Headlines Craniofacial Support

England & Wales · Charity number 1058461

Details

Other names	HEADLINES - THE CRANIOFACIAL SUPPORT GROUP, THE CRANIOFACIAL SUPPORT GROUP, Headlines, Headlines - The Craniofacial Support Group
Status	Registered
Legal form	Other
Registered	1996-10-04
Register	View on the Charity Commission register

Contact

Address	Headlines Craniofacial Support Arquen House 4-6 Spicer Street St Albans Hertfordshire AL3 4PQ
Phone	0330 120 0410
Email	info@headlines.org.uk
Website	www.headlines.org.uk

Activities

Objects: TO PRESERVE AND PROTECT THE HEALTH AND PROMOTE THE WELFARE OF PEOPLE WITH CRANIOSYNOSTOSIS AND RARE CRANIOFACIAL CONDITIONS BY:(1) PROVIDING SUPPORT THROUGHOUT THEIR LIFE TO OVERCOME THE PHYSICAL, PSYCHOLOGICAL AND SOCIAL IMPACTS OF LIVING WITH THESE CONDITIONS; (2) FACILITATING RESEARCH THAT SEEKS TO ADVANCE UNDERSTANDING, ENSURES THE PROVISION OF QUALITY CARE, AND IDENTIFIES THE BEST TREATMENTS FOR CRANIOSYNOSTOSIS AND RARE CRANIOFACIAL CONDITIONS; AND(3) RAISING AWARENESS AND EDUCATING PEOPLE TO IMPROVE PUBLIC UNDERSTANDING OF CRANIOSYNOSTOSIS AND RARE CRANIOFACIAL CONDITIONS.NOTHING IN THIS CONSTITUTION SHALL AUTHORISE AN APPLICATION OF THE PROPERTY OF THE CHARITY FOR PURPOSES WHICH ARE NOT CHARITABLE IN ACCORDANCE WITH SECTION 7 OF THE CHARITIES AND TRUSTEE INVESTMENT (SCOTLAND) ACT 2005 AND/OR SECTION 2 OF THE CHARITIES ACT (NORTHERN IRELAND) 2008.

Activities: PROVIDING SUPPORT AND INFORMATION FOR PATIENTS & THEIR FAMILIES WHO ARE AFFECTED BY CRANIOSYNOSTOSIS AND RARE CRANIOFACIAL CONDITIONS; RAISING

Downloaded from opencharities.uk/ew/1058461

AWARENESS WITH THE PUBLIC AND HEALTH PROFESSIONALS AND FACILITATING RESEARCH IN THESE CONDITIONS.

Classification

- **How:** Makes Grants To Individuals, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body, Other Charitable Activities
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities, The General Public/mankind

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£124,983	£113,999	-	-
2024-03-31	£98,331	£106,512	-	-
2023-03-31	£105,773	£123,596	-	-
2022-03-31	£112,841	£79,947	-	-
2021-03-31	£87,713	£55,383	-	-

Downloaded from opencharities.uk/ew/1058461

Trustees

Name	Role	Appointed
Lucy Pearse	Chair	2022-05-07
Charlotte Ashby		2020-06-27
David Coleman		2023-09-12
Dr Caroline Hilton		2018-04-15
Dr Mehran Moazen		2020-02-22
Laura Melles		2024-01-27
Mark Lindfield		2024-01-27
Neil Bowyer		2023-09-12
Paul Stuart Cornell		2020-06-27
Richard Williams		2024-01-27
Zoe Hilton-Webb		2024-01-27

Downloaded from opencharities.uk/ew/1058461

Headlines Craniofacial Support

England & Wales - Charity number 1058461

Accounts

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.

03 From the Chair of Trustees

04 Our objectives and activities

05 Structure, governance and management

06 Key achievements and performance in the year

08 Financial review

10 Receipts and payments accounts

12 Statement of assets and liabilities

13 Independent examiner's report

15 Reference and administrative details

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 first-ever 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.





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.

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 / 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 (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).
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.
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:

SIGNATURE

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
BN21 1BF

Dated: 24 July 2025









Reference and administrative details

Registered office and administration address

Arquen House
4-6 Spicer Street
St Albans
Herts.
AL3 4PQ

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
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

Headlines is a registered charity in England & Wales (no. 1058461) and Scotland (no. SCO50262)
© Headlines Craniofacial Support 2025

Headlines Craniofacial Support

England & Wales - Charity number 1058461

Accounts



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.

03 From the Chair of Trustees

04 Our objectives and activities

05 Structure, governance and management

06 Key achievements and performance in the year

08 Financial Review

10 Receipts and payments accounts

12 Statement of assets and liabilities

13 Independent examiner's report

15 Reference and administrative details

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 Pearse, 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 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



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



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

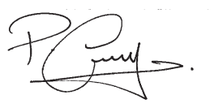
as at 31 March 2024

	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

Registered office and administration address

Arquen House
4-6 Spicer Street
St Albans
Herts.
AL3 4PQ

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 (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

Headlines
Craniofacial Support

Headlines Craniofacial Support

England & Wales - Charity number 1058461

Accounts

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.

