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NEWS FROM THEDACARE®
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“SHE’S MAKING HER OWN STRIDES AND MILESTONES” *Family Advocating for Awareness After Baby is Diagnosed with Virus Leading to Health Problems*

APPLETON, Wis. – Janae Nieuwenhuis was experiencing a fairly normal pregnancy, her third, until her 20-week anatomy scan.

“During that appointment, care teams informed me that the placenta appeared to be thick, which was unusual,” Janae explained. “So, we repeated the scan four weeks later. The placenta was still thick and the baby’s head was measuring small. That was when we really began to worry.”

Janae was referred to a maternal fetal specialist for further evaluation, which included genetic testing and a TORCH test for Cytomegalovirus (CMV), a common virus. According to the Centers for Disease Control and Prevention (CDC), once infected, a person retains the virus for life. Most people don’t know they have CMV because it rarely causes problems, or shows symptoms, in healthy individuals. However, CMV can be concerning in people who are pregnant or have a weakened immune system. Women who develop an active CMV infection during pregnancy can pass the virus to their babies (congenital CMV), who might then experience symptoms.

Testing confirmed that, at some point, Janae had contracted CMV.

What is CMV?

According to the CDC, CMV spreads from person to person through body fluids, such as blood, saliva, urine, semen and breast milk. There is no cure, but there are medications that can help treat the symptoms.

According to the [National CMV Foundation](#), it is estimated that 50-80% of adults in the United States have been infected with CMV by the time they reach 40 years old. Most people have been exposed to CMV at some point in their lives without realizing it.

The CMV Foundation notes that there are simple and effective prevention measures that people can take to help mitigate the risk of CMV transmission, especially during pregnancy.

Simple tips to help prevent CMV include:

- Do not share food, utensils, drinks or straws
- Do not put a pacifier in your mouth
- Avoid contact with saliva when kissing a child
- Do not share a toothbrush
- Wash your hands

[Jennifer Szmada, D.O., a pediatrician with ThedaCare Physicians Pediatrics-Appleton](#), explained that most people who contract CMV do not have symptoms. However, that is not always the case.

“Newborns who became infected with CMV before they were born (congenital CMV) can develop complications,” she said. “Many of these babies appear healthy at birth and then can develop signs over time – sometimes not for months or years after birth.”



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The CDC states that the following signs and symptoms are more common in babies who have congenital CMV:

- Hearing loss and vision loss (two of the most common signs and symptoms)
- Premature birth
- Low birth weight
- Yellow skin and eyes (jaundice)
- Enlarged and poorly functioning liver
- Purple skin splotches or a rash or both (Petechiae)
- Abnormally small head (microcephaly)
- Enlarged spleen
- Pneumonia
- Seizures
- Mental Disability

The CMV Foundation stated that hearing problems occur in up to 75% of babies with symptomatic congenital CMV. In almost all of these children, the hearing loss will progress throughout the course of their lives. According to the CDC, about 1 in 200 babies is born with congenital CMV infection. About one in five babies with congenital CMV infection will have birth defects or other long-term health problems. CMV is the most common infectious cause of birth defects in the US.

Experts recommend that if a person knows they were infected with CMV during a pregnancy, they should inform the baby's doctor so they can determine a care plan. Some experts may recommend testing a woman for CMV during pregnancy or testing the baby immediately following birth.

Welcoming Baby Lexi

Janae gave birth to baby Lexi in July 2023, and right away, she felt something was not quite right.

“Lexi had a small head and petechiae, which are little red dots on her skin. Those are both signs of complications from CMV,” Janae said. “She also failed her hearing test.”

After mom and baby were discharged from the hospital, the family took Lexi to her scheduled newborn appointment with their pediatrician, Dr. Szmanda, where Janae explained her symptoms. Dr. Szmanda ordered testing for Lexi and confirmed she was positive for CMV. They started antiviral medications right away.

“We’re so grateful for Dr. Szmanda,” said Janae.

According to the [National CMV Foundation](#), some states test for CMV, but not all do. Connecticut, Florida, Iowa, Kentucky, Louisiana, New York, Texas, Utah and Virginia require each infant that fails the newborn hearing screening to be tested for congenital CMV. Wisconsin does not.

After she tested positive, Lexi saw an Infectious Disease Specialist at Children's Wisconsin. Through many appointments, she has been diagnosed with hearing loss in both ears, polymicrogyria (PMG), infantile spasms/epilepsy, cerebral palsy, and high and low muscle tone. It was also confirmed that Lexi had fairly significant brain damage.

“She will probably have seizures the rest of her life,” her mother explained. “That is the frustrating part – we just don’t know what will happen in the future for Lexi.”

As Lexi turns 1, the family noted that she is not walking, talking, crawling or sitting.



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“It took a while for us to reach a point of acceptance. The overall thing we want for her is to be healthy, and happy, safe, loved and not in pain. Those are our goals,” said Janae.

The family has traveled to Milwaukee for numerous appointments.

“The appointments can take a toll on our family,” said Janae. “We have two other little girls and, while we have a lot of family support, traveling isn’t always the easiest.”

Lexi has begun weekly physical and occupational therapy appointments. Because of the [Connected for Kids partnership](#) ThedaCare has with Children’s Wisconsin and Bellin Health, Lexi can have more appointments in Appleton instead of Milwaukee. The partnership is aimed at improving the health and well-being of children and adolescents. The three organizations work closely together to enhance pediatric primary and specialty care to benefit children and families.

“We are grateful for the Connected for Kids partnership because we can now do some of the appointments at the Children’s Wisconsin Appleton Clinic that is just five minutes from our house,” said Janae. “It saves so much time and stress. We are not shuttling the kids to appointments and visits all of the time. It gives us the opportunity to be a family – and have more time to do things together.”

Family Sharing Information to Help Others

The family wants to share their story to help bring awareness to CMV and educate others. They are working with ThedaCare teams to offer pamphlets, information and resources in clinics.

As for her future care, Lexi will have a cochlear implant in the fall. The device can help provide a sense of sound to a person who is profoundly deaf or severely hard-of-hearing. From there, the family says they want to focus on the present.

“It’s hard to say what the future will be. There are so many unknowns,” said Janae. “We hope she continues to slowly make her own strides in life and show us what she is capable of doing. Maybe she will be able to crawl, or walk or say a few words. We’re embracing the small victories and her own milestones.”

They also remain optimistic and have a positive outlook on the situation.

“While this is not what we envisioned for our family or Lexi’s life, we cannot change anything, and we are making the best of it,” said Janae. “We still plan lots of family time, we take trips and give our girls important life experiences to share together. And that’s what I would recommend to all families if they are able to do so.”

About ThedaCare

For nearly 115 years, ThedaCare® has been improving the health and well-being of the communities it serves in Northeast and Central Wisconsin. The organization delivers care to more than 650,000



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residents in 17 counties, and employs approximately 7,000 providers and team members at 180 points of care, including eight hospitals. As an organization committed to being a leader in Population Health, team members are dedicated to empowering people to live their unique, best lives. ThedaCare is a not-for-profit health system with a level II trauma center, comprehensive cancer treatment, stroke and cardiac programs, as well as primary care. ThedaCare also partners with communities to understand needs, find solutions together, and encourage health awareness and action. In 2024, ThedaCare and Froedtert Health combined to form one system to strengthen local health care and provide high-quality services for treatment and prevention in a coordinated manner.

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