

Family Handout: *Chiari Malformation*

Common Questions for Families of Children with Chiari 1 Malformation

Q: What is a Chiari malformation?

A: A Chiari malformation is something a child is usually born with. It means part of the brain is lower than normal and gets crowded at the base of the skull, where the brain meets the spine.

Q: What problems can Chiari malformation cause for my child?

A: Many kids with Chiari malformation have no symptoms at all! It's often found when they have an MRI for another reason. If there are symptoms, they may include:

- Quick, sharp headaches in the back of the head, especially after coughing or sneezing
- Trouble swallowing or breathing (like snoring)
- Weakness, numbness, or trouble walking
- A curved spine, called scoliosis

Q: Is Chiari malformation common?

A: Yes. About 1 to 3 out of every 100 kids who get a brain or spine MRI are found to have Chiari 1 malformation. Sometimes MRI reports may not be clear, and a neurosurgeon might say everything looks normal.

Q: Does every Chiari malformation need treatment?

A: No. Most kids who see a neurosurgeon for this don't need surgery. In a large study, fewer than 15 out of 100 kids with Chiari needed an operation. The doctors at Connecticut Children's will talk with you if surgery is ever needed.

Q: Will Chiari malformation get worse over time?

A: Usually not. Most kids stay the same or even feel better over time.

Q: Does my child need more MRIs after the first one?

A: Most of the time, no. But if your child also has something called syringomyelia (a fluid-filled space in the spinal cord), they might need follow-up MRIs.

Q: Can my child play sports or do normal activities?

A: It depends. Some activities like gymnastics or contact sports might need to be limited. Your doctor will look at your child's MRI and talk with you to decide what's safe.

Q: The neurosurgeon said to come back only if new symptoms appear. What should I and my pediatrician watch for?

A: It's rare for new symptoms to show up. In one study, fewer than 3 out of 100 kids had new problems after seeing a neurosurgeon. None had problems after two years. Doctors usually stop follow-up visits after that. Kids under 5 are followed longer.

You should come back to the neurosurgeon if your child has:

- New headaches in the back of the head that happen with coughing or sneezing
- New trouble swallowing, especially liquids
- New weakness, numbness, or trouble walking

If your child has a curved spine (scoliosis), see an orthopedic doctor first. They can check if it might be related to Chiari.