

A stylized profile of a human head facing left, composed of numerous concentric, wavy teal lines of varying shades, creating a layered, topographical effect. The lines are more densely packed in the lower half, suggesting a jawline and neck.

Annual Report

2023-2024

The Executive Committee, which is comprised of the Trustees, are pleased to present their report and accounts for the year ended 31 March 2024.

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Headlines Craniofacial Support
Registered charity numbers: 1058461 and SC050262



From the Chair of Trustees

Sadly, this will be my last Annual Report as Chair, as my 3 year term ends this year. However, I am delighted to be handing over to Lucy Pearce, who has done such a great job as Vice Chair, and will take up her new role at the AGM in September.

It has been yet another very busy year for the charity, not only celebrating its 30th birthday but also launching a number of important new initiatives.

I have been especially proud to have been involved in developing our work for dads, and was pleased to join others for our first-ever in person event early last summer. The video that we launched in September has been extremely well-received, and we are also looking forward to the publication of a new booklet to accompany it. The 2 year grant we received from Pears Foundation to support this important aspect of our work has been very much appreciated.

As ever, our Family Weekend was a roaring success, with over 100 people joining us in Shropshire last September.

Elsewhere, our Director and trustees were active in promoting our work at various events in the UK and Europe: I should pay special tribute to our youngest trustee, Charlotte Ashby, who spoke powerfully about her experience of living with a rare craniofacial condition at the international scientific meeting of NEUcrest in France in March. It has been especially exciting to see other young adults who have grown up with Headlines taking seats on our board alongside Charlotte this year – we are very fortunate indeed to have such a dedicated and enthusiastic group to lead our charity forward. I would like to thank all of them for their fantastic support over the last three years and also Karen Wilkinson-Bell our Charity Director and Donna Connett for



making everything happen. They really are a 'Dynamic Duo', and I am truly appreciative of all of their help.

Finally, as always, we are incredibly grateful to everyone who has made a donation, however small, to support our work over the past year. As a very small charity, we really do appreciate every single penny. A huge thanks to you all.

Paul Cornell

Our objectives and activities

Headlines is the leading UK charity supporting people with craniosynostosis and other rare craniofacial conditions.

Our vision is for a world where the physical, psychological and social impacts of craniosynostosis and rare craniofacial conditions are no more.

Our current objects, as set out in our Constitution, are to:

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

We seek to achieve this in a variety of ways, including:

- the provision of a confidential helpline
- producing newsletters, an annual magazine and a range of information leaflets
- arranging events to bring those living with rare craniofacial conditions together, including an annual Family Weekend
- facilitating support groups
- organising conferences and information days
- working with the NHS and others to improve care for those living with craniosynostosis
- supporting innovative research projects that address the Top Ten Priority Research Questions for craniosynostosis.

Public benefit

The Trustees have complied with their duty in Section 17 of the Charities Act 2011 to have due regard to the guidance from the Charity Commission. The benefit to the public is manifestly demonstrated in the activities and achievements highlighted in this report.

Structure, governance and management

Headlines Craniofacial Support (previously known as The Craniofacial Support Group), is an unincorporated association, and a registered charity in England and Wales (no. 1058461) and Scotland (no. SCO50262).

The charity is governed by its Constitution, adopted 24 March 1996, amended on 24 April 2005 and 22 September 2018, and as amended by resolution on 29 June 2019. The charity was first registered with the Charity Commission for England & Wales in 1996 and with the Office of the Scottish Charity Regulator in 2021.

Anyone affected by or with an interest in craniosynostosis and rare craniofacial conditions can apply to become a member of the charity. The members of the charity elect the Executive Committee (Board), who are the Trustees of the charity, at the Annual General Meeting (AGM). Board members generally serve for a period of 5 years. The Board comprises not less than 5 and not more than 15 members. Existing members of the Board may co-opt new members to the Board who serve to the following AGM in the event of a casual vacancy.

The Trustees, all of whom are volunteers, are responsible for the overall strategic direction of the organisation. In addition to the AGM, the Board meets on at least a quarterly basis, including through video conferences.

The charity employs one part-time Charity Director and one part-time Administrator. New Trustees are recruited and appointed by the Board using a process of applications, interviews and “taster” Board meetings.

The Trustees have adopted the new Charity Governance Code for charities operating in England and Wales which was launched in July 2017.

