Pathfinders Neuromuscular Alliance

England & Wales · Charity number 1155884

Details

Other names	DMD PATHFINDERS
Status	Registered
Legal form	CIO
Registered	2014-02-21
Register	View on the Charity Commission register

Contact

Address	103 London Road Hailsham East Sussex BN27 3AH
Phone	07856207351
Email	info@pathfindersalliance.org.uk
Website	https://www.pathfindersalliance.org.uk

Activities

Objects: 1.The promotion of social inclusion of people with neuromuscular conditions who are socially excluded from society, or parts of society as a result of having Muscular Dystrophy and related neuromuscular conditions by 1. Providing a network of groups that encourage and enables them to participate more effectively with the wider community,2. Increasing or co-ordinating opportunities for them to engage with organisations and service providers to enable those providers to adapt services to better meet their needs,3. Raising public awareness of the issues affecting them in all areas relating to having a neuromuscular condition,4. Providing support to those between the age of 18 and 30 who are socially excluded to establish and grow a business or enterprise to relieve their needs and assist them to integrate into society. 2. To promote and protect the physical and mental health of people with Muscular Dystrophy and related neuromuscular conditions in the United Kingdom as the trustees shall determine.

Activities: Our main activity is to provide advice and information to adults living with Muscular Dystrophy and related neuromuscular conditions via information events, guides and resources, and peer support activity. We also raise awareness of issues facing adults with neuromuscular conditions and provide advice on health research committees and steering groups

Classification

- **How:** Makes Grants To Individuals, Provides Services, Provides Advocacy/advice/information
- **What:** General Charitable Purposes, Education/training, Disability
- **Who:** Children/young People, People With Disabilities

Geography

- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-04-05	£271,413	£218,208	-	-
2024-04-05	£232,201	£180,255	-	-
2023-04-05	£180,097	£171,817	-	-
2022-04-05	£244,062	£135,374	-	-
2021-04-05	£86,589	£57,232	-	-

Trustees

Name	Role	Appointed
Sarah Rose	Chair	2020-11-21
Andrew Tunks		2024-10-02
DANIEL BAKER		2024-11-08
Dr Kirsty Liddiard		2025-11-20
Joey Nathan Levene		2025-10-06
Vicky Mozley		2021-05-16

Pathfinders Neuromuscular Alliance

England & Wales - Charity number 1155884

Accounts

Charity number: 1155884

PATHFINDERS NEUROMUSCULAR ALLIANCE

TRUSTEES' ANNUAL REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 5 APRIL 2025

CONTENTS

REFERENCE AND ADMINISTRATIVE DETAILS

Trustees	Sarah Rose (Chair) Daniel Baker Andrew Tunks Vicky Mozley
Registered Charity Numbers	1155884 (England and Wales) SC045202 (Scotland)
Principal Office	103 London Road Hailsham BN27 3AH
Independent examiner	Jason Foxwell FCCA FCIE 12 Hillbourne Road Poole BH17 7JB
Bankers	The Cooperative Bank plc 1 Balloon Street Manchester M4 4BE CAF Bank Ltd 25 Kings Hill Avenue West Malling Kent ME19 4JQ

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 5 APRIL 2025

The Trustees present their annual report together with the financial statements of the charity for the year ended 5 April 2025.

Objectives and Activities

a. Charitable Objectives

Our charitable objectives are:

1. The promotion of social inclusion of people with neuromuscular conditions who are socially excluded from society, or parts of society as a result of having Muscular Dystrophy and related neuromuscular conditions by:
    a. Providing a network of groups that encourage and enables them to participate more effectively with the wider community;
    b. Increasing or co-ordinating opportunities for them to engage with organisations and service providers to enable those providers to adapt services to better meet their needs;
    c. Raising public awareness of the issues affecting them in all areas relating to having a neuromuscular condition;
    d. Providing support to those between the age of 18 and 30 who are socially excluded to establish and grow a business or enterprise to relieve their needs and assist them to integrate into society.
2. To promote and protect the physical and mental health of people with Muscular Dystrophy and related neuromuscular conditions in the United Kingdom as the trustees shall determine.

b. Aims

The aims for Pathfinders Neuromuscular Alliance are as follows:

1. To provide a voice for adults living with Muscular Dystrophy and related neuromuscular conditions. (Objects 1.1 & 1.3)
2. To provide a forum for adults living with Muscular Dystrophy and related neuromuscular conditions to share experiences, ideas and opinions in complete confidence. (Objects 1.2 & 1.3)
3. To provide information, advice and peer support to adults living with Muscular Dystrophy and related neuromuscular conditions. (Objects 1.2 & 1.3)
4. To identify, promote, and develop best practice, innovative treatments and technologies for adults living with Muscular Dystrophy and related neuromuscular conditions. (Object 1.2)
5. To campaign and influence treatments for adults living with Muscular Dystrophy and related neuromuscular conditions within health and local authorities, government, relevant professionals, disability organisations and charities. (Objects 1.1 & 1.2)

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 5 APRIL 2025 (Continued)

6. To work with health and local authorities, government, disability organisations and charities in improving care, support and services for adults living with Muscular Dystrophy and related neuromuscular conditions. (Objects 1.1, 1.2 & 1.3)
7. To increase awareness of adults living with Muscular Dystrophy and related neuromuscular conditions. (Object 1.1)

c. Public Benefit

We seek to provide a public benefit with the following activities:

1. Provide a voice (Objects 1.1 & 1.3)
    - Via our website, we demonstrate the realities and possibilities of being an adult with a muscle-weakening condition
    - We have given adults opportunities to share their expertise and experience as a voice for the community, especially with younger members on our UpLift programme
    - We have engaged in various media opportunities throughout the year, raising the profile of the organisation and commenting on issues that are important to us, e.g. access to NHS care
    - Through our peer researcher programmes, we have supported young people to lead on academic research into the experiences of disabled people with muscle weakening conditions
2. Provide a forum (Objects 1.2 & 1.3)
    - We have continued to run our UpLift project, providing a forum for young adults aged 18-30 to network, connect and learn while building advocacy and campaigning skills
    - We have run a range of social events for the neuromuscular community, bringing people together
    - We have run our peer research network, giving people with muscle-weakening conditions the chance to connect with each other and lead research into issues that matter to them
    - We have run peer support groups for adults with muscle weakening conditions who employ their own carers or personal assistants
    - We have run a campaign network of people with muscle weakening conditions to connect with each other and collaborate on campaigns

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 5 APRIL 2025 (Continued)

3. Provide information, advice and peer support (Objects 1.2 & 1.3)

   As well as the above, we have

   - Provided training to disabled people who employ PAs and to PAs for disabled people
   - Further rolled out our advice and training resources to disabled people who employ personal assistants, and their personal assistants and applied for funding to develop further resources
   - Established a disabled-led advocacy service to offer advocacy to people with muscle-weakening conditions

4. Identify, promote, and develop best practice, innovative treatments and technologies (Object 1.2)

   - We have collaborated on a wide range of research projects including ones on natural histories, bone density measurement, the experiences of DMD caregivers, and the experiences of LGBT people accessing social care
   - We have also developed a range of patient or user-led advisory and research leadership boards and trained patient experts who can now contribute lived experience in medical and academic spaces
   - We have developed a loan library to allow members to borrow innovative technologies such as an eyegaze computer control system

5. Campaign and influence treatments within health and local authorities, government, relevant professionals, disability organisations and charities. (Objects 1.1 & 1.2)

   - We have engaged with campaigns to ensure effective treatments are funded, and have also engaged with the drug development process where appropriate in order to remain aware of potential upcoming treatments and where they should be supported

6. Work with health and local authorities, government, disability organisations and charities in improving care, support and services (Objects 1.1, 1.2 & 1.3)

   - We have campaigned on access to hospitals for personal assistants of disabled people
   - We have supported campaigns about funding for appropriate treatment
   - Through our advocacy service we have taken on cases specifically focused on improving care and support
   - We have contributed to the Smart Suit project research by Duchenne UK

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 5 APRIL 2025 (Continued)

- We will be contributing to research on creating an app to hold information for people with DMD
- We have applied for funding to carry out research into adult social care and into bone health amongst other areas

7. Increase awareness (Object 1.1)
    - We have increased our social media profile, meaning better engagement with our content
    - Senior staff have carried out high profile media and news engagements that have raised the profile of the organisation
    - We have contributed to projects run for young people with muscle-weakening conditions to show the possibilities of the lives we lead as adults.

We can confirm that the trustees have had regard to the guidance issued by the Charity Commission on public benefit.

Achievements and performance

Financial review

a. Financial review

The majority of funding in 2024-25 continued to come from grants, both restricted and unrestricted, with significant ongoing funding from the National Lottery for our uplift project, as well as new grants from Skills for Care to run training and support for PA employers. We also secured a £10k grant to continue our advocacy service. This year was the final year of our Tudor Trust grant which has provided £30k every year for the last three years.

Our research and consultancy service continues to be a significant source of funding (£43k in 2024-25) thanks to several multi-year partnerships with universities to deliver co-produced research.

Our spending fell below our projections due to difficulty maintaining staff capacity levels with high rates of sickness among our staff team and some unexpected departures that took time to fill. However, we have negotiated extensions or alternative use of funds with our funders meaning unspent monies will be spent in the next financial year.

We continue to be in a good financial position, however we recognise the need to find sustainable unrestricted funding streams through community fundraising, consultancy and grant applications.

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 5 APRIL 2025 (Continued)

b. Reserves policy

It is the policy of the trustees to hold reserves to cover six months of operating expenses. In September 2024, the trustees decided to designate a series of funds to specific areas of work to address the significant unrestricted funding from previous years. The following was agreed:

- £30,000 for a social events fund, expected to be needed from March 2026 when our national lottery funding ends.
- A £5,000 restructuring fund expected to be needed between December 2024-March 2025. This was subsequently increased to £7,000 following the emergence of a legal issue that required specialist advice.
- A £5,000 IT equipment fund expected to be used in 2025-26 to replace outdated assistive technology equipment currently in use.
- A £4,000 fund to employ a part-time governance and company secretary. This was subsequently cancelled due to unexpected staffing changes.
- £2,500k to a campaigns and advocacy fund, bringing the total of this pot to £7,500

c. Going concern

After making appropriate enquiries, the Trustees have a reasonable expectation that the Charity has adequate resources to continue in operational existence for the foreseeable future. For this reason, they continue to adopt the going concern basis in preparing the financial statements.

Performance in year

Over the last year we launched our new advocacy service, providing advice and advocacy for people with muscle-weakening conditions. We had some challenges with staffing of this service in the first few months which meant initial referrals were slow to come through. However, with significant efforts in outreach, communications and marketing we began to see a steadier stream of referrals. The advocacy officer has also supported us to move forward with our campaign to ensure PAs can support their employers when they go into hospital. We have conducted a series of FOI requests and secured several meetings with partner organisations to move this forward, but it continues to be an area where we need more staff capacity to deliver results.

Our advocacy service has focused primarily on social care and health, although we have seen some referrals around housing and benefits. Some of the individuals who have got in contact with us have been seriously neglected by local authorities leading to deterioration of their physical and mental health. Our support has allowed people to finally access services, and in many cases we have supported individuals to make complaints. This is time intensive, but highlights the desperate situation of poor local authority support. These are also common themes that emerged from our members survey.

