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Congenital Microcephaly: Information for Parents

Congenital microcephaly is a rare condition in which the baby’s head does not grow as expected in utero. During pregnancy, the fetus’s head increases in size because his or her brain is growing. Therefore, when a baby has a smaller head then expected, the concern is that the brain is not growing as it should. This condition most commonly occurs during the first trimester of the pregnancy. Microcephaly also may develop after birth (acquired microcephaly) and would be identified during well-baby checkups. In the United States, about five of every 10,000 babies born will have microcephaly.

The exact reason for microcephaly is not always clear, but it can be caused by many different things. Microcephaly may be the result of a viral infection the mother had during pregnancy (especially during the first few months of pregnancy). Other causes may include radiation exposure; metabolic disorders such as maternal phenylketonuria (PKU) disease; exposure to toxic chemicals, alcohol, or drugs (especially during the first trimester; genetic conditions); and decreased nutrition during pregnancy. Other causes may include inflammation, an interruption of the blood flow and oxygen to the brain of the baby during the critical period of development, and birth trauma. In recent years, research has shown that babies of mothers who were infected with the Zika virus during pregnancy are at risk for developing microcephaly or other severe brain and nervous system disorders.

Microcephaly can be mild or severe. If severe, microcephaly may be associated with other lifelong problems such as

* seizures
* developmental delays, such as speech problems
* intellectual deficits, such as learning difficulties
* difficulties with movement and balance
* feeding problems, such as difficulty with swallowing
* hearing loss
* visual issues.

When looking at your baby, his or her head appears small in proportion to the rest of the body. This suspicion is confirmed when the head circumference is measured. Optimally, this measurement is obtained soon after birth. On some babies with microcephaly, you may also notice a backward slope of the forehead.

Congenital microcephaly may be diagnosed before birth during ultrasound evaluations, especially when the ultrasound is done late in the second trimester or early in the third trimester. Sometimes, microcephaly is diagnosed after delivery, when the physician or nurse practitioner does their physical exam. Your baby may need a scan (CT or MRI) of the head to further evaluate this issue.

Depending on the risk factors for your baby, additional tests may be ordered. For example, if the suspected cause is a viral infection, blood will be drawn to confirm or rule this out.

Microcephaly is a lifelong condition, and currently, there are no treatments for it. Because the effects of microcephaly can range from mild to severe, each baby will have a different care plan. Early intervention programs that include speech, physical, and occupational therapies will be the most helpful for these children.

Babies infected with the Zika virus before birth will need to be closely evaluated for congenital Zika syndrome. This syndrome has five unique features:

* severe microcephaly
* decreased brain tissue with a specific pattern of brain damage
* damage to the back of the eye
* congenital contractures (a condition that shortens and/ or tightens the muscles and tendons in the arms and legs, leading to deformity)
* increased muscle tone that restricts body movement after birth.

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If your baby has had this infection, he or she also may have other brain abnormalities. Because of the lifelong consequences of microcephaly, it is very important that your baby has regular well-baby visits with his or her primary care or pediatric providers.