03 From the Chair of Trustees

04 Our objectives and activities

05 Structure, governance and management

06 Key achievements and performance in the year

08 Financial Review

10 Receipts and payments accounts

12 Statement of assets and liabilities

13 Independent examiner's report

14 Reference and administrative details

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

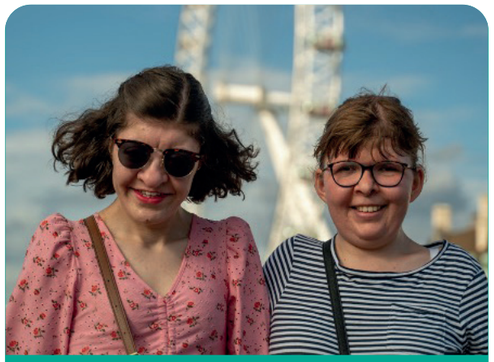
Our helpline handled **86** enquiries

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



7 get-togethers were hosted by our Young Persons Network

"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"

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

We secured **£8,500** to support the development of our new network for dads



Financial review

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

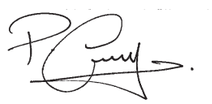
as at 31 March 2023

	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

Arquen House
4-6 Spicer Street
St Albans
Herts.
AL3 4PQ

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

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

Headlines
Craniofacial Support

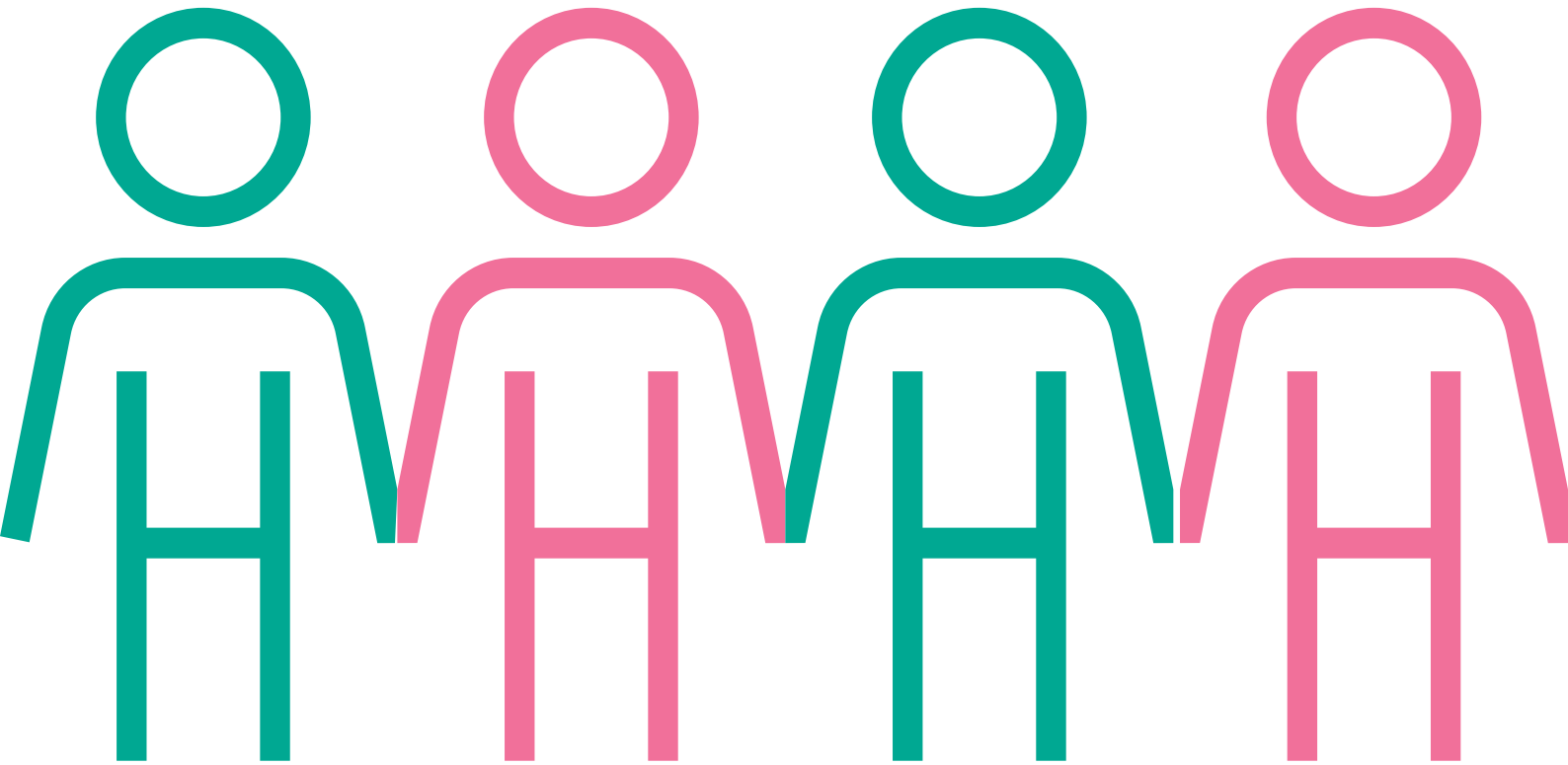
Headlines Craniofacial Support

England & Wales - Charity number 1058461

Accounts

Annual Report

2021-2022



The Executive Committee, which is comprised of the Trustees, are pleased to present their report and accounts for the year ended 31 March 2022.

03 Welcome from the Chair

04 Objectives and activities

05 Structure, governance and management

06 Our achievements and performance in the year

08 Financial Review

09 Statement of trustees' responsibilities

10 Reference and administrative detail

12 Receipts & Payments accounts

14 Statement of Assets and Liabilities

15 Independent examiner's report

Headlines Craniofacial Support
Registered charity numbers: 1058461 and SC050262

Headlines
Craniofacial Support

Welcome from the Chair of Trustees



As this is my first Annual Report as chairman, I would like to take the opportunity of thanking not only our outgoing chair, Wendy Edwards, for her service over the past 7 years, but also my fellow trustees who have offered unstinting support as I have taken over the reins. Headlines is fortunate to have such an amazing group of individuals willing to give so freely of their time and expertise to help steer the charity as it moves forward, and I am very grateful to them all.

As the achievements outlined in this report will testify, it has been another challenging but successful year as we continued to adapt to the effects of the pandemic. For me, the highlight was attending what was my family's first-ever Family Weekend back in September – the charity's first face to face event in over 2 years. It gave me a chance to talk with other parents about their experiences and it was marvellous to witness first hand the positive effect that Headlines has on people's lives. It was also amazing to see the children having such fun!

The year also saw the launch of the new Headlines Research Fund – a major step forward in our efforts to answer some of the important questions about the rare conditions we support. This really was a milestone for the charity, and we are all looking forward to seeing it grow and develop in the coming years.