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 5 APRIL 2025 (Continued)

To go some way to addressing this situation, we applied jointly with the University of Northumbria to conduct a two-year NIHR-funded research project into social care, looking at the current situation and ways to address the problems with the wider social care system. This is expected to commence in April 2025. We have also started a campaign on social care, and are currently looking to engage with government policymakers and gather evidence.

Our Uplift project continues to go from strength to strength, with far higher levels of engagement and regular members who attend and have built friendships with other project participants. We have run a series of very popular face-to-face events including our Weekender event in Leicester. Face-to-face events are extremely costly and time-consuming to run, with the complex needs of many of our participants requiring us to hire items such as profiling beds, hoists and shower chairs, and requiring daily engagement with accommodation and activity providers to ensure that all of the activities are fully inclusive. We are extremely appreciative of the National Lottery funding which allows us to provide this, and recognise the challenge for us to continue to provide these events. Young people who attend our face-to-face events report feeling more connected, informed and confident, with many building lasting friendships.

As part of the Uplift project we have also run numerous online events, including our Empower sessions, where a group of 15 young disabled people worked with a solutions-focused coach to identify their goals for the future and strategies to achieve these. This session also tackled issues such as mental health, confidence and self-esteem, with young people identifying the progress they have made over the last year and also during the length of the course.

Our Skills for Care project ran a series of classes for PA employers providing them with essential skills on how to employ personal assistants to provide their care and stay on the right side of their legal requirements as an employer. We also ran several classes for PAs where they learned from experienced employers about how to provide high quality support to people with muscle-weakening conditions.

We have undergone significant restructuring, governance and staff changes with the departure of Jamie Hale as CEO and the return of Jon Hastie, first as interim and now permanent CEO. This has taken time but we have emerged with a strong core team and a focused strategy, led by our members. We continue to need more trustees to support the organisation and to ensure we can sustainably deliver the services our members need over the long term.

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 5 APRIL 2025 (Continued)

Structure, governance and management

a. Constitution

Pathfinders Neuromuscular Alliance is a Charitable Incorporated Organisation (CIO), which was registered with the Charity Commission in England & Wales on 21 February 2014 under registration number 1155884 and is governed by its constitution which was last amended on 27 August 2020. The charity was also registered in Scotland on 31 October 2014 under registration number SC045202.

b. Methods of appointment or election of trustees

Individuals apply to the Trustee Board to become trustees and are interviewed. The Trustee Board can co-opt those people until they are elected at the AGM. Trustees receive a dedicated training and onboarding session from existing board members when they begin, and are able to access other training if desired or required.

c. Organisational structure

The charity structure is as follows:

<u>Core team</u>

Jon Hastie, CEO (manages core team & project leads)

[vacant], Deputy CEO/Communications and engagement manager

Social Media Officer

<u>Uplift Team</u>

Project Lead (Manager)

Project Assistant, Engagement and Volunteer Officer

<u>PA employer team</u>

Project Lead (Manager)

Project Assistant

<u>Research Team</u>

Research Manager,

Research Officer, Research Assistant

TRUSTEES' ANNUAL REPORT FOR THE YEAR ENDED 5 APRIL 2025 (Continued)

d. Risk management

The Board of Trustees and key management personnel have a rigorous approach to risk management, and the key risks facing the organisation are reviewed on an ongoing basis, with mitigating actions put in place to minimise the ongoing risk to the charity.

Statement of trustees' responsibilities

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Charity and of its incoming resources and application of resources, including its income and expenditure, for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles of the Charities SORP (FRS 102);
- make judgments and accounting estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards (FRS 102) have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue to operate.

The trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the Charity's transactions and disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the Constitution. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by the Board of trustees and signed on their behalf by:

Sarah Rose (Nov 19, 2025, 2:04pm)

Sarah Rose
Chair of trustees

Date: 19 Nov 2025

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF PATHFINDERS NEUROMUSCULAR ALLIANCE FOR THE YEAR ENDED 5 APRIL 2025

I report to the trustees on my examination of the accounts of the Charity for the year ended 5 April 2025.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 (the '2005 Act'), the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Charities Act 2011 ('the 2011 Act'). You are satisfied that your charity is not required by charity law to be audited and have chosen instead to have an independent examination.

I report in respect of my examination of your Charity's accounts as carried out under section 44(1)(c) of the 2005 Act and Section 145 of the 2011 Act. In carrying out my examination I have followed the Requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and the applicable Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent examiner's statement

Since the Charity has prepared its accounts on an accruals basis and is also registered in Scotland your examiner must be a member of a body listed in Regulation 11(2) of the Charities Accounts (Scotland) Regulations 2006 (as amended). Also, since the Charity's gross income exceeded £250,000, your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a fellow of both the Association of Chartered Certified Accountants (ACCA) and the Association of Charity Independent Examiners (ACIE), both of which are listed bodies in both Regulations.

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

1. accounting records were not kept in respect of the Charity as required by section 44(1)(a) of the 2005 Act and Regulation 4 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and section 130 of the 2011 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and do not comply with the applicable requirements concerning the form and content of the 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 a 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.

Jason Foxwell (Nov 19, 2025 9:24pm)

Jason Foxwell FCCA FCIE
independent-examiner.net
12 Hillbourne Road, Poole, BH17 7JB

Date: 19 Nov 2025

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 5 APRIL 2025

	Notes	Unrestricted Funds	Restricted Funds	Total Funds 2025	Total Funds 2024
		£	£	£	£
Income from:					
Donations and legacies	2	30,977	180,690	211,667	201,433
Charitable activities	3	47,721	11,803	59,524	29,648
Investment income – interest		222	-	222	1,120
Total income		**78,920**	**192,493**	**271,413**	**232,201**
Expenditure on:					
Raising funds		-	-	-	101
Charitable activities	4	52,435	165,773	218,208	180,154
Total expenditure		**52,435**	**165,773**	**218,208**	**180,255**
Transfers between funds		-	-	-	-
Net movement in funds		**26,485**	**26,722**	**53,207**	**51,946**
Reconciliation of funds:					
Total funds brought forward		119,610	119,734	239,346	187,399
Total funds carried forward		**146,095**	**146,456**	**292,551**	**239,346**

The Statement of Financial Activities includes all gains and losses recognised in the year.

All of the charity's activities derive from continuing operations.

The notes on pages 13 to 17 form an integral part of these accounts.

BALANCE SHEET AS AT 5 APRIL 2025

	Notes	2025 £	2025 £	2024 £	2024 £
Current Assets					
Debtors	8	2,875		-	
Cash at bank		289,676		239,346	
		292,551		239,346	
Creditors: amounts falling due within one year		(-)		(-)	
Net current assets			292,551		239,346
NET ASSETS			**292,551**		**239,346**
The funds of the charity:	9				
Restricted funds			146,456		119,734
Unrestricted funds			146,095		119,610
Total funds			**292,551**		**239,346**

The accounts were approved by the trustees, authorised for issue and signed on their behalf by:

Sarah Rose (Nov 19, 2025, 2:04pm)

Sarah Rose
Chair of Trustees Date: 19 Nov 2025

The notes on pages 13 to 17 form an integral part of these accounts.

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2025

1. ACCOUNTING POLICIES

1.1. Basis of preparation of the accounts

The financial statements have been prepared in accordance with 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 2015) - (Charities SORP (FRS 102)).

Pathfinders Neuromuscular Alliance meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

1.2. Income

All income is recognised once the Charity has entitlement to the income, it is probable that the income will be received and the amount of income receivable can be measured reliably.

Grants are included in the statement of financial activities on a receivable basis. The balance of income received for specific purposes but not expended during the period is shown in the relevant funds on the balance sheet. Where income is received in advance of entitlement of receipt, its recognition is deferred and included in creditors as deferred income. Where entitlement occurs before income is received, the income is accrued.

Donations are recognised in full in the Statement of Financial Activities when entitled, receipt is probable and when the amount can be quantified with reasonable accuracy. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

1.3. Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, 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 on raising funds includes all expenditure incurred by the Charity to raise funds for its charitable purposes and includes costs of all fundraising activities and events.

Expenditure on charitable activities is incurred on directly undertaking the activities which further the Charity's objectives, as well as any associated support costs.

All expenditure is inclusive of irrecoverable VAT.

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2025 (continued)

ACCOUNTING POLICIES (continued)

1.4. **Debtors**

Trade and other debtors are recognised at the settlement amount after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

1.5. **Cash at bank and in hand**

Cash at bank and in hand includes cash and short-term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

1.6. **Liabilities and provisions**

Liabilities are recognised when there is an obligation at the balance sheet date as a result of a past event, it is probable that a transfer of economic benefit will be required in settlement, and the amount of the settlement can be estimated reliably.

Liabilities are recognised at the amount that the Charity anticipates it will pay to settle the debt or the amount it has received as advanced payments for the goods or services it must provide.

Provisions are measured at the best estimate of the amounts required to settle the obligation.

1.7. **Financial instruments**

The Charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

1.8. **Fund accounting**

General funds are unrestricted funds which are available for use at the discretion of the trustees in furtherance of the general objectives of the Charity and which have not been designated for other purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the Charity for particular purposes. The costs of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2025 (continued)

2. INCOME FROM DONATIONS AND LEGACIES

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total funds 2025 £	Total funds 2024 £
Donations	977	-	977	2,711
Grants	30,000	180,690	210,690	198,722
Total	**30,977**	**180,690**	**211,667**	**201,433**

3. INCOME FROM CHARITABLE ACTIVITIES

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total funds 2025 £	Total funds 2024 £
Reimbursements	1,031	303	1,334	4,190
Access to Work	2,790	-	2,790	2,250
Consultancy	43,900	11,500	55,400	23,208
Total	**47,721**	**11,803**	**59,524**	**29,648**

4. ANALYSIS OF CHARITABLE EXPENDITURE

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total funds 2025 £	Total funds 2024 £
Staff costs	39,138	111,126	150,264	115,906
Project and event costs	1,168	39,526	40,694	47,401
Bank interest and charges	-	60	60	60
Insurance, governance and digital	6,762	8,463	15,225	6,355
Office costs, equipment and stationery	4,557	435	4,992	2,993
Promotional activity	313	3,354	3,667	4,811
Volunteer and staff expenses	497	2,809	3,306	2,628
Total	**52,435**	**165,773**	**218,208**	**180,154**

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2025 (continued)

5. INDEPENDENT EXAMINER'S REMUNERATION

	2025	2024
	£	£
Fees payable to the Charity's independent examiner for:		
- Independent examination of the charity's accounts	525	500
- Preparation of the charity's accounts	600	-
Total fees payable to the Charity's independent examiner	**1,125**	**500**

6. STAFF COSTS

	2025	2024
	£	£
Wages and salaries	139,272	107,711
Social security costs	7,672	5,118
Contribution to defined contribution pension schemes	3,320	3,077
	150,264	**115,906**

The average number of persons employed by the Charity during the year was 13.

There were no employees who earned in excess of £60,000 in either the current or preceding year.

