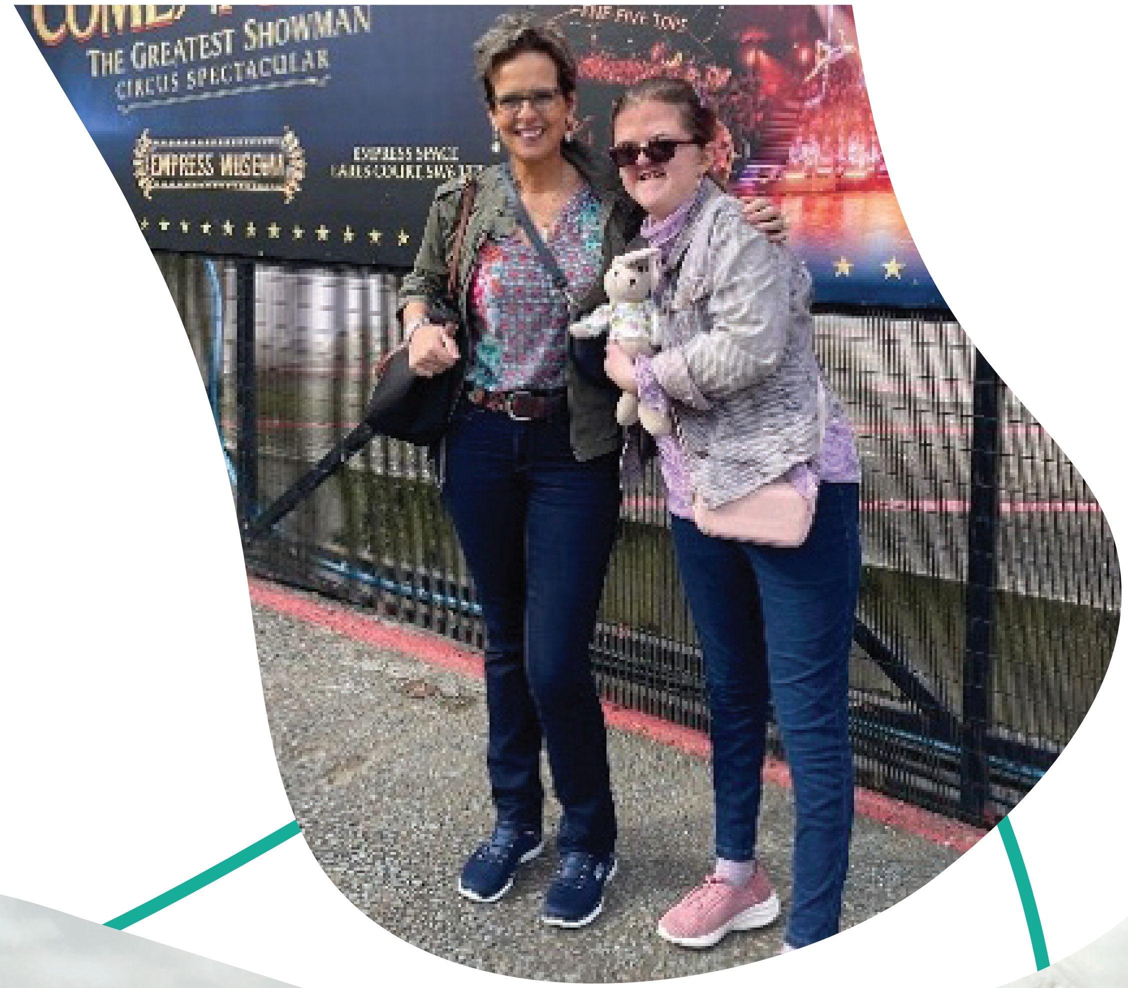
Annual Report & Accounts

2025 - 2026

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 2026



From the Chair of Trustees

This year has been another important and active one for Headlines, as we continue to support individuals and families affected by craniosynostosis and rare craniofacial conditions, whilst also investing in the future of the charity.

We have maintained our focus on delivering the core services that our community relies on, whilst also progressing key areas of development. This includes further planning to enable our community members to access psychological support through Hannah's Fund. Developing our psychological support offer remains central to our ambition to provide holistic support that reflects both the physical and emotional realities faced by those we serve.

