

Annual Report

2022-2023



The Executive Committee, which is comprised of the Trustees, are pleased to present their report and accounts for the year ended 31 March 2023.

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Headlines Craniofacial Support
Registered charity numbers: 1058461 and SC050262



From the Chair of Trustees

This is my second annual report as Chairman of Headlines and it's great to report that even in the face of the challenging economic pressures that we have all been experiencing, the charity has been resolute in sticking to its aims and objectives.

The Helpline is still going strong and fielding an increasing number of calls. The quality of our magazines, newsletters and leaflets continues to get better and better, in turn strengthening our reputation and helping our members even more.

This year, we produced a new series of films as part of the ACCORD project: they help highlight the issues that many of our members and their families face in their day-to-day lives. We also committed a staggering £58,000 from our reserves to fund new research projects, and look forward to reporting back on these in the near future.

Maintaining sustainability is difficult for any small charity and I would really like to thank everyone who has contributed via sponsorship or donations for all their support. We will never take this for granted.

Having successfully navigated our first 30 years, we are all looking forward to carrying on the good work into our fourth decade with renewed enthusiasm. Thank you to all trustees, staff and volunteers for all their unfaltering support and hard work.

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

We saw growth of

20%

across our social media channels



We distributed

2,500



copies of Headline News to members & supporters

We gained

104

new members, that's a total number of 2330 members



3

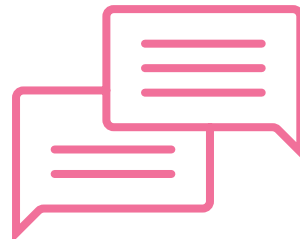
European events attended



Our helpline handled

86

enquiries



We awarded

£250

in Welfare Grants

We welcomed

125

people to our Family Weekend

We committed

£58,000

from our reserves to fund new research projects

We produced **5** new videos and a new booklet for adults with craniosynostosis



7

get-togethers were hosted by our Young Persons Network

We secured

£8,500

to support the development of our new network for dads



“The ACCORD project motivated me to share my experiences of living with craniosynostosis, probably for the first time. Getting to know other people with the condition and hearing their stories, even though our experiences have been different, has been so inspiring”



The receipts and payments accounts for the year ended 31 March 2023 show receipts of £105,773 (2022: £112,841) and expenses of £123,596 (2022: £79,947), resulting in a deficit of £17,823 (2022: surplus of £32,894).

As at 31 March 2023, the charity had cash balances of £193,967 (2022: £211,791) of which £38,474 (2022: £35,609) related to restricted funds.

The deficit for the financial year followed several years of surpluses. Headlines accounts are prepared on a 'cash accounting' basis, which can result in timing mismatches – monies may be received in one financial year, but the expenses incurred in subsequent years. This can result in some volatility, with one year showing a larger surplus, and the following year(s) a larger deficit, than would be the case under 'accruals' accounting. This timing mismatch partially explains the deficit for the year. Another driver was an expanded Family Weekend and some increases in other expenses (e.g. salaries and office running costs).

As indicated in last year's report, Headlines has now begun to support and, in some cases, to fund, various research projects. One major piece of work we have been able to progress this year is the ACCORD (Adults with Craniosynostosis: Creating Online Resources to Reduce Distress) project led by the Centre for Appearance Research at the University of the West of England (UWE), which is kindly funded by the VTCT Foundation. The project aimed to improve the information and psychological support available to adults living with craniosynostosis in the UK. During this financial year, we received the second and final tranche of funding from the VTCT Foundation for the project.

Other research projects are being funded by Headlines' own funds, a deliberate decision on the part of the Board of Trustees to utilise Headlines' reserves. Research costs during this financial year include support for a project run by a Specialist Speech and Language Therapist at the University of Oxford to research language and communication in children with non-syndromic sagittal synostosis.

As set out in the Statement of Assets and Liabilities below, Headlines has also 'Committed Expenditure' to fund further research. As well as funding the remainder of the project with the University of Oxford, we have agreed to fund a major project being run by Kings College London and Erasmus Medical Centre in Rotterdam which is looking to establish a screening pipeline for cranial bone pathology using patient stem cells (£44,907) and a piece of work being led by Birmingham Children's Hospital with support from Alder Hey Hospital to undertake a 10 year longitudinal analysis of developmental outcomes for children with single-suture craniosynostosis (£10,931). The Trustees have also 'designated' £1,750 for welfare grants for the new financial year (£2,000).

As well as the funding from the VTCT Foundation for the ACCORD project detailed above, we also received a grant from the Pears Foundation to support the development of our new Dads Network. We are hugely grateful to both organisations for their support of our work.

In addition, the generosity and fundraising of the Coleman family and the Co op Neighbourly Fund enabled us to provide free places for children at the Family Weekend again this year.

Unrestricted donations declined by 25% this year, partly reflecting timing mismatches from fundraising events delayed by the pandemic, the funds for which had been received in prior years.

We are extremely grateful to our major donors this year, which included the Ladies Section at Henbury Golf Club, Scannell Management, Just Desserts in Yorkshire, and the Birmingham office of law firm Squire Patton Boggs and its charitable foundation. Other notable donors and fundraisers include Paul Prentice, whose Star Wars Shoretrooper project continues to bring in significant funds for us, Stacey Hoffman who raised £1,245 with her family and friends and Kev Foley, who ran the Great North Run.

