

Dear **(Parent name)**,

Congratulations on the birth of your new baby! As part of Utah's goal to improve the health outcomes of Utah babies, we screen babies for congenital Cytomegalovirus (CMV) if they meet certain criteria. Because your baby _____, he/she had testing done on **(date)** on **(urine/saliva)** looking for congenital CMV.

Your baby's testing came back **POSITIVE**, meaning there is evidence for a congenital CMV infection. We will also notify your primary care provider **(name of provider, phone #)** of these results. CMV is the most common viral infection that infants are born with in the US. About **1 in 150 babies are born with congenital CMV** each year (30,000 - 40,000 babies). Ninety percent of babies with a congenital CMV infection will not show any signs or symptoms at birth; however, they are at risk for delayed hearing loss and other health problems.

Because congenital CMV related hearing loss and other health problems may be delayed, it is important to follow up with all recommended testing and services. The additional evaluations for your baby include:

- Diagnostic audiological evaluation ASAP, if not done already, with frequent monitoring of hearing;
- Referral to an infectious disease physician;
- Referral to an ENT;
- Referral to a pediatric ophthalmologist;
- Referral to early intervention services.

We know that this diagnosis and additional evaluations are overwhelming to say the least. To help with this follow-up process, one very helpful resource is the **multi-disciplinary cCMV clinic at Primary Children's Hospital**, facilitated by Albert Park, MD. This clinic includes an expert team of specialists that provide consultation, the evaluations listed above, treatment as needed, follow-up, and support to cCMV babies, families, and their providers. The **cCMV clinic phone number is 801-662-1705**.

We can also refer babies with congenital CMV and/or hearing loss to Utah's **Baby Watch early intervention program**, familyhealth.utah.gov/oec/baby-watch-early-intervention. This program provides early identification and developmental monitoring services for

infants and toddlers (ages birth to 3 years of age) that have or are at risk for disability or developmental delay.

Since we feel it is important for parents to be empowered by information, we wanted to include our website, cmv.utah.gov, where you can find more information about CMV. Additionally, one of the best ways to gain useful information is through parents sharing with other parents. We have included information on the National CMV Foundation nationalcmv.org. This organization was developed by parents and for parents. Lastly, if you would like to be connected to other Utah parents who have a baby with congenital CMV or if you have any unanswered questions, please feel free to contact us at 801-273-6600 or cmv@utah.gov.

We want you to feel supported while you navigate your baby's congenital CMV infection and care. Please let us know how we can help.

Best regards,

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