As ever, Headlines' success relies on the enthusiasm and efforts of its many members and supporters – your work and continuing dedication helps us help those who need it most, and I would like to thank each and every one of you for all that you do. I hope that you will join me in celebrating what we have achieved together this year.

Paul Cornell

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, who are the Trustees of the charity, at the Annual General Meeting (AGM). Executive Committee members serve for a period of 5 years. The Executive Committee comprises not less than 5 and not more than 15 members. Existing members of the Executive Committee may co-opt new members to the Committee 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 Executive Committee meets on at least a quarterly basis, including through video conferencing.

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

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

Our achievements and performance in the year

Education & awareness

We ran a campaign to raise awareness of the importance of research into craniosynostosis which reached over 3,000 people on Facebook and Twitter

We published issue 6 of Headline News and mailed this out to over 2,200 members and supporters

Our social media saw growth of almost one third across the 3 main channels



My baby has craniosynostosis:

A parent's guide to managing a diagnosis



Support & living with the condition

We published a new leaflet to support parents and began work on a video to accompany the leaflet

Our helpline responded to 102 enquiries over the course of the year, with the complexity of the enquiries continuing to increase

We made welfare grants totalling £750 to support families experiencing financial hardship

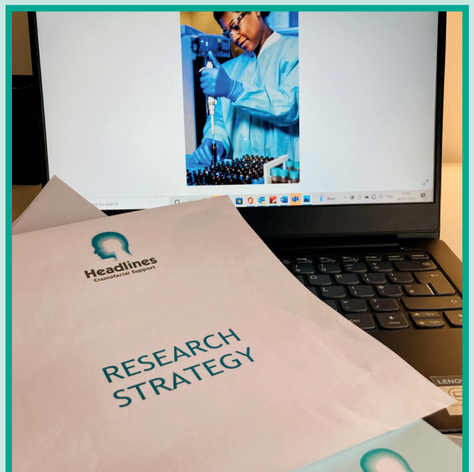
We welcomed 80 individuals and families to our Family Weekend in Shropshire in September, with free places bring offered to all children for the first time

Research & the provision of care

We launched a new 5 year Research Strategy focused on facilitating academic and clinical research, supporting social care and policy research, engaging patients, carers and families in research and enhancing communication and collaboration

We embarked on a new project with the Centre for Appearance Research to develop evidence-based resources for adults with craniosynostosis (ACCORD)

Our new Research Fund made its first-ever award, for a study looking into the impact of sagittal craniosynostosis on language development





Building the charity

Our membership grew to 2226 (2021: 2102)

We completed work on the new website and transitioned to a more accessible, user friendly platform which allows us to manage our own content

Financial review 2021-22

The receipts and payments accounts for the year ended 31 March 2022 show receipts of £112,841 (2021: £87,713) and expenses of £79,947 (2021: £55,383), resulting in a surplus of £32,894 (2021: £32,329). As at 31 March 2022, the charity had cash balances of £211,790 (2021: £178,896) of which £35,609 (2021: £16,394) related to restricted funds.

