

NOONAN SYNDROME ASSOCIATION

England & Wales · Charity number 1140671

Details

Other names	NSA
Status	Registered
Legal form	Other
Registered	2011-03-03
Register	View on the Charity Commission register

Contact

Address	The Marshal Room 23-25 Old Row Whalley Road Barrow Clitheroe Lancashire BB7 9AZ
Phone	07359 474430
Email	info@noonansyndrome.org.uk
Website	www.noonansyndrome.org.uk

Activities

Objects: THE RELIEF OF ALL PERSONS AFFECTED BY NOONAN SYNDROME BY ALL OR ANY OF THE FOLLOWING MEANS:-1) THE FACILITATION AND PROMOTION OF RESEARCH INTO THE CAUSES, EFFECTS, DIAGNOSIS, TREATMENT AND RELIEF OF NOONAN SYNDROME WITH THE USEFUL RESULTS OF THE RESEARCH BEING DISSEMINATED FOR THE BENEFIT OF THE PUBLIC;2) THE PROVISION OF FACILITIES, FINANCIAL AID, ADVICE AND SUPPORT SERVICES FOR PERSONS SUFFERING FROM NOONAN SYNDROME, THEIR FAMILIES, DEPENDANTS AND CARERS, INCLUDING THE FAMILIES AND DEPENDANTS OF THOSE WHO HAVE DIED FROM NOONAN SYNDROME AND PREGNANT MOTHERS WHERE IT IS BELIEVED THAT THEIR CHILD IS IN DANGER OF BEING BORN WITH NOONAN SYNDROME; AND3) BY ADVANCING THE EDUCATION OF THE PUBLIC IN RELATION TO THE EFFECTS OF NOONAN SYNDROME BY COMMUNICATING REPORTS AND DISSEMINATING INFORMATION BY ANY MEANS OR MEDIA CONCERNING RESEARCH WORK AND STUDIES UNDERTAKEN BY OR ON BEHALF OF THE CHARITY.

Activities: The SUPPORT of those affected by Noonan Syndrome and related conditions (on the Ras/MAPK Pathway) by events, social media, publications etc.RESEARCH to advance improvements in understanding

and in the care and management of those affected or at risk.RAISING AWARENESS of the condition

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£48,067	£81,393	-	-
2024-03-31	£30,427	£48,332	-	-
2023-03-31	£59,898	£80,474	-	-
2022-03-31	£63,260	£39,070	-	-
2021-03-31	£66,296	£32,321	-	-

Trustees

Name	Role	Appointed
Andrea Dawn Reid-Kelly		2017-11-20
Andrew Peter Thomas Milne		2026-01-24
Danielle Burnett		2026-01-24
David Beatty		2026-01-24
Dr Emma Burkitt-Wright		2024-07-13
Grayson Colin Bowler		2020-05-18
IAN ALEXANDER LEGG BAHon ACIB		
Jeanette Dyer		2020-05-18
Sharon Louise Allsopp		2014-01-18
Susan Miller		2024-08-13

Accounts

**Report of the Trustees and
Financial Statements for the Year Ended 31 March 2025
for
Noonan Syndrome Association**

Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
Powys
SY16 2NY

Noonan Syndrome Association
Contents of the Financial Statements
for the Year Ended 31 March 2025

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Noonan Syndrome Association

**Reference and Administrative Details
for the Year Ended 31 March 2025**

TRUSTEES

Sharon Allsopp Chair of Trustees
Andrea Reid - Kelly Deputy Chair
Grayson Bowler Treasurer
Michael Patton Medical Adviser (resigned 13.7.24)
Brian Carlton
Jeanette Dyer
Ian Legg
Emma Burkitt-Wright Medical advisor (appointed 13.7.24)
Susan Miller (appointed 13.8.24)

PRINCIPAL ADDRESS

The Marshal Room
23-25 Old Row
Whalley Road
Barrow
Lancashire
BB7 9AZ

**REGISTERED CHARITY
NUMBER**

1140671

INDEPENDENT EXAMINER

Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
Powys
SY16 2NY

BANKERS

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

Charity Manager

Sandie Dent

Correspondence Address

The Marshal Room
23-25 Old Row
Whalley Road
Barrow
Lancashire
BB7 9AZ

The trustees present their report with the financial statements of the charity for the year ended 31 March 2025. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

The objectives of the charity are to provide relief of all persons affected by Noonan Syndrome and related conditions (on the Ras/MAPK pathway) by all or any of the following means:

1. The provision of general advice, guidance and support services for persons affected by Noonan Syndrome and related conditions (on the Ras/MAPK pathway), their families, dependents and carers;
2. The facilitation and promotion of research into the causes, effects, diagnosis, treatment and relief of Noonan Syndrome and related conditions (on the Ras/MAPK pathway) with the useful results of research being disseminated for the benefit of the public;
3. The advancement in the education of the public in relation to the effects of Noonan Syndrome and related conditions (on the Ras/MAPK pathway) by communicating reports and disseminating information by any means or media concerning research work and studies undertaken by or on behalf of the charity.

In all that we do, our trustees have given careful consideration to the Charity Commission's general guidance on public benefit and have complied with the duty in section 4 of the 2011/2006 Charities Act.

ACHIEVEMENTS AND PERFORMANCE

Charitable activities

The Charity entered the year in a stable financial position, though with a recognition that regular giving and fundraising income streams were down on previous years.

During the financial year, the charity's Medical Advisor Trustee and co-founder, Prof. Michael Patton, retired and the charity welcomed Dr Emma Burkitt-Wright as the new Medical Advisor Trustee. Dr Burkitt-Wright has a long-standing relationship with the charity as a member of the Professional Advisory Group.

Sue Miller, a volunteer with a long-standing connection to the charity, also joined the board as a co-opted trustee, bringing the total trustees during the 2024-5 year to eight.

Support activities during the year included a Families Day & Conference with renowned guest speakers, themed webinars and updates to the associated factsheet resources, continued support from a wide range of complex member enquiries, production of regular informative newsletters and dissemination of findings from the Living with Noonan Syndrome research project, carried out in collaboration with Loughborough University.

Governance and operational activities included board reviews of the 3 year strategy, including detailed assessment of the cost/benefit of holding large Families and Conference weekend events. The Board is keen to find alternative options, to ensure more cost-effective and inclusive support for members, and a detailed options plan was drawn up to feed into the strategic planning process.

The year presented income generating challenges with a fall in regular giving and difficulties securing grant funding in a challenging funding landscape. Although income was slightly up on the previous year, it is down on earlier years. Strategic planning identified a priority around communications campaigns to support donations and member fundraising, in particular targeted professional campaigns around regular giving, and this is planned as a focus for the coming year.

FINANCIAL REVIEW

Financial position

The statement of Financial Activities shows a deficit for the year of £33,326 (2024: £17,905), and reserves now stand at £46,560 (2024: £79,886).

Reserves policy

The charity does not have a separate formal policy on Reserves but following Board discussions, the Chair, Treasurer and Charity Manager follow a policy based on achieving free reserves of a minimum of between 3 and 6 months' operating costs including those associated with the cost of a part time charity manager.

The charity has an established and appropriate financial management system which is regularly reviewed by the Board and put into day to day practice by the Charity Manager, Charity Treasurer, Finance Officer together with the Chair of Trustees.

Free reserves which equate to net current assets (excluding restricted funds) amount to £45,472 (2024: £59,278).

FUTURE PLANS

To further strengthen the board and, in particular, seek trustees with experience in finance, marketing and communications where possible to support the strategic plan, including the development of professional fundraising campaigns.

To review and update membership of the Professional Advisory Group to strengthen this resource with the addition of new medical professionals and inclusion of non-medical professionals with expertise valuable to the charity's membership.

Increase in the range of webinar topics, to include small group online support sessions such as an Educational Transitions small group session planned for early 2025-6. To continue providing medical topic webinars, starting with a Growth webinar and updated Growth Factsheet in Q1.

To hold a one-day regional conference with guest speakers and workshop sessions in place of the larger weekend families day event and hold these at locations across the UK, beginning with Manchester in 2025-6.

Create a new Multi-Agency subgroup to focus on non-medical support areas such as education and other social care projects highlighted as important to members. To explore how to provide new and existing support in the most inclusive and cost-effective ways.

Continue to support research projects and the dissemination of the new International guidelines for NS due to be completed in 2025-6. To better understand and develop relationships with other agencies for collaboration, shared dissemination and awareness raising.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust and constitutes an unincorporated charity.

Recruitment and appointment of new trustees

Trustees are elected by way of a resolution of the Charity at the Annual General Meeting. The Trustees also have the power at any time, and from time to time, to appoint any person to be a Trustee [subject to certain restrictions], either to fill a casual vacancy or as an addition to the existing members of the Board of Trustees but so that the total number of Trustees does not exceed any maximum number fixed in accordance with this Constitution. Any Trustee so appointed shall hold office only until the next following Annual General Meeting, and shall then be eligible for re-election.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Organisational structure

The charity is organised so that the trustees meet regularly to manage its affairs. Full Trustee Board meetings are held at least four times per year with other meetings held as required, both face to face and by conference call or internet.

There is an Annual General Meeting held for all the members of the charity at which Trustees are elected or confirmed.

The part time Charity Manager undertakes most of the day to day operations of the charity. In addition to a Chair, the trustees have appointed a Deputy Chair and a Treasurer.

Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error. It has an agreed set of financial procedures and policies, practices and guidance to cover its activities, including the reserves policy set out above.

Approved by order of the board of trustees on 24 January 2026 and signed on its behalf by:

A handwritten signature in black ink, appearing to read 'Sharon Allsopp', written over a horizontal line.

Sharon Allsopp - Trustee

**Independent Examiner's Report to the Trustees of
Noonan Syndrome Association**

Independent examiner's report to the trustees of Noonan Syndrome Association

I report to the charity trustees on my examination of the accounts of Noonan Syndrome Association (the Trust) for the year ended 31 March 2025.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under Section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under Section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by Section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

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.

