

WHAT TO KNOW IF YOUR BABY WAS BORN WITH CONGENITAL ZIKA SYNDROME



As a parent of a new baby with health conditions related to Zika infection during pregnancy, you may feel overwhelmed, worried, and unsure of how to care for your new baby. Read on to learn more about health conditions related to Zika and find out where you can go for help.

How Might Zika Affect My Baby?

Zika infection during pregnancy can lead to a pattern of conditions, called congenital Zika syndrome, in the baby. A baby with congenital Zika syndrome, might have one or more of the conditions in the blue box.

- Smaller than expected head size, called microcephaly
- Problems with brain development
- Feeding problems, such as difficulty swallowing
- Hearing loss
- Seizures
- Vision problems
- A problem with joint movement, called contractures
- Too much muscle tone restricting body movement soon after birth

We are still learning about the effects of Zika infection during pregnancy. Babies affected by Zika may have lasting special needs. Some of the conditions listed in the blue box can lead to problems with a child's progress in moving, learning, speaking and playing, called "developmental delay." Babies with congenital Zika syndrome may experience different outcomes as they develop, but it's difficult to know how each baby will be affected. These answers may only come with more time. It is important for you to work with your doctors to manage your baby's medical care together.

How Can I Support My Baby?

Babies with congenital Zika syndrome need support. One type of support involves getting your baby help as soon as possible for learning and developing skills, like feeding, sitting, or crawling. This type of help is called "early intervention services," and is available in the first 3 years of life. Other developmental support may be needed for any ongoing special needs. Another type of support is treatment of the conditions your baby may experience, like medication to help treat seizures.

To help your baby get the early support and services he or she might need:

- **Work with your doctor to create a coordinated care plan.**
 - » Work with your doctor to organize the care your baby might need. Additional testing, like hearing and vision testing, may be needed even if the first tests were normal.
 - **Keep regular appointments.**
 - » Take your baby for all recommended check-ups with his or her regular doctor, nurse, or other healthcare provider or recommended specialists. This is important for your baby's doctor or other healthcare providers to monitor your baby's development.
 - **Share your concerns.**
 - » If you have new concerns about your baby's development at any time, talk with your baby's doctor, nurse, early intervention provider, or healthcare provider. Don't wait. Acting early could make a real difference.
 - **Contact early intervention services in your community.**
 - » Reach out to your state or territory's early intervention program. Your baby may be eligible for free or low cost services. Find contact information at www.cdc.gov/FindEI.
- You do not need a doctor's referral or a medical diagnosis to have your baby evaluated for services.**



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Where to Find Resources and Support

Raising a child with congenital Zika syndrome can be challenging. Thankfully, help is available for you and your baby.

The resources below can help you find more information about Zika, locate services that might help your baby, and connect with other families.



FIND more information through:

- Your baby's regular doctor or a specialist whom your doctor recommends
- **CDC Zika Virus Website** | www.cdc.gov/zika
- Non-profit organizations
 - » **American Academy of Pediatrics** | Visit website: www.healthychildren.org
This organization is comprised of pediatricians committed to the health of infants, children, adolescents, and young adults.
 - » **March of Dimes:** www.marchofdimes.org | Ask questions: www.marchofdimes.org/ask-us.aspx
The March of Dimes is dedicated to improving the health of babies by preventing birth defects, premature birth, and infant mortality.
 - » **The Parent Training and Information Center** in your state: www.parentcenterhub.org/find-your-center
These centers provide information and training on early intervention and special education services to families of children with disabilities.



ACCESS regular pediatric, other health care, and early intervention services through:

- Your baby's regular doctor
- A specialist whom your doctor recommends. Babies with microcephaly might benefit from seeing other healthcare providers who specialize in certain types of care, like treating conditions of the nervous system, eye problems, or child development.
 - » State/local programs, such as early intervention and medical services for children with special healthcare needs. Call your state contact to get a free evaluation: www.cdc.gov/FindEI



GET peer support from families of children with microcephaly or other special healthcare needs through:

- Non-profit organizations
 - » **The Family Voices** affiliate or **Family-to-Family Health Information Center** in your state: www.familyvoices.org/states
 - » **Parent to Parent-USA** | Visit website: www.p2pusa.org
 - » **Partnerships for Parents** | Visit website: partnershipforparents.net/
- Your hospital social worker. Try talking to someone about how you're feeling, be it friend or professional. Hospitals often have a social worker who can counsel you initially and connect you with additional therapeutic resources. Get the support you need to take care of yourself and your baby.

Links to organizations outside of CDC are included for information only and do not indicate any form of endorsement or approval from CDC.

For a more complete list of resources for families, please visit

www.cdc.gov/zika/parents/families-of-newborns-affected-zika.html

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