The surplus for the year (and part of the end of year restricted funds balance) includes the receipt of £44,223 from the VTCT Foundation, in relation to a Research Project being conducted in conjunction with the Centre for Appearance Research at the University of the West of England (UWE). The project is titled 'Adults with Craniosynostosis: Creating Online Resources to Reduce Distress' (ACCORD) and aims to improve the information and psychological support available to adults living with craniosynostosis in the UK. This was the first part of a two-year grant from the VTCT Foundation and we are extremely grateful to them for their ongoing support and for funding this significant milestone for Headlines.

Without the research grant and expenses incurred on it in the financial year, we would have had a small surplus. We also received Restricted Fund donations from the Maximus Foundation and Sainsburys, and are grateful to them and the Coleman family for their generosity and fundraising to support the Family Weekend, enabling us to provide free places for children this year.

We had a 19% decline in unrestricted donations, largely due to a substantial corporate donation received in the prior year. We continue to have a wide range of supporters. Major donors this year included the Kilroot Foundation, the Squire Patton Boggs Charitable Trust, the Tindle Family Charitable Trust and the Chipping Sodbury Ladies Golf Club. Other notable donors and fundraisers include Paul Prentice, who has nominated Headlines as beneficiary charity for his Star Wars Shoretrooper project, raising nearly £5,000 again, Michael Jordan who ran the London Marathon raising almost £1,300, and some inspirational young fundraisers, including Grace Turner-Cox, Lucy Holland and the Coteford Junior School in Pinner whose exploits can be read in the most recent edition of Headline News! 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.

Our expenses for the year increased by 44%. This was largely due to being able to run the Family Weekend this year, having been unable to in the prior financial year due to the pandemic, and to the costs of the ACCORD Research project. Expenses for last year were really an anomaly and lower than usual due to the pandemic (expenses are up 5% compared to the year ended 31 March 2020).

We have successfully built up reserves through the last few financial years, which has been beneficial during the uncertainty of the pandemic. Our reserves policy is currently set to cover 12 months of unrestricted expenses. Partly in response to this, as well as the major new ACCORD Research project, the Trustees of Headlines have agreed to use some of the reserves to fund other research initiatives. During the last financial year, the new Research Committee committed approximately £9,300 to fund Sarah Kilcoyne at Oxford for her research into 'Language and communication in children with non-syndromic sagittal synostosis: A sibling control study'. The Trustees have also designated a further £50,700 to the new Headlines Research Fund as well as additional welfare grants (£2,000).

The Trustees are of the view that both the charity as a whole and our finances have come through the pandemic strongly. 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.

Reference and administrative details

Registered office and administration address
Arquen House
4-6 Spicer Street
St Albans
Herts.
AL3 4PQ

T: 0330 120 0410
E: info@headlines.org.uk

Charity no: 1058461 / SC050262

Trustees
The Executive Committee members, who are the charity's Trustees, who served in the year and up to the date of this report were:

Paul Cornell (Chair, appointed 26 June 2021)
Wendy Edwards (ex-Chair, resigned 26 June 2021)
Charlotte Ashby
Charles Edwards (Treasurer)
Barry Fletcher (Vice-Chair)
Caroline Hilton (Secretary)
Mehran Moazen
Darren Sloan
Colette Turnock

Patron
Professor Andrew Wilkie FMedSci FRS

Principal Advisors
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

Declaration
This report was approved by the Executive Committee on 20 July 2022 and signed on their behalf by:

