HEADLINE NEWS

ISSUE 7

Working towards a world where the physical, psychological and social impacts of craniosynostosis and rare craniofacial conditions are no more

Headlines
Craniofacial Support

In this issue

Get in touch

Headlines Craniofacial Support
Arquen House
4-6 Spicer Street
St Albans
AL3 4PQ

T: 0330 120 0410
E: info@headlines.org.uk

Helpline

For confidential advice and support
T: 07541 106 816
E: helpline@headlines.org.uk

@headlinescraniofacialsupport

@HeadlinesCranio

@headlinescraniofacial

www.headlines.org.uk

From the Chair

Welcome to this year's edition of Headline News.

A lot has happened since our last edition, so we've got a lot to cover! 2022 was an eventful year for the charity and 2023 is looking even more exciting.

We had another wonderful Family Weekend back in September 2022. The weather was great, and it was brilliant to see so many of the children (some of the adults too) pitting their wits against the many obstacles at the Pioneer Centre. Plans are now developing for this year's event. We'll keep you updated.

This past year has also seen the further development of our Research Fund, as trustees made a substantial additional allocation from our reserves to make some important new awards, details of which you can read about later in this issue. Although the current financial climate means we may not be in a position to commit to the same level of funding in the coming year, our ambitions to grow this aspect of our work remain. As Karen points out in her article on our forward strategy later on, we hope that members and other supporters will help us in our efforts to raise funds for this vital task.

In March we held the ACCORD project film premiere at a beautiful old cinema in Oxford. It was great to see so many familiar faces there. As chair of Headlines – but more importantly, as the father of a 16 year old with Saethre Chotzen syndrome - I believe that this project was a really important milestone for the charity: it recognises that we have an obligation to support everyone living with a rare craniofacial condition, not just in childhood but at different life stages, and that developing work for our adult community is a vital priority for the future.

It's so important that as a charity we can communicate our cause effectively to the public. Productions of this standard will really help us raise our profile in the community. Of course, it also gives our members a way of expressing the issues that they have had to deal with throughout their lives and I hope that they will help garner more public support for our cause.

The CranioDads group is also going from strength to strength and growing in numbers. I am looking forward to meeting some of the group at the Daytona Race Track in Milton Keynes in May for our Go-karting Day. It'll be great to see if we have any more budding Formula 1 stars amongst us, like Owen Tymon-Clydesdale, whose story we feature later in this issue!

Also coming up in July is the Big Picnic in Oxford, so come along and help us celebrate our 30th Birthday in style!

Enjoy this edition and I hope to see you at one of the many events soon.

Paul Cornell

Director's Cut

As this magazine arrives through your letterbox – or perhaps in your inbox - it will be almost exactly 30 years since a small group of families first met together to create The Craniofacial Support Group - later to become Headlines Craniofacial Support.

As we learn from our founding Chair, Steve Moody, overleaf, the focus in those early years was, understandably, on the immediate challenges facing families bringing up a child with craniosynostosis: the difficulties in obtaining a diagnosis, finding information about treatment and surgery, and seeking out others who might share similar experiences.

In the intervening decades, access to information and indeed to treatment and surgery here in the UK have undoubtedly improved beyond all recognition. The internet, born in the same year as we were, is now accessible to almost everyone, with social media making it possible for people to connect across the globe. Major new scientific discoveries are enabling us to understand so much more about the genetics of rare craniofacial conditions.

But for all the advances, the need for families and individuals to connect and find support in one another's lived experience has remained unchanged, and it's in this endeavour that Headlines still plays such a vital role. Whether it be through our Family Weekends , where children and families can meet up in a safe and welcoming environment, free from being judged for being 'different', or through the helpline, providing information and a friendly listening ear, the importance of being here is undimmed.

Everyone involved in Headlines today feels enormously proud to be able to carry the baton passed on to us by Steve and our other founding families, continuing the task of connecting members and supporting them at every stage of their journey.

And yet, as children grow up, their needs change – and that's why in this, our anniversary year, we're so pleased to have been able to begin addressing some of the gaps that we know exist in adulthood: the lack of information about some of the issues that may arise in later life - about starting a family, for example. Or finding employment when you have a visible difference resulting from your condition. Or the absence of support groups to prevent the isolation that sometimes accompanies living with a rare condition and not having anyone to talk to about it.

