

Headlines Craniofacial Support Research Fund



Headlines' Mission is to:

- Raise awareness and educate people to improve public understanding of craniosynostosis and rare craniofacial conditions
- Support people with craniosynostosis and rare craniofacial conditions throughout their life to overcome the physical, psychological and social impacts of living with these conditions
- Support research that seeks to advance understanding, ensures the provision of quality care, and identifies the best treatments for craniosynostosis and rare craniofacial conditions

Headlines has set up a new Research Fund in order to address our charitable objects of our mission. Our research fund aims to provide funding:

1. To identify the causes and best treatments for craniosynostosis and rare craniofacial conditions;
2. To enable people to live the best life they can with craniosynostosis and rare craniofacial conditions;
3. To improve the provision and quality of care available to people with craniosynostosis and rare craniofacial conditions.

Our Research Fund is available to researchers based at UK universities or in the NHS. Applications are invited for innovative research projects that meet the aims of the research fund though priority may be given to applications which also address the 10 Ten Priority Research Questions that were identified through a Priority Setting Process which involved members of Headlines Craniofacial Support. These questions are:

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?

A research fund of £20,000 for small research grants will be made available for the funding of small projects in the 2021/22 financial year.

Each grant awarded will be up to a maximum value of £10,000 but researchers can apply for smaller grants. Each application will be reviewed by the Headlines Research Panel which will include a patient and carer representative.

The timeline for the application process will be as follows:

- Friday 7th May 2021 - Call for funding applications opens
- Friday 2nd July 2021 at 5pm – Closing date for applications
- July 2021 – Applications reviewed by Research Panel and Patient/Carer representative
- End of July 2021 – Applicants to be advised of outcome