Chair of the Board of Trustees











Receipts and Payments

for the year ended 31 March 2022

	Unrestricted 2022 £	Restricted 2022 £	Total 2022 £	Unrestricted 2021 £	Restricted 2021 £	Total 2021 £
Receipts						
Donations, including gift aid	61,280	-	61,280	75,606	-	75,606
Charitable activities – FW 2021	3,548	3,000	6,548	-	-	-
Grant – VTCT Foundation (Digital)	-	-	-	-	10,500	10,500
Grant – VTCT Foundation (Research Project)	-	44,223	44,223	-	-	-
Merchandise	449	-	449	664	-	664
Bank interest and sundry income	341	-	341	943	-	943
	65,618	47,223	112,841	77,213	10,500	87,634
Payments						
Events – FW 2021	8,627	2,889	11,516	-	-	-
Research Projects	-	13,093	13,093	-	2,897	2,897
Other Events	304	-	304	-	-	-
Information Leaflets	-	1,143	1,143			
Book & Bunny Fund	-	-	-	-	193	193
Digital Capabilities / Upgrade project	-	3,993	3,993	-	1,474	1,474
Welfare Grants	750	-	750	200	-	200
Salary and related costs	39,383	2,890	42,273	24,048	15,393	39,441
Newsletters & website	400	-	400	3,990	-	3,990
Office Running costs	3,436		3,436	3,317	38	3,355
Fundraising costs	2,097	-	2,097	3,335	-	3,335
Legal and professional fees	217	-	217	99	-	99
Independent Examiner	450	-	450	400	-	400
Trustee meeting costs and AGM fees	275	-	275	-	-	-
	55,939	**24,008**	**79,947**	**35,389**	**19,995**	**55,383**
Net Receipts / (Payments) in the year	**9,679**	**23,215**	**32,894**	**41,824**	**(9,495)**	**32,329**
Transfer of Restricted to General Funds	4,000	(4,000)	-	1,160	(1,160)	-
Net Receipts / (Payments) in the year after Transfer	**13,679**	**19,215**	**32,894**	**42,984**	**(10,655)**	**32,329**
Balance at 1 April 2021	162,503	16,394	178,896	119,519	27,049	146,567
Balance at 31 March 2022	**176,182**	**35,609**	**211,790**	**162,503**	**16,394**	**178,896**

Notes:

1. The Receipts and Payments Accounts of the charity are prepared on a cash accounting basis.
2. Restricted Funds at 31 March 2022 primarily consists of grants from the VTCT Foundation for the Research Project being undertaken with UWE (£27,130), upgrading our Digital Capabilities (£5,033), and for further work on Patient Information Leaflets (£3,335).
3. Transfers of £4,000 from Restricted Funds to General Funds were made in the year (2021: £1,160), these related to work undertaken by Headlines staff in relation to the 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 since all meetings were held virtually due to the pandemic (2021: £0)
5. There were donations from Related Parties of £1,342 (2021: £2,271).
6. Other events for 2021 included costs associated with the Young Persons' Network.
7. In the year ended 31 March 2022, we provided welfare grants of £750 (2021: £200).
8. Fundraising Costs includes fees for fundraising events held during this financial year such as the Headlines Challenge Abseil (which raised over £4,000), and £1,508 of fees paid to third party fundraising platforms and on merchandise sales.

Statement of Assets and Liabilities

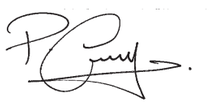
as at 31 March 2022

	Unrestricted 2022 £	Restricted 2022 £	Total 2022 £	Unrestricted 2021 £	Restricted 2021 £	Total 2021 £
Cash at Bank	**176,182**	**35,609**	**211,790**	**162,503**	**16,394**	**178,896**
Non-monetary Assets						
2021 Family Weekend expenses	-	-	-	1,580	-	1,580
Computer Equipment, at estimated net book value	-	183	183	-	367	367
Expenses paid in advance	-	-	-	2,712	-	2,712
Amounts Due	-	-	-	6,343	-	6,343
Non-monetary Liabilities						
Salaries and related costs	(2,073)	-	(2,073)	(1,233)	(921)	(2,154)
Unpaid expenses	(675)	(4,088)	**(4,763)**	(182)	-	**(182)**
Independent Examination fee	(550)	-	**(550)**	(450)	-	**(450)**

Notes:

1. Unrestricted funds includes designated funds of £60,000 for a Headlines Research Fund (£20,000 of which is carried over from prior year) and £2,000 for Welfare Grants (2020: total of £22,000).
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 2022, but which are with respect to the financial year ended 31 March 2022, including expenses related to salary costs (such as payments to HMRC) and accruals for expenses related to both the UWE and Headlines-funded research projects that have not yet been claimed.

The accounts on pages 12 to 14 were approved by the Executive Committee on 27 June 2022 and signed on their behalf by:



Chair of the Board of Trustees

20 July 2022

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 2022 which are set out on pages 12 to 14.

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: 20 July 2022

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

Headlines
Craniofacial Support

Headlines Craniofacial Support

England & Wales - Charity number 1058461

Accounts

Annual Report
2020-2021



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

Headlines
Craniofacial Support

Report of the Board of Trustees

The Executive Committee, which is comprised of the Trustees, present their report and accounts for the year ended 31 March 2021.

03 Welcome from the Chair

04 Objectives and activities

05 Structure, governance and management

06 Our achievements and performance in the year

08 Financial Review

09 Statement of trustees' responsibilities

10 Reference and administrative detail

12 Receipts & Payments accounts

14 Statement of Assets and Liabilities

15 Independent examiner's report

Headlines Craniofacial Support
Registered charity numbers: 1058461 and SC050262

Welcome from the Chair of Trustees



I write this report with some sadness as it is my last one as Chair of Headlines Craniofacial Support. However, I am delighted to leave at a time when the charity has survived what could have been a very difficult year as the COVID19 pandemic took over our lives in so many ways.