Later in this issue, you can read more about our ACCORD project, in which adult members have been working alongside research psychologists to produce resources to tackle some of these important issues. We know it's only the start of what's needed, but as Headlines moves into its fourth decade with a refreshed forward plan, it is wonderful to feel that we, like our members, are growing up too – and that our mission to support all those affected by craniosynostosis and rare craniofacial conditions throughout their lives is more relevant than ever.

Karen Wilkinson-Bell

Forthcoming events

Dads meet up

Monday 8th May
Daytona Karting, Milton Keynes

Young Persons Network meet up

Saturday 20th May
London

30th Birthday Big Picnic

Sunday 2nd July
Oxford

SkyDive Challenge

Saturday 15th July
Nottingham

Family Weekend

September

How it all began

This year marks 30 years since the creation of The Craniofacial Support Group, which would later become Headlines.

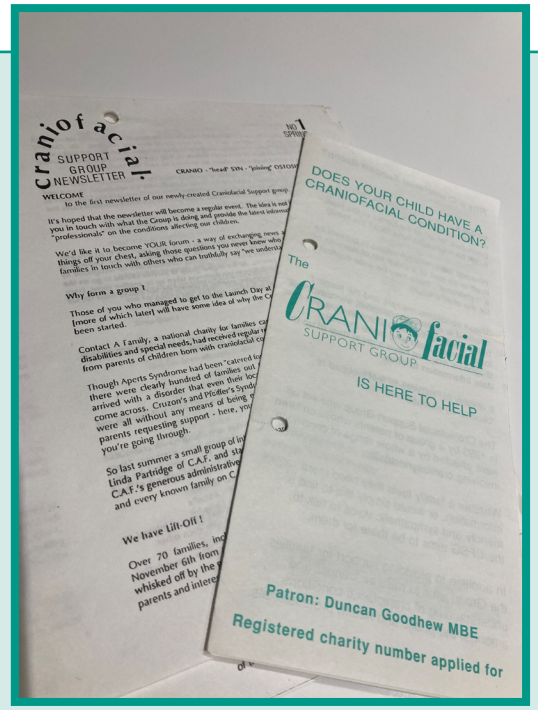
Our founding Chair, Steve Moody, shares his memories of how it all started.

Our first child was born in December 1990 in Leamington Spa. Erica had got pregnant from IVF and subsequently was asked if she'd be prepared to take part in some research into fetal growth rates before birth via weekly ultrasound measurements. That surveillance had shown no abnormalities so we were completely unprepared for being told the day after the birth that our child had a condition called Crouzon syndrome.

The paediatrician who told us said we were very lucky that one of the team involved had seen the condition before, which was very rare, and recognised it. Without that early diagnosis there was serious risk of complications if left untreated.

Naturally we wanted information, to talk to someone - preferably other parents dealing with it - about this brand new situation that had come crashing into our lives without warning.

By chance we lived a half hour or so outside Birmingham where there was one of just 4 supra-regional specialist paediatric craniofacial teams set up to treat children with a wide range of conditions affecting the face, skull and the underlying bone structure. This specialist team were at the Birmingham Children's Hospital, which over the next 10 years or more became the centre of our lives, especially in the first 3 years.



However, we were only getting specialist surgical information generally, with little of the personal support and day to day information that should have been available from meeting other parents dealing with the extraordinary situation we were in.

Erica found an organisation in London called Contact a Family who specialised in supporting individuals and groups working in the rare diseases world. Through them we got contact with a family in Oxfordshire with a Crouzons child of a similar age to ours, and a small London- based group providing peer to peer help and information to parents of children with Apert syndrome, another craniofacial condition we'd never heard of.

Meanwhile, at Birmingham Children's Hospital, we were meeting other parents in a similar position, some of whom had not even been given a name for the condition their child had, let alone a route to contact others dealing with similar problems.

When our child was about two and a half, Contact a Family came to Erica and I with a proposal to fund an initial meeting for a small group of parents of craniofacial children with a view to starting a support group. Clearly this was what was needed from our experiences.

That first meeting was in a hotel in Bar Hill, near Cambridge. Present were as I recall about 5 parents and a couple of CaF representatives. The clear need for a mutually supportive organisation was quickly identified and we all agreed to take it forward.

CaF offered some seed money to get us up and running - £1000 if I recall correctly - and we agreed a committee to take it forward, with me as Chair.

That led to our very first general meeting, in October 1993, at a hotel in Coventry, where a large number of parents, affected children, and young adults with various craniofacial conditions gathered for a very successful day. From that day the Craniofacial Support Group burst into the world.

