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

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Disclaimer

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.

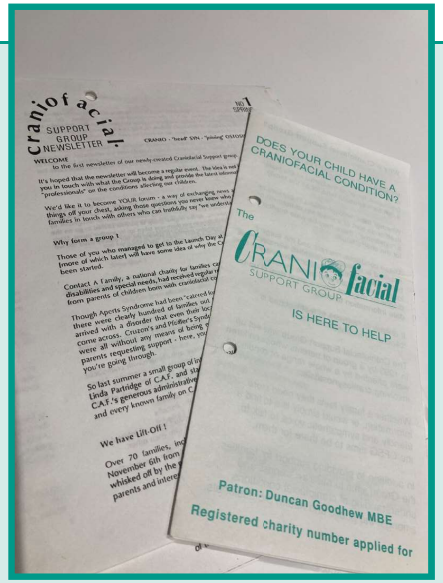
Our founding Chair, Steve Moody, shares his memories of how it all started.

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