7. TRUSTEES' REMUNERATION AND EXPENSES

During the year, no trustees received any remuneration, benefits or had any expenses reimbursed (2024 – Nil).

8. DEBTORS

	2025	2024
	£	£
Trade debtors	2,875	-
	2,875	**-**

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 5 APRIL 2025 (continued)

9. STATEMENT OF FUNDS

	Balance at 6 Apr 2024 £	Income £	Expenditure £	Transfer of funds £	Balance at 5 Apr 2025 £
Unrestricted					
General fund	58,214	76,130	(42,438)	(44,500)	47,406
Designated funds					
Access to work	-	2,790	(6,929)	-	(4,139)
Advocacy and campaigns	7,634	-	(3,056)	2,500	7,078
IT assistive equipment	-	-	-	5,000	5,000
Pathfinders annual awards	3,750	-	-	-	3,750
Restructuring fund	-	-	-	7,000	7,000
Social events fund	-	-	-	30,000	30,000
Wind-up reserves	50,000	-	-	-	50,000
Restricted funds					
Advocacy Lottery Community fund	19,535	-	(8,397)	(500)	10,638
HDH Wills advocacy fund	1,500	-	(935)	-	565
LSE NIHR SSCR Evidence Implementn	(3,532)	8,001	(2,475)	-	1,995
Lottery previous years	17,786	-	(14,162)	-	3,624
Overheads project charge	-	302	(6,964)	7,180	518
PTC Online Skills	44	-	-	-	44
PTC Research	22,693	-	(11,112)	(1,352)	10,229
PTC Strive Content Creators	1,068	-	(586)	-	482
Skills for Care Additional Funding Jan 24	-	3,500	(4,070)	-	(570)
Skills for Care Oct 24 – Mar 25	-	44,000	(40,685)	(2,826)	489
Sureserve generator project	1,139	-	(792)	-	47
To be derestricted	12,497	-	-	-	12,497
Tudor Trust development	7,500	-	(175)	-	7,325
ULO funding additional SFC 24-25	-	3,550	(3,550)	-	-
Uplift lottery 24-25	39,518	58,299	(68,991)	(2,205)	26,621
Uplift lottery 25-26	-	64,848	-	-	64,848
Wesleyan advocacy fund	-	9,993	(2,891)	(297)	6,805
Total	**239,346**	**271,413**	**(218,208)**	**-**	**292,551**

Signable

Issuer	Pathfinders Neuromuscular Alliance
Document generated	Wed, 19th Nov 2025 13:12:29 GMT
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Parties involved with this document

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Pathfinders Neuromuscular Alliance

England & Wales - Charity number 1155884

Accounts

CHARITY COMMISSION FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From (Period start date): 6th April 2023 to (Period end date): 5th April 2024

Charity name: Pathfinders Neuromuscular Alliance

Charity registration number: 1155884

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	Our charitable objectives are: 1. The promotion of social inclusion of people with neuromuscular conditions who are socially excluded from society, or parts of society as a result of having Muscular Dystrophy and related neuromuscular conditions by: ● Providing a network of groups that encourage and enables them to participate more effectively with the wider community, ● Increasing or co-ordinating opportunities for them to engage with organisations and service providers to enable those providers to adapt services to better meet their needs, ● Raising public awareness of the issues affecting them in all areas relating to having a neuromuscular condition, ● Providing support to those between the age of 18 and 30 who are socially excluded to establish and grow a business or enterprise to relieve their needs and assist them to integrate into society. 2. To promote and protect the physical and mental health of people with Muscular Dystrophy and related neuromuscular conditions in the United Kingdom as the trustees shall determine. The aims for Pathfinders Neuromuscular Alliance are as follows: ● To provide a voice for adults living with Muscular Dystrophy and related neuromuscular conditions. (Objects 1.1 & 1.3) ● To provide a forum for adults living with Muscular Dystrophy and related neuromuscular conditions to share experiences, ideas and opinions in complete confidence. (Objects 1.2 & 1.3) ● To provide information, advice and peer support to adults living with Muscular Dystrophy and related neuromuscular conditions. (Objects 1.2 & 1.3) ● To identify, promote, and develop best practice, innovative treatments and technologies for adults living with Muscular Dystrophy and related neuromuscular conditions. (Object 1.2) ● To campaign and influence treatments for adults living with Muscular Dystrophy and related neuromuscular

		conditions within health and local authorities, government, relevant professionals, disability organisations and charities. (Objects 1.1 & 1.2) ● To work with health and local authorities, government, disability organisations and charities in improving care, support and services for adults living with Muscular Dystrophy and related neuromuscular conditions. (Objects 1.1, 1.2 & 1.3) ● To increase awareness of adults living with Muscular Dystrophy and related neuromuscular conditions. (Object 1.1)
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	Provide a voice (Objects 1.1 & 1.3) ● Via our website, we demonstrate the realities and possibilities of being an adult with a muscle-weakening condition ● We have given adults opportunities to share their expertise and experience as a voice for the community, especially with younger members on our UpLift programme ● We have engaged in various media opportunities throughout the year, raising the profile of the organisation and commenting on issues that are important to us, e.g. access to NHS care ● Through our peer researcher programmes, we have supported young people to lead on academic research into the experiences of disabled people with muscle-weakening conditions Provide a forum (Objects 1.2 & 1.3) ● We have continued to run our UpLift project, providing a forum for young adults aged 18-30 to network, connect and learn while building advocacy and campaigning skills ● We have run a range of social events for the neuromuscular community, bringing people together ● We have run our peer research network, giving people with muscle-weakening conditions the chance to connect with each other and lead research into issues that matter to them ● We have run peer support groups for adults with muscle-weakening conditions who employ their own carers or personal assistants ● We have run a campaign network of people with muscle-weakening conditions to connect with each other and collaborate on campaigns Provide information, advice and peer support (Objects 1.2 & 1.3) *As well as the above, we have* ● Provided training to disabled people who employ PAs and to PAs for disabled people ● Further rolled out our advice and training resources to disabled people who employ personal assistants, and their personal assistants and applied for funding to develop further resources ● Established a disabled-led advocacy service to offer advocacy to people with muscle-weakening conditions Identify, promote, and develop best practice, innovative treatments and technologies (Object 1.2) ● We have collaborated on a wide range of research projects including ones on natural histories, bone density measurement, the experiences of DMD caregivers, and the experiences of LGBT people accessing social care

		● We have also developed a range of patient or user-led advisory and research leadership boards and trained patient experts who can now contribute lived experience in medical and academic spaces ● We have developed a loan library to allow members to borrow innovative technologies such as an eyegaze computer control system Campaign and influence treatments within health and local authorities, government, relevant professionals, disability organisations and charities. (Objects 1.1 & 1.2) ● We have engaged with campaigns to ensure effective treatments are funded, and have also engaged with the drug development process where appropriate in order to remain aware of potential upcoming treatments and where they should be supported Work with health and local authorities, government, disability organisations and charities in improving care, support and services (Objects 1.1, 1.2 & 1.3) ● We have campaigned on access to hospitals for personal assistants of disabled people ● We have supported campaigns about funding for appropriate treatment ● Through our advocacy service we have taken on cases specifically focused on improving care and support ● We have contributed to the *Smart Suit* project research by Duchenne UK ● We will be contributing to research on creating an app to hold information for people with DMD ● We have applied for funding to carry out research into adult social care and into bone health amongst other areas Increase awareness (Object 1.1) ● We have increased our social media profile, meaning better engagement with our content ● Senior staff have carried out high profile media and news engagements that have raised the profile of the organisation ● We have contributed to projects run for young people with muscle-weakening conditions to show the possibilities of the lives we lead as adults
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	We can confirm that the trustees have had regard to the guidance issued by the Charity Commission on public benefit

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	We do not make grants direct to individuals

Policy on social investment including program related investment	Para 1.38	We have not invested funds, although we transferred some to a higher interest account.
Contribution made by volunteers	Para 1.38	We are grateful to our trustees, advisors, and everyone who has volunteered their time and energy to speak or present at any of our sessions.
Other		N/A

Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	Organisational Development We moved to a new HR system allowing more accurate tracking of employee time and activities, and continued our review of policies. We finalised our new membership process, and ensured that it was operating correctly through Monday.com. We developed a more stable way of working at a more managed level of capacity for the organisation, enabling us to better meet the needs of our beneficiaries. Fundraising We raised funds from a variety of methods, including online shopping 'percentages', grant funding, project funds etc. These allowed us to continue and complete a number of projects, with specific funding to run our advocacy service, to maximise the impact of our transition to adulthood research, to update our website and resources, and to start a loan bank including generators and powerbanks, and an eyegaze computer control system. These have benefited our members through a wider ability to offer services such as advocacy, better knowledge of our information and resources, and the opportunity to test technology, allowing people to purchase or secure funding for tools and technology that will maximise their independence Staffing We were able to sustain the scale of our previous staff team, while also bringing in

		new roles, including the Campaigns Officer and Advocacy Officer, a Research Assistant, two people working on Independent Living Training, a writer and copyeditor updating our resources and a web editor, on top of our existing staff team. Connections We built international links further, through the European Alliance of Muscular Disorder Associations and through Rare Disease Europe, as well as building on our connections with neuromuscular clinics and specialists across the country, ensuring that we were up to date with best practice nationally and internationally. We also reached almost 130,000 people on social media across the year, and improved our responsive engagement. We also developed new branding which has given our online presence a more cohesive appearance, and professionalised it further Research Our Research Officer proged the Becoming an Adult with DMD project, and the Empowering Transition research, including holding two events. These have focused on using the findings of the research to implement real change for people with muscle-weakening conditions going through the process of moving into adulthood and had 30-40 attendees each. Research was presented at Critical Disability Studies Seminars, a conference at the University Hospitals Birmingham, international DMD meetings, and more. The work was perceived as having a material impact on how these services would be developed and delivered. PA and PA Employer Training We delivered training for Personal Assistants to disabled people, and their employers. These included bespoke workshops and group modules, building on previously created resources and delivering them to a wider audience. Attendees reported increased confidence and skills, and that they benefited from these community spaces. Delivering this project also built staff confidence and skills, helped raise awareness of the importance of Personal Assistants for disabled people, and ensured wider skilling across the care community. By using trainers with lived experience, we also

		emphasised the concept of the disabled person as an expert. Advocacy We launched an advocacy service for people with muscle-weakening conditions. This has taken on cases including care funding, wheelchair seating and CHC funding, and has fundraised to support itself where we anticipated that the funding would come from reserves. This service has shown clear benefit for the people accessing it. Campaigns We recruited a Campaigns Officer to lead on our work supporting people with muscle-weakening conditions to campaign on issues that matter to them. This role has also worked to build a campaigning network of people with muscle-weakening conditions to collaborate and support shared campaigns. We are working on issues including care, housing, and access to hospital for personal assistants to accompany disabled people. We are hoping to see results from our campaigns in the next year. UpLift Our Youth Development Project has remained actively on track, with the residential event a huge success, and generally excellent attendance at the online events we are delivering, exceeding targets. As well as the confidence-boosting residential, this project has delivered online and in-person sessions on everything from travel to technology and housing. These sessions have upskilled a group of young people while providing work for older people with muscle-weakening conditions delivering them. Events As well as events delivered through programmes such as UpLift, we delivered events including a Mental Health Awareness Event and a Summer Party. These were vital for bringing the community together, ensuring engagement, connection, a reduction in isolation, and positive experiences for attendees. Other We completed a rebranding and updated our website. We are currently finalising the

		content that will be returning to the website, further developing a “magazine” section of it, and expect to finalise this summer 2024.