This year we have seen the completion of long-term research commitments, as well the launch of exciting new research projects exploring shared decision making in craniofacial care and developing speech and language support. We believe strongly in using our resources to deliver meaningful impact, continuing to work towards our charitable objectives. We are also building income streams in new and innovative ways and remain confident in the long-term stability of the charity. We are particularly thankful to those who trained so hard to run the London Marathon in support of Headlines, helping to sustain our work.

As always, our work would not be possible without our small and dedicated staff team, who work cohesively with commitment, energy and care to continue to drive the charity forward while remaining focused on service user needs. Sadly, this will be the last annual report for our Charity Director, Karen Wilkinson-Bell, who will be retiring at our AGM, after eight years of service. On behalf of the Board of Trustees and our members, I would like to thank Karen for her determination and hard work in leading the charity over this period. She has worked skilfully with Trustees, providing clarity and purpose, and ensuring that we remain forward thinking and proactive. Karen has also worked tirelessly to build relationships with professionals across the supra centres and within academic research, achieving significant success in raising our profile and strengthening our connections both within the UK and across Europe. As our first employed Charity Director, she leaves Headlines in a strong position, and we wish her a very joyful retirement.

> “Thank to all our supporters - our members, fundraisers, donors and volunteers. Your continued encouragement, generosity and involvement enable us to continue our work and to build a stronger future for our community.”

We remain extremely grateful to our Trustees, who generously give their time, skills, and experience to guide the charity. Their ongoing commitment ensures that Headlines stays focused, well-governed and responsive to the needs of those we serve.

Finally, I would like to thank all our supporters - our members, fundraisers, donors and volunteers. Your continued encouragement, generosity and involvement enable us to continue our work and to build a stronger future for our community.

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

Provide support

We provide support for people throughout their life to overcome the physical, psychological and social impacts of living with craniosynostosis and rare craniofacial conditions;

Faciliate research

We facilitate research that seeks to advance understanding, ensures the provision of quality care, and identifies the best treatments for craniosynostosis and rare craniofacial conditions;

Raise awareness

We 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 and networks
- organising conferences and information days
- working with the NHS and other stakeholders to improve care for those living with craniosynostosis
- supporting innovative research projects that address key priority questions for craniosynostosis and rare craniofacial conditions

Public benefit

The Trustees have complied with their duty in Section 17 of the Charities Act 2011 to have due regard to the guidance issued by the Charity Commission. The Trustees consider that the charity's aims, objectives and activities, as outlined above, demonstrate clear public benefit.

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. SC050262). The charity is governed by its Constitution, adopted on 24 March 1996 and subsequently amended. The charity was first registered with the Charity Commission for England and 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. Members elect the Board of Trustees at the Annual General Meeting (AGM). Trustees typically serve for a defined term in line with the Constitution.

The Board comprises not fewer than five and not more than fifteen Trustees. The Board may co-opt Trustees to fill casual vacancies between AGMs. The Trustees, who are all volunteers, are responsible for the overall strategic direction and governance of the charity.

The Board meets regularly throughout the year, including via video conference. Day-to-day operations are managed by a small staff team, supporting the delivery of the charity's activities and services.

New Trustees are recruited through an open and transparent process, including application, interview and attendance at Board meetings prior to appointment. Trustees are provided with induction information and ongoing support to enable them to fulfil their role effectively.

The Trustees are committed to maintaining high standards of governance and have regard to the Charity Governance Code for charities in England and Wales.

Key achievements and performance in the year

117 individuals from 27 families connected at our annual Family Weekend.

10% average growth in our social media channels enabling more people to access information and support.

Hannah's Fund enhanced emotional wellbeing support through the continued development of access to counselling and psychological therapy

81 individuals and families received direct support through our confidential helpline, providing timely information, reassurance and guidance at key points in their journey

Our membership grew to **2,626**

Babble bags were introduced in partnership with Alder Hey Children's Hospital

We continued to provide a wide range of support to individuals and families affected by craniosynostosis and rare craniofacial conditions. Our confidential helpline remained a vital point of contact, with **81 enquiries handled** during the year, offering information and reassurance at key moments in the patient journey.