Thomas Landers BA FCA

Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
Powys
SY16 2NY

24 January 2026

Noonan Syndrome Association

Statement of Financial Activities
for the Year Ended 31 March 2025

		Unrestricted fund £	Restricted funds £	31.3.25 Total funds £	31.3.24 Total funds £
	Notes				
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	35,598	11,980	47,578	30,374
Investment income	3	489	-	489	53
Total		<u>36,087</u>	<u>11,980</u>	<u>48,067</u>	<u>30,427</u>
EXPENDITURE ON					
Charitable activities	4				
Research		6,306	20,000	26,306	25,677
Support Network		32,132	11,500	43,632	11,322
Awareness		11,455	-	11,455	11,333
Total		<u>49,893</u>	<u>31,500</u>	<u>81,393</u>	<u>48,332</u>
NET INCOME/(EXPENDITURE)		(13,806)	(19,520)	(33,326)	(17,905)
RECONCILIATION OF FUNDS					
Total funds brought forward		59,278	20,608	79,886	97,791
TOTAL FUNDS CARRIED FORWARD		<u>45,472</u>	<u>1,088</u>	<u>46,560</u>	<u>79,886</u>

The notes form part of these financial statements

Noonan Syndrome Association

Balance Sheet
31 March 2025

	Notes	31.3.25 £	31.3.24 £
CURRENT ASSETS			
Debtors	9	3,407	28,901
Cash at bank		44,123	70,396
		<u>47,530</u>	<u>99,297</u>
CREDITORS			
Amounts falling due within one year	10	(970)	(19,411)
		<u>46,560</u>	<u>79,886</u>
NET CURRENT ASSETS			
		<u>46,560</u>	<u>79,886</u>
TOTAL ASSETS LESS CURRENT LIABILITIES			
		46,560	79,886
NET ASSETS		<u>46,560</u>	<u>79,886</u>
FUNDS	12		
Unrestricted funds		45,472	59,278
Restricted funds		1,088	20,608
TOTAL FUNDS		<u>46,560</u>	<u>79,886</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 24 January 2026 and were signed on its behalf by:

Sharon Allsopp - Trustee

The notes form part of these financial statements

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Income recognition

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

2. DONATIONS AND LEGACIES

	31.3.25	31.3.24
	£	£
Donations	33,501	27,784
Gift aid	2,577	2,590
Grants	11,500	-
	<u>47,578</u>	<u>30,374</u>

Grants received, included in the above, are as follows:

	31.3.25	31.3.24
	£	£
Novo Nordisk Limited	3,000	-
Sense - The National Deafblind and Rubella Association	8,500	-
	<u>11,500</u>	<u>-</u>

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2025

3. INVESTMENT INCOME

	31.3.25	31.3.24
	£	£
Deposit account interest	54	53
Other interest	435	-
	<u>489</u>	<u>53</u>

4. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 5)	Support costs (see note 6)	Totals
	£	£	£
Research	25,578	728	26,306
Support Network	42,905	727	43,632
Awareness	11,154	301	11,455
	<u>79,637</u>	<u>1,756</u>	<u>81,393</u>

5. DIRECT COSTS OF CHARITABLE ACTIVITIES

	31.3.25	31.3.24
	£	£
Postage and stationery	529	1,350
Promotional material	84	450
Family day	31,828	-
Travel expenses	771	595
Computer & IT support costs	2,619	1,949
Charity Manager	17,933	16,747
Research	20,000	20,000
Administration costs	5,873	5,388
Staff & volunteer training	-	198
	<u>79,637</u>	<u>46,677</u>

6. SUPPORT COSTS

	Finance	Governance costs	Totals
	£	£	£
Research	28	700	728
Support Network	54	673	727
Awareness	54	247	301
	<u>136</u>	<u>1,620</u>	<u>1,756</u>

Notes to the Financial Statements - continued
for the Year Ended 31 March 2025

7. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2025 nor for the year ended 31 March 2024.

Trustees' expenses

During the year no trustees were reimbursed for travelling expenses (2024 - nil).

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	30,044	330	30,374
Investment income	53	-	53
Total	<u>30,097</u>	<u>330</u>	<u>30,427</u>
EXPENDITURE ON			
Charitable activities			
Research	5,677	20,000	25,677
Support Network	11,322	-	11,322
Awareness	11,333	-	11,333
Total	<u>28,332</u>	<u>20,000</u>	<u>48,332</u>
NET INCOME/(EXPENDITURE)	1,765	(19,670)	(17,905)
RECONCILIATION OF FUNDS			
Total funds brought forward	57,513	40,278	97,791
TOTAL FUNDS CARRIED FORWARD	<u>59,278</u>	<u>20,608</u>	<u>79,886</u>

9. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.3.25 £	31.3.24 £
Trade debtors	-	10
Accrued income	2,526	8,169
Prepayments	881	20,722
	<u>3,407</u>	<u>28,901</u>

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2025

10. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.3.25 £	31.3.24 £
Trade creditors	-	900
Other creditors	970	18,511
	<u>970</u>	<u>19,411</u>

11. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted fund £	Restricted funds £	31.3.25 Total funds £	31.3.24 Total funds £
Current assets	46,442	1,088	47,530	99,297
Current liabilities	(970)	-	(970)	(19,411)
	<u>45,472</u>	<u>1,088</u>	<u>46,560</u>	<u>79,886</u>

12. MOVEMENT IN FUNDS

	At 1.4.24 £	Net movement in funds £	At 31.3.25 £
Unrestricted funds			
General fund	59,278	(13,806)	45,472
Restricted funds			
Noonan Syndrome Research Fund	10,585	(9,504)	1,081
The Andrew Family Research Fund	10,016	(10,016)	-
Support costs	7	-	7
	<u>20,608</u>	<u>(19,520)</u>	<u>1,088</u>
TOTAL FUNDS	<u>79,886</u>	<u>(33,326)</u>	<u>46,560</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	36,087	(49,893)	(13,806)
Restricted funds			
Noonan Syndrome Research Fund	480	(9,984)	(9,504)
Families Event	11,500	(11,500)	-
The Andrew Family Research Fund	-	(10,016)	(10,016)
	<u>11,980</u>	<u>(31,500)</u>	<u>(19,520)</u>
TOTAL FUNDS	<u>48,067</u>	<u>(81,393)</u>	<u>(33,326)</u>

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2025

12. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1.4.23 £	Net movement in funds £	At 31.3.24 £
Unrestricted funds			
General fund	57,513	1,765	59,278
Restricted funds			
Noonan Syndrome Research Fund	30,255	(19,670)	10,585
The Andrew Family Research Fund	10,016	-	10,016
Support costs	7	-	7
	<u>40,278</u>	<u>(19,670)</u>	<u>20,608</u>
TOTAL FUNDS	<u>97,791</u>	<u>(17,905)</u>	<u>79,886</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	30,097	(28,332)	1,765
Restricted funds			
Noonan Syndrome Research Fund	330	(20,000)	(19,670)
TOTAL FUNDS	<u>30,427</u>	<u>(48,332)</u>	<u>(17,905)</u>

The Andrew Family Research Fund:
This is to fund medical research directly relevant to Noonan Syndrome.

13. RELATED PARTY DISCLOSURES

During the year the trustees made donations to the charity totalling £1,691 2024: £1,440).

Noonan Syndrome Association
Detailed Statement of Financial Activities
for the Year Ended 31 March 2025

	31.3.25 £	31.3.24 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	33,501	27,784
Gift aid	2,577	2,590
Grants	11,500	-
	<u>47,578</u>	<u>30,374</u>
Investment income		
Deposit account interest	54	53
Other interest	435	-
	<u>489</u>	<u>53</u>
Total incoming resources	<u>48,067</u>	<u>30,427</u>
EXPENDITURE		
Charitable activities		
Postage and stationery	529	1,350
Promotional material	84	450
Family day	31,828	-
Travel expenses	771	595
Computer & IT support costs	2,619	1,949
Charity Manager	17,933	16,747
Research	20,000	20,000
Administration costs	5,873	5,388
Staff & volunteer training	-	198
	<u>79,637</u>	<u>46,677</u>
Support costs		
Finance		
Bank charges	136	61
Governance costs		
Indemnity insurance	618	694
Accountancy and legal fees	1,002	900
	<u>1,620</u>	<u>1,594</u>
Total resources expended	<u>81,393</u>	<u>48,332</u>
Net expenditure	<u>(33,326)</u>	<u>(17,905)</u>

This page does not form part of the statutory financial statements

Accounts

**Report of the Trustees and
Financial Statements for the Year Ended 31 March 2024
for
Noonan Syndrome Association**

**Morgan Griffiths LLP
Chartered Accountants
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9 High Street
Newtown
Powys
SY16 2NY**

Noonan Syndrome Association

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Noonan Syndrome Association

**Reference and Administrative Details
for the Year Ended 31 March 2024**

TRUSTEES

Sharon Allsopp Chair
Andrea Reid - Kelly Deputy Chair
Grayson Bowler Treasurer
Michael Patton Medical Adviser
Brian Carlton
Jeanette Dyer
Ian Legg

PRINCIPAL ADDRESS

PO Box 692
Blackburn
BB2 9RF

**REGISTERED CHARITY
NUMBER**

1140671

INDEPENDENT EXAMINER

Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
Powys
SY16 2NY

BANKERS

Barclays Bank PLC
Leicester
LE87 2BB

Charity Manager

Sandie Dent

Correspondence Address

PO Box 692, Blackburn, BB2 9RF

Noonan Syndrome Association

Report of the Trustees for the Year Ended 31 March 2024

The trustees present their report with the financial statements of the charity for the year ended 31 March 2024. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

The objectives of the charity are to provide relief of all persons affected by Noonan Syndrome and related conditions (on the Ras/MAPK pathway) by all or any of the following means:

1. The provision of general advice, guidance and support services for persons affected by Noonan Syndrome and related conditions (on the Ras/MAPK pathway), their families, dependents and carers;
2. The facilitation and promotion of research into the causes, effects, diagnosis, treatment and relief of Noonan Syndrome and related conditions (on the Ras/MAPK pathway) with the useful results of research being disseminated for the benefit of the public;
3. The advancement in the education of the public in relation to the effects of Noonan Syndrome and related conditions (on the Ras/MAPK pathway) by communicating reports and disseminating information by any means or media concerning research work and studies undertaken by or on behalf of the charity.

In all that we do, our trustees have given careful consideration to the Charity Commission's general guidance on public benefit and have complied with the duty in section 4 of the 2011/2006 Charities Act.

ACHIEVEMENT AND PERFORMANCE

Charitable activities

The Charity entered the year in a strong financial position and a commitment to spend funds on:

- payment of the two research grant awards on successful completion of these projects
- delivering a Conference and Families Day/Activities Weekend in April 2024 (planned, organised, and with some expenditure falling into the 2023-4 financial year).

Planned strategic objectives delivered during the year including a review of key policies, development of formal recruitment process and packs for trustees and other volunteers, comprehensive safeguarding training for designated safeguarding leads, the Chair of trustees and the charity manager, and continued planning and delivering of online webinars on topical and important issues for members.

The two research projects 'pump-primed' by NSA grants completed successfully, helping those research teams secure future funding from other sources to progress their findings. The 'Living with Noonan Syndrome' social research project was also successfully delivered during the year, with early results from the survey element feeding into the charity's mid-term strategic review, and a fuller report from the in-depth interviews expected later in 2024. This has been an important project for the charity and will feed into the full strategic review late in 2024, to inform activities for 2025-6 and beyond.