Additional information (optional)
You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	Our main objectives were: Internal: ● Increase trustee recruitment to have a wider board - the actions in the objectives were completed but the recruitment was not successful ● Updating CRM processes - this has been completed successfully ● Revisiting governance - we moved to BrightHR and have ensured those policies are up to date. We are still finalising the renewed policies ● Fundraising boost: We exceeded our community fundraising target, but not our corporate target. We exceeded our grant application target. External: ● Making waves with campaigning and policy work: we have been involved in supporting campaigns on care and housing and have contributed to more than three policy initiatives, stakeholder outreach, or consultations ● Outreach to organisations: we have built new medical and academic partnerships ● Sharing: we have run a wide number of events that have brought people together and reduced isolation, including target events and others ● Advocacy support: We have started to deliver an advocacy service at Pathfinders but have not yet worked with 30 individuals ● Information, advice and resources: We have reviewed all the information on our website and will be ensuring

		everything is released on the website again as soon as some design elements are completed, the rest of this objective has been completed ● Communicating our stories: We have had more media coverage and aim to build on this in future
Performance of fundraising activities against objectives set	Para 1.41	In the last financial year, we had an income of £180,100. This financial year, our income has been £232,202. We have performed very well in grant fundraising, but are still developing our community fundraising.
Investment performance against objectives	Para 1.41	N/A
Other		N/A

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	We have very significant reserves and plan to designate these as soon as possible to fund new projects we have identified.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	We hold reserves to allow flexibility in responding to community need, including six months of unrestricted reserves plus costs to cover potential redundancy. Our reserves have increased unexpectedly this year and we will designate all funds above £50,000 to specific projects before the end of the next financial year 2024-25. *In September 2024 the trustees designated £67,500 to fund new projects and initiatives and will designate further funds in 2024-25 to bring down the reserves level.
Amount of reserves held	Para 1.22	**£119,610**
Reasons for holding zero reserves	Para 1.22	N/A
Details of fund materially in deficit	Para 1.24	N/A
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	N/A

Additional information (optional)
You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	Our principal source of funds is from the National Lottery (UpLift Youth Development Project and Advocacy Project). We have also received funding from Skills for Care, Tudor Trust, Pfizer, Skipton Building Souceity, Sureserve Foundation, PTC Therapeutics, Northumbria University, individual donations and fundraising, and other sources.
Investment policy and objectives including any social investment policy adopted	Para 1.46	N/A
A description of the principal risks facing the charity	Para 1.46	The principal risks include: Staff turnover and core staff moving on from their roles in the organisation Low numbers of trustees Lack of monthly accounts
Other		N/A

Structure, Governance and Management

Description of charity's trusts:		N/A
Type of governing document (trust deed, royal charter)	Para 1.25	Constitution
How is the charity constituted? (e.g unincorporated association, CIO)	Para 1.25	Charitable Incorporated Organisations
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	Individuals apply to the Trustee Board to become trustees and are interviewed. The Trustee Board can co-opt those people until they are elected at the AGM

Additional information (optional)
You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	Trustees receive a dedicated training and onboarding session from existing board members when they begin, and are able to access other training if desired or required
The charity's organisational structure and any wider network with which the charity works	Para 1.51	The charity structure is as follows: ● Jamie Hale - CEO ● Michaela Hollywood - Deputy CEO ● Suzanne Glover - Research Officer ● Quinn Clark - Personal Assistant and Research Assistant ● Cath McNicol - UpLift Project Lead ● Jacqui Adeniji-Williams - UpLift Project Officer ● Kyle Jenkins - UpLift Project and Campaigns Assistant ● Connor Brockbank - UpLift Engagement and Support Officer ● Sam Cornelius- Light - Advocacy officer and Independent Living Officer (PA Training) ● Charley Walker - Independent Living Officer (PA Employer Training) ● Hayleigh Morrow - Campaigns Officer ● Adam Langley - Social Media and Outreach Assistant
Relationship with any related parties	Para 1.51	N/A
Other		N/A

Reference and Administrative details

Charity name	Pathfinders Neuromuscular Alliance
Other name the charity uses	
Registered charity number	1155884
Charity's principal address	103 London Road Hailsham BN27 3AH

Names of the charity trustees who manage the charity

Number	Trustee Name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Sarah Rose	Co-chair		
2	Vicky Mozley	Co-chair		
3	Karen Hoe			
4	Sanjeev Mann			
5	Fleur Perry	Co-opted	23/02/2024 onwards	
6				
7				
8				
9				
10				
11				

12				
13				
14				
15				
16				
17				
18				
19				
20				

Corporate trustees – names of the directors at the date the report was approved

Director name		

Name of trustees holding title to property belonging to the charity

Trustee name	**Dates acted if not for whole year**	

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	N/A
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	N/A
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	N/A

Additional information (optional)

Names and addresses of advisers (Optional information)

Number	Type of Advisor	Name	Address
1	Independent Advisor to the Board of Trustees	Andrew Tunks	
2			
3			
4			
5			

Name of chief executive or names of senior staff members (Optional information)

Number	Position	Name	Address
1	CEO	Jamie Hale	N/A
2	Deputy CEO	Michaela Hollywood	N/A

Exemptions from disclosure

Reason for non-disclosure of key personnel details

N/A

Other optional information

N/A

Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signatures	Sarah Rose	Andrew Tunks
Full name(s)	SARAH ROSE Sarah Rose (Dec 20, 2024, 1:32pm)	Andrew Tunks Andrew Tunks (Dec 20, 2024, 5:11pm)
Position (e.g., Secretary, Chair, etc.)	Chair of Trustees	Trustee
Date	20 Dec 2024	20 Dec 2024

CHARITY COMMISSION FOR ENGLAND AND WALES

Pathfinders Neuromuscular Alliance	1155884

Receipts and payments accounts

CC16a

For the period from	06/04/2023	To	05/04/2024

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Consultancy	23208		-	23208	6172
Fundraising (donations)	2711		-	2711	10148
Fundraising (events)			-		76
Grants	30000	168722	-	198722	160,835
Interest	1120		-	1120	230
Reimbursements	276	3914	-	4190	2,637
Access to Work	2250			2250	
			-		
***Sub total** (Gross income for AR)*	**59,565**	**172,636**	**-**	**232,201**	**180,097**
A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	**-**	**-**	**-**	**-**	**-**
Total receipts	**59,565**	**172,636**	**-**	**232,201**	**180,097**
A3 Payments					
Bank interest and charges	10	50	-	60	**78**
Employment costs	845	115061	-	115906	**116,727**
Insurance, governance and digital	713	5642	-	6355	**5,910**
Office costs, equipment and stationary	252	2741	-	2993	**5,958**
Payment and transaction costs			-		-
Project and event costs	252	47149	-	47401	**40,005**
Promotional activity	-	4811	-	4811	**2,141**
Volunteer and staff expenses	49	2579	-	2628	**998**
Fundraising costs	8	93	-	101	-
Sub total	**2,129**	**178,126**	**-**	**180,255**	**171,817**
A4 Asset and investment purchases, (see table)					
	-	-	-	-	
	-	-	-	-	
Sub total	**-**	**-**	**-**	**-**	**-**
Total payments	**2,129**	**178,126**	**-**	**180,255**	**171,817**
Net of receipts/(payments)	**57,436**	**-5,490**	**-**	**51,946**	**8,281**
A5 Transfers between funds			-	-	-
A6 Cash funds last year end	**62,174**	**125,224**	**-**	**187,399**	**179,118**
Cash funds this year end	**119,610**	**119,734**	**-**	**239,346**	**187,399**

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	CAF Bank	19,610	99,734	-
	Co-op Bank Savings	100,000	20,000	-
	Co-op Bank Current	-	-	-
	Total cash funds	119,610	119,734	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities				
			-	

Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval
	Sarah Rose	ARAH ROSE	20 Dec 2024
	Andrew Tunks	Andrew Tunks	20 Dec 2024

Sarah Rose (Dec 20, 2024, 1:32pm)

Andrew Tunks (Dec 20, 2024, 5:13pm)

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF PATHFINDERS NEUROMUSCULAR ALLIANCE

I report to the trustees on my examination of the accounts of Pathfinders Neuromuscular Alliance ('the charity') for the year ended 5 April 2024.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 (the '2005 Act'), the Charities Accounts (Scotland) Regulations 2006 (as amended), and the Charities Act 2011 ('the 2011 Act'). You are satisfied that your charity is not required by charity law to be audited and have chosen instead to have an independent examination.

I report in respect of my examination of the Trust's accounts carried out under section 44 (1) (c) of the 2005 Act and section 145 of the 2011 Act. In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 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 as required by Section 44 (1) (a) of the 2005 Act and Regulation 4 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and section 130 of the 2011 Act; or
2. the accounts do not accord with those records; and
3. the accounts do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

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.

Mr J P Foxwell FCCA FCIE
independent-examiner.net

39 Enfield Road, Poole, BH15 3LJ

Date: 23 December 2024

Pathfinders Neuromuscular Alliance

England & Wales - Charity number 1155884

Accounts

CHARITY COMMISSION FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From 06/04/2022 To 05/04/2023

