# Annual Report & Accounts

2024 - 2025



## Annual Report and Accounts

The Executive Committee, which is comprised of the Trustees, are pleased to present their report and accounts for the year ended 31 March 2025.

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## From the Chair of Trustees

This is my first Annual Report as Chair of Headlines, and I am enormously proud of what the charity has achieved over the past 12 months.

We saw the completion of the first external project funded through the Headlines Research Fund—an important milestone that highlighted the value of investing in research to provide answers to the many questions we have about the impact and treatment of the conditions we support.

In September, we were delighted to host the firstever conference for our Young Persons Network (YPN) at UCL in London. The event was led by and for YPN members, including several trustees who have themselves grown up with Headlines.

The previous month, 110 individuals and families enjoyed some late summer sunshine at our Family Weekend in the Peak District. Post-event feedback reminded us how important it is to bring families together to connect with others who share the unique challenges of living with craniofacial conditions. It remains as vital today as it was

when we were first established 30 years ago.

Another milestone came in the autumn, with the transition of Hannah's Fund to Headlines. This important step will extend the support we offer by providing access to counselling and psychotherapy.

Leading a small charity that is entirely reliant on voluntary donations and the goodwill of its members and supporters can be challenging: our staff team - Karen and Donna - continue to be the driving force to our charity work. Their tenacity and dedication to ensure the needs of our community are heard and met is greatly appreciated, thank you both. We are also incredibly fortunate to have a board of trustees who give so generously of their time.

I am especially grateful to our outgoing Chair, Paul Cornell, for agreeing to stay on as Vice Chair while I navigated this year's transition. We are also deeply indebted to our wonderful Treasurer, Charles Edwards, who will retire at the next AGM after eight years of outstanding service. He will be sorely missed. We extend our appreciation also to Darren Sloan who is stepping back from the board after five years of dedicated service, offering strategic thinking, safeguarding, technology and website development support to the charity.

Finally, I would like to thank everyone who has supported our work over the past twelve months, either through likes and shares on social media, engaging with our many events across the year or through building connections and support networks. There have been some incredible fundraising efforts this year despite the challenging climate we currently face. Without you, none of what we do would be possible.

Lucy Pearse



## 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



#### Support

We welcomed another 110 people to our annual Family Weekend at Mount Cook Adventure Centre in the Peak District.

We took over the co-ordination and administration of Hannah's Fund, set up by the family of the late Hannah Lindfield, offering access to talking therapies for those with craniosynostosis and their families.

Our Young Person's Network hosted their first-ever conference at UCL in London.

We handled 80 enquiries though our confidential helpline.

We welcomed another 85 people into membership, bringing the total number of members to 2571 at the end of the year.

We published a new information leaflet for dads, to accompany the video we produced last year.



#### Research

The first external project funded through the Headlines Research Fund was completed: the study, led by Dr Jo Horton from Birmingham Children's Hospital with colleagues from 3 of the NHS Specialist Craniofacial Unit, explored developmental outcomes for children with single suture craniosynostosis from birth to 10 years old.



# Fatebook Fatebook

#### Education & awareness

We presented at the Annual Scientific Meeting of the British Association of Oral & Maxillofacial Surgeons (BAOMS) in Oxford.

We distributed 2,600 copies of our annual magazine Headline News.

We produced a new leaflet for the Specialist Units and other settings such as GP practices and non-specialist hospitals giving information on what we do.

Our social media channels grew by an average of 15% over the course of the year.

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## **Financial Review**

The receipts and payments accounts for the year ended 31 March 2025 show receipts of £124,983 (2024: £98,331) and expenses of £113,999 (2024: £106,512), resulting in a surplus of £10,984 (2024: deficit of £15,916). As at 31 March 2025, the charity had cash balances of £189,036 (2024: £178,052) of which £28,199 (2024: £21,695) related to restricted funds. Headlines adopts 'cash' accounting.

There were two primary reasons why we had a surplus for the year. Firstly, the trustees of Hannah's Fund (charity number 1175857) decided to close that charity and transferred their remaining funds to Headlines (£22,615). This balance is shown within the Donations line in the Receipts & Payments accounts below, and is a 'Restricted Fund', as the trustees of Headlines have agreed to use those funds to offer access to counselling and psychotherapy for people with craniosynostosis and their families, objectives that are consistent with those of Hannah's Fund.

The second main reason for the surplus was that although one of the major research projects being funded by Headlines was largely completed in the 2024/25 financial year, we had not received invoices to pay the grant to the relevant university (see 'Grants awarded awaiting payment' in the Statement of Assets and Liabilities below). 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 this, the trustees of Headlines had budgeted for a large deficit this financial year, but because of the delay in being invoiced for one of the research projects, combined with the receipt of monies from Hannah's Fund, we have ended up with a surplus.

