

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

Morgan Griffiths LLP
Chartered Accountants
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9 High Street
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Noonan Syndrome Association
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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

Noonan Syndrome Association
Report of the Trustees
for the Year Ended 31 March 2025

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.

Noonan Syndrome Association
Report of the Trustees
for the Year Ended 31 March 2025

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
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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	48,067	30,427
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	81,393	48,332
Net expenditure	<u>(33,326)</u>	<u>(17,905)</u>

This page does not form part of the statutory financial statements