We brought families together through our programme of events, including our annual Family Weekend, which welcomed **117 individuals from 27 families.** These opportunities to connect remain central to our work, helping to reduce isolation and build strong, supportive networks within our community.

We further strengthened our support offer through the continued development of **Hannah's Fund**, expanding access to counselling and psychological support. This remains an important area of focus as we respond to the emotional and mental health needs of those we support.

We also worked in partnership with the **Specialist Speech and Language Therapy team** at **Alder Hey Children's Hospital** to support the introduction of "Babble Bags" for their craniofacial parent support groups, helping to provide practical tools and early support for families.

Membership of the charity continued to grow, with an increase of just **over 2% during the year**, bringing total membership to **2,626**, reflecting the ongoing relevance and reach of our work.

The charity continued to invest in research that seeks to improve understanding and treatment of craniosynostosis and related conditions. Significant progress was made in funding the advancement of the **Screening Pipeline/Stem Cells research project undertaken by Kings College London and Erasmus Medical Centre in Rotterdam,** representing a major area of strategic investment.

We continued to raise awareness through a range of communications and engagement activities. Our social media channels saw **average growth of just over 10%**, helping us to reach a wider audience and ensure that support and information is accessible to those who need it.

We also continued to produce newsletters, information materials and digital content to support members and improve understanding of craniosynostosis and rare craniofacial conditions. Our annual magazine, **Headline News**, was mailed to a record 2,650 supporters, highlighting the growing reach of the charity and strong engagement from our community.

Fundraising and supporter engagement remained an important part of our awareness-raising work. We were delighted to secure our **first official place in the London Marathon**, raising over **£2,500**, and are extremely grateful for this and all fundraising efforts undertaken on behalf of the charity.

We were also pleased to secure a **£15,000 award from The National Lottery Community Fund,** contributing towards the costs of delivering our Family Weekend.

Supporting young people remained a key priority. Our **Young Persons Network (YPN)** continued to provide a platform for connection and peer support, enabling young people to share experiences and shape the work of the charity.

During the year, we also launched a **new Teens Group**, creating additional opportunities for younger members to engage in a supportive, age-appropriate environment and strengthening our overall offer to young people within the community.

Financial Review

Income from donations and Gift Aid remained the charity's primary funding source at £55,139 (2025: £96,372), demonstrating continued support from the community, although at a reduced level compared to the previous year. A new grant of £15,000 was received from The National Lottery Community Fund towards the 2025 Family Weekend.

Income from charitable activities, including events such as the Family Weekend, amounted to £4,840 (2025: £7,217). Additional income streams included merchandise sales (£512) and bank interest and sundry income (£2,454), both lower than in the prior year.

Total income for the year ended 31 March 2026 was £77,945 (2025: £124,983). This reduction reflects lower grant income compared to the previous year, particularly as 2025 included significant restricted funding from the VTCT Foundation and other grant sources.

Total expenditure for the year was £126,140 (2025: £113,999), reflecting increased investment in key charitable programmes and organisational capacity, including the purchase of a new laptop.

The charity made significant investments in its charitable objectives, including:

- £37,157 on the Screening Pipeline/Stem Cells research project (see below)
- £19,053 on events supporting beneficiaries (including Family Weekend activities)
- Continued support for welfare grants, speech and language resources, and patient information.

Staffing remained the largest single area of expenditure at £51,033 (2025: £49,149), reflecting the charity's commitment to maintaining capacity to deliver services and support beneficiaries effectively.

Overall, the charity recorded a net deficit of £49,211 for the year (2025: surplus of £10,984). As indicated above, just over £37,000 of this relates to completion of the Kings College/ Erasmus MC Screening Pipeline/Stem Cells research project, which Trustees had agreed to fund in 2023 and thus reflects the Trustees' strategic decision in previous years to draw on reserves to fund key research projects.

Reserves Position and Policy

The Trustees recognise the importance of maintaining sufficient reserves to ensure the charity's ongoing sustainability and ability to respond to beneficiary needs.

The Trustees aim to maintain reserves sufficient to cover approximately 12 months of unrestricted expenditure. The operating deficit in the year reflects a deliberate strategy to apply reserves to priority projects and activities aligned with the charity's objectives rather than an underlying structural imbalance.

