's a missed opportunity to save a baby from the devastating effects of CMV, including death in the womb and permanent disabilities."

A study in a French hospital found five to 10 minutes of counseling about CMV prevention resulted in fewer women contracting the virus. In another study, pregnant mothers shown a video and offered hygiene tips were much less likely to get CMV (5.9 percent) than those not given information on prevention (41.7 percent).

"It's as if doctors are saying, 'I'm going to cherry-pick what you know and you don't know,'" said Erica Steadman, 30, a digital marketing manager in Crete, Ill., who says her obstetricians never mentioned the virus.

Mrs. Steadman, helping Evelyn onto a school bus, says her obstetricians never mentioned CMV to her. "It's as if doctors are saying, 'I'm going to cherry-pick what you know and you don't know,'" she said.

Whitten Sabbatini for The New York Times

Her 3-year-old daughter, Evelyn, was born with microcephaly, deafness and such high levels of CMV in her urine that doctors were surprised she survived. "Withholding information is the same as putting pregnant women and their children in danger," Mrs. Steadman said.

Guidelines from ACOG suggest that pregnant women will find CMV prevention "impractical and burdensome," especially if they are told not to kiss their toddlers on the mouth — a possible route of transmission.

But Kim Hill, a mother of four in Raleigh, N.C., did not find it that hard. Her second daughter, Kaitlyn, now 7, was born with signs of CMV infection and became hearing-impaired. So when she became pregnant with twins, Ms. Hill stopped sharing food with her kids and regularly scrubbed her hands.

"People canceled trips and rearranged their whole lives not to travel to Zika areas," Mrs. Hill said. "All we are saying is, wash your hands."

A Push to Screen

In most states, babies are not universally screened at birth for CMV infection, on the grounds that most won't be injured by the virus and clinicians don't want to worry parents unnecessarily. The consequences of infection are often not detected until months or years after delivery.

"A common scenario is a child is born who looks completely normal, and who may or may not pass the newborn hearing screening, and then as they age, at 6 months or 12 months or older, hearing becomes an issue," said Dr. Albert H. Park, the chief of pediatric otolaryngology at the University of Utah.

Now some experts are pushing for routine screening of newborns for CMV. The idea is to identify those who are infected in the first 21 days so that they can be given regular hearing tests, an eye test, a magnetic resonance imaging test of the brain, and perhaps antiviral treatment.

Roughly 10 to 15 percent of infected newborns hear well at birth, but start losing the ability by age 5. Until recently, even if a newborn failed a hearing test, clinicians did not always test to see if CMV was the cause.

It remains unclear how and why CMV causes hearing loss. But infants who receive a timely diagnosis can be given hearing aids or access to early-intervention programs to have the best chance of learning to talk.

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Laura Sweet of Cumberland, Me., with her daughter Jane, 2, who was readjusting the connection cochlear implant. Cheryl Senter for The New York Times	n to her
In January, Connecticut began testing any infant who failed a hearing scree CMV infection, and Illinois now offers parents the option.	ning for
Utah was the first state, in 2013, to carry out CMV screening of newborns w pass hearing tests.	ho did not

After she learned that CMV had caused her daughter Daisy's deafness, Sara Doutré and her mother, Ronda Menlove, then a legislator in Utah, worked to get the law in place so "no other baby fell through the cracks in the system," Mrs. Doutré said.

The Centers for Disease Control and Prevention is funding a pilot study that aims to universally screen 30,000 newborns in Minnesota for CMV as part of an existing program in the state health department, Dr. Schleiss said.

The screening question has taken on much greater importance with a recent discovery.

A study published in The New England Journal of Medicine last year found that infants with CMV symptoms at birth who took an antiviral drug for six months had moderately better hearing at 2 years, compared with newborns who took it for six weeks.

The six-month group also performed better on a test intended to assess cognitive, communication and motor skills. The finding suggests that the roughly 10 percent of babies born with multiple symptoms of CMV infection, like brain abnormalities and hearing loss, could benefit from antiviral drugs.

The finding does not apply to infected infants without symptoms at birth, experts noted, and it's not yet known whether antiviral medication is safe and effective in babies whose only symptom is hearing loss.

In Maine, Jane Sweet, almost 2, now wears cochlear implants. Because of early-intervention services like physical therapy, she walked at 16 months.

Still, it's not clear what the future holds. CMV infection left abnormalities in Jane's brain, which may presage developmental troubles.

"We won't know until she's in school if she has learning delays," Ms. Sweet said.

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