The charity began supporting new research projects looking into Adult Noonan Syndrome and Learning in Young People with NS. Both subject areas are increasingly relevant and important to our members and the future of understanding, treatment and interventions for people with NS.

The charity opened an account with CAF bank to enable online banking, further increasing administrative efficiency to build on the significant systems and process improvements carried out in the previous year.

Towards the end of the year, we began detailed planning for a spring 2024 Conference and Families Day/weekend event, using feedback from the October 2022 event to inform a range of workshop topics and speakers.

Membership continued to grow during the year, almost doubling by year end.

Noonan Syndrome Association

Report of the Trustees for the Year Ended 31 March 2024

FINANCIAL REVIEW

Financial position

The statement of Financial Activities shows a deficit for the year of £17,905 (2023: £20,576), and reserves now stand at £79,886 (2023: £97,791).

Reserves policy

The charity does not have a separate formal policy on Reserves but following Board discussions, the Chair, Treasurer and Charity Manager follow a policy based on achieving free reserves of a minimum of between 3 and 6 months' operating costs including those associated with the cost of a part time charity manager.

The charity has an established and appropriate financial management system which is regularly reviewed by the Board and put into day to day practice by the Charity Manager, Charity Treasurer, Finance Officer together with the Chair of Trustees.

Free reserves which equate to net current assets (excluding restricted funds) amount to £59,278 (2023: £57,513).

FUTURE PLANS

The Board reviews its strategic plan annually with a mid-point review led by the Strategy & Finance subgroup. Significant progress has been made over the year, though limited internal staff resource continues to be a challenge in progressing objectives within the ambitious timescales agreed. We will continue to review and adjust timescales to ensure they are realistic, but overall good progress has been made against key objectives which have strengthened the charity's operational structure and increased our visibility and standing.

Over the coming financial year, we will progress actions on our Communications plan, including active recruitment of specialist volunteers to support with this. The plan supports several strategic objectives and is critical to the Charity's aim to increase regular giving and raise its profile within the health and social care sectors.

We will also make further enhancements to website resources and continue exploring options for reaching and supporting more members across the UK. We will deliver a Conference and Families Event with national and international speakers who have expert knowledge of Noonan Syndrome.

As the charity's membership continues to grow significantly, so the activities and resource to deliver them need also to grow. Managing this in a safe and positive way will continue to be a key focus during 2024/25.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust and constitutes an unincorporated charity.

Recruitment and appointment of new trustees

Trustees are elected by way of a resolution of the Charity at the Annual General Meeting. The Trustees also have the power at any time, and from time to time, to appoint any person to be a Trustee [subject to certain restrictions], either to fill a casual vacancy or as an addition to the existing members of the Board of Trustees but so that the total number of Trustees does not exceed any maximum number fixed in accordance with this Constitution. Any Trustee so appointed shall hold office only until the next following Annual General Meeting, and shall then be eligible for re-election.

Noonan Syndrome Association

**Report of the Trustees
for the Year Ended 31 March 2024**

STRUCTURE, GOVERNANCE AND MANAGEMENT

Organisational structure

The charity is organised so that the trustees meet regularly to manage its affairs. Full Trustee Board meetings are held at least four times per year with other meetings held as required, both face to face and by conference call or internet.

There is an Annual General Meeting held for all the members of the charity at which Trustees are elected or confirmed.

The part time Charity Manager undertakes most of the day to day operations of the charity. In addition to a Chair, the trustees have appointed a Deputy Chair and a Treasurer.

Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error. It has an agreed set of financial procedures and policies, practices and guidance to cover its activities, including the reserves policy set out above.

Approved by order of the board of trustees on 25 January 2025 and signed on its behalf by:

A handwritten signature in black ink, appearing to read 'Sharon Allsopp', with a stylized flourish at the end.

Sharon Allsopp - Trustee

**Independent Examiner's Report to the Trustees of
Noonan Syndrome Association**

Independent examiner's report to the trustees of Noonan Syndrome Association

I report to the charity trustees on my examination of the accounts of Noonan Syndrome Association (the Trust) for the year ended 31 March 2024.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under Section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under Section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by Section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

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.



Thomas Landers BA FCA

Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
Powys
SY16 2NY

25 January 2025

Noonan Syndrome Association

Statement of Financial Activities
for the Year Ended 31 March 2024

		Unrestricted fund £	Restricted funds £	31.3.24 Total funds £	31.3.23 Total funds £
	Notes				
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	30,044	330	30,374	30,268
Charitable activities	4				
Research		-	-	-	8,021
Support Network		-	-	-	8,542
Awareness		-	-	-	10,042
Investment income	3	53	-	53	-
Other income		-	-	-	3,025
Total		<u>30,097</u>	<u>330</u>	<u>30,427</u>	<u>59,898</u>
EXPENDITURE ON					
Charitable activities	5				
Research		5,677	20,000	25,677	6,474
Support Network		11,322	-	11,322	49,832
Awareness		11,333	-	11,333	24,168
Total		<u>28,332</u>	<u>20,000</u>	<u>48,332</u>	<u>80,474</u>
NET INCOME/(EXPENDITURE)		1,765	(19,670)	(17,905)	(20,576)
RECONCILIATION OF FUNDS					
Total funds brought forward		57,513	40,278	97,791	118,367
TOTAL FUNDS CARRIED FORWARD		<u>59,278</u>	<u>20,608</u>	<u>79,886</u>	<u>97,791</u>

The notes form part of these financial statements

Noonan Syndrome Association

**Balance Sheet
31 March 2024**

	Notes	31.3.24 £	31.3.23 £
CURRENT ASSETS			
Debtors	10	28,901	6,565
Cash at bank		70,396	96,028
		<u>99,297</u>	<u>102,593</u>
CREDITORS			
Amounts falling due within one year	11	(19,411)	(4,802)
		<u>79,886</u>	<u>97,791</u>
NET CURRENT ASSETS			
		<u>79,886</u>	<u>97,791</u>
TOTAL ASSETS LESS CURRENT LIABILITIES			
		<u>79,886</u>	<u>97,791</u>
NET ASSETS		<u>79,886</u>	<u>97,791</u>
FUNDS	13		
Unrestricted funds		59,278	57,513
Restricted funds		20,608	40,278
TOTAL FUNDS		<u>79,886</u>	<u>97,791</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 25 January 2025 and were signed on its behalf by:


Sharon Allsopp - Trustee

The notes form part of these financial statements

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Income recognition

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

2. DONATIONS AND LEGACIES

	31.3.24	31.3.23
	£	£
Donations	27,784	27,341
Gift aid	2,590	2,927
	<u>30,374</u>	<u>30,268</u>

Noonan Syndrome Association

**Notes to the Financial Statements - continued
for the Year Ended 31 March 2024**

3. INVESTMENT INCOME

	31.3.24 £	31.3.23 £
Deposit account interest	53	-
	<u>53</u>	<u>-</u>

4. INCOME FROM CHARITABLE ACTIVITIES

	31.3.24 £	31.3.23 £
Grants Activity		
Grants Research	-	8,021
Grants Support Network	-	8,542
Grants Awareness	-	10,042
	<u>-</u>	<u>26,605</u>
	<u>-</u>	<u>26,605</u>

Grants received, included in the above, are as follows:

	31.3.24 £	31.3.23 £
Novo Nordisk Limited	-	10,105
Sense - The National Deafblind and Rubella Association	-	8,500
St George's Hospital Charity	-	8,000
	<u>-</u>	<u>26,605</u>
	<u>-</u>	<u>26,605</u>

5. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 6) £	Support costs (see note 7) £	Totals £
Research	25,346	331	25,677
Support Network	10,660	662	11,322
Awareness	10,671	662	11,333
	<u>46,677</u>	<u>1,655</u>	<u>48,332</u>
	<u>46,677</u>	<u>1,655</u>	<u>48,332</u>

6. DIRECT COSTS OF CHARITABLE ACTIVITIES

	31.3.24 £	31.3.23 £
Postage and stationery	1,350	1,035
Promotional material	450	668
Sundries	-	878
Family day	-	35,635
Travel expenses	595	187
Computer & IT support costs	1,949	14,957
Charity Manager	16,747	18,783
Research	20,000	-
Administration costs	5,388	6,666
Staff & volunteer training	198	-
	<u>46,677</u>	<u>78,809</u>
	<u>46,677</u>	<u>78,809</u>

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2024

7. SUPPORT COSTS

	Finance £	Governance costs £	Totals £
Research	13	318	331
Support Network	24	638	662
Awareness	24	638	662
	<u>61</u>	<u>1,594</u>	<u>1,655</u>

Activity	Basis of allocation
Management	Based on time
Finance	Based on time
Governance costs	Based on time

8. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2024 nor for the year ended 31 March 2023.

Trustees' expenses

During the year no trustees were reimbursed for travelling expenses (2023 - nil).

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	26,681	3,587	30,268
Charitable activities			
Research	21	8,000	8,021
Support Network	42	8,500	8,542
Awareness	42	10,000	10,042
Other income	3,025	-	3,025
Total	<u>29,811</u>	<u>30,087</u>	<u>59,898</u>
EXPENDITURE ON			
Charitable activities			
Research	6,474	-	6,474
Support Network	18,045	31,787	49,832
Awareness	14,168	10,000	24,168
Total	<u>38,687</u>	<u>41,787</u>	<u>80,474</u>
NET INCOME/(EXPENDITURE)	(8,876)	(11,700)	(20,576)
RECONCILIATION OF FUNDS			
Total funds brought forward	66,389	51,978	118,367

Noonan Syndrome Association

**Notes to the Financial Statements - continued
for the Year Ended 31 March 2024**

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted fund £	Restricted funds £	Total funds £
TOTAL FUNDS CARRIED FORWARD	57,513	40,278	97,791

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.3.24 £	31.3.23 £
Trade debtors	10	-
Accrued income	8,169	5,599
Prepayments	20,722	966
	28,901	6,565

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.3.24 £	31.3.23 £
Trade creditors	900	3,902
Other creditors	18,511	900
	19,411	4,802

12. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted fund £	Restricted funds £	31.3.24 Total funds £	31.3.23 Total funds £
Current assets	78,689	20,608	99,297	102,593
Current liabilities	(19,411)	-	(19,411)	(4,802)
	59,278	20,608	79,886	97,791

13. MOVEMENT IN FUNDS

	At 1.4.23 £	Net movement in funds £	At 31.3.24 £
Unrestricted funds			
General fund	57,513	1,765	59,278
Restricted funds			
Noonan Syndrome Research Fund	30,255	(19,670)	10,585
The Andrew Family Research Fund	10,016	-	10,016
Support costs	7	-	7
	40,278	(19,670)	20,608
TOTAL FUNDS	97,791	(17,905)	79,886

Noonan Syndrome Association

**Notes to the Financial Statements - continued
for the Year Ended 31 March 2024**

13. MOVEMENT IN FUNDS - continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	30,097	(28,332)	1,765
Restricted funds			
Noonan Syndrome Research Fund	330	(20,000)	(19,670)
TOTAL FUNDS	<u>30,427</u>	<u>(48,332)</u>	<u>(17,905)</u>

Comparatives for movement in funds

	At 1.4.22 £	Net movement in funds £	At 31.3.23 £
Unrestricted funds			
General fund	66,389	(8,876)	57,513
Restricted funds			
Noonan Syndrome Research Fund	21,955	8,300	30,255
Families Event	20,000	(20,000)	-
The Andrew Family Research Fund	10,016	-	10,016
Support costs	7	-	7
	<u>51,978</u>	<u>(11,700)</u>	<u>40,278</u>
TOTAL FUNDS	<u>118,367</u>	<u>(20,576)</u>	<u>97,791</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	29,811	(38,687)	(8,876)
Restricted funds			
Noonan Syndrome Research Fund	8,300	-	8,300
Families Event	8,500	(28,500)	(20,000)
Support costs	3,287	(3,287)	-
Awareness	10,000	(10,000)	-
	<u>30,087</u>	<u>(41,787)</u>	<u>(11,700)</u>
TOTAL FUNDS	<u>59,898</u>	<u>(80,474)</u>	<u>(20,576)</u>

The Andrew Family Research Fund:

Noonan Syndrome Association
Notes to the Financial Statements - continued
for the Year Ended 31 March 2024

13. MOVEMENT IN FUNDS - continued

This is to fund medical research directly relevant to Noonan Syndrome.