After some years of successful operation we felt it was time to rename the group. An invitation was made in a newsletter soliciting ideas and 'Headlines' was the obvious winner.

Here we are now, 30 years later, with an amazing and highly successful organisation, members in a number of countries around the world, working to educate professionals working in the field, publishing a bright colourful newsletter, providing individual support and information, getting groups together to share their experiences, everything we could have dreamed of……. and were desperately in need of, all those years ago.

Marching forward: our strategic review

As well as our 30th anniversary, 2023 also marks the final year of Headlines' 2018-2023 strategy. Back in October last year, our trustee board and staff met to review the progress we had made since launching the strategy, and to consider what needs to happen next.

Karen Wilkinson-Bell updates us on the exercise so far.

"The away day in October was an opportunity for the trustees to reflect on our key achievements over the past five years, which include some really important milestones, such as the introduction of the new website, new resources for parents, the launch of a network to support Dads and – most recently – the creation of a Research Fund.

However, it also flagged up areas where we still have a lot to do: improving early diagnosis, and awareness of the condition amongst healthcare professionals outside of the Specialist Craniofacial Units, for example.

Following the board review, Headlines members and external stakeholders (including the Specialist Craniofacial Units and the NHS Specialist Commissioning team) were also invited to offer their thoughts and input, on our direction for the next 3-5 years.

This feedback confirmed that our 3 main strategic priorities – Education & Awareness, Support & Living with the Condition and Research & the Provision of Care - were still valid, but suggested that we need to think about how we tackle a number of new issues within those priority areas.

In particular, members indicated strong support for our efforts to fund research – a new area for us since the 2018-23 strategy was launched. Other points of note were the importance of continuing to campaign for early diagnosis and greater awareness of the condition, and for better access to employment opportunities for adults with craniosynostosis.

Of course, our ability to move things forward rests on our continuing efforts to raise sufficient funds: we are a small and very 'lean' charity (only 2 part-time paid staff, both of whom work from home) and our modest operating costs have helped us remain afloat whilst many other small charities have gone under during the pandemic. However, if we are to realise our longer term ambitions, particularly in relation to research, we need donors who can really help us up our game.

Having taken some time out to revisit the 'big picture', so to speak, we now need to turn our attention to the short term plans that will help us achieve our goals – and I am looking forward to working with the board to do just that in the coming months.

We are enormously grateful to all of those who have taken the time to contribute so far. The charity has travelled a long way over the past five years, and even more exciting times lie ahead!"

Awareness & Education

Raise awareness and educate people to improve public understanding of craniosynostosis and rare craniofacial conditions

Provide information on the condition

- Making sure people understand their condition and have information available to them when they need it
- Working with experts in the conditions to keep the patient information up to date

Raise awareness of the condition and increase public profile

- Making the public aware of the condition and the charity through events, website, newsletters and social media
- Running campaigns to highlight the condition such as Craniofacial Awareness Week

Support & Living with the Condition

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

- Bringing members and families together at regular 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

Living with the condition

- 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
- Working to improve access to employment for those with rare craniofacial conditions

Research & Provision of Care

Support research that seeks to advance understanding, ensure the provision of quality care, and identifies the best treatments for craniosynostosis and rare craniofacial conditions

Advance understanding, improve diagnosis and improve treatments

- Identifying research priorities
- Supporting health professionals and researchers to undertake research and enhance knowledge
- Involving patients in research

Enhance care, improve standards and quality of life for people with the condition

- Bringing health professionals and patients together to discuss needs
- Working with health commissioners and governing bodies to improve access
- Ensuring the views/voices of those living with rare craniofacial conditions are at the heart of decision-making about treatment & care

Family Weekend 2022

September saw us back at the Pioneer Centre in Shropshire for another great weekend of fun. Well over 100 people joined us for a range activities from high wires to raft-building – as well as for a wonderful session with tarantulas and pythons, expertly led by a team from the Dinosaur & Wildlife Education Centre in Stourport.

Trustees Caroline Hilton and Lucy Pearse hosted a discussion for parents on educational needs on Saturday afternoon, and MC Extraordinaire John Connett kept everyone entertained with prize bingo, a Big Quiz and Disco.

Also with us was a group of members from our Young Persons Network who were on hand to speak to parents and other young people about their experiences of living with craniosynostosis.

We are very grateful to all who supported the weekend – and to the Coleman family in particular, whose fundraising efforts once again made it possible to offer all children free places.