As at 31 March 2026 just under £110,000 was held in general funds, which is in line with the stated policy.

Trustees continue to monitor reserves closely and will prioritise rebuilding income streams, through fundraising and grant applications, in the forthcoming year to ensure reserves remain within target.

Going Concern

The Trustees have considered the charity's financial position and are satisfied that it remains appropriate to prepare the financial statements on a going concern basis. This is based on the charity's current reserves, ongoing donor support, and planned fundraising activity.

Risk Management

The Trustees have considered the major risks to which the charity is exposed and have implemented processes to identify, monitor and mitigate these risks where possible. Key risks include a reduction in income, particularly from donations and grants, and the impact this may have on the charity's ability to sustain its programme of activities.

To mitigate these risks, the Trustees actively monitor income and expenditure against budget, maintain oversight of cash flow and reserves, and prioritise expenditure in line with the charity's core objectives. Efforts are ongoing to diversify income streams, including pursuing new grant opportunities and strengthening fundraising activity. Operational risks, including staffing capacity and governance, are also reviewed regularly to ensure the charity continues to operate effectively and in compliance with regulatory requirements. A new risk register was introduced during the course of the year, to enable risks to be monitored on an ongoing basis.

Serious incidents

There were no serious incidents to report during the year.

Receipts and Payments

for the year ended 31 March 2026

	Unrestricted 2026 £	Restricted 2026 £	Total 2026 £	Unrestricted 2025 £	Restricted 2025 £	Total 2025 £
Receipts						
Donations, incl. gift aid	55,139	-	55,139	73,289	23,083	96,372
Charitable activities (e.g. Family Weekend)	4,840	-	4,840	6,325	892	7,217
Grant – NL Community Fund	-	15,000	15,000	-	-	-
Grant - VTCT Foundation	-	-	-	-	15,240	15,240
Small Grants	-	-	-	-	573	573
Merchandise	512	-	512	1,139	-	1,139
Bank interest and sundry income	2,454	-	2,454	4,442	-	4,442
	62,945	**15,000**	**77,945**	**85,195**	**39,788**	**124,983**
Payments						
Events (e.g. Family Weekend)	4,053	15,000	19,053	23,236	1,892	25,128
Screening Pipeline/stem cells research project	37,157	-	37,157	1,781	-	1,781
ACCORD research	-	-	-	84	-	84
Birmingham Hospital research	-	-	-	-	8,198	8,198
Counselling/psycho-therapy costs	-	-	-	-	5,966	5,966
Dads Network	-	-	-	-	3,287	3,287
Other Events	940	-	940	739	250	989
Information Leaflets	-	142	142	-	383	383
Digital Capabilities	-	900	900	-	556	556
Welfare Grants	700	-	700	250	-	250
Salary and related costs	51,033	-	51,033	49,149	-	49,149
Newsletters & website	4,959	-	4,959	4,749	-	4,749
Office Running costs	3,355	-	3,355	3,602	328	3,930
Fundraising costs	4,172	-	4,172	5,468	-	5,468
Legal / professional fees	2,066	-	2,066	3,245	-	3,245
Independent Examination	840	-	840	750	-	750
Trustee meeting and AGM costs	823	-	823	86	-	86
Trustee meeting costs and AGM fees	86	-	86	261	-	261
	110,098	**16,042**	**126,140**	**93,139**	**20,860**	**113,999**
Purchase of laptop	-	1,016	1,016	-	-	-
Net (Payments)/Receipts in the year	**(47,153)**	**(2,058)**	**(49,211)**	**(7,944)**	**18,928**	**10,984**
Transfers between Funds	-	-	-	12,424	(12,424)	-
Net (Payments)/Receipts in the year after Transfer	**(47,153)**	**(2,058)**	**(49,211)**	**4,480**	**6,504**	**10,984**
Balance at 1 April 2025	160,837	28,199	189,036	156,357	21,695	178,052
Balance at 31 March 2026	**113,684**	**26,141**	**139,825**	**160,837**	**28,199**	**189,036**

Notes:

1. The Receipts and Payments Accounts of the charity are prepared on a cash accounting basis.

2. Restricted Funds at 31 March 2026 consists primarily of the remainder of funds transferred from Hannah's Fund (£22,615 plus related donations, giving a total of £23,078), and of grants received from the VTCT Foundation for the Birmingham Hospital longitudinal analysis project (£911), for upgrading our Digital Capabilities (£1,116), and for further work on Patient Information Leaflets (£673).