In terms of 'Unrestricted' income and expenses, there is a small surplus for the year of £4,480 (2024: surplus of £863). This reflects an increase in Unrestricted income of 9% (primarily from higher donations), partially offset by a 4% increase in unrestricted expenses.

We are extremely grateful to our major donors this year, in particular the ongoing generosity of The Kilroot Foundation. Other notable donors include Aldermore Bank and the TK Maxx and Homesense Foundation. In addition, many thanks are due to Paul Prentice, who continues to donate the proceeds of his 3-D Star Wars Shoretroopers, and to the Beardmore family and their friends who raised significant funds, which the trustees have designated to support future family events.

For the first time this year we also had a runner in the London Marathon: many congratulations to Thomas Sole, we are very grateful for his fundraising efforts. Other fundraisers have also been out in force again - too many to mention all, but these included Abbi and Steve Woodley (Family Fun Day), Victoria Ward (Great South Run), the Pitt family (Darts tournament and Aperts Awareness Month fundraiser), Ellie Murrins (50kms in November) and Sritika Kinnear (Half Marathon). Huge thanks to all of our runners, climbers, sky divers, and campers - we really do appreciate all of your efforts. We are also appreciative of those who directed support to Headlines in memory of their loved ones.

We received £39,788 this year in Restricted Funds (2024: £20,431). Receipts this year included £22,615 received from Hannah's Fund (see above) along with £468 of related donations, so a total of £23,083 for work related to counselling and psychotherapy. In addition, the VTCT Foundation generously granted Headlines £15,240 to support our work to transition Hannah's Fund. Finally, we are also grateful to the support of Outdoors For All who granted us £5,000 to support the Family Weekend (this amount was paid directly to the venue, so is not reflected in the accounts below).

Expenditure within Restricted Funds was £20,860 (2024: £16,752). The largest items within this related to the Birmingham Children's Hospital research project looking into developmental outcomes for children with single-suture craniosynostosis (kindly funded by the VTCT Foundation), and to the Dads Network (kindly funded by the Pears Foundation).

Our reserves policy is currently set to cover 12 months of unrestricted expenses. Taking account of the committed expenditure, we are in excess of this, and the Board will be considering ways to bring reserves down closer to the policy.

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 2025

	Unrestricted 2025	Restricted 2025	Total 2025 £	Unrestricted 2024	Restricted 2024	Total 2024 £
Receipts						
Donations, including gift aid	73,289	23,083	96,372	65,723	-	65,723
Charitable activities (eg Family Weekend)	6,325	892	7,217	8,468	-	8,468
Grant – Pears Foundation	-	-	-	-	8,500	8,500
Grant – VTCT Foundation	-	15,240	15,240	-	10,931	10,931
Small Grants	-	573	573	-	1,000	1,000
Merchandise	1,139	-	1,139	766	-	766
Bank interest and sundry income	4,442	-	4,442	2,943	-	2,943
	85,195	39,788	124,983	77,900	20,431	98,331
Payments						
Events (eg Family Weekend)	23,236	1,892	25,128	19,103	-	19,103
ACCORD research	84	-	84	-	6,164	6,164
Birmingham Hospital research	-	8,198	8,198	-	1,822	1,822
Counselling/psycho-therapy costs	0	5,966	5,966	-	-	-
Screening Pipeline/stem cells research project	1,781	-	1,781	-	-	-
Dads Network	-	3,287	3,287	-	7,437	7,437
Other Events	739	250	989	1,010	-	1,010
Information Leaflets	-	383	383	-	637	637
Oxford univ. research project	-	-	-	3,098	-	3,098
Digital Capabilities	-	556	556	-	692	692
Welfare Grants	250	-	250	700	-	700
Salary and related costs	49,149	-	49,149	47,329	-	47,329
Newsletters & website	4,749	-	4,749	4,525	-	4,525
Office Running costs	3,602	328	3,930	4,377		4,377
Fundraising costs	5,468	-	5,468	6,097	-	6,097
Legal / professional fees	3,245	-	3,245	2,610	-	2,610
Independent Examiner	750	-	750	650	-	650
Trustee meeting costs and AGM fees	86	-	86	261	-	261
	93,139	20,860	113,999	89,760	16,752	106,512
Net Receipts / (Payments) in the year	(7,944)	18,928	10,984	(11,860)	3,679	(8,181)
Transfer of Restricted to Unrestricted Funds	12,424	(12,424)	-	12,723	(12,723)	-
Grants Repaid	-	-	-	-	(7,735)	(7,735)
Net Receipts / (Payments) in the year after Transfer	4,480	6,504	10,984	863	(16,779)	(15,916)
Balance at 1 April 2024	156,357	21,695	178,052	155,494	38,474	193,967
Balance at 31 March 2025	160,837	28,199	189,036	156,357	21,695	178,052