14. RELATED PARTY DISCLOSURES

During the year the trustees made donations to the charity totalling £1,440 2023: £1,590).

Noonan Syndrome Association
Detailed Statement of Financial Activities
for the Year Ended 31 March 2024

	31.3.24 £	31.3.23 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	27,784	27,341
Gift aid	2,590	2,927
	<u>30,374</u>	<u>30,268</u>
Investment income		
Deposit account interest	53	-
Charitable activities		
Grants	-	26,605
Other income		
Other Income	-	3,025
	<u>30,427</u>	<u>59,898</u>
Total incoming resources		
	30,427	59,898
EXPENDITURE		
Charitable activities		
Postage and stationery	1,350	1,035
Promotional material	450	668
Sundries	-	878
Family day	-	35,635
Travel expenses	595	187
Computer & IT support costs	1,949	14,957
Charity Manager	16,747	18,783
Research	20,000	-
Administration costs	5,388	6,666
Staff & volunteer training	198	-
	<u>46,677</u>	<u>78,809</u>
Support costs		
Finance		
Bank charges	61	-
Governance costs		
Indemnity insurance	694	669
Accountancy and legal fees	900	996
	<u>1,594</u>	<u>1,665</u>
Total resources expended	<u>48,332</u>	<u>80,474</u>
Net expenditure	<u>(17,905)</u>	<u>(20,576)</u>

This page does not form part of the statutory financial statements

Accounts

**Report of the Trustees and
Financial Statements for the Year Ended 31 March 2023
for
Noonan Syndrome Association**

**Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
Powys
SY16 2NY**

Noonan Syndrome Association

**Contents of the Financial Statements
for the Year Ended 31 March 2023**

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Noonan Syndrome Association

**Reference and Administrative Details
for the Year Ended 31 March 2023**

TRUSTEES

Sharon Allsopp Chair
Andrea Reid - Kelly Deputy Chair
Grayson Bowler Treasurer
Michael Patton Medical Adviser
Brian Carlton
Jeanette Dyer
Ian Legg

PRINCIPAL ADDRESS

PO Box 692
Blackburn
BB2 9RF

**REGISTERED CHARITY
NUMBER**

1140671

INDEPENDENT EXAMINER

Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
Powys
SY16 2NY

BANKERS

Barclays Bank PLC
Leicester
LE87 2BB

Charity Manager

Sandie Dent

Correspondence Address

PO Box 692, Blackburn, BB2 9RF

The trustees present their report with the financial statements of the charity for the year ended 31 March 2023. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

The objectives of the charity are to provide relief of all persons affected by Noonan Syndrome and related conditions (on the Ras/MAPK pathway) by all or any of the following means:

1. The provision of general advice, guidance and support services for persons affected by Noonan Syndrome and related conditions (on the Ras/MAPK pathway), their families, dependents and carers;
2. The facilitation and promotion of research into the causes, effects, diagnosis, treatment and relief of Noonan Syndrome and related conditions (on the Ras/MAPK pathway) with the useful results of research being disseminated for the benefit of the public;
3. The advancement in the education of the public in relation to the effects of Noonan Syndrome and related conditions (on the Ras/MAPK pathway) by communicating reports and disseminating information by any means or media concerning research work and studies undertaken by or on behalf of the charity.

In all that we do, our trustees have given careful consideration to the Charity Commission's general guidance on public benefit and have complied with the duty in section 4 of the 2011/2006 Charities Act.

ACHIEVEMENT AND PERFORMANCE

Charitable activities

The Charity entered the year in a strong financial position, with an agreed strategy to invest surplus funds into:

- further strengthening its operational systems and processes
- developing a new website and commissioning the professional creation of medical factsheets
- delivering a Families Day/Activities Weekend, which had not been possible in the two preceding years due to the Covid-19 pandemic

Other planned key strategic objectives were delivered during the year, including a successful application to the Cranfield Trust to further develop the Charity's strategy and 3-year business plan. This involved Mentor/Critical Friend support for the Charity Manager over a six-month period. We also continued to deliver online webinars on a range of medical and non-medical topics to support our members.

With the two research projects 'pump-primed' by NSA grants underway, the Charity supported an additional project delivered in collaboration with Loughborough University: Living with Noonan Syndrome. This social research study will explore, through surveys and in-depth interviews, the day-to-day experience of families and individuals affected by Noonan Syndrome and provide greater understanding of how the condition impacts on people's lives. This understanding will not only contribute to learning within the health and social care sectors but will also help inform the Charity's future support activities.

The planned retirement of the Finance Officer in October gave us time to develop and implement new financial processes with no disruption to the Charity's operations. We invested in Xero finance software and recruited an external professional bookkeeper to handle the day-to-day recording and reconciliation of the Charity's accounts.

Towards the end of the year, we launched the new website and medical factsheets as planned. The enhanced look and searchability of the site has resulted in an increase in new members, including health and social care professionals. In October, we held a Families Weekend/Conference at Whitemoor Lakes Activity Centre, with workshops, presentations and a medical Q&A session for adults and a range of exciting activities for children.

FINANCIAL REVIEW

Financial position

The statement of Financial Activities shows a deficit for the year of £20,576 (2022: surplus £24,190), and reserves now stand at £97,791 (2022: £118,367).

Reserves policy

The charity does not have a separate formal policy on Reserves but following Board discussions, the Chair, Treasurer and Charity Manager follow a policy based on achieving free reserves of a minimum of between 3 and 6 months' operating costs including those associated with the cost of a part time charity manager.

The charity has an established and appropriate financial management system which is regularly reviewed by the Board and put into day to day practice by the Charity Manager, Charity Treasurer, Finance Officer together with the Chair of Trustees.

Free reserves which equate to net current assets (excluding restricted funds) amount to £57,513 (2022: £66,389).

FUTURE PLANS

The Board reviews its strategic plan annually with a mid-point review carried out by the Strategy & Finance subgroup to check progress. Significant progress has been made over the year, though limited internal staff resource can be a challenge in progressing objectives within the ambitious timescales agreed. We will continue to review and adjust timescales to ensure they are realistic, but overall good progress has been made against key objectives which have strengthened the charity's operational structure.

Over the coming financial year, we will be working with Cranfield Trust again, to develop a Communications Plan. This plan supports several strategic objectives and will be critical in the Charity's aim to increase regular giving and raise its profile within the health and social care sectors. We will also make further enhancements to the website, explore options for regional support for members, and recruit operational volunteers and two additional trustees with relevant experience in finance, marketing and/or communications.

As the charity's membership continues to grow, so the activities and resource to deliver them need also to grow. Managing this in a safe and positive way will continue to be a key focus during 2023/24.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust and constitutes an unincorporated charity.

Recruitment and appointment of new trustees

Trustees are elected by way of a resolution of the Charity at the Annual General Meeting. The Trustees also have the power at any time, and from time to time, to appoint any person to be a Trustee [subject to certain restrictions], either to fill a casual vacancy or as an addition to the existing members of the Board of Trustees but so that the total number of Trustees does not exceed any maximum number fixed in accordance with this Constitution. Any Trustee so appointed shall hold office only until the next following Annual General Meeting, and shall then be eligible for re-election.

Organisational structure

The charity is organised so that the trustees meet regularly to manage its affairs. Full Trustee Board meetings are held at least four times per year with other meetings held as required, both face to face and by conference call or internet.

There is an Annual General Meeting held for all the members of the charity at which Trustees are elected or confirmed.

The part time Charity Manager undertakes most of the day to day operations of the charity. In addition to a Chair, the trustees have appointed a Deputy Chair and a Treasurer.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error. It has an agreed set of financial procedures and policies, practices and guidance to cover its activities, including the reserves policy set out above.

Approved by order of the board of trustees on 30 January 2024 and signed on its behalf by:

A handwritten signature in black ink, appearing to read 'Sharon Allsopp', with a stylized flourish at the end.

Sharon Allsopp - Trustee

Independent examiner's report to the trustees of Noonan Syndrome Association

I report to the charity trustees on my examination of the accounts of Noonan Syndrome Association (the Trust) for the year ended 31 March 2023.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under Section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under Section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by Section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

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.



