

**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
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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
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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><u>26,605</u></u>	<u><u>35,900</u></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><u>26,605</u></u>	<u><u>35,900</u></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><u>78,809</u></u>	<u><u>1,665</u></u>	<u><u>80,474</u></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><u>78,809</u></u>	<u><u>26,556</u></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