

David Johnson



Many families will recognise Consultant Plastic, Reconstructive and Craniofacial Surgeon David Johnson, who has been Director of the Oxford Craniofacial Unit since 2014.

Here he tells us more about his fascinating role and how he got there.

Can you start by telling readers a little about yourself and why you went into plastic & reconstructive surgery?

I grew up in the North East of England in a small village in County Durham. My ancestors were from a humble coal mining background. I went to school in Newcastle and had the most amazingly fulfilled childhood. I met my wife at school when we were 'just seventeen'... I love and cherish everything 'Geordie' and my accent undergoes an involuntary transformation as soon as I drive north past Scotch Corner on the M1! I have 4 grown up children who are very happy and I'm so proud of them.

I undertook my pre-clinical medical degree at Cambridge University and my clinical degree at Oxford University. I always knew I wanted to be a plastic surgeon - there was just something about the practical scope for creativity that fascinated me ever since I was a teenager when I watched a TV documentary in the mid 1980s called 'The Boy David' - about a Peruvian child with severe facial disfigurement who was abandoned by his family and ultimately adopted by his surgeon.

How long have you been at Oxford?
Since my clinical medical student training I have worked in various surgical training positions around the South of England. My

senior registrar training was in Oxford and my craniofacial fellowship was in the Australian Craniofacial Unit in Adelaide in 2005. I was appointed as a craniofacial plastic surgery consultant in Oxford in 2006.

What do you most/least enjoy about your work?

You won't be surprised to find that I most enjoy operating – in particular, the creative challenge of working out how to remodel different aspects of the skull in a bespoke way. My favourite operation is a Le Fort III midface advancement.

I am now at a stage in my career where I am discharging young adults that I operated on as babies and, as such, it is an enormous privilege for me to watch children grow up and to see them fulfilling their natural potential.

I least enjoy dealing with so many increasing challenges with resource allocations and pressures on service support staff in the NHS. Needless to say, I find it so upsetting when children's operations are cancelled or postponed because of lack of beds or resources.

What do you enjoy doing when you're not at work?

I get enormous enjoyment following the extraordinary lives and events of my 4 children – frequently all in different countries and in different time zones. WhatsApp messages randomly ping throughout the night!

I have a much-loved black Labrador called Dougie and my wife and I get our weekend relaxation walking through the beautiful Oxfordshire countryside with him. I rarely get a chance to watch TV but I always try to watch the England rugby games and the Formula 1 races.



What have been your proudest work achievements?

It is difficult to pick out one particular achievement but there are a number of opportunities I have been lucky enough to get involved with in my working life. Since university, I have always had a major interest in anatomy and as a junior doctor I used to proffer anatomical textbooks for a publishing company in my spare time. I was then invited to be a major editor in the most modern rewriting of the world-famous Gray's Anatomy and was extremely proud when I saw the book finally in print.

Last year, as President of the European Society of Craniofacial Surgery I had the privilege of organising and hosting the biennial meeting in Oxford. This was the largest meeting the society has ever had, and which successfully brought together world class presentations and inspiring guest talks from 15 different countries. A proud achievement for me.

How would you bring about improvements in the treatment and care of those born with craniosynostosis?

Whilst there has been amazing progress made in the treatment of children with craniosynostosis there are also so many more improvements needed.

The resolution of important ongoing debates such as when is the best time to operate and what is the best operation for single suture synostosis is only going to happen with highly coordinated multicentred research looking at pre-agreed outcome measures. The 5 units in the UK are theoretically in an ideal position to be able to undertake this challenge but there



is, I believe, a fundamental flaw to achieving this at the present time and this is why some progress has been unnecessarily slow. Research in a lot of units is mostly done by individuals in their spare time - in the evenings and at weekends and after very busy clinics and full operating days and with no allocated time in the working week. This is a rate limiting step and I think this has to change. I would like to see significant dedicated time allocated in job plans for those team members in the 5 designated units who have the ambition and skills to undertake such research.