Thomas Landers BA FCA

Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
Powys
SY16 2NY

30 January 2024

Noonan Syndrome Association

Statement of Financial Activities
for the Year Ended 31 March 2023

	Notes	Unrestricted fund £	Restricted funds £	31.3.23 Total funds £	31.3.22 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	26,681	3,587	30,268	27,360
Charitable activities	3				
Research		21	8,000	8,021	23,150
Support Network		42	8,500	8,542	12,750
Awareness		42	10,000	10,042	-
Other income		<u>3,025</u>	<u>-</u>	<u>3,025</u>	<u>-</u>
Total		<u>29,811</u>	<u>30,087</u>	<u>59,898</u>	<u>63,260</u>
EXPENDITURE ON					
Charitable activities	4				
Research		6,474	-	6,474	7,376
Support Network		18,045	31,787	49,832	21,831
Awareness		<u>14,168</u>	<u>10,000</u>	<u>24,168</u>	<u>9,863</u>
Total		<u>38,687</u>	<u>41,787</u>	<u>80,474</u>	<u>39,070</u>
NET INCOME/(EXPENDITURE)		(8,876)	(11,700)	(20,576)	24,190
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>66,389</u>	<u>51,978</u>	<u>118,367</u>	<u>94,177</u>
TOTAL FUNDS CARRIED FORWARD		<u>57,513</u>	<u>40,278</u>	<u>97,791</u>	<u>118,367</u>

The notes form part of these financial statements

Noonan Syndrome Association

**Balance Sheet
31 March 2023**

	Notes	31.3.23 £	31.3.22 £
CURRENT ASSETS			
Debtors	10	6,565	10,912
Cash at bank		<u>96,028</u>	<u>108,259</u>
		102,593	119,171
CREDITORS			
Amounts falling due within one year	11	(4,802)	(804)
		<u>97,791</u>	<u>118,367</u>
NET CURRENT ASSETS			
		<u>97,791</u>	<u>118,367</u>
TOTAL ASSETS LESS CURRENT LIABILITIES			
		97,791	118,367
NET ASSETS			
		<u>97,791</u>	<u>118,367</u>
FUNDS	13		
Unrestricted funds		57,513	66,389
Restricted funds		<u>40,278</u>	<u>51,978</u>
TOTAL FUNDS		<u>97,791</u>	<u>118,367</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 30 January 2024 and were signed on its behalf by:



Sharon Allsopp - Trustee

The notes form part of these financial statements

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Income recognition

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

2. DONATIONS AND LEGACIES

	31.3.23	31.3.22
	£	£
Donations	27,341	24,593
Gift aid	<u>2,927</u>	<u>2,767</u>
	<u><u>30,268</u></u>	<u><u>27,360</u></u>

Noonan Syndrome Association

**Notes to the Financial Statements - continued
for the Year Ended 31 March 2023**

3. INCOME FROM CHARITABLE ACTIVITIES

		31.3.23	31.3.22
	Activity	£	£
Grants	Research	8,021	23,150
Grants	Support Network	8,542	12,750
Grants	Awareness	<u>10,042</u>	<u>-</u>
		<u>26,605</u>	<u>35,900</u>

Grants received, included in the above, are as follows:

	31.3.23	31.3.22
	£	£
Novo Nordisk Limited	10,105	10,900
Novacyt Group	-	25,000
Sense - The National Deafblind and Rubella Association	8,500	-
St George's Hospital Charity	<u>8,000</u>	<u>-</u>
	<u>26,605</u>	<u>35,900</u>

4. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 5) £	Support costs (see note 7) £	Totals £
Research	6,141	333	6,474
Support Network	49,166	666	49,832
Awareness	<u>23,502</u>	<u>666</u>	<u>24,168</u>
	<u>78,809</u>	<u>1,665</u>	<u>80,474</u>

5. DIRECT COSTS OF CHARITABLE ACTIVITIES

	31.3.23	31.3.22
	£	£
Telephone	-	479
Postage and stationery	1,035	1,333
Promotional material	668	-
Sundries	878	2,080
Family day	35,635	-
Travel expenses	187	-
Computer & IT support costs	14,957	2,394
Charity Manager	18,783	20,270
Administration costs	<u>6,666</u>	<u>-</u>
	<u>78,809</u>	<u>26,556</u>

Noonan Syndrome Association

**Notes to the Financial Statements - continued
for the Year Ended 31 March 2023**

6. GRANTS PAYABLE

	31.3.23	31.3.22
	£	£
Research	-	3,150
Support Network	-	7,743
	<u>-</u>	<u>10,893</u>

The total grants paid to institutions during the year was as follows:

	31.3.23	31.3.22
	£	£
Great Ormond Street Hospital	-	7,743
Loughborough University	-	3,150
	<u>-</u>	<u>10,893</u>

7. SUPPORT COSTS

	Governance costs £
Research	333
Support Network	666
Awareness	666
	<u>1,665</u>

Activity	Basis of allocation
Management	Based on time
Governance costs	Based on time

8. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2023 nor for the year ended 31 March 2022.

Trustees' expenses

During the year no trustees were reimbursed for travelling expenses (2022 - nil).

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	27,060	300	27,360
Charitable activities			
Research	-	23,150	23,150
Support Network	-	12,750	12,750
	<u>-</u>	<u>12,750</u>	<u>12,750</u>
Total	<u>27,060</u>	<u>36,200</u>	<u>63,260</u>

EXPENDITURE ON

Noonan Syndrome Association

**Notes to the Financial Statements - continued
for the Year Ended 31 March 2023**

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted fund £	Restricted funds £	Total funds £
Charitable activities			
Research	4,226	3,150	7,376
Support Network	14,088	7,743	21,831
Awareness	9,863	-	9,863
Total	28,177	10,893	39,070
NET INCOME/(EXPENDITURE)	(1,117)	25,307	24,190
RECONCILIATION OF FUNDS			
Total funds brought forward	67,506	26,671	94,177
TOTAL FUNDS CARRIED FORWARD	66,389	51,978	118,367

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.3.23 £	31.3.22 £
Accrued income	5,599	2,652
Prepayments	966	8,260
	6,565	10,912

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.3.23 £	31.3.22 £
Trade creditors	3,902	-
Other creditors	900	804
	4,802	804

12. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted fund £	Restricted funds £	31.3.23 Total funds £	31.3.22 Total funds £
Current assets	62,315	40,278	102,593	119,171
Current liabilities	(4,802)	-	(4,802)	(804)
	57,513	40,278	97,791	118,367

Noonan Syndrome Association

**Notes to the Financial Statements - continued
for the Year Ended 31 March 2023**

13. MOVEMENT IN FUNDS

	At 1.4.22 £	Net movement in funds £	At 31.3.23 £
Unrestricted funds			
General fund	66,389	(8,876)	57,513
Restricted funds			
Noonan Syndrome Research Fund	21,955	8,300	30,255
Families Event	20,000	(20,000)	-
The Andrew Family Research Fund	10,016	-	10,016
Support costs	7	-	7
	<u>51,978</u>	<u>(11,700)</u>	<u>40,278</u>
TOTAL FUNDS	<u>118,367</u>	<u>(20,576)</u>	<u>97,791</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	29,811	(38,687)	(8,876)
Restricted funds			
Noonan Syndrome Research Fund	8,300	-	8,300
Families Event	8,500	(28,500)	(20,000)
Support costs	3,287	(3,287)	-
Awareness	10,000	(10,000)	-
	<u>30,087</u>	<u>(41,787)</u>	<u>(11,700)</u>
TOTAL FUNDS	<u>59,898</u>	<u>(80,474)</u>	<u>(20,576)</u>

Comparatives for movement in funds

	At 1.4.21 £	Net movement in funds £	At 31.3.22 £
Unrestricted funds			
General fund	67,506	(1,117)	66,389
Restricted funds			
Noonan Syndrome Research Fund	1,655	20,300	21,955
Families Event	15,000	5,000	20,000
The Andrew Family Research Fund	10,016	-	10,016
Support costs	-	7	7
	<u>26,671</u>	<u>25,307</u>	<u>51,978</u>
TOTAL FUNDS	<u>94,177</u>	<u>24,190</u>	<u>118,367</u>

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2023

13. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	27,060	(28,177)	(1,117)
Restricted funds			
Noonan Syndrome Research Fund	20,300	-	20,300
Families Event	5,000	-	5,000
The Andrew Family Research Fund	3,150	(3,150)	-
Support costs	7,750	(7,743)	7
	<u>36,200</u>	<u>(10,893)</u>	<u>25,307</u>
TOTAL FUNDS	<u>63,260</u>	<u>(39,070)</u>	<u>24,190</u>

The Andrew Family Research Fund:

This is to fund medical research directly relevant to Noonan Syndrome.

14. RELATED PARTY DISCLOSURES

During the year the trustees made donations to the charity totalling £1,590 2022: £2,181).

Noonan Syndrome Association
Detailed Statement of Financial Activities
for the Year Ended 31 March 2023

	31.3.23 £	31.3.22 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	27,341	24,593
Gift aid	2,927	2,767
	<u>30,268</u>	<u>27,360</u>
Charitable activities		
Grants	26,605	35,900
Other income		
Other Income	3,025	-
Total incoming resources	<u>59,898</u>	<u>63,260</u>
EXPENDITURE		
Charitable activities		
Telephone	-	479
Postage and stationery	1,035	1,333
Promotional material	668	-
Sundries	878	2,080
Family day	35,635	-
Travel expenses	187	-
Computer & IT support costs	14,957	2,394
Charity Manager	18,783	20,270
Administration costs	6,666	-
Grants to institutions	-	10,893
	<u>78,809</u>	<u>37,449</u>
Support costs		
Governance costs		
Indemnity insurance	669	733
Accountancy and legal fees	996	888
	<u>1,665</u>	<u>1,621</u>
Total resources expended	<u>80,474</u>	<u>39,070</u>
Net (expenditure)/income	<u>(20,576)</u>	<u>24,190</u>

This page does not form part of the statutory financial statements

Accounts

**Report of the Trustees and
Financial Statements for the Year Ended 31 March 2022
for
Noonan Syndrome Association**

Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
Powys
SY16 2NY

Noonan Syndrome Association
Contents of the Financial Statements
for the Year Ended 31 March 2022

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Detailed Statement of Financial Activities	14

Noonan Syndrome Association

**Reference and Administrative Details
for the Year Ended 31 March 2022**

TRUSTEES	Katie Ballard Chair (resigned 31.3.22) Sharon Allsopp Deputy Chair Stephen Hoey Treasurer (resigned 8.5.21) Michael Patton Medical Adviser Ian Legg Grayson Bowler (Treasurer from 9th May 2021) Brian Carlton Jeanette Dyer Andrea Reid - Kelly Gemma Wilkes (resigned 28.1.22)
PRINCIPAL ADDRESS	PO Box 692 Blackburn BB2 9RF
REGISTERED CHARITY NUMBER	1140671
INDEPENDENT EXAMINER	Morgan Griffiths LLP Chartered Accountants Cross Chambers 9 High Street Newtown Powys SY16 2NY
BANKERS	Barclays Bank PLC Leicester LE87 2BB

Charity Manager

Sandie Dent

Correspondence Address

PO Box 692, Blackburn, BB2 9RF

Noonan Syndrome Association
Report of the Trustees
for the Year Ended 31 March 2022

The trustees present their report with the financial statements of the charity for the year ended 31 March 2022. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

The objectives of the charity are to provide relief of all persons affected by Noonan Syndrome and related conditions (on the Ras/MAPK pathway) by all or any of the following means:

1. The provision of general advice, guidance and support services for persons affected by Noonan Syndrome and related conditions (on the Ras/MAPK pathway), their families, dependents and carers;
2. The facilitation and promotion of research into the causes, effects, diagnosis, treatment and relief of Noonan Syndrome and related conditions (on the Ras/MAPK pathway) with the useful results of research being disseminated for the benefit of the public;
3. The advancement in the education of the public in relation to the effects of Noonan Syndrome and related conditions (on the Ras/MAPK pathway) by communicating reports and disseminating information by any means or media concerning research work and studies undertaken by or on behalf of the charity.