Headlines has had to adapt and my thanks to all our wonderful supporters and volunteers for embracing these changes. A number of Headlines members took on the 2.6 Challenge, others shaved their lockdown locks off, or undertook other challenging fundraising activities to help ensure the financial stability of Headlines during the pandemic.

We found ourselves going virtual with Zoom becoming our saviour, enabling us to reach out to more members, and more regularly. We saw the launch of the Dads and Teens Networks, with the Young Person's Network (led by one of our new trustees, Charlotte Ashby) and Family Day also going online with great success. The Family Day enabled different age groups to come together for quizzes, games and conversations.

Particular thanks to our staff members Karen Wilkinson-Bell and Donna Connett who have ridden out the storm of the pandemic and have been there throughout to support members who had questions on referrals to the craniofacial teams, delays in treatment or who just need a friendly person to chat to. We worked closely with NHS England and the Designated Craniofacial Units during the pandemic and built relationships which can only benefit our members in the future. We funded our first research project and set up a new Research Fund to be launched in May 2021 to support our members' top ten research priority questions.

I feel privileged to be stepping down at a time when the charity is looking to the future with such optimism. When I took up the role of Chair in 2017, we launched a new and aspirational 5-year strategy on the back of a full consultation with all our stakeholders. I am delighted that due to the dedication and varied skillset of our staff, voluntary trustees and other volunteers, many of these strategic objectives have come to fruition over the last four years. Importantly, behind the scenes we have also been upgrading our financial systems and technology provision, all of which I hope will leave the charity in a good position as I welcome our new Chair Paul Cornell. I am sure Headlines will continue to thrive under his leadership.

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 (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, who are the Trustees of the charity, at the Annual General Meeting (AGM). Executive Committee members serve for a period of 5 years. The Executive Committee comprises not less than 5 and not more than 15 members. Existing members of the Executive Committee may co-opt new members to the Committee 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 Executive Committee meets on at least a quarterly basis, including through telephone conferences.

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

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

Our achievements and performance in the year

Education and awareness

- Our social media channels saw significant growth, with a 20% increase in followers on Facebook and a near doubling of followers on Twitter and Instagram
- We developed and ran a new campaign across social media for CranioAwareness Month in September which highlighted the stories of young people with different forms of craniosynostosis: entitled 'Positive Futures', the campaign videos were viewed over 20,000 times and resulted in our largest coverage on social media to date
- We published 4 issues of our quarterly electronic newsletter and mailed out over 2,000 copies of our annual magazine Headline News



Support and living with the condition

- Our membership grew by 7% to just over 2,100
- Our confidential helpline responded to 122 enquiries, with almost half of these coming from parents with concerns about their baby's head shape
- We welcomed almost 100 people to our first-ever Virtual Conference & Information Day in October, with renowned speakers from across the UK providing expert insights on topics such as endoscopic surgery and new advances in genetics
- We re-launched our Welfare Fund, which provides small grants to members, in recognition of the possible additional hardships facing members as a result of the pandemic
- Our Young Person's Network moved online, meeting a total of 4 times during the year, with new trustee Charlotte Ashby now representing the group on the Headlines board
- We launched 'CranioDads', a new peer support network offering dads the opportunity of meeting up with other fathers following the diagnosis of their child (and beyond). The network met 3 times during the year and now has its own WhatsApp group
- We continued with our programme of updating our patient information, with the completion of two further condition-specific leaflets for Apert and Crouzon syndrome

Research and the provision of care

- We completed our first-ever joint study with the Centre for Appearance Research into the long term psychological impacts of living with craniosynostosis and began follow up work on addressing its key findings
- We worked with the Royal College of Speech & Language Therapists (RCSLT) to develop and launch a new leaflet on craniosynostosis for Speech & Language Therapists
- We embarked on plans to launch a new Research Fund focused on finding answers to our 'Top Ten' research questions
- We presented an update of our work at the annual NHS Craniofacial Audit meeting by videoconference in May and have continued to liaise closely with the 4 Highly Specialised Craniofacial Units and NHS England on a range of issues including improving early diagnosis rates and rapid referral to specialist care
- We contributed to an NHS consultation looking at patient experiences of digital care during the pandemic
- We continued to contribute to the NIHR Cleft & Craniofacial Clinical Studies Group, with our Director joining two of our trustees on the group
- We attended and presented at a Specialist Genetics meeting convened by our Patron, Professor Andrew Wilkie, in December
- We joined the patient advisory group for the European Reference Network for rare/complex craniofacial conditions (ERN CRANIO), which brings together specialist healthcare providers from across Europe



Building the charity

- We began a programme of work to update our website and digital capabilities, supported by a grant from the VTCT Foundation
- We completed a major piece of work to streamline and update our membership database, enabling us to improve support to members
- We successfully completed our application for registration with the Office of the Scottish Charity Regulator (OCSR), enabling us to start developing our services in Scotland
- We formally elected 3 new trustees to the board at the AGM in June

Financial Review

The receipts and payments accounts for the year ended 31 March 2021 show receipts of £87,713 (2020: £100,721) and expenses of £55,383 (2020: £76,090), resulting in a surplus of £32,329 (2020: £24,631). As at 31 March 2021, the charity had cash balances of £178,896 (2020: £146,567) of which £16,394 (2020: £27,049) related to restricted funds.

