

Annual Report

2020-2021



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



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.

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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. SC050262). 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

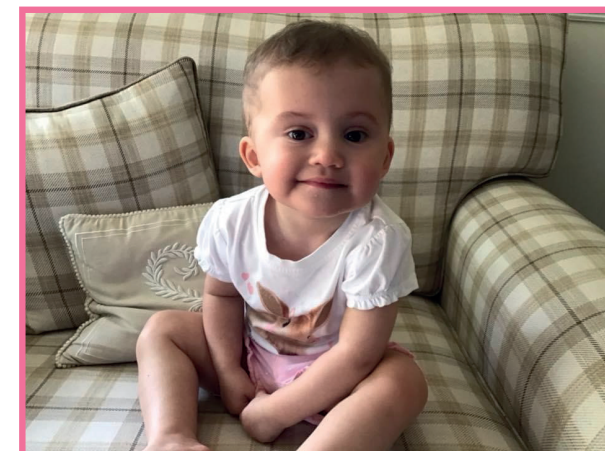


Support and living with the condition

- 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

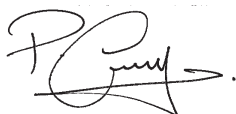
Bankers: CAF Bank Ltd, 25 Kings Hill Avenue, Kings Hill, West Malling, Kent ME19 4JQ

Independent Examiner:

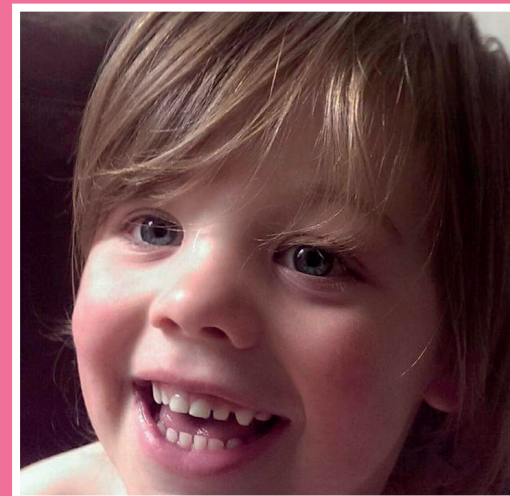
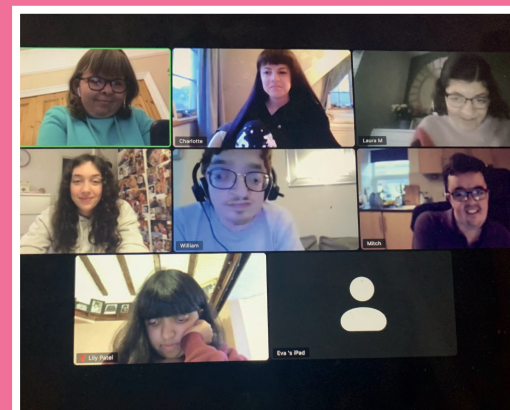
Nicola Anderson FCA, 189 Baldwins Lane, Croxley Green, Herts., WD3 3LL

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

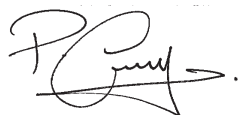
as at 31 March 2021

	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