We are still finalising arrangements for this year's Family Weekend, but if you and your family are interested in coming along and would like further details, please get in touch with our Administrator, Donna Connett, via **info@headlines.org.uk**

Reaching out: European connections

In 2021, Headlines joined ERN CRANIO, the European Network for rare/complex craniofacial conditions, which comprises of representatives from 35 hospitals across 15 EU/EEA member states along with affiliated partners and patient representatives.

Last November, our Director Karen Wilkinson-Bell attended the Network's annual meeting in Berlin, and met representatives from other patient groups from around Europe. In February, the patient representatives gathered in Rotterdam where they were warmly welcomed by LAPOSA from The Netherlands. Afterwards, we invited them to tell us more about their organisation and the work they do.

Aangenaam Headlines!

My name is Marc Kleinveld and I'm father of a daughter with Apert syndrome, I am the chair of LAPOSAand it is wonderful tointroduce ourselves to you.

LAPOSA is also a patient organisation that represents craniofacial conditions. And we would very much like to get in touch with you and share stories.

The way we, Headlines and LAPOSA, have met is kind of remarkable. Let me explain just a little.

Headlines is also a member of the European Reference Network, called ERN. And what they do is marvellous. They share and combine information, of all participating countries, based on your experiences and feedback on how to get the best care for people with craniofacial conditions, and share them with the surgical staff. The ERN is a talking partner with the surgical staff so that your voice is heard. I find that process

remarkable and wonderful.

So we as LAPOSA also have a representative in the ERN, her name is Mariët Faasse and she met with Karen Wilkinson-Bell, your charity's director. And when the ERN was in Rotterdam, we decided to get together and introduce ourselves.

LAPOSA is a national organisation that has three tasks. Our primary task is organising activities and get togethers for our members. We want to be a community that stands strong together, shares stories and be a place where we feel heard and seen. We call them 'contactdays'.

The second task we have is representing our members' voice with the hospitals. We gather information, experiences and evaluate annually how the process in the hospital is going. This works both ways. The hospital also asks us if we can help them, for example we have co-written the Dutch patient version of the treatment guidelines. This way the patients and parents have the proper information at hand. We have direct contact with the staff.

This is also our third task; getting the right information to the right people. It means the information is readable for the average patient or parent and we can help getting this information to our members and our website. A nice example is that the head of the Craniofacial Department in Rotterdam has now asked doctors to also provide a one-page summary in plain words for us so that we can distribute it.

In the Netherlands we organise multiple contactdays a year. We have day trips or activities for all ages; young families with small children, young people up to 18 years of age and adults from 18 and older. They all have a separate activities.

And then, once a year we have the Family day, a big event with all the members and their family. This is always a fantastic day to see each other again and share stories. Being a small country has its benefits!

This is the first contact we have had and hopefully we can build this up to something more. We will see where it goes from here. Perhaps we can have some exchange of stories in the future?

With warm regards

Marc Kleinveld

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 proofread 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!

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!

Spotlight on: Specialist Speech and Language Therapy

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."

The project has been co-produced with a group of Headlines members who worked with the team from CAR to develop content 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 curls 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 my story beforehand. Their investment in my story and such kindness had a huge impact on me. An incredible experience. Was this the acceptance, hope of being and belonging I had quietly longed for all my life?

It all felt incredibly surreal that day. I felt almost dazed – like being in a full-force gale. Was this a dream? Whilst being filmed I felt real sorrow for those listening. Hearing myself talk about what I went through sounded tragic; what was I putting these poor folk through? My sister was with me that day, which I was so grateful for. I have been acutely aware of the negative impact Crouzon's has had on my family. But maybe this filming day and the research has helped her to have a voice too. These things often have positive ripples that we are not aware of at the time.

The image in my mind straight after the filming was of huge, thick steel doors being swung wide open. The doors of silence burst open; my emotional story in plain sight. It felt like a whole new world of me had been 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.