3. The grant received from the National Lottery Community Fund was to support the Family Weekend. Grants received from the VTCT Foundation in the financial year ended 31 March 2025 (£15,240) related to the Counselling / psycho-therapy project to help Headlines prepare to absorb the work of Hannah's Fund.

4. Transfers of £12,424 from Restricted Funds to Unrestricted Funds were made in 2025. These primarily related to work undertaken by Headlines staff in relation to the VTCT-funded Counselling / psycho-therapy 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 (2025: Nil). No trustees were reimbursed travel costs related to the management and governance of the charity in the year (2025: Nil). One trustee received £200 for services as a play specialist at Headlines events, and was reimbursed £55.65 for related travel expenses.

6. There were donations (including membership and for attendance at the Family Weekend) from Related Parties of £720 (2025: £1,017). Attendance at the Family Weekend was paid for at the same rate as for other attendees.

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 2026, we provided welfare grants of £700 (2025: £250).

9. 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 2026

	Unrestricted 2026 £	Restricted 2026 £	Total 2026 £	Unrestricted 2025 £	Restricted 2025 £	Total 2025 £
Cash at Bank	113,684	26,141	**139,825**	160,836	28,200	**189,036**
Non-monetary Assets (note 2)						
Computer Equipment, at estimated net book value	1,016	-	**1,016**	-	-	-
Expenses paid in advance	514	-	**514**	3,564	-	**3,564**
Amounts Due	575	-	**575**	-	-	-
Non-monetary Liabilities (Note 3)						
Income received in advance	-	-	-	(950)	-	**(950)**
Salaries and related costs	(2,374)	-	**(2,374)**	(2,249)	-	**(2,249)**
Unpaid expenses	(1,380)	-	**(1,380)**	(1,173)	-	**(1,173)**
Independent Examination fee	(870)	-	**(870)**	(840)	-	**(840)**
Committed expenditure						
Grants awarded awaiting payment	-	-	-	(39,658)	-	**(39,658)**

Notes:

1. Committed expenditure from unrestricted funds relates to commitments we have made to fund research projects, but where the expenses have not occurred in the financial year. In 2026 this related to no projects (2025: 2 projects). Unrestricted funds also include designated funds of £550 for Welfare Grants (2025: £1,050).
2. Non-monetary assets comprise expenses paid in advance for events occurring or services provided after the end of the financial year. In 2025 this primarily related to expenses for the Family Weekend to be held in September 2026. Amounts due relates to an accidental double payment to a supplier. This was repaid in April 2026.
3. Non-monetary liabilities represent expenses paid after 31 March 2026, but which are with respect to the financial year ended 31 March 2026, including expenses related to salary costs (such as payments to HMRC) and other expenses where invoices had not been received and paid prior to the end of the financial year. In addition, in 2025 £950 of income had been received before the end of the financial year relating to the Family Weekend taking place in August 2025. No advance income was received in 2026.

The accounts on pages 14-15 were approved by the Board of Trustees on 21 July 2026 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 2026 which are set out on pages 14 to 16.

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.

John Caladine FCCA CTA FCIE
Chartered Certified Accountant and Independent Examiner

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Dated: 23 July 2026

Reference and administrative details

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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 (Treasurer from 30 August 2025)

Charles Edwards (retired 30 August 2025)

Dr Caroline Hilton (Secretary)

Zoe Hilton-Webb

Mark Lindfield

Laura Melles

Dr Mehran Moazen

Dr Lucy Pearse (Chair)

Hannah Pitt (from 26 April 2025)

Richard Williams

Patron

Professor Andrew Wilkie FMedSci FRS

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ME19 4JQ

Independent Examiner

Caladine Ltd
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BN21 1BF

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

Headlines
CRANIOFACIAL SUPPORT