In all that we do, our trustees have given careful consideration to the Charity Commission's general guidance on public benefit and have complied with the duty in section 4 of the 2011/2006 Charities Act.

Noonan Syndrome Association
Report of the Trustees
for the Year Ended 31 March 2022

ACHIEVEMENT AND PERFORMANCE

Charitable activities

The Charity entered the year in a strong financial position due to reduced expenditure (postponement of Families Day in 2020) but stable regular-giver and grant income in the previous year.

With the continuing Covid-19 uncertainty and the vulnerability of many members as we entered the 2021-22 financial year, a series of online webinars were planned and held in place of the in-person Families Day event. We used a professional company to host quarterly webinars and an AGM and found this to be a cost-effective and successful way to support members remotely. Guest medical professionals gave presentations and took part in live Q&A sessions, with good member attendance and very positive feedback.

We invited applications for the two 'pump-primer' research grants which had been postponed in the previous year and, following an extensive application review process, awarded both grants. The funding will support two exciting and innovative research projects which will contribute to Noonan Syndrome learning and hopefully attract longer-term external funding to take the research forward beyond the initial project term.

The new specialist Rasopathies clinic at Great Ormond Street Hospital opened, with the NSA contributing towards the cost of the part-time specialist nurse in collaboration with the main funder, One Great Day. The clinic started later than planned due to pandemic-related delays but opened with a substantial patient list and ongoing demand throughout the year. We provided support to the GOSH team in collecting information for a business case to secure future funding.

With the new charity manager in place, and the previous manager retained on a part-time basis as Finance Officer, the Board of Trustees focused on a review of charity governance. This included a Board skills audit, developing Terms of Reference for subgroups and a Code of Conduct for trustees, as well as a formal trustee recruitment pack and process. The Board also reviewed the 15-month plan, revisiting the charity's aims and objectives. This led to development of a formal Theory of Change and a three-year strategic plan to support it.

During the year, Treasurer Steve Hoey resigned due to a change in work commitments and Trustee Gemma Wilks resigned due to family commitments. An existing Trustee, Grayson Bowler, stepped into the Treasurer role with unanimous agreement of the Board. At the end of the year, Chair Katie Ballard also resigned due to increased work commitments. The Board held an Extraordinary Meeting and unanimously voted in the Deputy Chair, Sharon Allsopp, as Chair for the coming financial year.

In line with the Board's commitment to improve systems and processes to make the charity more efficient and effective, we invested in a professional CRM system and various integrated apps which will help in managing and communicating with our growing membership base.

FINANCIAL REVIEW

Financial position

The statement of Financial Activities shows a surplus for the year of £24,190 (2021: £32,321), and reserves now stand at £118,367 (2021: £94,177).

Reserves policy

The charity does not have a separate formal policy on Reserves but following Board discussions, the Chair, Treasurer and Charity Manager follow a policy based on achieving free reserves of a minimum of between 3 and 6 months' operating costs including those associated with the cost of a part time charity manager.

The charity has an established and appropriate financial management system which is regularly reviewed by the Board and put into day to day practice by the Charity Manager, Charity Treasurer, Finance Officer together with the Chair of Trustees.

Free reserves which equate to net current assets (excluding restricted funds) amount to £66,389 (2021: £67,506).

FUTURE PLANS

A Families Day/Activities Weekend is planned for early October 2022, which will be the first in-person event since before the Covid-19 pandemic. However, the success of the online webinars - and their potential for greater inclusivity than in-person events - mean we will continue to offer these as an additional support activity for members each year.

With the Charity surplus high at the end of this financial year, the Board is keen to invest in areas which will improve operational and support activities. Some are already in progress and will be completed in 2022-23:

- Developing a new, more functional and attractive website;
- Commissioning a series of digital and print medical factsheets on relevant aspects of NS;
- Recruitment of new trustees and volunteers to support subgroup activities;
- Continued investment in new systems and processes to support the charity's operations, such as exploring online banking options; and
- Seeking free professional consultancy through The Cranfield Trust to support strategic objectives.

Key strategic objectives include increasing income and diversity of income, and widening the range of support available to members (i.e. regional events, new webinar topics, communications). As the charity's membership grows, so the activities and resource to deliver them need also to grow. Managing this in a safe and positive way will continue to be a key focus during 2022/23.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust and constitutes an unincorporated charity.

Recruitment and appointment of new trustees

Trustees are elected by way of a resolution of the Charity at the Annual General Meeting. The Trustees also have the power at any time, and from time to time, to appoint any person to be a Trustee [subject to certain restrictions], either to fill a casual vacancy or as an addition to the existing members of the Board of Trustees but so that the total number of Trustees does not exceed any maximum number fixed in accordance with this Constitution. Any Trustee so appointed shall hold office only until the next following Annual General Meeting, and shall then be eligible for re-election.

Organisational structure

The charity is organised so that the trustees meet regularly to manage its affairs. Full Trustee Board meetings are held at least four times per year with other meetings held as required, both face to face and by conference call or internet.

There is an Annual General Meeting held for all the members of the charity at which Trustees are elected or confirmed.

The part time Charity Manager undertakes most of the day to day operations of the charity. In addition to a Chair, the trustees have appointed a Deputy Chair and a Treasurer.

Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error. It has an agreed set of financial procedures and policies, practices and guidance to cover its activities, including the reserves policy set out above.

Approved by order of the board of trustees on 28 January 2023 and signed on its behalf by:

Sharon Allsopp - Trustee

**Independent Examiner's Report to the Trustees of
Noonan Syndrome Association**

Independent examiner's report to the trustees of Noonan Syndrome Association

I report to the charity trustees on my examination of the accounts of Noonan Syndrome Association (the Trust) for the year ended 31 March 2022.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under Section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under Section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by Section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

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.

Thomas Landers BA FCA
Institute of Chartered Accountants in England & Wales
Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
Powys
SY16 2NY

Date:

Noonan Syndrome Association

Statement of Financial Activities
for the Year Ended 31 March 2022

		Unrestricted fund £	Restricted funds £	31.3.22 Total funds £	31.3.21 Total funds £
	Notes				
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	27,060	300	27,360	40,476
Charitable activities	3				
Research		-	23,150	23,150	-
Support Network		-	12,750	12,750	25,820
Total		<u>27,060</u>	<u>36,200</u>	<u>63,260</u>	<u>66,296</u>
EXPENDITURE ON					
Charitable activities	4				
Research		4,226	3,150	7,376	3,384
Support Network		14,088	7,743	21,831	22,692
Awareness		9,863	-	9,863	7,899
Total		<u>28,177</u>	<u>10,893</u>	<u>39,070</u>	<u>33,975</u>
NET INCOME/(EXPENDITURE)		(1,117)	25,307	24,190	32,321
RECONCILIATION OF FUNDS					
Total funds brought forward		67,506	26,671	94,177	61,856
TOTAL FUNDS CARRIED FORWARD		<u><u>66,389</u></u>	<u><u>51,978</u></u>	<u><u>118,367</u></u>	<u><u>94,177</u></u>

The notes form part of these financial statements

Noonan Syndrome Association

Balance Sheet
31 March 2022

	Notes	31.3.22 £	31.3.21 £
CURRENT ASSETS			
Debtors	10	10,912	10,911
Cash at bank		108,259	83,986
		<u>119,171</u>	<u>94,897</u>
CREDITORS			
Amounts falling due within one year	11	(804)	(720)
		<u>118,367</u>	<u>94,177</u>
NET CURRENT ASSETS			
		<u>118,367</u>	<u>94,177</u>
TOTAL ASSETS LESS CURRENT LIABILITIES			
		118,367	94,177
NET ASSETS		<u>118,367</u>	<u>94,177</u>
FUNDS	13		
Unrestricted funds		66,389	67,506
Restricted funds		51,978	26,671
TOTAL FUNDS		<u>118,367</u>	<u>94,177</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 28 January 2023 and were signed on its behalf by:

Sharon Allsopp - Trustee

The notes form part of these financial statements

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

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Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

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The charity is exempt from tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

2. DONATIONS AND LEGACIES

	31.3.22	31.3.21
	£	£
Donations	24,593	38,023
Gift aid	2,767	2,453
	<u>27,360</u>	<u>40,476</u>

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2022

3. INCOME FROM CHARITABLE ACTIVITIES

		31.3.22 £	31.3.21 £
Grants	Activity		
	Research	23,150	-
Grants	Support Network	12,750	25,820
		<u>35,900</u>	<u>25,820</u>

Grants received, included in the above, are as follows:

	31.3.22 £	31.3.21 £
Vinci UK Foundation	-	15,000
Novo Nordisk Limited	10,900	10,820
Novacyt Group	25,000	-
	<u>35,900</u>	<u>25,820</u>

4. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 5) £	Grant funding of activities (see note 6) £	Support costs (see note 7) £	Totals £
Research	3,984	3,150	242	7,376
Support Network	13,277	7,743	811	21,831
Awareness	9,295	-	568	9,863
	<u>26,556</u>	<u>10,893</u>	<u>1,621</u>	<u>39,070</u>

5. DIRECT COSTS OF CHARITABLE ACTIVITIES

	31.3.22 £	31.3.21 £
Telephone	479	895
Postage and stationery	1,333	2,584
Sundries	2,080	640
Family day	-	165
Travel expenses	-	296
Computer & IT support costs	2,394	70
Charity Manager	20,270	16,491
Administration costs	-	3,500
	<u>26,556</u>	<u>24,641</u>

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2022

6. GRANTS PAYABLE

	31.3.22	31.3.21
	£	£
Research	3,150	-
Support Network	7,743	7,743
	<u>10,893</u>	<u>7,743</u>

The total grants paid to institutions during the year was as follows:

	31.3.22	31.3.21
	£	£
Great Ormond Street Hospital	7,743	7,743
Loughborough University	3,150	-
	<u>10,893</u>	<u>7,743</u>

7. SUPPORT COSTS

	Governance costs
	£
Research	242
Support Network	811
Awareness	568
	<u>1,621</u>

Activity	Basis of allocation
Management	Based on time
Governance costs	Based on time

8. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2022 nor for the year ended 31 March 2021.

Trustees' expenses

During the year no trustees were reimbursed for travelling expenses (2021- one trustee was reimbursed £198).