The surplus for the year (and part of the end of year restricted funds balance) includes the receipt of £10,500 from the VTCT Foundation, these funds will be used in the coming financial year to further expand our digital capabilities. We are extremely grateful to the VTCT Foundation for their ongoing support.

In terms of unrestricted donations, income slightly increased year-on-year. Despite the pandemic, our supporters continued their fantastic efforts to raise funds and we are grateful to them all. Paperchase Ltd kindly donated £13,622 following Headlines being nominated as one of the charities for their 2019 Christmas cards. We received £5,000 from the F&M Sainsbury's Charitable Trust , and the Coleman family raised over £6,000 which we have agreed with them will be used to provide free places for children at the Family Weekend to be held later in 2021.

Other notable donors include the family of Isla Maplethorpe and the Mackey family, whose supporters raised over £10,000 between them, and Paul Prentice, whose very generous decision to nominate Headlines as beneficiary charity for his Star Wars Shoretrooper project resulted in donations of £4,950 during the year.

In what has been such a difficult year for so many, 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.

Our expenses for the year decreased by 27%. While some of this was due to lower costs on events given the pandemic, and on lower remaining costs on the Research project with University of the West of England, we were also able to manage our expenses closely throughout the effects of the pandemic, as we moved more of our support and events online.

This is the third year in succession in which Headlines has generated a surplus, following deficits in several prior years. As the activities of the charity continue to expand in line with the 5-year strategy finalised in 2018, we have increased our staffing, and while the grant from the VTCT Foundation has helped us bridge to being able to employ our first Charity Director, in future years we will need to cover those higher staffing costs from our reserves and future donations. The prudent nature of our approach to reserves was beneficial, particularly at the start of the pandemic when it was very uncertain whether donations would be maintained. Our reserves policy is currently set to cover 12 months of unrestricted expenses. Partly in response to this, the Trustees have agreed to 'designate' some of those reserves to support a new Headlines Research Fund (of £20,000) and additional welfare grants (£2,000).

The Trustees have carefully considered the ongoing impact of Covid-19 on whether the charity remains a going concern. While it is possible that our fundraising income may reduce in the coming year as a result of Covid-19 (as some donations have been received in this financial year for events that have been deferred into the forthcoming financial year), given the prudence of our reserves 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 risk register 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.

Reference and administrative details

Registered office and administration address
Arquen House
4-6 Spicer Street
St Albans
Herts.
AL3 4PQ

T: 0330 120 0410
E: info@headlines.org.uk

Charity no: 1058461 / SC050262

Trustees
The Executive Committee members, who are the charity's Trustees, who served in the year and up to the date of this report were:

Wendy Edwards -(outgoing Chair, resigned 26 June 2021)
Paul Cornell - (incoming Chair, subject to election at the AGM, appointed 27 June 2020)
Charlotte Ashby - (from 12 October 2020)
Charles Edwards - (Treasurer)
Barry Fletcher - (Vice-Chair)
Caroline Hilton - (Secretary)
Mehran Moazen
Pia Shaper- (resigned 12 October 2020)
Darren Sloan
Colette Turnock

Patron
Professor Andrew Wilkie FMedSci FRS

Principal Advisors
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

Declaration
This report was approved by the Executive Committee on 26 June 2021 and signed on their behalf by:

Chair of the Board of Trustees











Receipts and Payments

for the year ended 31 March 2021

	Unrestricted 2021 £	Restricted 2021 £	Total 2021 £	Unrestricted 2020 £	Restricted 2020 £	Total 2020 £
Receipts						
Donations, including gift aid	75,606	-	75,606	64,459	-	64,459
Charitable activities – Events 2019	-	-	-	5,646	5,365	11,011
Grant - Conference	-	-	-	-	800	800
Grant – VTCT Foundation (Director)	-	-	-	-	20,090	20,090
Grant – VTCT Foundation (Digital)	-	10,500	10,500	-	-	-
Gala Dinner / Ball	-	-	-	3,780	-	3,780
Merchandise	664	-	664	482	-	482
Bank interest and sundry income	943	-	943	99	-	99
	77,213	10,500	87,713	74,466	26,255	100,721
Payments						
Events - 2019	-	-	-	5,684	5,365	11,049
Events - 2020	-	-	-	1,580	-	1,580
Events - Conference	-	-	-	277	800	1,078
Other events	-	-	-	1,460	-	1,460
Research Project	-	2,897	2,897	-	6,519	6,519
Book & Bunny Fund	-	193	193	-	243	243
Gala Dinner / Ball	-	-	-	240	-	240
Fundraising costs	3,335	-	3,335	6,458	-	6,458
Digital Capabilities / Upgrade project	-	1,474	1,474	-	-	-
Welfare Grants	200	-	200	-	-	-
Salary and related costs	24,048	15,393	39,441	21,209	15,501	36,710
Newsletters, website & information leaflets	3,990	-	3,990	6,113	-	6,113
Office Running costs	3,317	38	3,355	3,259	558	3,817
Legal and professional fees	99	-	99	122	-	122
Independent Examiner	400	-	400	350	-	350
Trustee meeting costs and AGM fees	-	-	-	351	-	351
	35,389	**19,995**	**55,383**	**47,102**	**28,987**	**76,090**
Net Receipts / (Payments) in the year	**41,824**	**(9,495)**	**32,329**	**27,363**	**(2,732)**	**24,631**
Transfer of Restricted to General Funds	1,160	(1,160)	-	6,750	(6,750)	-
Net Receipts / (Payments) in the year after Transfer	**42,984**	**(10,655)**	**32,329**	**34,113**	**(9,482)**	**24,631**
Balance at 1 April 2020	119,519	27,049	146,567	85,406	36,530	121,936
Balance at 31 March 2021	**162,503**	**16,394**	**178,896**	**119,519**	**27,049**	**146,567**

Notes:

1. The Receipts and Payments Accounts of the charity are prepared on a cash accounting basis.
2. Restricted Funds at 31 March 2021 consists of grants from the VTCT Foundation for upgrading our Digital Capabilities (£9,026); for further work on Patient Information Leaflets - this money was re-purposed from an underspend on the Research project with UWE (£4,478); and for the Director role (£2,890).
3. Transfers of £1,160 from Restricted Funds to General Funds were made in the year (2020: £6,750), these related to a transfer of the remaining balance in the Book & Bunny Fund (£1,160).
4. No Trustees were reimbursed travel costs related to the management and governance of the charity in the year since all meetings were held virtually due to the pandemic (2020: one Trustee expenses of £102).
5. There were donations from Related Parties of £2,271 (2020: £1,326).
6. Other events for 2020 included costs associated with the Young Persons' Programme, local days out and attending events.
7. In the year ended 31 March 2021, we provided welfare grants of £200 (2020: £400 provided as offset against Family Weekend income).
8. The increase in Salary & Related costs is a result of having 2 part-time members of staff for all of the financial year, compared to having 2 part-time members of staff for some of the prior year.

Statement of Assets and Liabilities

as at 31 March 2021

	Unrestricted 2021 £	Restricted 2021 £	Total 2021 £	Unrestricted 2020 £	Restricted 2020 £	Total 2020 £
Cash at Bank	162,503	16,394	178,896	119,519	27,048	146,567
Non-monetary Assets						
2020 Family Weekend expenses	-	-	-	1,580	-	1,580
2021 Family Weekend expenses	1,580	-	1,580	-	-	-
Computer Equipment, at estimated net book value	-	367	367	-	200	200
Expenses paid in advance	2,712	-	2,712	2,469	-	2,469
Amounts Due	6,343	-	6,343	13,622	-	13,622
Non-monetary Liabilities						
2020 Conference income in advance	-	-	-	-	(800)	(800)
Salaries and related costs	(1,233)	(921)	(2,154)	(488)	(957)	(1,445)
Unpaid expenses	(182)	-	(182)	(542)	(2,565)	(3,107)
Independent Examination fee	(450)	-	(450)	(400)	-	(400)

Notes:

1. Unrestricted funds includes designated funds of £20,000 for a Headlines Research Fund and £2,000 for Welfare Grants (2020: no designated funds).
2. Non-monetary assets comprise the estimated value of the charity's equipment (such as a computer), expenses incurred in the financial year ended 31 March 2021 which are for events taking place after that date, and donations paid into the Bank after the end of the financial year but dated before the end of the financial year.
3. Non-monetary liabilities represent certain expenses paid after 31 March 2021, but which are with respect to the financial year ended 31 March 2021.

The accounts on pages 12 to 14 were approved by the Executive Committee on 27 May 2021 and signed on their behalf by:



Chair of the Board of Trustees

Independent examiner's report

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 2021 which are set out on pages 12 to 14.

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: 17 June 2021

Registered office and administration address:

Arquen House
4-6 Spicer Street
St Albans
Herts.
AL3 4PQ

T: 0330 120 0410
E: info@headlines.org.uk

Charity no: 1058461 / SC050262

Headlines
Craniofacial Support