Charity name: Pathfinders Neuromuscular Alliance

Charity registration number:1155884

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	Our charitable objectives are: 1. The promotion of social inclusion of people with neuromuscular conditions who are socially excluded from society, or parts of society as a result of having Muscular Dystrophy and related neuromuscular conditions by: 1. Providing a network of groups that encourage and enables them to participate more effectively with the wider community; 2. Increasing or co-ordinating opportunities for them to engage with organisations and service providers to enable those providers to adapt services to better meet their needs; 3. Raising public awareness of the issues affecting them in all areas relating to having a neuromuscular condition; 4. Providing support to those between the age of 18 and 30 who are socially excluded to establish and grow a business or enterprise to relieve their needs and assist them to integrate into society. 2. To promote and protect the physical and mental health of people with Muscular Dystrophy and related neuromuscular conditions in the United Kingdom as the trustees shall determine. The aims for Pathfinders Neuromuscular Alliance are as follows: To provide a voice for adults living with Muscular Dystrophy and related neuromuscular conditions. (Objects 1.1 & 1.3) *We have engaged on matters of policy, including those around the COVID-19 pandemic, housing, and access to treatments for Spinal Muscular Atrophy* To provide a forum for adults living with Muscular Dystrophy and related neuromuscular conditions to share experiences, ideas and opinions in complete confidence. (Objects 1.2 & 1.3) *We have continued to manage peer facilitated support through our online forum, as well as expanding our social events, kicking off our youth development project,* Uplift, *starting a peer facilitate*

		space for people using direct payments to employ a PA or carer, and delivering sessions to people with neuromuscular conditions in schools and alongside other organisations. To provide information, advice and peer support to adults living with Muscular Dystrophy and related neuromuscular conditions. (Objects 1.2 & 1.3) *We have created and updated website resources, and run a range of workshops, talks, and discussion events that have allowed adults with muscular dystrophy and related neuromuscular conditions to network, seek support, and offer support to one another. We have created new peer support spaces to reach a wider number of people.* To identify, promote, and develop best practice, innovative treatments and technologies for adults living with Muscular Dystrophy and related neuromuscular conditions. (Object 1.2) *We have carried out research into the process of transitioning to adulthood for people with DMD and are currently disseminating those findings and looking to utilise them for policy influence. We have also engaged with research projects looking to support people with muscle-weakening conditions with tools for upper limb function. We have promoted and supported a range of research projects including:* *–scoping review of social care and support priorities for young people with neuromuscular conditions, University of York* *--chaplaincy services and spiritual care of children, young people and parents facing end of life,University of York* *–attitudes towards treatment of DMD, Newcastle University* *–sexual functioning and fertility in DMD,Newcastle University* *– assistive Technology, University College London* *– supporting genders project, University of Northumbria* *– Bone health for patients with DMD, University of Glasgow* *– supporting the functioning of Pfizer patient boards* To campaign and influence treatments for adults living with Muscular Dystrophy and related neuromuscular conditions within health and local authorities, government, relevant professionals, disability organisations and charities. (Objects 1.1 & 1.2) *We have been involved with a range of campaigns, with a particular focus on housing, social care, and personalised care. We hope to boost our campaign work further next year.* To work with health and local authorities, government, disability organisations and charities in improving care, support and services for adults living with Muscular Dystrophy and related neuromuscular conditions. (Objects 1.1, 1.2 & 1.3) *As well as our direct support and advocacy work and our housing research and campaigns, we have participated in the Campaign for Personalised Care, our own Crafting for Change campaign, and developed training for people with muscle-weakening conditions in employing their own carers or PAs.* To increase awareness of adults living with Muscular Dystrophy and related neuromuscular conditions. (Object 1.1)

		Through our campaign work, and wider events we have increased awareness of adults living with neuromuscular conditions. With the Keyfort Group naming us their charity of the year and an expansion in community fundraising work and media work next year, we hope to see that expand.
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	PTC Skills Online *We completed the Online Skills Project, through which we worked with a cohort of young people with DMD, supporting them to develop skills in online speaking, and organising and running informational sessions for other young people with DMD.* PTC Research *The Pathfinders Research Team reached the final stages of data collection, analysis and dissemination planning for the transition to adulthood with the DMD project. Peer researchers had the opportunity to enhance their research skills while contributing to the applied and theoretical understanding of transition issues for young adults.* Uplift *Our Youth Development Project got properly underway, with a wide range of events run for young people aged 18-30 with muscle-weakening conditions, including social, informational, and community events online and offline. We built relationships with other partners, and strengthened our connections with members in the target age group, working towards our first residential in 2023-24.* Skills for Care Employer Training *We designed a training course for people with muscle-weakening conditions (and people with high support needs more broadly) in employing and managing their own PA teams. This has given people far more confidence in their ability to live independently and manage their care. We are delivering this going forward into 2023-24.* Skills for Care PA Training *We completed a training project for the PAs and carers of people with muscle-weakening conditions. This offers them training in the support needs of people with this family of conditions, and has improved job performance, recruitment, and retention as part of this. This remains on our website going forward.* Core Work *Through our core capacity, we supported the above projects, applied for a range of grants successfully, including the Skills for Care employer training, a further year of PTC Research, and a Tudor Trust development grant, and have other applications outstanding. We also moved to a new project management system, CRM, membership process, and transformed our social media engagement.*
Statement confirming whether the trustees have had regard to	Para 1.18	The trustees have observed the work carried out by Pathfinders closely and agree that it meets the public benefit test.

the guidance issued by the Charity Commission on public benefit		

Additional information (optional)
You may choose to include further statements where relevant about:

	SORP reference	
Contribution made by volunteers	Para 1.38	We would not be able to carry out the work we do without the endless commitment of our volunteers, especially the trustees, and those members who share their experiences and knowledge generously within our facebook group.

Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	Our main achievements have been as follows: Completing the first year of the Uplift project, which reached a total of approximately 60 young people with muscle-weakening conditions, giving them skills which will both benefit their own expertise in self-advocacy, and also in building campaigns with wider social benefit. Completing delivery of our PA training programme, which is now hosted on our website and available for all PAs to take. Securing funding for, and beginning, our sibling training designed for people employing PAs, to give them the skills they need to recruit, manage, and support their care team. Completing the second year of our PTC-funded research on transition to adulthood for people with DMD, and securing the funding for the third year of this research project, which will have national benefit for people with neuromuscular conditions transitioning to adulthood. Securing funding to upgrade our web presence, advice, and guidance, to further professionalise as an organisation. We wish to register particular thanks to several people, including co-founder Jon Hastie, who moved on to a new role in July 2022 and to remember with gratitude a number of people who passed away during this year, including co-founder Mark Chapman, current trustee Anthony Price, former trustee and Chair of Trustees

		Lucy Watts, former trustee Alan Pockley, and members including Harry Thompson and Philip Carroll.

Additional information (optional)
You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	The objectives we set in our strategic plan were: **Internal work: IDEAS** *Improving our governance* We intended to carry out a full policy review, drafting outstanding policies and sending them to trustees for approval, as well as updating our risk register and scheduling policy and risk register reviews. We have drafted the majority, and only have a few outstanding. We have updated our risk register and scheduled reviews. We also intended to strengthen our board of trustees, and have continued to promote the role to members, adding more information to the website about the role, mapping skills informally and have recruited a trustee and an advisor who do not have neuromuscular conditions themselves. *Demonstrating our impact* We have developed ways of mapping impact in our projects, including collection of formal and informal feedback, which has informed our website, reports, and funding bids. We will put case studies on our website next year alongside our web development. We are carrying out our annual survey, but have decided not to join any accreditation schemes due to our size and the potential workshop. *Expanding our membership* We have improved and clarified our membership application process. We have commissioned design for our information packs and will finish those in the upcoming year, along with welcome information. As we have carried out more in-person events this has

		improved our outreach, and we are almost ready to launch our new member sign-up process. *Aligning our branding* We have reviewed and improved our social media presence, commissioned graphic design through a different provider (Katy Etherington), and have secured funding to rewrite all our website information in a consistent tone and style in the upcoming year. *Securing financial sustainability* We have improved community links and therefore fundraising, including raising £4517.76 through donations, including an excellent event by Hayleigh Barclay, a number of fundraising platforms such as Amazon Smile and EasyFundraising, and funds raised at member funerals. We have benefited from a corporate partnership with bPerfect Cosmetics and Tess Daly, which raised £5630, and has taught us a lot about managing corporate partnerships and relationships We have brought in successful grants including from PTC to continue our research, Skills for Care to run employer training, the Tudor Trust for development, and through a Wellcome funded project on users of long-term ventilation, as well as a commission from Action Duchenne. **External work: SCORE** *Setting up campaigns and events* We intended to run the following events: Informational: - Accessible travel - Managing your care - Living independently - Managing emergencies - Social - Online quiz - Drop-in space - Themed event Campaigns - Care and support, considering workforce challenges Supporting members with their campaigns, where we have supported Sarah Rose's *Crafting for Change*, and the work of members including Fleur Perry's work on housing and home ventilation, and Sanjeev Mann and Jamie Hale's work on access to arts venues in Scotland and England respectively. *Crafting for Change* encouraged a range of members to craft and create items for sale - which was an excellent example of community fundraising. Similarly, Hayleigh Barclay organised an incredibly successful local

		fundraising event, which again we felt privileged to be the recipients of support from. *Continuing our projects* We have continued our Youth Development Project, Uplift, our research on Transition to Adulthood with DMD, our Content Creators Academy work producing information and advice resources (which we will complete in 2023-24), and our PA Training Programme. *Offering information, advice, and support* We have explored funding for an advocacy service and whilst grants were unsuccessful we anticipate funding this for a short period from our reserves to prove demand, making it easier to seek further funding. We have refreshed some of our information and advice resources, thanks to the Content Creators project, and have recruited someone to transform old resources using our new templates in 2023-24. We have been involved in small-scale resource creation, but not through funding partnerships. *Raising awareness* We have delivered two *What It's Like* articles and intend to continue using the same format. We have also delivered three social media takeovers demonstrating the reality of living with a muscle-weakening condition. We have pitched original content to the media and worked on outreach to press and media contacts. This includes Jamie undertaking media spokesperson training, which will show benefits in the upcoming years. *Engaging members and organisations* We have not encouraged significant volunteering due to limited resources to support volunteers. We have had regular events through the Uplift project and are looking at other ways of holding regular events in the next year. We hoped to organise a neuromuscular round-table but were unable to do so due to capacity. Overall we have achieved the vast majority of our objectives. The majority of those we could not achieve, we have postponed for the next year, due to staff capacity.
Performance of fundraising activities against objectives set	Para 1.41	Our objective was to apply for two grants of £50,000-£100,00, two grants of £20,000-£50,000 and four grants of £0-£20,000. We received funding for two projects of £0-£20,000, including a series of webinars for Action Duchenne, and a Tudor Trust Development Grant. We are awaiting the outcome of a further two grants of this scale. We made six grant applications for £20,000-£50,000 (against a target of two), of which three were successful

		- the Skills for Care PA Employer Training, an additional year of the PTC-funded transition to adulthood with DMD, and support on a Wellcome funded project called *Cripping Breath* were successful. Two were unsuccessful, and one is outstanding. We focused on smaller grant applications and on grants that fitted more closely with member and organisational needs, and therefore have not applied for the two grants of £50,000-£100,000. We are currently writing applications for projects at this scale and have developed a way of finding appropriate funding and tracking our funding applications more smoothly, which will also speed up writing and submitting them.
Investment performance against objectives	Para 1.41	We did not have investment objectives set.
Other		

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	Pathfinders Neuromuscular Alliance is in a strong position, with grants ongoing throughout the next financial year for all job roles, an increase in fundraising, and applications open with a range of funders.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	We currently hold reserves in excess of policy and are in the process of creating a job role in advocacy and engagement, which will spend reserves whilst also demonstrating the need for this to receive funding in future. We will also carry out a staff pay review against inflation and cost of living.
Amount of reserves held	Para 1.22	
Reasons for holding zero reserves	Para 1.22	N/A
Details of fund materially in deficit	Para 1.24	N/A
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	None

Additional information (optional)
You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	Our principle sources of funds are: ● National Lottery Grant for our Youth Development Project ● Funds for our Research Officer role from PTC Therapeutics ● Funds for the employer and the PA training through Skills for Care ● Core costs grant from the Tudor Trust ● Development grant from the Tudor Trust ● Partnerships and community fundraising
Investment policy and objectives including any social investment	Para 1.46	We do not have an investment policy.

policy adopted		
A description of the principal risks facing the charity	Para 1.46	The principal risks facing the charity are: ● Death or serious illness of a trustee or staff member, with especial reference to our co-Chair of Trustees, Sarah Rose, or our CEO, Jamie Hale due to them being the only signatories on a bank mandate requiring two signatures, which we are managing by updating the bank mandate and ensuring we have robust leave policies in date ● Withdrawal of funding by a major funder such as the National Lottery or PTC Therapeutics, where we ensure that we are up to date with all reporting and maintain open communications with funders if we have concerns ● Loss of staff members, where significant project knowledge is held by individuals, which we are managing by transferring all project management to software where deadlines and information can be held and accessed communally ● A failure to secure core funding to replace the £30,000 p/a funded by Tudor Trust from FY 2024-25 onwards, where we are in the process of exploring alternative funders.
Other		

Structure, Governance and Management

Description of charity's trusts:		N/A
Type of governing document (trust deed, royal charter)	Para 1.25	Constitution
How is the charity constituted? (e.g unincorporated association, CIO)	Para 1.25	CIO
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	Trustees are advertised for publicly, and can be appointed to the board by a majority vote of existing trustees. This has been invaluable given the turnover of trustees we have experienced.