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund	Restricted funds	Total funds
	£	£	£
INCOME AND ENDOWMENTS FROM			
Donations and legacies	38,821	1,655	40,476
Charitable activities			
Support Network	-	25,820	25,820
Total	<u>38,821</u>	<u>27,475</u>	<u>66,296</u>

EXPENDITURE ON

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2022

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted fund £	Restricted funds £	Total funds £
Charitable activities			
Research	3,384	-	3,384
Support Network	11,872	10,820	22,692
Awareness	7,899	-	7,899
Total	23,155	10,820	33,975
NET INCOME	15,666	16,655	32,321
RECONCILIATION OF FUNDS			
Total funds brought forward	51,840	10,016	61,856
TOTAL FUNDS CARRIED FORWARD	67,506	26,671	94,177

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.3.22 £	31.3.21 £
Accrued income	2,652	2,453
Prepayments	8,260	8,458
	10,912	10,911

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.3.22 £	31.3.21 £
Other creditors	804	720

12. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted fund £	Restricted funds £	31.3.22 Total funds £	31.3.21 Total funds £
Current assets	67,193	51,978	119,171	94,897
Current liabilities	(804)	-	(804)	(720)
	66,389	51,978	118,367	94,177

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2022

13. MOVEMENT IN FUNDS

	At 1.4.21 £	Net movement in funds £	At 31.3.22 £
Unrestricted funds			
General fund	67,506	(1,117)	66,389
Restricted funds			
Noonan Syndrome Research Fund	1,655	20,300	21,955
Families Event	15,000	5,000	20,000
The Andrew Family Research Fund	10,016	-	10,016
Support costs	-	7	7
	<u>26,671</u>	<u>25,307</u>	<u>51,978</u>
TOTAL FUNDS	<u>94,177</u>	<u>24,190</u>	<u>118,367</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	27,060	(28,177)	(1,117)
Restricted funds			
Noonan Syndrome Research Fund	20,300	-	20,300
Families Event	5,000	-	5,000
The Andrew Family Research Fund	3,150	(3,150)	-
Support costs	7,750	(7,743)	7
	<u>36,200</u>	<u>(10,893)</u>	<u>25,307</u>
TOTAL FUNDS	<u>63,260</u>	<u>(39,070)</u>	<u>24,190</u>

Comparatives for movement in funds

	At 1.4.20 £	Net movement in funds £	At 31.3.21 £
Unrestricted funds			
General fund	51,840	15,666	67,506
Restricted funds			
Noonan Syndrome Research Fund	-	1,655	1,655
Families Event	-	15,000	15,000
The Andrew Family Research Fund	10,016	-	10,016
	<u>10,016</u>	<u>16,655</u>	<u>26,671</u>
TOTAL FUNDS	<u>61,856</u>	<u>32,321</u>	<u>94,177</u>

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2022

13. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	38,821	(23,155)	15,666
Restricted funds			
Noonan Syndrome Research Fund	1,655	-	1,655
Families Event	15,000	-	15,000
Support costs	10,820	(10,820)	-
	<u>27,475</u>	<u>(10,820)</u>	<u>16,655</u>
TOTAL FUNDS	<u>66,296</u>	<u>(33,975)</u>	<u>32,321</u>

The Andrew Family Research Fund:

This is to fund medical research directly relevant to Noonan Syndrome.

14. RELATED PARTY DISCLOSURES

During the year the trustees made donations to the charity totalling £2,181 (2021: £2,053).

Noonan Syndrome Association
Detailed Statement of Financial Activities
for the Year Ended 31 March 2022

	31.3.22 £	31.3.21 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	24,593	38,023
Gift aid	2,767	2,453
	<u>27,360</u>	<u>40,476</u>
Charitable activities		
Grants	35,900	25,820
	<u>35,900</u>	<u>25,820</u>
Total incoming resources	<u>63,260</u>	<u>66,296</u>
EXPENDITURE		
Charitable activities		
Telephone	479	895
Postage and stationery	1,333	2,584
Sundries	2,080	640
Family day	-	165
Travel expenses	-	296
Computer & IT support costs	2,394	70
Charity Manager	20,270	16,491
Administration costs	-	3,500
Grants to institutions	10,893	7,743
	<u>37,449</u>	<u>32,384</u>
Support costs		
Governance costs		
Indemnity insurance	733	781
Accountancy and legal fees	888	810
	<u>1,621</u>	<u>1,591</u>
Total resources expended	<u>39,070</u>	<u>33,975</u>
Net income	<u><u>24,190</u></u>	<u><u>32,321</u></u>

This page does not form part of the statutory financial statements

Accounts

**Report of the Trustees and
Financial Statements for the Year Ended 31 March 2021
for
Noonan Syndrome Association**

Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
Powys
SY16 2NY

Noonan Syndrome Association
Contents of the Financial Statements
for the Year Ended 31 March 2021

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Detailed Statement of Financial Activities	15

Noonan Syndrome Association

**Reference and Administrative Details
for the Year Ended 31 March 2021**

TRUSTEES

Mrs K Ballard Chair
Miss S L Allsopp Deputy Chair
S Hoey Treasurer
Professor M A Patton FRCP Medical Adviser
I A Legg BA (HONS) ACIB
G Bowler (appointed 18.5.20)
B Carlton
Mrs J Dyer (appointed 18.5.20)
Ms A Reid - Kelly
Mrs G L Wilkes
Ms A Swift (resigned 27.6.20)

PRINCIPAL ADDRESS

PO Box 692
Blackburn
BB2 9RF

**REGISTERED CHARITY
NUMBER**

1140671

INDEPENDENT EXAMINER

Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
Powys
SY16 2NY

BANKERS

Barclays Bank PLC
Leicester
LE87 2BB

Charity Manager

Sandie Dent

Correspondence Address

PO Box 692, Blackburn, BB2 9RF

Noonan Syndrome Association
Report of the Trustees
for the Year Ended 31 March 2021

The trustees present their report with the financial statements of the charity for the year ended 31 March 2021. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

The objectives of the charity are to provide relief of all persons affected by Noonan Syndrome and related conditions (on the Ras/MAPK pathway) by all or any of the following means:

1. The provision of general advice, guidance and support services for persons suffering from Noonan Syndrome and related conditions (on the Ras/MAPK pathway), their families, dependents and carers;
2. The facilitation and promotion of research into the causes, effects, diagnosis, treatment and relief of Noonan Syndrome and related conditions (on the Ras/MAPK pathway) with the useful results of research being disseminated for the benefit of the public;
3. The advancement in the education of the public in relation to the effects of Noonan Syndrome and related conditions (on the Ras/MAPK pathway) by communicating reports and disseminating information by any means or media concerning research work and studies undertaken by or on behalf of the charity.

In all that we do, our trustees have given careful consideration to the Charity Commission's general guidance on public benefit and have complied with the duty in section 4 of the 2011/2006 Charities Act.

ACHIEVEMENT AND PERFORMANCE

Charitable activities

The challenges which the Covid-19 epidemic has brought were beginning to make themselves clear towards the end of the 2019/2020 year, most notably by influencing the Trustees to postpone the Families Day and Activities Weekend. The main brunt of the restrictions brought on by the pandemic was, however, felt in 2020/2021. With the continuing uncertainty and the vulnerability of many members, the Families event had yet again to be postponed and is now scheduled for early October 2022.

Similarly, with the medical profession's focus on Covid, it was deemed inappropriate to proceed with the next round of invitations for research pump-priming. This will now take place during the 2021/22 year.

On a more positive note, discussions continued on how the charity could support the new specialist Rasopathies clinic at Great Ormond Street Hospital. It was agreed that the NSA would fund the costs of a part time specialist nurse for the clinic in collaboration with One Great Day, the main sponsoring charity for the development. Despite the postponement of the actual London Marathon, NSA had great support in the virtual Marathon led by Matthew Legg, son of the outgoing Chair of the NSA, Ian Legg and which he was running in memory of his brother Mark who had Noonan Syndrome.

During the lockdown, NSA took the approach of signposting reliable NHS/HM Government advice to members and by careful management of resources, maintained a good level of income and fundraising to ensure that the charity could come through the pandemic in good financial health. This was helped in no small way by the generous support received from members and particularly from Novo Nordisk who funded 6 months staff resource for the charity. Thanks must also go to Huddersfield Golf Club as NSA was their chosen charity which resulted in a donation of £4.75k.

The year also heralded notable changes in the management of the charity. Ian Legg, the chair of the charity from its inception announced that he would be standing down after 10 years. Longstanding trustee Katie Ballard took over as Chair towards the end of 2020 and one of her first tasks was to start the recruitment process for the role of Charity Manager as Peter Clarke, who had also been in that post for a decade, said that he would be looking to retire. After a recruitment made more challenging because of the pandemic restrictions, Sandie Dent was confirmed as taking up the role from early March 2021, although Peter would be staying on for some time in support.

The appointment of a new Chair provided the opportunity for the charity to look again at its aims and direction. A membership survey enabled the charity to collate the views of its major stakeholders, trustees and members on its key aims and vision. Trends in responses were identified and these were incorporated into a new 15-month plan for the charity as the year came to a close. The new developments are covered in more detail below.

FINANCIAL REVIEW

Financial position

The statement of Financial Activities shows a surplus for the year of £32,321(2020: £554), and reserves now stand at £94,177 (2020: £61,856).

Reserves policy

The charity does not have a separate formal policy on Reserves but following Board discussions, the Chair, Treasurer and Charity Manager follow a policy based on achieving free reserves of a minimum of between 3 and 6 months' operating costs including those associated with the cost of a part time charity manager.

The charity has an established and appropriate financial management system which is regularly reviewed by the Board and put into day to day practice by the Charity Manager, Charity Treasurer, Finance Officer together with the Chair of Trustees.

Free reserves which equate to net current assets (excluding restricted funds) amount to £67,506 (2020: £51,840).

FUTURE PLANS

The NSA, as with many other charities, faced uncertainty at the start of 2020/21 as the Covid-19 pandemic took hold. Because of the vulnerable status of members and some trustees, face-to-face activities could not be delivered even outside of government-mandated lockdowns. Plans for 2020/21 were changed, and continued to change throughout the year, but the overall priorities and aims of the charity did not. A key strength of the Board during this year has been its ability to revise plans to navigate that uncertain and changing landscape, whilst maintaining the core objective of supporting members and planning for the future.

Future plans include:

- delivering a series of online medical webinars during 2021 in place of the Families Weekend;
- funding two clinical research projects and one social research project;
- taking advantage of the charity's robust financial position to improve systems and processes, including investing in new technology; and
- further developing the charity's strategic plan.

Key strategic objectives include increasing membership, income and diversity of income, and increasing the range of support activities available to members (i.e. holding regional events). As the charity's membership grows, so the activities and resource to deliver them need also to grow. Managing this growth in a safe and positive way will be a key focus during 2021/22.