Key achievements and performance in the year



Over
70 members
joined us for a
Big Picnic in Oxford to
celebrate our
30th Birthday

We launched
a **brand
new video**
for dads



We held another
fantastic Family
Weekend with over
100 people
joining us at
the Pioneer Centre
in Shropshire in
September



Our Young Person's
Network held
5 MeetUps
over the course
of the year



Our helpline
responded to
91 enquiries
over the course
of the year



We published a
new booklet
for parents
to support them
when their child is
undergoing surgery in
the early years

We ran our
first-ever
in person
event for
dads, at Daytona
Racing in Milton
Keynes



The number
of members
rose to 2465, an
increase
of 6%
on 2023-24



Work began on
2 new
projects
funded through the
Headlines Research
Fund

Financial review

The receipts and payments accounts for the year ended 31 March 2024 show receipts of £98,331 (2023: £105,773) and expenses of £106,512 (2023: £123,596), resulting in a deficit of £15,916 (2023: deficit of £17,823). As at 31 March 2024, the charity had cash balances of £178,052 (2023: £193,967) of which £21,695 (2023: £38,474) related to restricted funds.

The overall deficit for the financial year was lower than budgeted by the Board, and moderately lower than last year's deficit. As we have outlined in prior annual reports, Headlines' trustees have decided to expand the charity's activities into supporting research into craniosynostosis, both directly (using our own reserves) and through seeking funding from external sources (these go through 'Restricted Funds'). Given a sizeable underspend in one of the major research projects, and delays to the start or completion of others, the deficit for the financial year is lower than expected.

In terms of 'Unrestricted' income and expenses, there is a very small surplus for the year of £863 (2023: deficit of £20,688). This reflects an increase in Unrestricted income of 50% (primarily driven by a 43% increase in donations, higher income from the Family Weekend, interest income and merchandise sales), partially offset by a 13% increase in unrestricted expenses.

We are extremely grateful to our major donors this year, including the ongoing support of Squire Patton Boggs and their Charitable Trust. Other notable donors include Premier Foods Ltd, the Davies Foundation and Mazars Charitable Trust. In addition, we had a generous donation from Dormole Ltd, which the trustees decided to use to provide free child places at the Family Weekend. Our fundraisers have also been out in force again this year and included Paul Prentice, whose sales of 3-D Star Wars Shoretroopers continues to bring in significant funds, a Skydive led by TeamLewis and the Connett family, a gruelling 4x4x48 challenge undertaken by one of our trustees, David and his team, with lots of people raising money through runs, mountain climbs, campouts, haircuts etc. We are sincerely grateful to all of our fundraisers, individual and corporate donors. We are also appreciative of those who directed support to Headlines in memory of their loved ones.

We received £20,431 this year in Restricted Funds including a further £8,500 from the Pears Foundation to support events for the 'Dads Network'. We also received £10,931 from the VTCT Foundation to fund a research project being run by Birmingham Children's Hospital looking into developmental outcomes for children with single-suture craniosynostosis. We noted the latter project in last year's report as being funded by Headlines directly, but during this financial year, the VTCT Foundation kindly agreed to fund it. We are extremely grateful to both the VTCT Foundation and the Pears Foundation for their ongoing support of our work, as well as to the Neighbourly Ltd team linked with the Southern Co-op for £1,000 to put towards expenses for the Family Festival Day we are holding in the summer of 2024.

Expenditure within Restricted Funds was £16,752 (2023: £43,857). The majority of expenses in Restricted Funds last year related to the ACCORD (Adults with Craniosynostosis: Creating Online Resources to reduce Distress) project. This project generated much lower expenses in this financial

year (£6,164), compared to last and it was formally completed this year, resulting in an underspend of £7,735 which was returned to the VTCT Foundation. Other expenses within Restricted Funds primarily related to the Dads network, and the start of the Birmingham Children's Hospital project mentioned above.

In addition, as set out in the Statement of Assets and Liabilities below, Headlines has 'Committed Expenditure' to fund further research. The majority of this relates to a project being run by University College London which is aiming to establish a screening pipeline for cranial bone pathology using patient stem cells (£40,407). We reported on this in last year's annual report, but the start of the project was delayed and expenses have not yet been incurred.

Our reserves policy is currently set to cover 12 months of unrestricted expenses. Taking account of the committed expenditure, we are broadly in line with this.