Additional information (optional)
You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	We have an onboarding process for new trustees to ensure that they understand the role and significance of being a trustee, and training on the platforms and systems we use.
The charity's organisational structure and any wider network with which the charity works	Para 1.51	We are overseen by a trustee board comprising two Co-Chairs of Trustees, Sarah Rose and Vicky Mozley. Since Jon Hastie's departure, Pathfinders has been run by a sole CEO, Jamie Hale, with Michaela Hollywood as a Deputy CEO.
Relationship with any related parties	Para 1.51	We currently share a storage locker with CRIPtic Arts, also managed by Jamie Hale, because this enabled us to access a storage locker at lower cost than we otherwise would have been able to.
Other		

Reference and Administrative details

Charity name	Pathfinders Neuromuscular Alliance
Other name the charity uses	Formerly known as DMD Pathfinders
Registered charity number	1155884

Charity's principal address	% Sarah Rose 103 London Road Hailsham BN27 3AH

Names of the charity trustees who manage the charity

		Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
	1	Sarah Rose	Co-Chair of Trustees	Whole year	
	2	Vicky Mozley	Co-Chair of Trustees	Whole year	
	3	Hayleigh Barclay	SMA Rep	Whole year	
	4	Sanjeev Mann	DMD Rep	From 09/08/2022-Present	
	5	Karen Hoe		From 17/08/2023-Present	
	6	Anthony Price		Until his death in Feb 2023	
	7				
	8				
	9				
	10				
	11				
	12				
	13				
	14				
	15				
	16				
	17				
	18				
	19				
	20				

Corporate trustees – names of the directors at the date the report was approved

Director name		

Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole year	

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	None
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	

Additional information (optional)

Names and addresses of advisers (Optional information)

	Type of adviser	Name	Address
	Informal	Andrew Tunks	
	Name of chief executive or names of senior staff members (Optional information)		
	Matthew James Robinson-Hale - CEO; Michaela Hollywood - Deputy CEO		

Exemptions from disclosure

Reason for non-disclosure of key personnel details

Other optional information

Declarations

Signature		
Full name	Sarah Rose	Vicky Mozley
Position	Co-Chair of Trustees	Co-Chair of Trustees
Date	29/08/2023	30/08/2023

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF PATHFINDERS NEUROMUSCULAR ALLIANCE

I report to the trustees on my examination of the accounts of Pathfinders Neuromuscular Alliance ('the charity') for the year ended 5 April 2023.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 (the '2005 Act'), the Charities Accounts (Scotland) Regulations 2006 (as amended), and the Charities Act 2011 ('the 2011 Act'). You are satisfied that your charity is not required by charity law to be audited and have chosen instead to have an independent examination.

I report in respect of my examination of the Trust's accounts carried out under section 44 (1) (c) of the 2005 Act and section 145 of the 2011 Act. In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 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 as required by Section 44 (1) (a) of the 2005 Act and Regulation 4 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and section 130 of the 2011 Act; or
2. the accounts do not accord with those records; and
3. the accounts do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

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.

Mr J P Foxwell FCCA FCIE
independent-examiner.net

39 Enfield Road, Poole, BH15 3LJ

Date: 15 September 2023

CHARITY COMMISSION FOR ENGLAND AND WALES

thfinders Neuromuscular Alliance | 1155884

Receipts and payments accounts

CC16a

For the period from	06/04/2022	To	05/04/2023

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Consultancy	6172		-	6,172	-
Fundraising (donations)	10147.76		-	10,148	5,463
Fundraising (events)	76		-	76	-
Grants	30180	130,655.13	-	160,835	233,401
Interest	229.86		-	230	
Reimbursements	2276.55	360	-	2,637	5,199
			-	-	
***Sub total** (Gross income for AR)*	49,082	131,015	-	180,097	244,063
A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	49,082	131,015	-	180,097	244,063
A3 Payments					
Bank interest and charges	78		-	78	114
Employment costs	25178.18	91,549.17	-	116,727	109,391
Insurance, governance and digital	3597.4	2312.54	-	5,910	6,123
Office costs, equipment and stationary	2019.33	3938.61	-	5,958	7,799
Payment and transaction costs			-	-	2
Project and event costs	415.56	39589.12	-	40,005	11,735
Promotional activity		2140.55	-	2,141	210
Volunteer and staff expenses	366.31	631.76	-	998	-
	-	-	-	-	-
Sub total	31,655	140,162	-	171,817	135,374
A4 Asset and investment purchases, (see table)					
	-	-	-	-	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	31,655	140,162	-	171,817	135,374
Net of receipts/(payments)	17,427	- 9,147	-	8,281	108,689
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	44,747	134,371	-	179,118	70,429
Cash funds this year end	62,174	125,224	-	187,399	179,118

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Restricted funds	62,174	125,224	-
	Unrestricted funds		-	-
		-	-	-
	Total cash funds	62,174	125,224	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities	Accounts Payable	Restricted project costs	1,000	30 April 2023
			-	

Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval
	Sarah Rose	SARAH ROSE	29/08/2023
	vmozley	Vicky Mozley	30/08/2023

Pathfinders Neuromuscular Alliance

England & Wales - Charity number 1155884

Accounts

pathfinders
neuromuscular
alliance

ANNUAL REPORT 2021-22

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CHAIR OF TRUSTEES

Pathfinders Neuromuscular Alliance has made huge strides this year. A big thank you to dedicated staff, volunteers and supporters for their part in creating such a supportive space, reaching out to others and building on our reputation as a user-led organisation.

There have been a number of projects running and more in the planning stages. The PA Training modules are an example of how the charity listens, identifies a need and does something about it. Congratulations to all involved in bringing this project to life.

With the pandemic still very much present, the online socials have played a vital role in keeping in touch, enabling us to share our experiences and support each other. The Uplift project will also provide opportunities to connect with each other and develop skills. We look forward to seeing how this project develops.

This has been a period of stability, building on foundations and consolidating the charity's position. There is much going on in the background that is not always visible for example, the research project on Transition and the campaigning about Personalised Care needs. Always keeping our core values in mind, the coming year is going to be an exciting one for Pathfinders.

Sarah Rose

Co-Chair of the Board of Trustees

Sarah Rose - co-Chair of Trustees

Vicky Mozley - co-Chair of Trustees

MISSION

Pathfinders is a user-led organisation by and for people with muscle-weakening conditions. We want everyone to have choice and control over where and how they live their lives, with access to peers, community and connection. We offer social and educational opportunities, providing advice, information, support and advocacy, as well as campaigning, and running projects designed to help our members overcome barriers.

VISION

We want to build a society in which people with muscle-weakening conditions are able to lead full, expansive, and self-determined lives. We believe social care and healthcare should be easily accessibl1e, and treatments should be publicly funded and freely available.

We recognise the skills, aspirations, and achievements of our members, and look to a world which enables everyone to reach their full potential.

VALUES

Pathfinders believes in:

- Being a user-led organisation
- Being diverse and inclusive
- Recognising everyone has different situations, achievements, skills, and aspirations
- Empowering our members
- The value of collective experience
- Working constructively and collaboratively with other organisations
- Campaigning for change
- Creating a positive, fun, and engaging environment

CHARITABLE OBJECTIVES

1. The promotion of social inclusion of people with neuromuscular conditions who are socially excluded from society, or parts of society as a result of having Muscular Dystrophy and related neuromuscular conditions by:

a) Providing a network of groups that encourage and enables them to participate more effectively with the wider community,

b) Increasing or co-ordinating opportunities for them to engage with organisations and service providers to enable those providers to adapt services to better meet their needs,

c) Raising public awareness of the issues affecting them in all areas relating to having a neuromuscular condition,

d) Providing support to those between the age of 18 and 30 who are socially excluded to establish and grow a business or enterprise to relieve their needs and assist them to integrate into society.

2. To promote and protect the physical and mental health of people with Muscular Dystrophy and related neuromuscular conditions in the United Kingdom as the trustees shall determine.

OUR AIMS

Every year, we look at our aims as a charity, and assess what we have done to achieve those aims. This helps us understand whether we are providing the community with the things we have said we will offer as a charity.

To provide a voice for adults living with Muscular Dystrophy and related neuromuscular conditions

We have engaged on matters of policy, including those around the COVID-19 pandemic, housing, and access to treatments for people with Spinal Muscular Atrophy

To provide information, advice and peer support to adults living with Muscular Dystrophy and related neuromuscular conditions

We have continued to manage peer facilitated support through our online forum

To provide a forum for adults living with Muscular Dystrophy and related neuromuscular conditions to share experiences, ideas and opinions in complete confidence

We have created and updated website resources, and run a range of workshops, talks, and discussion events that have allowed adults with muscular dystrophy and related neuromuscular conditions to network, seek support, and offer support to one another.

To identify, promote, and develop best practice, innovative treatments and technologies for adults living with Muscular Dystrophy and related neuromuscular conditions.

We have identified challenges in the housing market and made recommendations about increasing the stock of accessible housing. We have also supported campaigns for treatments for Spinal Muscular Atrophy to be available to appropriate adults.

We have carried out research into the process of transitioning to adulthood for people with DMD and are currently disseminating those findings and looking to utilise them for policy influence

To campaign and influence treatments for adults living with Muscular Dystrophy and related neuromuscular conditions within health and local authorities, government, relevant professionals, disability organisations and charities.

We have been involved with a range of campaigns, with a particular focus on housing, social care, and personalised care

To work with health and local authorities, government, disability organisations and charities in improving care, support and services for adults living with Muscular Dystrophy and related neuromuscular conditions.

As well as our direct support and advocacy work and our housing research and campaigns, we have led a campaign on allowing people access to their Personal Assistants (PAs) or carers while in hospital, and developed a training package for PAs on supporting people with muscle-weakening conditions

To increase awareness of adults living with Muscular Dystrophy and related neuromuscular conditions.

Through designing training for PAs and carers and our campaign work, we have increased awareness of adults with muscular dystrophy and related conditions

REFLECTIONS

Jamie Hale
CEO

During this financial year, the COVID-19 pandemic has continued to affect our members, and radically limit our ability to undertake in-person work. We have, however, continued to provide a wide range of services online, including support and advocacy, training and development, advice and information, and research and campaigns.