At an international level, I find it upsetting that so many countries do not have access to even the most basic of craniofacial care. Perhaps this may be my new challenge when I near retirement.

Can you tell us something about yourself that might surprise readers?

Whilst at school and university, my nickname was 'Skelly' (on account of my skinny physique) and I used to have dyed blond hair (see photo from the 80's) and play in a rock band called 'Pepper's Ghost'. I was the singer/songwriter, and guitarist with a few semi-professional recordings – but, alas, with no X Factor success!

One 'claim to fame' was that my band was hired to play at a Cambridge May Ball but there was an electrical fault which unfortunately ended the concert after only the first note was played. We still received the full payment and so a newspaper reporter reviewing the event published his calculations that the extrapolated hourly rate of pay for just one note theoretically made us the highest paid band in the world!

Young Persons Network

Trustee Charlotte Ashby provides a recap of what the YPN has been up to this year and what's planned for the rest of 2023.



At the end of last year, we spent time discussing what we wanted the YPN to be, and the kind

of activities we wanted going forward. The YPN is organised and run by the older teens and adults in the group, so lots of what we plan is decided by these kinds of discussions. After these chats on Zoom, the main thing we wanted was to hold more in-person meet ups, building on the ones we had held in London and Birmingham in 2022.

Currently meetups are held online, and in London and Birmingham, as these are the most easily accessible for current YPN members. However we are aiming to hold a number of in-person and online meetups in 2023, and are always open to suggestions for new venues, activities and events!

Spotlight on: Specialist Speech and Language Therapy

We have also been working with Darren, one of our other trustees, who has been helping us to revamp our page on the Headlines website. After some meetings on Teams, a few of us have had a go at designing web pages and we are hoping to get creative with making our YPN section of the Headlines website more inviting and showcase more of what we do. One of our members, Gabby, is also trying to restart the blog that we began a few years ago with new blog posts, which will also go on the website.

We have received feedback from some parents and children that they would really appreciate talking to a young person about how they have navigated being a teenager and then a young adult, as sometimes it can be helpful to speak to someone who has actually 'done it' and reassure them. We are planning to trial an informal system where if a parent or child with craniosynostosis would like to have a chat with a young adult, then we can facilitate this via email, text or phone call, for example. There are a number of young people who would be more than happy to have a chat or answer questions.

If you're aged 16-30 and have a craniofacial condition or a sibling with a craniofacial condition and are interested in joining the Young Persons Network or coming along to a virtual or in-person meet up to see what it is like, we would love to see you! We also have a Facebook and WhatsApp group, an Instagram page and a Tiktok account that can be followed or joined if you would like to see more of what we get up to.

Please do get in touch with us at info@headlines.org.uk or via our social media channels if you would like more information!

Speech and Language Therapists play a vitally important role in the multidisciplinary teams at the NHS-designated Specialist Craniofacial Units. Sarah Kilcoyne from the specialist team at Oxford tells us more about their work.



"We estimate that around 6 -10 % of children may experience delays in their speech and language development. However, in certain forms of craniosynostosis, the incidence can be much higher, so making sure that those with craniosynostosis receive effective speech and language support when and where it's needed is absolutely crucial."

In the NHS-designated Craniofacial Units, Specialist Craniofacial Speech and Language Therapists are there specifically to look after the speech, language and feeding needs of children, young people and adults with craniosynostosis.

We also work to ensure that children and young people are under the care of local speech and language therapy services so

that intervention is provided close to home. When local SLTs are providing a service, the specialist craniofacial SLTs can provide specialist advice about speech, language and feeding difficulties specifically related to craniosynostosis and craniofacial conditions. However, we know that the provision of local speech and language therapy has been dramatically impacted by the COVID-19 pandemic, with many people unable to access local services.

For that reason, we've been working to try and ensure that free resources to encourage children's speech and language are available online; for example, resources for children aged 1-3 years of age, and specifically for children with craniosynostosis, are available via our 'Sing & Say' project on the Oxford University Hospitals website www.ouh.nhs.uk/singandsay/ As it's such a rare condition, many speech and language therapists in the community may never have ever seen another child with craniosynostosis. It was because of this that the Craniofacial Specialist SLTs worked with the Royal College of Speech and Language Therapists (RCSLT) and Headlines to compile a new leaflet to give community SLTs therapists an overview about how to support people with craniosynostosis.