The Trustees are confident that the charity has sufficient funds to continue to operate and meet our liabilities as they fall due, over the next 12 months (from the date of this report). Therefore, the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

Risk

The Trustees consider risks to the charity regularly and the board reviews the key risks at least annually. Consistent with our scale and obligations, our aim is to mitigate risk whilst remaining an agile, entrepreneurial, mission- and values-based organisation.

Serious incidents

There were no serious incidents to report during the year.

Statement of trustees' responsibilities

The Trustees are responsible for preparing this report and financial statements in accordance with applicable law and regulation. The Trustees have prepared the annual report in accordance with the Charities (Accounts and Reports) Regulations 2008 but have taken advantage of the provisions for smaller charities to prepare receipts and payments accounts.

Receipts and Payments

for the year ended 31 March 2024

	Unrestricted 2024 £	Restricted 2024 £	Total 2024 £	Unrestricted 2023 £	Restricted 2023 £	Total 2023 £
Receipts						
Donations, including gift aid	65,723	-	65,723	45,900	-	45,900
Charitable activities (eg Family Weekend)	8,468	-	8,468	4,839	1,000	5,839
Grant – Pears Foundation	-	8,500	8,500	-	8,500	8,500
Grant – VTCT Foundation (Research Project)	-	10,931	10,931	-	44,222	44,222
Small Grants	-	1,000	1,000	-	-	-
Merchandise	766	-	766	293	-	293
Bank interest and sundry income	2,943	-	2,943	1,019	-	1,019
	77,900	20,431	98,331	52,051	53,722	105,773
Payments						
Events - Family Weekend	19,103	-	19,103	17,235	1,111	18,346
ACCORD research	-	6,164	6,164	-	40,493	40,493
Birmingham Hospital research	-	1,822	1,822	-	-	-
Dads Network	-	7,437	7,437	-	-	-
Other Events	1,010	-	1,010	354	-	354
Information Leaflets	-	637	637	-	1,500	1,500
Oxford univ. research project	3,098	-	3,098	5,163	-	5,163
Digital Capabilities	-	692	692	-	753	753
Welfare Grants	700	-	700	250	-	250
Salary and related costs	47,329	-	47,329	44,961	-	44,961
Newsletters & website	4,525	-	4,525	4,052	-	4,052
Office Running costs	4,377	-	4,377	4,039	-	4,039
Fundraising costs	6,097	-	6,097	1,841	-	1,841
Legal / professional fees	2,610	-	2,610	695	-	695
Independent Examiner	650	-	650	550	-	550
Trustee meeting costs and AGM fees	261	-	261	599	-	599
	89,760	16,752	106,512	79,739	43,857	123,596
Net Receipts / (Payments) in the year	(11,860)	3,679	(8,181)	(27,688)	9,865	(17,823)
Transfer of Restricted to General Funds	12,723	(12,723)	-	7,000	(7,000)	-
Grant repaid	-	(7,735)	(7,735)			
Net Receipts / (Payments) in the year after Transfer	863	(16,779)	(15,916)	(20,688)	2,865	(17,823)
Balance at 1 April 2023	155,494	38,474	193,967	176,182	35,609	211,790
Balance at 31 March 2024	156,357	21,695	178,052	155,494	38,474	193,967

Notes:

1. The Receipts and Payments Accounts of the charity are prepared on a cash accounting basis.
2. Restricted Funds at 31 March 2024 consists of the remainder of grants received from the VTCT Foundation for the Birmingham Hospital longitudinal analysis project (£9,109), for upgrading our Digital Capabilities (£3,589), and for further work on Patient Information Leaflets (£1,198), from the Pears Foundation for the Cranio Dads Network (£6,799), and from the Neighbourly / Southern Co-op (£1,000).
3. Transfers of £12,723 from Restricted Funds to Unrestricted Funds were made in the year (2023: £7,000), these primarily related to work undertaken by Headlines staff in relation to the ACCORD research project being undertaken with UWE, and in supporting the Dads' Network.
4. Grants repaid of £7,735 represents the return to the VTCT Foundation of the underspend on the ACCORD research project.
5. Grants received from the VTCT Foundation in the financial year (£10,931) relates to the research project with Birmingham Hospital to undertake a 10-year longitudinal analysis into developmental outcomes for children with single-suture craniosynostosis. In the prior accounting year, to 31 March 2023, grants received from the VTCT Foundation related to the ACCORD research project.
6. One trustee was reimbursed travel costs of £116 related to the management and governance of the charity in the year (2023: £0)
7. There were donations from Related Parties of £930 (2023: £1,220).
8. Other events for the year included costs associated with the Young Persons' Network and for the 30-year anniversary picnic in Oxford.
9. In the year ended 31 March 2024, we provided welfare grants of £700 (2023: £250).
10. Fundraising Costs includes fees for fundraising events held during this financial year and fees paid to third party fundraising platforms and on merchandise sales.