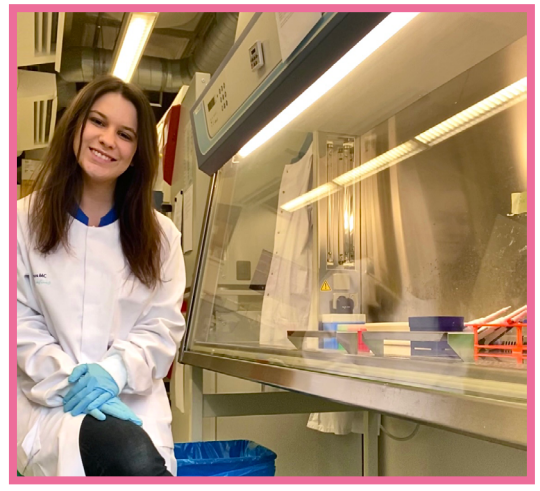
Although the allocation of funds means that we are no longer able to take any further applications this year, we very much hope to be in a position to raise further funds for this vital aspect of our work as a charity as we move forward in 2023 and beyond.

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.

NEUcrest

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.



"As readers of this magazine will know, children with craniosynostosis are born with one or several cranial sutures fused, something which should only happen when the skull stops growing, once a child reaches adulthood.

The fusion of the sutures can affect a baby's vision, breathing, teething and hearing, and may cause increased intracranial pressure which can lead to cognitive impairment.

Children often undergo invasive surgery to reopen the cranial sutures and create space for the brain to grow. In some cases, patients need follow up surgery as the sutures may close again. The continuous closing of the sutures, even after undergoing surgery to reopen them, constitutes a major challenge in treating craniosynostosis.

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.

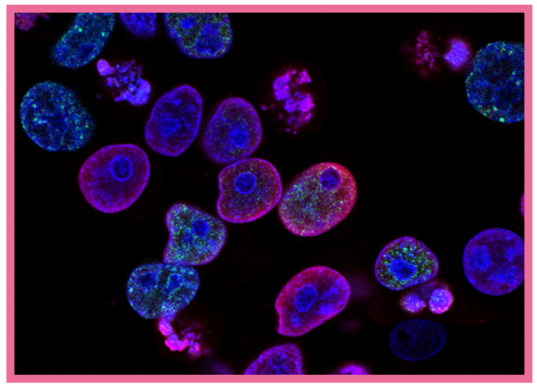
Research in Focus

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."



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 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 craniosynostosis. Frogs, 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!

Ogmore Valley Brass Band raised £225.00 holding Christmas

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

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!

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

Our Superstar Law Firm Fundraisers!

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.

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, from Nuneaton in Warwickshire, has loved motorsport from a very young age. Last year, he ventured into the world of karting and hasn't looked back since. After just 4 months of practice, he set a new track record with the fastest lap ever on the Indy Circuit in the Junior Category at the Daytona Tamworth Circuit, making him a Daytona Junior Superstar.

As well as regular practice sessions, Owen also competes in Daytona's Junior SODI RT8 Championship, which runs monthly . As a result of competing in the Championship, he is automatically included in the SODI World Series (SWS) global amateur karting championship. The SWS culminates with an International Final each year, where the 300 very best drivers worldwide compete in an intense 3-day competition.

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 Burnside-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!

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.

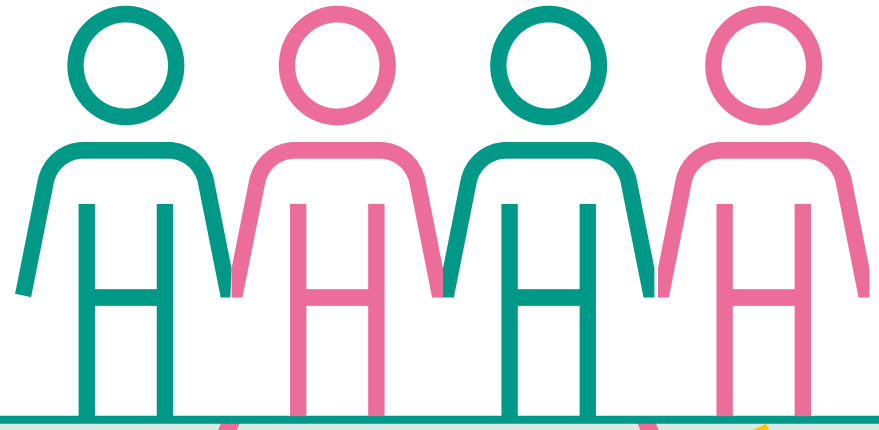
If you're interested, you can download information on what's involved in becoming a trustee on the Charity Commission website www.gov.uk/government/publications/the-essential-trustee-what-you-need-to-know-cc3

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:

@headlinescraniofacialsupport

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@headlinescraniofacial

www.headlines.org.uk

Headlines
Craniofacial Support