

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

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

Noonan Syndrome Association

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for the Year Ended 31 March 2024**

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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
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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><u>59,278</u></u>	<u><u>20,608</u></u>	<u><u>79,886</u></u>	<u><u>97,791</u></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	-	8,021
Grants	-	8,542
Grants	-	10,042
	<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>

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>

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>

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		
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