We would like to thank all of our fundraisers, individual and corporate donors, along with those who directed support to Headlines in memory of their loved ones.

Our reserves policy is currently set to cover 12 months of unrestricted expenses. Taking account of our committed expenditure, we remain 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 2023

	Unrestricted 2023 £	Restricted 2023 £	Total 2023 £	Unrestricted 2022 £	Restricted 2022 £	Total 2022 £
Receipts						
Donations, including gift aid	45,900	-	45,900	61,280	-	61,280
Charitable activities (eg Family Weekend)	4,839	1,000	5,839	3,548	3,000	6,548
Grant – Pears Foundation	-	8,500	8,500	-	-	-
Grant – VTCT Foundation (Research Project)	-	44,222	44,222	-	44,223	44,223
Merchandise	293	-	293	449	-	449
Bank interest and sundry income	1,019	-	1,019	341	-	341
	52,051	53,722	105,773	65,618	47,223	112,841
Payments						
Events – Family Weekend	17,235	1,111	18,346	8,627	2,889	11,516
ACCORD research project	-	40,493	40,493	-	13,093	13,093
Other Events	354	-	354	304	-	304
Information Leaflets	-	1,500	1,500	-	1,143	1,143
Oxford univ. research project	5,163	-	5,163	-	-	-
Digital Capabilities project	-	753	753	-	3,993	3,993
Welfare Grants	250	-	250	750	-	750
Salary and related costs	44,961	-	44,961	39,383	2,890	42,273
Newsletters & website	4,052	-	4,052	400	-	400
Office Running costs	4,039	-	4,039	3,436	-	3,436
Fundraising costs	1,841	-	1,841	2,097	-	2,097
Legal and professional fees	695	-	695	217	-	217
Independent Examiner	550	-	550	450	-	450
Trustee meeting costs and AGM fees	599	-	599	275	-	275
	79,739	43,857	123,596	55,939	24,008	79,947
Net Receipts / (Payments) in the year	(27,688)	9,865	(17,823)	9,679	23,215	32,894
Transfer of Restricted to General Funds	7,000	(7,000)	-	4,000	(4,000)	-
Net Receipts / (Payments) in the year after Transfer	(20,688)	2,865	(17,823)	13,679	19,215	32,894
Balance at 1 April 2022	176,182	35,609	211,790	162,503	16,394	178,896
Balance at 31 March 2023	155,494	38,474	193,967	176,182	35,609	211,790

Notes:

1. The Receipts and Payments Accounts of the charity are prepared on a cash accounting basis.
2. Restricted Funds at 31 March 2023 primarily consists of the remainder of grants received from the VTCT Foundation for the ACCORD Research Project being undertaken with UWE (£24,858), for upgrading our Digital Capabilities (£4,280), and for further work on Patient Information Leaflets (£1,835), and from the Pears Foundation for the Cranio Dads Network (£7,500).
3. Transfers of £7,000 from Restricted Funds to General Funds were made in the year (2022: £4,000), these related to work undertaken by Headlines staff in relation to the ACCORD Research Project being undertaken with UWE.
4. No Trustees were reimbursed travel costs related to the management and governance of the charity in the year (2022: £0)
5. There were donations from Related Parties of £1,220 (2022: £1,342).
6. Other events for 2022 included costs associated with the Young Persons' Network.
7. In the year ended 31 March 2023, we provided welfare grants of £250 (2022: £750).
8. 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

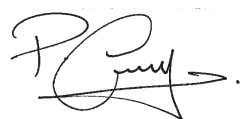
as at 31 March 2023

	Unrestricted 2023 £	Restricted 2023 £	Total 2023 £	Unrestricted 2022 £	Restricted 2022 £	Total 2022 £
Cash at Bank	155,494	38,473	193,967	176,182	35,609	211,790
Non-monetary Assets						
Computer equipment, at estimated net book value	-	-	-	-	183	183
Expenses paid in advance	-	-	-	-	-	-
Amounts due	-	-	-	-	-	-
Non-monetary Liabilities						
Salaries and related costs	(1,868)	-	(1,868)	(2,073)	-	(2,073)
Unpaid expenses	(1,735)	(14,405)	(16,140)	(675)	(4,088)	(4,763)
Independent examination fee	(650)	-	(650)	(550)	-	(550)
Committed expenditure						
Grants awarded awaiting payment	(58,419)	-	(58,419)	(8,799)	-	(8,799)

Notes:

1. Committed expenditure from Unrestricted funds represents grants awarded by Headlines for 3 research projects. Unrestricted funds also includes designated funds of £1,750 for Welfare Grants (2022: £2,000).
2. Non-monetary assets comprise the estimated value of the charity's equipment (such as a computer).
3. Non-monetary liabilities represent certain expenses paid after 31 March 2023, but which are with respect to the financial year ended 31 March 2023, 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.
4. Committed expenditure relates to commitments we have made to fund research projects, but where the expenses have not occurred in this financial year.

The accounts on pages 10 to 12 were approved by the Board of Trustees on 10 July 2023 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 2023 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



Reference and administrative details

Registered office and administration address

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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
David Coleman (appointed 30 January 2023)
Paul Cornell (Chair)
Charles Edwards (Treasurer)
Barry Fletcher (resigned 17 September 2022)
Dr Caroline Hilton (Secretary)
Lucy Pearse (appointed 2 May 2022)
Dr Mehran Moazen
Darren Sloan

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