If you're concerned about any aspect of your child's speech and language development, you should ask your specialist team for a referral to the Craniofacial Specialist SLT."

ACCORD: our first-ever project for adults nears completion

An independent cinema in Oxford provided the perfect backdrop for the launch of a series of new films made by and for adults with craniosynostosis.

Produced by award-winning film company, Fine Rolling Media, in conjunction with research psychologists from the Centre for Appearance Research at UWE Bristol; the films are the culmination of Headlines' ACCORD project, a 21-month piece of work funded by the VTCT Foundation.

As Dr Nicola Stock, Associate Professor at CAR, explains:

“The project has built on the findings of the research we conducted in 2019, which highlighted the fact that many adults affected by craniosynostosis have concerns about important issues such as starting a family and finding employment, and that there was an absence of dedicated support for them.”

for the films and the written materials which accompany them. The group consisted of adults with various forms of craniosynostosis, 7 of whom agreed to appear in the films. Each film focuses on a different aspect of living with craniosynostosis in adulthood, from being different, to navigating treatment, dealing with dating and social relationships, and finding employment.

“Although the framework for the project was informed by the research evidence,” Nicola says, “our adults brought their own experiences and views to shape the resources. It has been a hugely insightful and rewarding process for all of us.”

Following the special screening in Oxford, the films and a new booklet covering the themes explored in the films are being formally evaluated and will be made available on the Headlines website. The work is also being presented at the annual conference of the Craniofacial Society of Great Britain & Northern Ireland in Cardiff.



Sally's story

Sally was one of the group of adults with craniosynostosis leading the ACCORD project: here she tells us about her experience of being involved.

"Participating in the research project feels like another aspect of my story has opened. It was such a cathartic experience. Another silence broken, facilitating further healing and insight."

2022 has been a very significant year – another part of the journey of discovery with Crouzon's, which started when I joined the ACCORD project in 2019.

Although I have had extensive surgery for Crouzon's, my appearance now hides this truth. Scars are hidden in my thick curly and my many facial scars are hidden in wrinkles – aging can be kind in that way. My surgeons (long before the formation of specialist units) focused on the aesthetic correction as much as the physiological need. I was bullied extensively for my different appearance at school. However, since then many people find it hard to believe I have endured so much and continue to be significantly affected by Crouzon's physically. Subsequently, I learned to dismiss my experiences and brushed off all I endured, both to others and myself. Therefore, part of me didn't feel good enough for the attention afforded to my story in being part of ACCORD.

The filming day with the ACCORD team was in October 2022. Everyone was so lovely, kind, dedicated and compassionate. They had clearly immersed themselves in



opened. I had been heard and embraced. That can be very scary if one is unable to feel safe within that opening and depth, so I cannot thank every member of the team enough for the compassionate love and support given that day and through the process.

Another major event took place in 2022, when my son sustained a severe brain injury in a road accident. Suddenly I was back there intimately immersed in the world of ICU, monitors, cranial bolt, ICP, followed by his slowly returning consciousness, trying to piece together events. It took me back to my own experiences when young.

In supporting his recovery and linking with a brain injury charity, Headway, I made sense of my own neurological injury as a result of surgery, CSF leaks and subsequent intracranial pressure fluctuations. I have been able to piece together and make sense of my own experiences, physiological and psychological. I have gained a stronger voice with medics and, perhaps more importantly, to myself.

As a Psychotherapist my specialism is in developmental trauma. In this aspect I am increasingly drawn towards the experiences of those of us with craniosynostosis. The next part of ACCORD I am involved in is the older adults' story – the experiences and meaning-making of those of us who are 40+.

