

Conservatively Managed Pediatric Outcomes

The Second Edition of Conquer Chiari: A Patient's Guide was recently published and below is an excerpt regarding outcome data for children who were treated conservatively (meaning no surgery).....

Non-Surgical (Wait & See) Outcomes

As mentioned in the previous chapter, the majority of Chiari patients do NOT undergo surgery. Rather, if symptoms are mild, or not typical of Chiari, a conservative approach of wait and see is often adopted. Despite the common nature of conservative management, when *A Patient's Guide* first came out it included only one study focused on the conservative outcomes.

Fortunately times have changed and while the numbers are still not overwhelming, they are significant enough to begin to draw some conclusions.

Pediatric

Figure 5-2 summarizes 5 studies that looked at the conservative management of pediatric Chiari. The specifics of each study are slightly different so the results cannot really be combined, but they all followed the children regularly for several years and do show that in general not many children who are managed conservatively end up requiring surgery (3.5%-9.5%).

Figure 5-2: Selected Pediatric Conservative Treatment Outcome Studies

Authors	Year	# of Patients	% Surgery
Strahle et al.	2011	147	9.5%
Benglis et al.	2011	124	4.0%
Whitson et al.	2015	52	5.8%
Leon et al.	2019	427	3.5%
Davidson et al.	2020	218	6.4%

In what might be the strongest study, doctors from the University of Alabama-Birmingham reported on over 400 pediatric Chiari patients conservatively treated. They excluded anyone who had surgery within 9 months of the initial consultation figuring that it was likely not due to new symptoms developing in that timeframe. Over time only 15 children ended up having surgery an average of 21 months after the initial evaluation. Five of the children developed cough related headaches, 5 developed syrinxes, and 5 developed general headaches.

Similarly, in the most recent study, surgeons from Children's National Medical Center looked at 218 Chiari cases and found that only 14 patients developed new symptoms after the initial consultation that required surgery.

Other studies have focused on patients who are asymptomatic (symptom free) at the time of diagnosis or who have symptoms not typical of Chiari. For example, a 2011 study from the University of Miami included 43 children who were asymptomatic when the Chiari was discovered and were followed for an average of 3 years. None of these children required surgery or even developed any symptoms or neurological deficits. The same study included 67 children who had symptoms the authors categorized as not typical of Chiari. Over the course of follow-up, none of these children required surgery either.

In fact, a 2019 literature review found that out of around 700 asymptomatic Chiari children, only about 5% went on to develop any symptoms. And out of 100 symptomatic Chiari children treated conservatively, nearly half (48%) actually improved over time. In contrast, just 7% got worse.

It is important to note that when conservatively managed children are given annual MRIs, changes in the amount of herniation are common. A 2015 study from Dartmouth followed 52 such children who underwent annual imaging for up to 7 years after initial diagnosis. The researchers found that in any given year, nearly one-fourth of the group exhibited a

tonsillar position change of at least 2mm. Over the course of the study the tonsillar position remained stable in half the group, improved in 38%, and got worse in 12%.

Although there hasn't been a single, definitive study on the conservative management of children, the evidence is building that asymptomatic cases overwhelmingly stay that way, that even symptomatic cases may improve with time, and that very few non-surgical cases become surgical in the near to mid-term.

One note of caution is warranted however, namely that no study has followed these children into adulthood to see if symptoms develop much later in life.

Source: Labuda, Richard. *Conquer Chiari: A Patient's Guide to the Chiari Malformation (2nd Edition)*. C&S Patient Education Foundation, 2021.

Conquer Chiari's research updates highlight and summarize interesting publications from the medical literature while providing background and context. The summaries do contain some medical terminology and assume a general understanding of Chiari. Introductory information and many more research articles can be found www.conquerchiari.org

Conquer Chiari is a 501(c)(3) public charity dedicated to improving the experiences and outcomes of Chiari patients through education, awareness and research.