We have been able to develop projects applied for during the previous financial year, ensuring that we have continued to support people with DMD specifically, whilst also widening our provisions for people with other muscle-weakening conditions.

The events and programmes we have run to benefit people with muscle-weakening conditions including direct 1:1 support and advocacy, supporting and managing peer-facilitated discussion and advice spaces, running social events, and leading on a wide range of projects, including research into transition to adulthood for young people with Duchenne Muscular Dystrophy (DMD), designing and running a training programme for Personal Assistants (PAs) of people with muscle-weakening conditions, running an 'online skills' training project for people with DMD, and running an accessible housing campaign.

We also put considerable time into updating our procedures, including a new membership process and fundraising guide.

Finally, we began the process of running UpLift, a National Lottery funded project which will run for four years, supporting young people aged 18-30 to build self-advocacy and campaigning skills through a series of online and in-person events,

Jamie Hale

Jamie Hale

KEY ACHIEVEMENTS

The first independent-living based training programme for PAs and carers designed and led by people with muscle-weakening conditions

[I feel] far more confident in the care I'm receiving

[I have] PAs I trust to understand my needs

The first research project on the experiences of people with DMD, led by people with DMD themselves, giving people the chance to develop their academic skills, and have research published

I wanted to join the project so that I could use my academic research skills to help produce research which may directly benefit others with DMD and other neuromuscular conditions.

I have a personal connection with the research topic, and as a university graduate, I have found using my skills very rewarding.

Projects supporting people with DMD to develop skills as online freelancers, whilst creating resources for the community

I learnt a lot about being part of a team - where everyone has their tasks and the importance of trusting that they will do them.

I felt this improved my confidence and helped me a lot in talking to new people

ACHIEVEMENTS AGAINST OBJECTIVES SET

In our last strategic plan, we prioritised organisational and financial stabilisation and development, increased engagement, information and advice, running campaigns, and events, and securing funding applications for future projects.

We almost completed our policy review, and have the remaining policy development in progress. We also moved to more resilient financial management software, allowing for us to better analyse our financial situation, reflecting our organisational growth.

All our projects are proceeding well and comfortably within reporting deadlines and requirements, and we have added a lot of valuable resources to our website, which we continue to do.

Where we have struggled to reach our objectives, this has been due to limited staff capacity and time - a sector-wide problem, and one we are endeavouring to resolve by trying to create a situation in which staff are not always expected to be working at capacity.

FINANCIAL REVIEW

In our last strategic plan we had the objective of £10,000 of community fundraising during the year. We did not achieve this objective, but identified a number of factors that affected this, and intend to focus on brand, identity, and marketing to support our community fundraising work going forward, alongside applying for funds for this important work.

We set out different objectives for grant fundraising and comfortably acheived those. We are principally funded by grant-making organisations, including the Tudor Trust and National Lottery, by government bodies such as Skills for Care, and by pharmaceutical companies including PTC Therapeutics. We are also funded in partnership working with other neuromuscular organisations such as Duchenne UK..

The funding we have secured from the National Lottery will allow us to run a multi-year project titled UpLift, developing campaign and self-advocacy skills in people with muscle-weakening conditions.

We are confident in the ongoing reserves situation and in the financial stability of the organisation.

OUR WORK

ORGANISATIONAL DEVELOPMENT

We continued to work with Jamie Hale and Jon Hastie as CEOs, and had a significant number of staff across the year including:

- Michaela Hollywood
- Suzanne Glover
- Cath McNicol
- Jacqui Adeniji-Williams
- Adam Langley
- Julian Fiorentini
- Olivia Morgan
- Melissa Gordon
- Sanjeev Mann

We focused on building capacity with regard to social media and membership administration. Our social media work was carried out primarily by Sanjeev Mann whilst funded by the Tudor Trust as a development officer, and included commissioning blogs and articles as well as day to day management and growth. This has benefited our members through the increased awareness and outreach that Pathfinders now has.

By employing Kate Mellor as an administration assistant, we were able to design new membership processes and streamline many of our administration and payroll tasks. This has benefited our members in that less of our charity resource is spent on administration and payroll, meaning members are better contacted and supported, and that staff time is able to be managed to maximise member benefit.

SUPPORT AND ADVOCACY

We have continued our 1:1 support and advocacy work, assisting members, families, and professionals around them. The two key areas of need we have identified have been around access to social care and to employment. This has had a significant impact on the individual beneficiaries. As well as supporting individuals with these processes, we have also ensured that we are providing information for groups who need it.

This includes running a series of sessions around work for people with DMD on the Online Skills project, and the training course we designed for Personal Assistants, with the intention of ensuring better quality support for people with muscle-weakening conditions. This has allowed our work to have a benefit for the wider community of people with muscle-weakening conditions that we serve, regardless of their membership of the organisation.

OUR WORK

PROJECT: UpLift: Disability Advocacy Project

We received a funding agreement for UpLift from the National Lottery - a youth development project focused on supporting people to build skills in areas including self-advocacy and campaigns, whilst also focusing on an independent adulthood with muscle-weakening conditions.

We set up a steering committee and began work on the pilot year, which will run from 2022 to 2023 and includes a range of events on adult living with neuromuscular conditions, including around sex, relationships, driving, care, housing, and independence.

PROJECT: Content Creators Academy

At the start of the year we started our Content Creators Academy; specifically for people living with DMD. This offered training in working freelance as a content creator with DMD, alongside offering paid work in content creation, supporting people in building skills and a portfolio, whilst producing content relevant to other young people with DMD (and other muscle-weakening conditions).

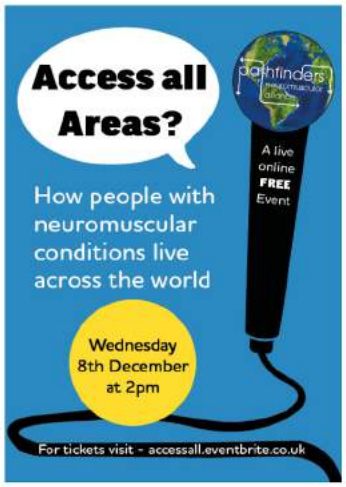
At project outset, we delivered 3 workshops online to support freelance content creators:

1. Becoming a disabled key influencer
2. Permitted work and disability benefits
3. Business planning as a freelancer, and Access to Work funding

We then began to commission work including articles, infographics, and a podcast, which we're looking forward to completing and publishing over the next year.

OUR WORK

PROJECT: Online Skills Training



We designed a project for people with DMD, connecting young people with DMD, adults with DMD, and parents of young people with DMD, focused on Encouraging Independence, through online webinars and coaching sessions titled Ask the Adults, Ask the Parents, and Ask Gen Z, leading to open conversation and connection.

We also worked with two cohorts of young people with DMD to support them in developing skills to run online events, through weekly event planning meetings and workshops led by people with muscle-weakening conditions. These covered research, marketing, flyer design, and public speaking. The workshops empowered young people with DMD to run online events, including Shut Up and Drive - an event on driving with DMD, Wheelie Good Holidays - an event on travelling with DMD, Anime Explained, and Access All Areas.

The project had a significant impact on a wide range of participants. One mother noted that her son had gained some confidence and "it was a good opportunity for him to engage with others online and do something different". Another participant said "I felt this improved my confidence and helped me a lot in talking to new people" and others said they had become more confident in "presenting in front of people", "working as part of a team", and "being able to speak clearly".

RESEARCH: Transition to Adulthood with DMD

We have continued into a second year of our peer-led research into transition to adulthood for people with DMD. This research has developed significantly with important findings emerging. Our Research Officer, Dr Suzanne Glover worked with peer researchers to carry out interviews across Europe, analysing them to understand how adults with DMD understand their experiences of transitioning to adulthood.

It showed how young adults with DMD often see the world as incompatible for people with DMD when considering many of the important milestones of transition to adulthood. This includes transitions in educational settings, post-educational opportunities, as well as navigating new and existing social relationships entering adult life. The research suggests that much of this perceived incompatibility is fuelled by experiences of ableism and subsequent internalised ableism. Once the analysis has been completed, we will be focusing on disseminating these findings, hoping to use them to create change.

OUR WORK

RESEARCH: Housing Accessibility Campaign

This took place from April to October, and was a research study and scoping exercise to inform future work on housing accessibility for adults with DMD.

Dr Jon Rey-Hastie (CEO at Pathfinders) worked with Dr Janet Hoskin at the University of East London to carry out research into future housing accessibility for adults with DMD. This found that there is not enough accessible housing in the UK and not enough information available for people to find current accessible housing.

This led us to make key recommendations, including:

- Information about finding accessible housing on the private housing market needs to be readily available and accessible for disabled people
- Information about finding social housing needs to be readily available and. accessible for disabled people
- Government and Local Authorities must commit to increase the provision of accessible housing
- Local Authority housing services should be joined up with social care and health support

This research has led to a better understanding of the housing market for disabled people, with benefit to disabled people more broadly, outside our membership, but grounded in a specific knowledge of the needs of people with neuromuscular conditions. The knowledge has also informed much of our support and advocacy work around housing.

"Working on the accessibility housing research project illuminated to me the amount of work there is yet to be done to get enough suitable accessible housing in the UK.

On a personal level, working on this project was my first employment and gave me confidence and I built on skills I had gained at university. The project also led to my following two employed positions at Pathfinders"

Kate Mellor

OUR WORK

PROJECT: Training for PAs and Carers

Pathfinders identified that people with muscle-weakening conditions often have specific requirements in accessing personal support, and that having a training programme for Personal Assistants (carers) of people with muscle-weakening conditions would be very beneficial. Through informal polling and discussions with members, we identified significant challenges with recruitment and retention, and a lack of training material which both explored the common factors shared by people with muscle-weakening conditions, and the role of the PA.

This training programme offers a transferable certification of completion, allowing PAs to move between roles while demonstrating knowledge of the needs of our community.
We developed 13 modules in total:

1. Introduction to neuromuscular conditions
2. Independence and the social model of disability
3. Neuromuscular conditions and common emergencies
4. Common equipment used by people with neuromuscular conditions
5. Ventilation
6. Posture, skin and position
7. Swallowing and nutrition
8. Physiotherapy and exercise
9. Working in someone's home and workplace
10. Supporting disabled people as parents
11. Respect, intimacy and personal care
12. Supporting people with sex and relationships
13. Supporting people with their emotional health

> I feel that the course has given me some reassurance in my management of carers. It's encouraged me to remember I always have choice in my care and I must always speak up about my preferences.

> I've been employing carers for over 10 years and I've never come across training that is so relevant and up-to-date for someone with a muscle wasting condition. I frequently send carers on mandatory training which does not cater for any of my specific care needs. I feel this can have a negative impact on the quality of my care and staff morale. I can honestly say that there has been a buzz in the air with my care team over the past few weeks because of this training.

The modules were all led by people with muscle-weakening conditions, with specialists contributing where appropriate, and were delivered across a range of training days.

Following the end of this project, these modules are available for free online for anyone to take - whether a PA or carer, a friend, a family member, or a professional, offering a range of information in what muscle-weakening conditions are and how they affect people.