One of the problems with having a rare condition is that there are so many levels to the mystery. It can feel very isolating. I grew up feeling alone, like no one else had been here before or could know what it's like. A silence. Through Headlines, Hannah's



Fund, and now the ACCORD project, there is connection, a shared story, even though our journeys are very different.

After these seismic events the ground can certainly feel precarious. It has been life changing, especially within my current life-stage (in my 50s). What this all means for me I don't know yet. I just know there is no going back. What I do know though is that I have been empowered to meet the challenges whatever they might be."

Research in Focus

In 2021, we were delighted to launch a new Research Fund open to researchers based at UK universities or in the NHS undertaking innovative research projects focusing on Headlines' Top Ten Priority Research Questions. Since the last issue of Headline News went to press, our trustees agreed to make another allocation from our reserves towards the Fund, and a further call for applications was made in autumn 2022.

We were pleased to receive a number of strong applications and after a rigorous process of internal and external peer review and assessment, the Research Committee were able to make two new awards.

The first of these was for a project looking into developmental outcomes for children with single suture craniosynostosis being carried out jointly by Drs Anna Kearney from Alder Hey and Jo Horton from Birmingham Children's Hospital. The project will run for 12 months and we look forward to reporting the findings in the next issue of Headline News.

The second award was for a collaboration between the Plastic and Reconstructive Surgery Department of the Erasmus Medical Center in The Netherlands and the Centre for Craniofacial and Regenerative Biology at King's College London which is focusing on producing stem cells to enable us to better understand how craniosynostosis arises. One of the research team involved tells us more about this cutting edge work overleaf.

Although the allocation of funds means that we are no longer able to take any further applications this year, we very much hope to be in a position to raise further funds for this vital aspect of our work as a charity as we move forward in 2023 and beyond.

Filipa Duarte is a biomedical researcher from Porto. She completed a Masters in Neurosciences in Stem Cells & Nervous System Repair at Kings College London before joining the NEUcrest programme to undertake her PhD. Her research is one of three projects being part-funded through the new Headlines Research Fund.

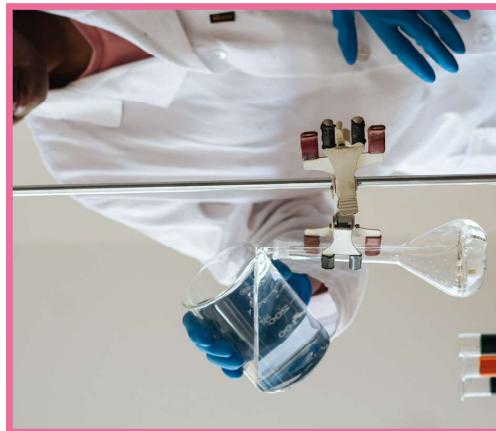


Our ambition is to develop ways of keeping the sutures open during the children's growth; however, to achieve this, we need to understand the biological events that cause disruption in the growth of the skull. Often craniosynostosis is caused by variations in genes critical for craniofacial development.

Although much progress has been made in identifying the genes linked to craniosynostosis, 70% of reported cases are still of unknown genetic origin. By understanding which and how genes are affected, we will be able to work out the most suitable treatment approaches for each individual.

My project arises from a collaboration between the Plastic and Reconstructive Surgery Department and the Department of Internal Medicine of the Erasmus Medical Center in The Netherlands, and the Centre for Craniofacial and Regenerative Biology at King's College London. Bringing together two institutions specialising in craniofacial and bone disorders allows us to maximise synergies and provide better healthcare to children with rare conditions like craniosynostosis.

Personalised therapies are becoming increasingly needed in therapeutic medicine. Human-induced pluripotent stem cells (hiPSCs) are cells that can generate every other type of cells in the body. In our lab, we made a 'disease model' of craniosynostosis by using hiPSCs. In this model we can also use cells from individuals with craniosynostosis. Because these cells carry the person's own genes, they are ideal for understanding the specific consequences of their genetic variation. This means that we can create specific models of the individual's condition.