#### Notes:

- 1. The Receipts and Payments Accounts of the charity are prepared on a cash accounting basis.
- 2. Restricted Funds at 31 March 2025 consists primarily of the remainder of funds transferred from Hannah's Fund (£22,615 plus related donations, giving a total of £23,078), of grants received from the VTCT Foundation for the Birmingham Hospital longitudinal analysis project (£911), for upgrading our Digital Capabilities (£3,032), and for further work on Patient Information Leaflets (£815).
- 3. Grants received from the VTCT Foundation in the financial year (£15,240) relates to the Counselling / psycho-therapy project to help Headlines prepare to absorb the work of Hannah's Fund. In the prior accounting year, to 31 March 2024, grants received from the VTCT Foundation related to the research project with Birmingham Hospital to undertake a 10-year longitudinal analysis into developmental outcomes for children with single-suture craniosynostosis. In addition, Outdoors For All contributed £5,000 directly to the company where we held our 2024 Family Weekend (that amount is therefore not reflected in these accounts).
- 4. Transfers of £12,424 from Restricted Funds to Unrestricted Funds were made in the year (2024: £12,723). These primarily related to work undertaken by Headlines staff in relation to the VTCT-funded Counselling / psychotherapy project to help Headlines prepare to absorb the work of Hannah's Fund, and in supporting the Dads' Network.

- 5. No trustees received remuneration in their capacity as a trustee (2024: Nil). No trustees were reimbursed travel costs related to the management and governance of the charity in the year (2024: one trustee £116).
- 6. There were donations from Related Parties of £1,017 (2024: £930). In addition, the trustees of Hannah's Fund decided to close that charity and transfer the remaining funds (£22,615) to Headlines. During the financial year, two of the trustees of Hannah's Fund also became trustees of Headlines.
- 7. Other events for the year included costs associated with the Young Persons' Network and attendance at conferences.
- 8. In the year ended 31 March 2025, we provided welfare grants of £250 (2024: £700).
- Fundraising Costs includes fees for fundraising events held during this financial year and fees paid to third party fundraising platforms and on merchandise sales.
- 10. Grants repaid in the year ended 31 March 2024 of £7,735 represented the return to the VTCT Foundation of the underspend on the ACCORD research project.

## Statement of assets and liabilities

#### as at 31 March 2025

	Unrestricted 2025 £	Restricted 2025	Total 2025 £	Unrestricted 2024 £	Restricted 2024 £	Total 2024 £
Cash at Bank	160,836	28,199	189,036	156,357	21,695	178,052
Non-monetary Assets						
Computer equipment, at estimated net book value	-	-	-	-	-	-
Expenses paid in advance	3,564	-	3,564	-	100	100
Amounts due	-	-	-	-	-	-
Non-monetary Liabilities						
Income received in advance	(950)	-	(950)	(1,380)	-	(1,380)
Salaries and related costs	(2,249)	-	(2,249)	(2,228)	-	(2,228)
Unpaid expenses	(1,173)	-	(1,173)	(918)	(2,733)	(3,651)
Independent examination fee	(840)	-	(840)	(750)	-	(750)
Committed expenditure						
Grants awarded awaiting payment	(39,658)	-	(39,658)	(41,439)	-	(41,439)

#### 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 (2024: £1,050).
- 2. Non-monetary assets comprise expenses paid in advance for events occurring after the end of the financial year, primarily this relates to expenses for the Family Weekend to be held in August 2025.
- 3. Non-monetary liabilities represent certain expenses paid after 31 March 2025, but which are with respect to the financial year ended 31 March 2025, 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, £950 of income had been received before the end of the financial year, with respect to events occurring in the next financial year, primarily being the Family Weekend (2024: £1,380).

The accounts on pages 10 to 12 were approved by the Executive Committee on 22 July 2025 and signed on their behalf by:

Leagle.

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 2025 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.

#### Gemma Stace / John Caladine FCCA CTA FCIE

Chartered Certified Accountant and Independent Examiner

Caladine Ltd Chantry House 22 Upperton Road Eastbourne East Sussex BN211BF

Dated: 24 July 2025



## Reference and administrative details

## Registered office and administration address

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T: 0330 120 0410

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
David Coleman
Paul Cornell (Chair until 31 August 2024)
Charles Edwards (Treasurer)
Dr Caroline Hilton (Secretary)
Zoe Hilton-Webb
Mark Lindfield
Laura Melles
Dr Mehran Moazen
Lucy Pearse (Chair from 31 August 2024)
Darren Sloan
Richard Williams

#### **Patron**

Professor Andrew Wilkie FMedSci FRS

#### Bankers

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

#### **Independent Examiner**

Caladine Ltd Chantry House 22 Upperton Road Eastbourne East Sussex BN211BF 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 offer a confidential helpline and regular newsletters, conference and information days and an annual Family Weekend. We also support research into the causes and treatment of rare craniofacial conditions.

#### Join us! Membership is free.

Find us on social media:



**@headlinescraniofacialsupport** 



@headlinescraniofacial

