

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

Morgan Griffiths LLP
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Noonan Syndrome Association
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for the Year Ended 31 March 2022

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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.

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

	31.3.22	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	<u>23,155</u>	<u>10,820</u>	<u>33,975</u>
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	<u>67,506</u>	<u>26,671</u>	<u>94,177</u>

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
	<u>10,912</u>	<u>10,911</u>

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.3.22 £	31.3.21 £
Other creditors	804	720
	<u>804</u>	<u>720</u>

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)
	<u>66,389</u>	<u>51,978</u>	<u>118,367</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

	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