In February this year, Headlines' Director Karen Wilkinson-Bell was invited over to Rotterdam to contribute to a day-long session for the NEUcrest network, a Europe-wide initiative which aims to train 15 PhD students to be part of the next generation of leading European young scientists focusing specifically on the neural crest - a group of cells which become multiple different cell types and contribute to tissues and organs (including the craniofacial bones) as an embryo develops. Here, two of the NEUcrest research fellows tell us more about their exciting work.



Research in Focus

Patient-derived hiPSC disease models are valuable drug screening tools and a functional and safe approach to guide pharmacology and therapeutic research.

Besides testing new therapies, we also use the disease model to identify which genes are affected and causing the craniosynostosis. We know it is really important for patients to receive genetic evidence of their condition: providing a genetic cause for a patient's condition can help clinicians decide on the best therapeutical approach.

Furthermore, by knowing the consequences of a genetic mutation, both affected individuals and their families can receive genetic counselling to inform the ways in which they manage possible challenges. Lastly, the scientific community will benefit from additional knowledge on genetic variants. By creating a course of action from the individual patient to disease model and back to patient, we can systematize this practice to patients with other conditions.

We hope that every institution and member involved in this project, including Headlines, can benefit from the partnership and that together we can contribute to the development of medical research which improves the lives of children and all those with rare conditions."

egg becomes a tadpole, like the ones that we can see in a pond or a lake. This usually takes from three to four days. This type of gestation is called external because it doesn't happen in a womb, unlike mammals like ourselves. This is extremely helpful to us, because we can study how these tadpoles develop by just looking at them under a microscope, in real time and without the need to sacrifice a mother.

My line of research is to study rare conditions that affect the normal development of the craniofacial skeleton and the eye. In particular, with respect to the eye, I am interested in the genetic causes of microphthalmia and anophthalmia (very rare conditions in which the eyes do not grow properly). The aim is to understand the reason why such conditions occur and hopefully provide families that are facing these situations with better understanding and diagnosis.

But eye conditions are not the only ones that our laboratory is interested in. In the past few years, we have been working with other rare conditions, like craniostenosis. Frogs,

Marco Antonaci is from Italy and studied molecular and cellular biology in Milan before moving to the School of Biological Sciences at the University of East Anglia in Norwich to undertake his doctoral training, working with RNAs and rare diseases.

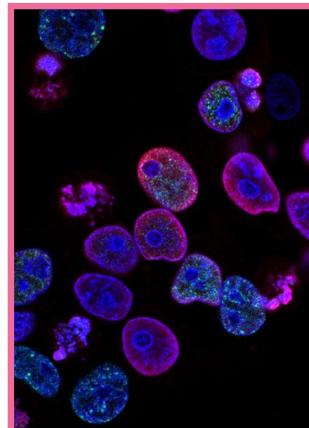
Marco's research is exploring how frogs can teach us about human genetic conditions.

"When it comes to biomedical research, one of the most common questions that people ask is why we use animals to study human conditions. The answer, as strange as it sounds, is that most of the animals that are used in a laboratory share with us a big portion of their DNA. This has an important implication: in most cases, those animals can be also affected by those human conditions.

Where I work, in the lab of Professor Grant Wheeler, we study human genetic conditions by using an unusual animal – frogs. The reason is that these conditions (in humans and frogs) are already visible during the early stages of development. The early stages of development for a frog are when the fertilised



and tadpoles in particular, are a great tool for helping us understand why they occur. As always, the final goal of our research is to help the people affected and their families, in the hope that, one day, we might be able to provide faster and better diagnosis and treatments."



Fundraising Fun

Headlines relies entirely on donations to fund its work – we receive no government funding whatsoever – and as a very small charity, every penny raised really does make a huge difference. Whether you're running a marathon, holding a bake sale or

having a party, there are hundreds of ways you can support us.

We are incredibly grateful to all those amazing members and supporters who've raised funds for us over the past twelve months – we hope you enjoy reading about some of their exploits here!