At the time of writing this report, we are now 21 months into the pandemic and still navigating an uncertain landscape. Reflecting back on the 2020/21 year and achievements the charity made despite the difficult environment, it is clear that the solid financial position at the start of the reporting period put the charity in a strong position to survive, adapt, and even thrive during the challenging year to come.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust and constitutes an unincorporated charity.

Recruitment and appointment of new trustees

Trustees are elected by way of a resolution of the Charity at the Annual General Meeting. The Trustees also have the power at any time, and from time to time, to appoint any person to be a Trustee [subject to certain restrictions], either to fill a casual vacancy or as an addition to the existing members of the Board of Trustees but so that the total number of Trustees does not exceed any maximum number fixed in accordance with this Constitution. Any Trustee so appointed shall hold office only until the next following Annual General Meeting, and shall then be eligible for re-election.

Organisational structure

The charity is organised so that the trustees meet regularly to manage its affairs. Full Trustee Board meetings are held at least four times per year with other meetings held as required, both face to face and by conference call or internet.

There is an Annual General Meeting held for all the members of the charity at which Trustees are elected or confirmed.

The part time Charity Manager undertakes most of the day to day operations of the charity. In addition to a Chair, the trustees have appointed a Deputy Chair, Sharon Allsopp, and a Treasurer, Steve Hoey

Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error. It has an agreed set of financial procedures and policies, practices and guidance to cover its activities, including the reserves policy set out above.

Noonan Syndrome Association
Report of the Trustees
for the Year Ended 31 March 2021

Approved by order of the board of trustees on 22 January 2022 and signed on its behalf by:

Mrs K Ballard - Trustee

**Independent Examiner's Report to the Trustees of
Noonan Syndrome Association**

Independent examiner's report to the trustees of Noonan Syndrome Association

I report to the charity trustees on my examination of the accounts of Noonan Syndrome Association (the Trust) for the year ended 31 March 2021.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

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.

Thomas Landers BA FCA
Institute of Chartered Accountants in England & Wales
Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
Powys
SY16 2NY

22 January 2022

Noonan Syndrome Association

Statement of Financial Activities
for the Year Ended 31 March 2021

		Unrestricted fund £	Restricted funds £	31.3.21 Total funds £	31.3.20 Total funds £
	Notes				
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	38,821	1,655	40,476	52,160
Charitable activities	3				
Support Network		-	25,820	25,820	-
Total		<u>38,821</u>	<u>27,475</u>	<u>66,296</u>	<u>52,160</u>
EXPENDITURE ON					
Charitable activities	4				
Research		3,384	-	3,384	3,699
Support Network		11,872	10,820	22,692	39,268
Awareness		7,899	-	7,899	8,639
Total		<u>23,155</u>	<u>10,820</u>	<u>33,975</u>	<u>51,606</u>
NET INCOME		<u>15,666</u>	<u>16,655</u>	<u>32,321</u>	<u>554</u>
RECONCILIATION OF FUNDS					
Total funds brought forward		51,840	10,016	61,856	61,302
TOTAL FUNDS CARRIED FORWARD		<u><u>67,506</u></u>	<u><u>26,671</u></u>	<u><u>94,177</u></u>	<u><u>61,856</u></u>

The notes form part of these financial statements

Noonan Syndrome Association

Balance Sheet
31 March 2021

	Notes	31.3.21 £	31.3.20 £
CURRENT ASSETS			
Debtors	10	10,911	10,058
Cash at bank		83,986	52,602
		<u>94,897</u>	<u>62,660</u>
CREDITORS			
Amounts falling due within one year	11	(720)	(804)
		<u>94,177</u>	<u>61,856</u>
NET CURRENT ASSETS			
		<u>94,177</u>	<u>61,856</u>
TOTAL ASSETS LESS CURRENT LIABILITIES			
		94,177	61,856
NET ASSETS		<u>94,177</u>	<u>61,856</u>
FUNDS	13		
Unrestricted funds		67,506	51,840
Restricted funds		26,671	10,016
TOTAL FUNDS		<u>94,177</u>	<u>61,856</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 22 January 2022 and were signed on its behalf by:

K Ballard - Trustee

The notes form part of these financial statements

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Income recognition

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

2. DONATIONS AND LEGACIES

	31.3.21	31.3.20
	£	£
Donations	38,023	50,397
Gift aid	2,453	1,763
	<u>40,476</u>	<u>52,160</u>

Noonan Syndrome Association

**Notes to the Financial Statements - continued
for the Year Ended 31 March 2021**

3. INCOME FROM CHARITABLE ACTIVITIES

		31.3.21 £	31.3.20 £
Grants	Activity Support Network	25,820	-

Grants received, included in the above, are as follows:

	31.3.21 £	31.3.20 £
Vinci UK Foundation	15,000	-
Novo Nordisk Limited	10,820	-
	<u>25,820</u>	<u>-</u>

4. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 5) £	Grant funding of activities (see note 6) £	Support costs (see note 7) £	Totals £
Research	3,146	-	238	3,384
Support Network	14,153	7,743	796	22,692
Awareness	7,342	-	557	7,899
	<u>24,641</u>	<u>7,743</u>	<u>1,591</u>	<u>33,975</u>

5. DIRECT COSTS OF CHARITABLE ACTIVITIES

	31.3.21 £	31.3.20 £
Telephone	895	960
Postage and stationery	2,584	3,040
Promotional material	-	1,737
Sundries	640	1,267
Family day	165	26,927
Travel expenses	296	368
Computer & IT support costs	70	1,003
Charity Manager	16,491	14,425
Administration costs	3,500	-
	<u>24,641</u>	<u>49,727</u>

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2021

6. GRANTS PAYABLE

	31.3.21	31.3.20
	£	£
Support Network	7,743	-
	<u>7,743</u>	<u>-</u>
The total grants paid to institutions during the year was as follows:		
	31.3.21	31.3.20
	£	£
Great Ormond Street Hospital	7,743	-
	<u>7,743</u>	<u>-</u>

7. SUPPORT COSTS

	Governance costs
	£
Research	238
Support Network	796
Awareness	557
	<u>1,591</u>
Activity	Basis of allocation
Management	Based on time
Governance costs	Based on time

8. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2021 nor for the year ended 31 March 2020.

Trustees' expenses

During the year one trustee was reimbursed for travelling expenses amounting to £198 (2020 nil).

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund	Restricted funds	Total funds
	£	£	£
INCOME AND ENDOWMENTS FROM			
Donations and legacies	52,160	-	52,160
EXPENDITURE ON			
Charitable activities			
Research	3,699	-	3,699
Support Network	28,768	10,500	39,268
Awareness	8,639	-	8,639
Total	<u>41,106</u>	<u>10,500</u>	<u>51,606</u>
NET INCOME/(EXPENDITURE)	<u>11,054</u>	<u>(10,500)</u>	<u>554</u>

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2021

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted fund £	Restricted funds £	Total funds £
RECONCILIATION OF FUNDS			
Total funds brought forward	40,786	20,516	61,302
TOTAL FUNDS CARRIED FORWARD	<u>51,840</u>	<u>10,016</u>	<u>61,856</u>

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.3.21 £	31.3.20 £
Prepayments and accrued income	2,453	1,763
Prepayments	8,458	8,295
	<u>10,911</u>	<u>10,058</u>

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.3.21 £	31.3.20 £
Other creditors	720	804
	<u>720</u>	<u>804</u>

12. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted fund £	Restricted funds £	31.3.21 Total funds £	31.3.20 Total funds £
Current assets	68,226	26,671	94,897	62,660
Current liabilities	(720)	-	(720)	(804)
	<u>67,506</u>	<u>26,671</u>	<u>94,177</u>	<u>61,856</u>

13. MOVEMENT IN FUNDS

	At 1.4.20 £	Net movement in funds £	At 31.3.21 £
Unrestricted funds			
General fund	51,840	15,666	67,506
Restricted funds			
Noonan Syndrome Research Fund	-	1,655	1,655
Families Event	-	15,000	15,000
The Andrew Family Research Fund	10,016	-	10,016
	<u>10,016</u>	<u>16,655</u>	<u>26,671</u>
TOTAL FUNDS	<u>61,856</u>	<u>32,321</u>	<u>94,177</u>

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2021

13. MOVEMENT IN FUNDS - continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	38,821	(23,155)	15,666
Restricted funds			
Noonan Syndrome Research Fund	1,655	-	1,655
Families Event	15,000	-	15,000
Support costs	10,820	(10,820)	-
	<u>27,475</u>	<u>(10,820)</u>	<u>16,655</u>
TOTAL FUNDS	<u>66,296</u>	<u>(33,975)</u>	<u>32,321</u>

Comparatives for movement in funds

	At 1.4.19 £	Net movement in funds £	At 31.3.20 £
Unrestricted funds			
General fund	40,786	11,054	51,840
Restricted funds			
The Andrew Family Research Fund	10,016	-	10,016
Eve Martin Fund	500	(500)	-
The National Lottery	10,000	(10,000)	-
	<u>20,516</u>	<u>(10,500)</u>	<u>10,016</u>
TOTAL FUNDS	<u>61,302</u>	<u>554</u>	<u>61,856</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	52,160	(41,106)	11,054
Restricted funds			
Eve Martin Fund	-	(500)	(500)
The National Lottery	-	(10,000)	(10,000)
	<u>-</u>	<u>(10,500)</u>	<u>(10,500)</u>
TOTAL FUNDS	<u>52,160</u>	<u>(51,606)</u>	<u>554</u>

The Andrew Family Research Fund:

13. MOVEMENT IN FUNDS - continued

This is to fund medical research directly relevant to Noonan Syndrome.

14. RELATED PARTY DISCLOSURES

During the year the trustees made donations to the charity totalling £2,053 (2020: £3,430).

Noonan Syndrome Association
Detailed Statement of Financial Activities
for the Year Ended 31 March 2021

	31.3.21 £	31.3.20 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	38,023	50,397
Gift aid	2,453	1,763
	<u>40,476</u>	<u>52,160</u>
Charitable activities		
Grants	25,820	-
	<u>66,296</u>	<u>52,160</u>
Total incoming resources		
	66,296	52,160
EXPENDITURE		
Charitable activities		
Telephone	895	960
Postage and stationery	2,584	3,040
Promotional material	-	1,737
Sundries	640	1,267
Family day	165	26,927
Travel expenses	296	368
Computer & IT support costs	70	1,003
Charity Manager	16,491	14,425
Administration costs	3,500	-
Grants to institutions	7,743	-
	<u>32,384</u>	<u>49,727</u>
Support costs		
Governance costs		
Indemnity insurance	781	751
Accountancy and legal fees	810	1,128
	<u>1,591</u>	<u>1,879</u>
Total resources expended		
	<u>33,975</u>	<u>51,606</u>
Net income		
	<u><u>32,321</u></u>	<u><u>554</u></u>

This page does not form part of the statutory financial statements