

Dear (PCP),

Your patient, _____, was recently tested for CMV. Their results came back POSITIVE meaning there is evidence for a congenital CMV infection. We wanted to notify you of these results and provide you and your patient with some information and resources.

Cytomegalovirus is the most common congenital infection affecting more than 40,000 pregnant people and their babies in the U.S. per year. That means that in Utah, there is approximately one baby born per day with congenital CMV (cCMV). If a healthy adult or child gets CMV, they may have no symptoms while others may have mild flu-like symptoms. However, if a pregnant person gets CMV, the virus can infect the baby. A small number of babies (10%) will be more severely affected and will have symptoms at birth. The majority of cCMV babies will not have any obvious symptoms at birth, but 15% of these babies born with cCMV will have or develop hearing loss which is often progressive in nature. Severely affected children with cCMV can experience concerns with vision, cognitive, and motor development.

Because cCMV related symptoms, like hearing loss, may have delayed onset and/or be progressive, it is important this baby receives follow-up. When a child has been diagnosed, we recommend the following steps to help improve the health outcomes of the child:

- Diagnostic audiological evaluation ASAP, if not already done, with frequent monitoring of hearing as recommended by the baby's pediatric audiologist;
- Referral to an infectious disease physician;
- Referral to an ENT if the baby has diagnosed hearing loss;
- Referral to a pediatric ophthalmologist to rule out CMV induced visual concerns;
- Referral to early intervention.

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, evaluation, treatment as needed, follow-up and support to cCMV babies, families, and their providers. The cCMV clinic phone number is 801-662-1705. Note: It is important that babies that have tested positive for cCMV receive continual follow-up, as symptoms may develop over time.

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. Although it is possible that the baby and family think they may have no need for services, 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. If you have any unanswered questions, please feel free to contact us at 801-273-6600.

We ask that you inform your patient and their family of these CMV resources, as well as check in with them to see if they are receiving these important follow-up services. Thank you for all that you do for parents and babies in Utah. If you have any questions, need CMV materials, or would like an educational presentation on cCMV, please email us at cmv@utah.gov.

Best regards,

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