

Top Ten Research Questions

Update from the Cleft & Craniofacial Anomalies Clinical Studies Group

Ingrid Laurence and Helen Keighley, parent representatives, and Wendy Edwards, Headlines representative, on the Cleft & Craniofacial Anomalies Clinical Studies Group, funded by NHS England, were tasked to draw up a list of top ten patient priority research questions in craniosynostosis and other associated craniofacial conditions (both non-syndromic and syndromic).

We are delighted to report that, following a long consultation with members and health professionals, a list of over 30 questions were proposed. These were then reduced to 17 questions which were discussed at our Inaugural Headlines Conference in February 2017. These have since been ranked by our members to produce the Top Ten Priority Research Questions below:

1. What are the long-term effects on development for a) syndromic and b) non-syndromic craniofacial patients – physical and psychological?
2. What is the most reliable way to determine whether a child has a level of ICP that could cause impaired brain function?
3. Which types of craniofacial surgery work best, and what is the optimum age to perform them?
4. What are the causes of single suture and non-syndromic synostosis?
5. Can better scans/monitoring help identify Craniosynostosis during pregnancy?
6. What do paediatricians, GPs and health visitors know about craniofacial conditions, and what is the most effective way to improve their knowledge?
7. How is an adult patient affected physiologically by their craniofacial condition – intracranial pressure/risk of stroke/other issues – and how are they monitored?
8. Are there links between Craniosynostosis and other medical conditions (autism/dyslexia/gynaecological/gastro/endocrine/bones)?
9. What is the risk of further surgery for each of the craniofacial conditions?
10. Are adult craniofacial patients likely to suffer from mental health difficulties, or are they more resilient, due to their upbringing with the condition?

Thanks to everyone who has helped in identifying these research gaps, as now we can begin to work with others to find the answers. Research requires money, time, patients and

patience, but we plan to put our best foot forward and find ways to work in partnership to address these questions.