James Cowie, who was also born with craniosynostosis, ran the Sheffield Half Marathon in March and has raised almost £500



Kev Foley's nephew **Finn** was born with sagittal craniosynostosis and underwent surgery in 2018. Kev took up running during the first lockdown, much to his sister (and Finn's mum) Laura's amusement. Kev later decided to enter the Great North Run and went on to raise over £1,100 for Headlines. Laura says Finn is extremely proud of his uncle. Well done and thanks from us all at Headlines, Kev!



Kind-hearted staff at **Just Desserts** in Yorkshire ran a whole series of events to raise a whopping £5170.20



Caitlin Lower raised £50.00 organising a raffle for her charity badge at Brownies.



Ogmore Valley Brass Band raised £225.00 holding Christmas

Caroline Brash whose son, Isaac was born with craniosynostosis, raised almost £250 running the Yorkshire Marathon: it was Caroline's first-ever marathon – and possibly her last, as she describes it as one of the toughest and most painful things she's ever done!



Stacey Hoffman and her family and friends have been organising a whole series of events to raise awareness of craniosynostosis, raising £1245.00 for Headlines in the process. Their activities have included sponsored head shaves, kids parties, disco nights and raffles and much more – amazing stuff, Stacey!

Our Superstar Law Firm Fundraisers!



On top of these highlights, we also ran a World Cup sweepstake, invited colleagues to try and Fast for a Day, and held numerous raffles at various events throughout the year.

We're now on a mission to organise another year packed full of fundraising events to raise even more money for 2023!

Looking ahead, upcoming events include an Inter-Office Bike Challenge: in May, each of the firm's UK offices will be competing to see which office can out cycle the others and cycle the furthest in a day. The bikes will be set up in communal areas for colleagues to help cheer each other on. Colleagues will also be able to see in real time how far each office has cycled, helping to further spur on the competitive spirit! We're also organising a Fast for a Day throughout the month of Ramadan. As well as fasting, colleagues will be able to use the day for reflection and to express gratitude by writing down three things they are grateful for, and one thing they would like to improve on.

As well as this, there are a number of colleagues entering marathons later on in the year in support of Headlines, with more raffles being held at a variety of events, another office challenge and plenty more!

Finally, in addition to all of the fundraising activities, The Squire Patton Boggs Charitable Trust has donated £5,000 to Headlines.

We're really proud to have Headlines as the Birmingham office's chosen charity again for 2023, and we're hoping to raise even more money with everyone's continued efforts and support."

Thank you Squire Patton Boggs - Headlines is enormously grateful to you all for your support!

If you work for a company that has a charity of the year scheme, why not nominate Headlines?

Champion in the making

13 year old Owen Tymon-Clydesdale has dreams of making it to the pinnacle of motorsport and following in the footsteps of his F1 idol, Max Verstappen.



Owen also competes in CLUB100, which is the highest level of 'Arrive & Drive' 2-stroke kart racing, and the most prestigious karting championship in Europe.

For the 2023 season, Owen has joined the professional motorsport team, Tooley Motorsport, which will enable him compete at a high level nationally, and gain more experience as well as exposure.

Now he is using his remarkable talent to help Headlines.

As his dad, Paul, explains: "Owen's youngest brother, Ewan, was treated for sagittal craniosynostosis at Birmingham Children's Hospital in 2018. He also has ASD and Burnsie-Butler Syndrome. We're really keen to raise awareness of Headlines and the work it does to support those with rare craniofacial conditions like Ewan. Karting has a huge audience nationally and internationally, and we feel Owen's motorsport success offers a great opportunity and platform to promote Headlines".

The Headlines logo will feature alongside Owen's sponsors over the coming season, as he navigates his way around the circuits. You can follow his progress on Facebook and Instagram via @OWENTC_RACING33

We wish Owen continuing success and have every confidence we'll see him on that F1 podium sometime in the not too distant future!



Last year, we were delighted to learn from one of our members, Claire O'Connor, that she had nominated us as her company's 'Charity of the Year'. Claire works as a solicitor at the Birmingham office of global law firm Squire Patton Boggs. Her son, Leo, was born with metopic craniosynostosis, and his story was featured in Headline News 6.

