



Headlines – Craniofacial Support Group

5 YEAR STRATEGY

Vision: A world where physical, psychological and social impacts of craniosynostosis and rare craniofacial conditions are no more

Strapline: Supporting all those affected by craniosynostosis and rare craniofacial conditions

Mission:

Full version:

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

Abridged version:

Supporting all those affected by craniosynostosis and rare craniofacial conditions: by raising awareness and educating the public; by supporting people throughout their life to overcome psychological and social impacts; and by supporting research that advances understanding and ensures quality care is available

Awareness & Education <i>Raise awareness and educate people to improve public understanding of craniosynostosis and rare craniofacial conditions</i>	Support & Living with the Condition <i>Support people with craniosynostosis and rare craniofacial conditions throughout their life to overcome the physical, psychological and social impacts of living with these conditions</i>	Research & Provision of Care <i>Support research that seeks to advance understanding, ensures the provision of quality care, and identifies the best treatments for craniosynostosis and rare craniofacial conditions</i>
<p><i>Provide information on the condition</i></p> <ul style="list-style-type: none"> • Making sure people understand their condition and have the information available to them when they need it • Working with experts in the conditions to keep the patient information up to date 	<p><i>Support</i></p> <ul style="list-style-type: none"> • Bringing members and families together at regular and annual events to share experiences • Supporting people on the helpline and through social media groups • Developing a teen and young adults programme • Supporting all members throughout their life 	<p><i>Advance understanding, improve diagnosis and improve treatments</i></p> <ul style="list-style-type: none"> • Identifying research priorities • Supporting health professionals and researchers to undertake research and enhance knowledge • Involving patients in research
<p><i>Raise awareness of the condition and increase the public profile</i></p> <ul style="list-style-type: none"> • Making the public aware of the conditions and the charity through events, website, newsletters and social media • Running campaigns to highlight the condition such as Craniofacial Awareness Week • Attendance and presenting at relevant meetings and conferences • Partnering and collaborating with other relevant organisations to increase profile of our work 	<p><i>Living with the condition</i></p> <ul style="list-style-type: none"> • Helping people gain access to psychological and social support • Connecting people with experts in the community • Linking up with national and local initiatives on improving daily life of people with differences • Providing welfare grants 	<p><i>Enhance care, improve standards and quality of life for people with the condition</i></p> <ul style="list-style-type: none"> • Bringing health professionals and patients together to discuss needs • Working with health commissioners and governing bodies to improve care
<p>BY WHEN: 2023</p>	<p>BY WHEN: 2023</p>	<p>BY WHEN: 2023</p>