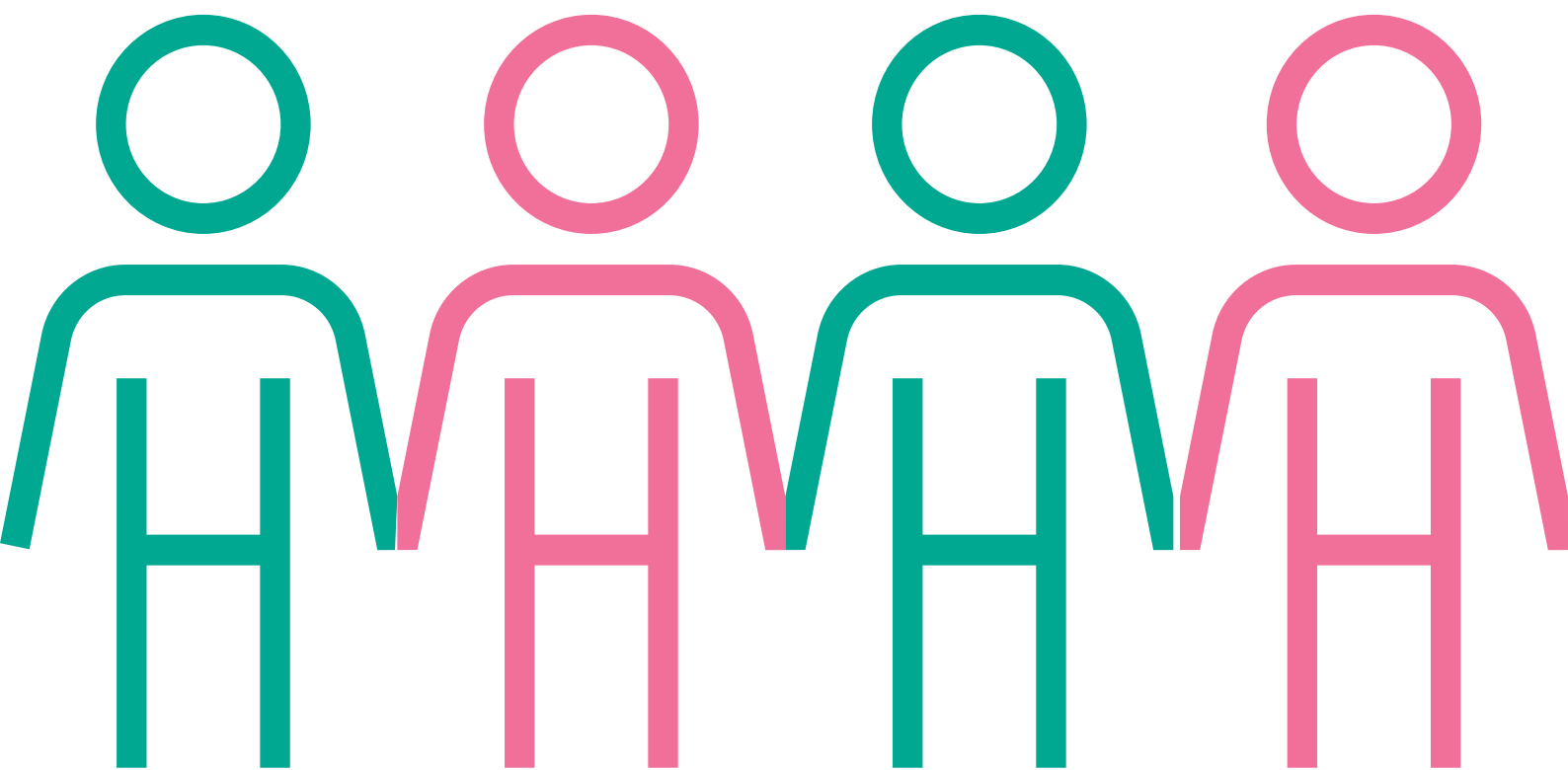


# Annual Report

## 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.

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**Headlines Craniofacial Support**

Registered charity numbers: 1058461 and SC050262



## 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. 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 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 being 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](mailto: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

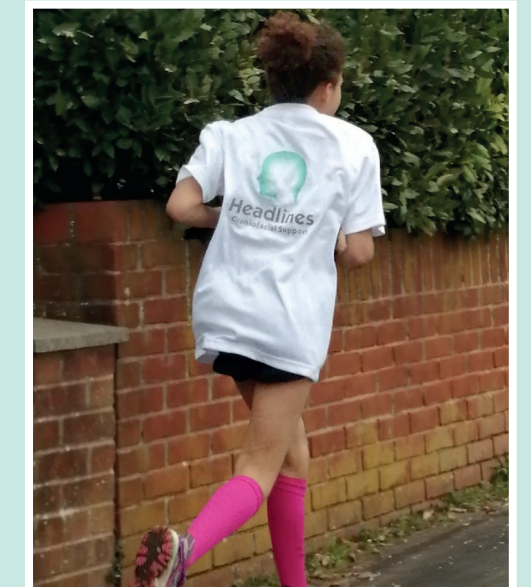
Independent Examiner:

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 £
<b>Receipts</b>						
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
<b>Payments</b>						
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
<b>Net Receipts / (Payments) in the year</b>	<b>9,679</b>	<b>23,215</b>	<b>32,894</b>	<b>41,824</b>	<b>(9,495)</b>	<b>32,329</b>
Transfer of Restricted to General Funds	4,000	(4,000)	-	1,160	(1,160)	-
<b>Net Receipts / (Payments) in the year after Transfer</b>	<b>13,679</b>	<b>19,215</b>	<b>32,894</b>	<b>42,984</b>	<b>(10,655)</b>	<b>32,329</b>
Balance at 1 April 2021	162,503	16,394	178,896	119,519	27,049	146,567
<b>Balance at 31 March 2022</b>	<b>176,182</b>	<b>35,609</b>	<b>211,790</b>	<b>162,503</b>	<b>16,394</b>	<b>178,896</b>

## 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 £
<b>Cash at Bank</b>	176,182	35,609	211,790	162,503	16,394	178,896
<b>Non-monetary Assets</b>						
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
<b>Non-monetary Liabilities</b>						
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](http://www.headlines.org.uk) to join.

### Find us on social media:



@headlinescraniofacialsupport



@HeadlinesCranio



@headlinescraniofacial



[www.headlines.org.uk](http://www.headlines.org.uk)

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