Over the course of the year, staff at the firm raised an incredible £5,186.50 for Headlines and are now into their second year. We invited Claire and her colleagues to tell us more about what they've been up to.

"The highlights of the past year included a Partner Swap, where Partners at the firm were nominated to swap their day-to-day jobs for one afternoon to take on various roles across the Birmingham office.

The roles ranged from concierge, lift assistant, delivering post, running a drinks trolley, looking after reception and testing the firm alarms. Colleagues then got to vote for which Partners they wanted to see swap their jobs by placing donations in the run up to the big day.

Another highlight was the National Trainee Challenge, where trainee lawyers completed a 16km walk to raise money as part of a national walking challenge involving trainees from all of the firm's UK offices.

Have you visited our online shop?

Headlines products are available on our website, with safe, easy ordering and special deals! Every single purchase you make helps us in our work to support those affected by rare craniofacial conditions.

Our fun and informative book 'Octavia & Henry at their Craniofacial Unit' provides a child-friendly view of what happens in hospital for the treatment of craniosynostosis and features our cuddly soft toy rabbit.

Book & cuddly toy rabbit £5 inc P&P
SPECIAL OFFER: Book + 2 rabbits just £8 inc P&P

Our striking and highly practical branded hessian bag was designed by award-winning Edinburgh University design student Emma Mitchell, whose family are members of Headlines.

Bags £6 each inc P&P
SPECIAL OFFER: 4 bags for £20 inc P&P

Show your support for Headlines with our enamelled pin badges!

Just £3 each inc. P&P

We now have a range of branded clothing in a variety of sizes!

**Cotton t-shirts £10
Sports vests £12
Sports t-shirts £15**

Buy online at www.headlines.org.uk/shop
Delivery normally within 3-4 days of order. All offers subject to availability – UK residents only. For overseas orders, please contact us via info@headlines.org.uk

Get involved

Headlines needs you!

Readers Panel

We have an active panel of members who assist us by reading and assessing our information materials – if you'd like to join, drop an email to info@headlines.org.uk and we will add you to our list.

Become a Trustee

We are always on the lookout for suitably qualified members to join our board of trustees – we're particularly keen to hear from people with a finance/accounting or legal background, but would also love to hear from anyone who feels their skills could help us achieve our future ambitions.

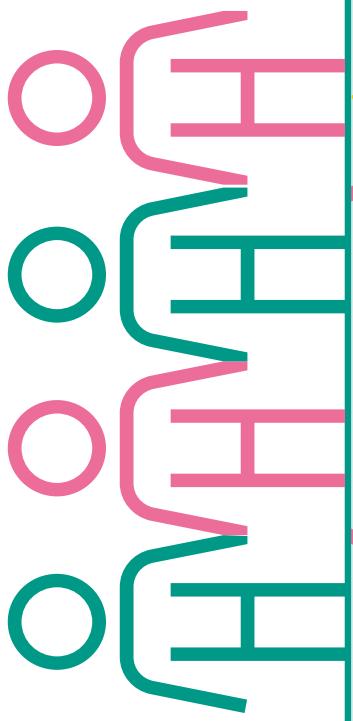
If you're interested, you can download information on what's involved in becoming a trustee on the Charity Commission website www.gov.uk/government/publications/the-essential-trustee-what-you-need-to-know-cc3

Fundraise for us

Headlines relies entirely on donations to fund its work – we receive no government funding. Whether you're having a party, running a marathon or holding a bake sale, every bit you raise can make a real difference. For free, downloadable posters, visit www.headlines.org.uk/fundraising

Take part in research

Taking part in a research study can be a very interesting and rewarding experience – for further information on current studies, check out www.headlines.org.uk/get-involved-in-research



Headlines is the only national charity supporting those affected by craniosynostosis and rare craniofacial conditions. As well as providing information for parents, carers and families, we also offer a confidential helpline and regular newsletters, conference and information days and an annual Family Weekend.

Join us!

Membership is free.
Visit www.headlines.org.uk to join.

Find us on social media:

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 www.headlines.org.uk