Statement of assets and liabilities

as at 31 March 2024

	Unrestricted 2024 £	Restricted 2024 £	Total 2024 £	Unrestricted 2023 £	Restricted 2023 £	Total 2023 £
Cash at Bank	156,357	21,695	178,052	155,494	38,473	193,967
Non-monetary Assets						
Computer equipment, at estimated net book value	-	-	-	-	-	-
Expenses paid in advance	-	100	100	-	-	-
Amounts due	-	-	-	-	-	-
Non-monetary Liabilities						
Income received in advance	(1,380)	-	(1,380)	-	-	-
Salaries and related costs	(2,228)	-	(2,228)	(1,868)	-	(1,868)
Unpaid expenses	(918)	(2,733)	(3,651)	(1,735)	(14,405)	(16,140)
Independent examination fee	(750)	-	(750)	(650)	-	(650)
Committed expenditure						
Grants awarded awaiting payment	(41,439)	-	(41,439)	(58,419)	-	(58,419)

Notes:

1. Committed expenditure from Unrestricted funds relates to commitments we have made to fund 2 research projects, but where the expenses have not occurred in this financial year. Unrestricted funds also includes designated funds of £1,050 for Welfare Grants (2023: £1,750).
2. Non-monetary assets comprise expenses paid in advance for events occurring after the end of the financial year.
3. Non-monetary liabilities represent certain expenses paid after 31 March 2024, but which are with respect to the financial year ended 31 March 2024, including expenses related to salary costs (such as payments to HMRC) and other expenses where invoices had not been received prior to the end of the financial year. In addition, £1,380 of income had been received before the end of the financial year, with respect to events occurring in the next financial year (2023: £0).

The accounts on pages 10-12 were approved by the Board of Trustees on 23 July 2024 and signed on their behalf by:



Chair of the Board of Trustees

Independent examiner's report

To the Trustees of Headlines Craniofacial Support

I report to the trustees on my examination of the accounts of Headlines Craniofacial Support (charity registration no.1058461/SC050262) for the year ended 31 March 2024 which are set out on pages 10 to 12.

Responsibilities and basis of report

As the trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 (the '2005 Act'), the Charities Accounts (Scotland) Regulations 2006 (as amended), and the Charities Act 2011 ('the 2011 Act').

You are satisfied that your charity is not required by charity law to be audited and have chosen instead to have an independent examination.

I report in respect of my examination of the Trust's accounts carried out under section 44 (1) (c) of the 2005 Act and section 145 of the 2011 Act. In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention giving me cause to believe that in any material respect:

- accounting records were not kept as required by section 44 (1) (a) of the 2005 Act and Regulation 4 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and section 130 of the 2011 Act; or
- the accounts do not accord with those records; and
- the accounts do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Nicola Anderson FCA FCIE
Chartered Accountant and
Independent Examiner

189 Baldwins Lane
Croxley Green
Rickmansworth
Herts. WD3 3LL

Dated: 24 July 2024



Reference and administrative details

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E: info@headlines.org.uk
Charity no: 1058461 / SC050262

Trustees

The Trustees who served in the year and up to the date of this report were:

Charlotte Ashby
Neil Bowyer (Appointed 16 September 2023)
David Coleman
Paul Cornell (Chair)
Charles Edwards (Treasurer)
Dr Caroline Hilton (Secretary)
Zoe Hilton-Webb (Appointed 27 January 2024)
Mark Lindfield (Appointed 27 January 2024)
Laura Melles (Appointed 27 January 2024)
Dr Mehran Moazen
Lucy Pearse
Darren Sloan
Richard Williams (Appointed 27 January 2024)

Patron

Professor Andrew Wilkie FMedSci FRS

Bankers

CAF Bank Ltd, 25 Kings Hill Avenue, Kings Hill, West Malling, Kent ME19 4JQ

Independent Examiner

Nicola Anderson FCA, 189 Baldwins Lane, Croxley Green, Herts., WD3 3LL

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



@HeadlinesCranio



@headlinescraniofacial



www.headlines.org.uk

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