

Porencephaly

Patient Information Series – What you should know, what you should ask.

What is Porencephaly?

Porencephaly is a rare condition where a cyst or cavity forms within the brain's cerebral hemispheres. These fluid-filled gaps can vary greatly in size and are either connected to the brain ventricles or the outer surface of the brain. Porencephaly can affect a child's physical and cognitive development depending on its size and location.

What Causes Porencephaly?

Porencephaly can occur due to a variety of reasons. It may develop because of an abnormal development of the brain, or as a result of damage to the brain. The damage might be caused by infections, stroke, or traumatic injury. In some cases, the exact cause remains unknown.

Should I Have More Tests Done?

Following the initial diagnosis usually made via ultrasound, you may be referred for further detailed imaging tests such as a fetal MRI. These tests help to confirm the diagnosis, determine the extent of the brain involvement, and rule out additional anomalies. Genetic counseling and testing may also be offered to you, to check for related genetic conditions.

What Are the Things to Watch for During My Pregnancy?

Your medical team will guide you on specific things to monitor based on your individual situation. Generally, expect regular follow-up appointments and additional ultrasounds or MRIs to monitor your baby's development and the progression of the condition. Immediate medical advice should be sought if you notice any unusual symptoms or changes in your health or pregnancy.

What Does It Mean for My Baby After It is Born?

The impact of porencephaly on your baby can vary. Some children with small cysts may experience minimal effects, while others with larger lesions might face significant challenges, such as developmental delays, motor impairments, or seizures. Early intervention with pediatric neurologists and other specialists can optimize outcomes and provide support for developmental skills.

Will It Happen Again?

The risk of porencephaly occurring in future pregnancies generally depends on the underlying cause. If a genetic factor is involved, genetic counseling will help clarify recurrence risks. In cases where porencephaly is due to external factors like infection or trauma, the risk may not necessarily be increased. Discussing your individual risk factors with a specialist is important.

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What other questions should I ask?

- What are the possible outcomes for my baby with this diagnosis?
- What specialists will need to be involved in my baby's care after birth?
- How can I prepare to support my child's needs after they are born?
- Are there specific treatments or therapies that will help my child?
- Can you recommend any support groups or resources for parents in similar situations?

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