ACKNOWLEDGEMENTS

Prepared by Jamie Hale for the Board of Trustees, November 2022

With thanks to:

The staff, trustees and volunteers who keep Pathfinders going, and the members who generously share their advice and support in our facebook groups and at our events.

Thank you for your continued support of Pathfinders

Contact:

General - info@pathfindersalliance.org.uk

Trustees - trustees@pathfindersalliance.org.uk

CEO - Jamie Hale jamie@pathfindersalliance.org.uk

Charity Name	No (if any)
Pathfinders Neuromuscular Alliance	1155884

Receipts and payments accounts

CC16a

For the period from	Period start	To	Period end
	6th April 2021		5th April 2022

Section A Receipts and payments

	Unrestricted to the nearest £	Restricted to the nearest £	Endowment to the nearest £	Total to the nearest £	Last year to the nearest £
A1 Receipts					
Fundraising	5,463	-	-	5,463	4,149
Grants	37,565	195,837	-	233,401	78,789
Reimbursements	5,199	-	-	5,199	3,651
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
***Sub total** (Gross*	48,226	195,837	-	244,062	86,589
A2 Asset and					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	48,226	195,837	-	244,062	86,589
A3 Payments					
Bank interest and charges	102	12	X -	114	69
Employment costs	29,396	79,995	-	109,391	49,419
Insurance, governance, and	4,078	2,045	-	6,123	2,693
Office, equipment and	7,799	-	-	7,799	3,500
Project and event costs	53	11,682	-	11,735	354
Promotional activity		210	-	210	168
Payment and transaction costs	2	-	-	2	1,030
	-	-	-	-	-
	-	-	-	-	-
Sub total	41,430	93,944	-	135,374	57,233
	CORRECT	CORRECT			
A4 Asset and					
	-	-	-	-	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	41,430	93,944	-	135,374	57,233
Net of receipts/(payments)	6,795	101,893	-	108,688	29,356
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	37,952	32,478	-	70,430	41,073
Cash funds this year end	44,747	134,371	-	179,118	70,429

Section B Statement of assets and liabilities at the end of the per

Categories	Details	Unrestricted to nearest £	Restricted to nearest £	Endowment to nearest £
B1 Cash funds		44,747	134,371	-
		-	-	-
		-	-	-
	Total cash funds	44,747	134,371	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

	Details	Fund to which	Amount due	When due
B5 Liabilities	Unpaid invoice to NJC Secretarial	PTC Research	58	13/10/22
	Unpaid invoice to Luca Buccella	PTC Research	1,156	30/11/22
			-	
			-	
			-	

Signed by one or two	Signature	Print Name	Date of
	Sarah Rose (Dec 12, 2022 18:37 GMT)	Sarah Rose	Dec 12, 2022
	Victoria Mozley (Dec 13, 2022 13:41 GMT)	Victoria Mozley	Dec 13, 2022

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF PATHFINDERS NEUROMUSCULAR ALLIANCE

I report to the trustees on my examination of the accounts of Pathfinders Neuromuscular Alliance ('the charity') for the year ended 5 April 2022.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 (the '2005 Act'), the Charities Accounts (Scotland) Regulations 2006 (as amended), and the Charities Act 2011 ('the 2011 Act'). You are satisfied that your charity is not required by charity law to be audited and have chosen instead to have an independent examination.

I report in respect of my examination of the Trust's accounts carried out under section 44 (1) (c) of the 2005 Act and section 145 of the 2011 Act. In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 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 as required by Section 44 (1) (a) of the 2005 Act and Regulation 4 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and section 130 of the 2011 Act; or
2. the accounts do not accord with those records; and
3. the accounts do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

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.

Mr J P Foxwell FCCA FCIE
independent-examiner.net

39 Enfield Road, Poole, BH15 3LJ

Date: 13 December 2022

Charity Name	No (if any)
Pathfinders Neuromuscular Alliance	1155884

Receipts and payments accounts

CC16a

For the period from	Period start	To	Period end
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	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
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			-	-
			-	-
			-	-
			-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

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Mr J P Foxwell FCCA FCIE
independent-examiner.net

39 Enfield Road, Poole, BH15 3LJ

Date: 13 December 2022

Pathfinders Neuromuscular Alliance

England & Wales - Charity number 1155884

Accounts

Pathfinders Neuromuscular Alliance Annual Report April 2020 - March 2021

The CIO started the year as DMD Pathfinders and in September 2020 became Pathfinders Neuromuscular Alliance.

Introduction

Pathfinders Neuromuscular Alliance is a user-led charity (reg no.1155884) which promotes choice, control and quality of life for teenagers and adults with neuromuscular conditions in the UK. It campaigns for improved standards of health and social care and provides advice, guidance and support to teenagers and adults with neuromuscular disorders (NMD) on issues such as independent living, housing, employment and welfare rights.

Pathfinders registered address is at Flat 1, 80 Coley Ave, Reading RG1 6FJ

About Muscular Dystrophy

Muscle-weakening conditions are known to affect at least 70,000 children and adults in the UK.

Pathfinders Neuromuscular Alliance supports all people diagnosed with a primary muscle-weakening condition (a condition where the main effect is muscle-weakening, rather than this happening as a result of another aspect of the condition), or where one's medical team suspects that this is the case.

This includes all the Muscular Dystrophies, and conditions such as mitochondrial myopathies, and we also include Spinal Muscular Atrophy and Motor Neurone Disease.

The Muscular Dystrophies are genetic conditions that cause muscles to weaken, leading to an increased level of functional impairment. Some of these lead to shortened life expectancy.

Pathfinders Neuromuscular Alliance charitable objects

In September 2020 when DMD Pathfinders became Pathfinders Neuromuscular Alliance, the charitable objects were amended. References to Duchenne Muscular Dystrophy were changed to Muscular Dystrophy and related neuromuscular conditions. The new charitable objects of Pathfinders Neuromuscular Alliance are as follows:

1. The promotion of social inclusion of people with neuromuscular conditions who are socially excluded from society, or parts of society as a result of having Muscular Dystrophy and related neuromuscular conditions by

    1. Providing a network of groups that encourage and enables them to participate more effectively with the wider community,
    2. Increasing or co-ordinating opportunities for them to engage with organisations and service providers to enable those providers to adapt services to better meet their needs,
    3. Raising public awareness of the issues affecting them in all areas relating to having a neuromuscular condition,
    4. Providing support to those between the age of 18 and 30 who are socially excluded to establish and grow a business or enterprise to relieve their needs and assist them to integrate into society.

2. To promote and protect the physical and mental health of people with Muscular Dystrophy and related neuromuscular conditions in the United Kingdom as the trustees shall determine.

Pathfinders Neuromuscular Alliance aims

Pathfinders also has a set of aims through which to achieve its charitable objectives. In September 2020 the aims of DMD Pathfinders were amended in line with the change to Pathfinders Neuromuscular Alliance to change all references to DMD to Muscular Dystrophy and related neuromuscular conditions.

The aims for 2020-21 were as follows:

I. To provide a voice for adults living with Muscular Dystrophy and related neuromuscular conditions. (Objects 1 & 3)

II. To provide a forum for adults living with Muscular Dystrophy and related neuromuscular conditions to share experiences, ideas and opinions in complete confidence. (Objects 2 & 3)

III. To provide information, advice and peer support to adults living with Muscular Dystrophy and related neuromuscular conditions. (Objects 2 & 3)

IV. To identify, promote, and develop best practice, innovative treatments and technologies for adults living with Muscular Dystrophy and related neuromuscular conditions. (Object 2)

V. To campaign and influence treatments for adults living with Muscular Dystrophy and related neuromuscular conditions within health and local authorities, government, relevant professionals, disability organisations and charities. (Objects 1 & 2)

VI. To work with health and local authorities, government, disability organisations and charities in improving care, support and services for adults living with Muscular Dystrophy and related neuromuscular conditions. (Objects 1, 2 & 3)

VII. To increase awareness of adults living with Muscular Dystrophy and related neuromuscular conditions. (Object 1)

Reflections on the year

As with most charities, the 2020-21 financial year has been dominated by Covid-19, which had a transformative impact on how we as an organisation were able to deliver on our core aims.

As an organisation already working fully remotely, DMD Pathfinders was able to quickly adapt to lockdown and mandated homeworking. The challenges came in the form of additional needs of our community, to protect well-being, campaign against discrimination and respond to the closure of other services.

After the significant reduction in services from other charities in the sector, DMD Pathfinders took the decision to change its name to Pathfinders Neuromuscular Alliance and widen its remit to include people with all forms of Muscular Dystrophy and related neuromuscular conditions. This has led to a significant increase in our community and the number of users we have supported.

As part of our transformation our CEO Jon Rey-Hastie reduced his hours and Pathfinders recruited Jamie Hale to job-share the CEO role. Our trustee board also expanded to add a number of people with muscle-weakening conditions other than DMD, widening our representation of other conditions.

Although our in-person outreach activities ceased, our provision of online information and social events meant that we increased our engagement with adults with muscle-weakening conditions.

This is largely thanks to the ongoing Tudor Trust grant as well as a specific Covid-19 grant provided by the National Lottery.

We have seen a number of successful online events this year, which have attracted a wide range of people, both professionals, parents, young people and adults with muscle-weakening conditions. We have seen an increase in advice and information resources on our website. We have also contributed to national campaigns around the impact of Covid-19 on disabled people, and in particular decisions to prioritise treatment.

This year also provided us with the space to develop proposals for new projects and secure additional funding, some of which have already come to fruition this year and will support ongoing work in 2021.

While many services for people in the neuromuscular community have closed during the pandemic, Pathfinders has remained a vital source of peer support, inspiration and valuable information. Some of the feedback we have received speaks for itself:

"I thoroughly enjoyed taking part in the Pathfinders quiz. As well as testing my knowledge (do love a good quiz!) it was so nice to chat to others at the same time. A chance to catch up with old friends and get to know others from the comfort of my home. Everyone made me feel welcome, conversation flowed and I can see it becoming a regular activity." Sarah, East Sussex

"I'm just popping on to tell you about how beneficial the Catch up with Cath on zoom is. With the majority of us still shielding I took the opportunity to chat over a nice cuppa with my good friend Cath. I love the fact that technology can enable us to interact with each other so much easier. Especially with these restrictions, you can't just call in to your friends house and get them to "stick on the kettle" anymore. I feel what Cath is doing on Monday afternoons is very important for us, it's good to chat for our mental health ... Oh yeah I forgot to say you can do it from the comfort of your own bed" Conor, County Antrim

"It's good to have something to look forward to and my favourite part about the weekly quizzes Is the competitive aspect. The quiz is important to me because it brings some normality at this current time." Harry, Northumberland

"I really enjoy the social events that Pathfinders put on. I've found the quizzes so lovely, especially during Covid times, as it's been a great way to socialise. I particularly enjoyed the afternoon tea that was held on zoom. It was great being able to enjoy food, company and lovely conversations with people, as the lockdown has been very isolating." Stephanie, Northamptonshire

"... it's been a real pleasure to take part in some of the online events. I always look forward to the weekly quiz with our entertaining hosts Cath and Sanjeev. It's become a great social event with lots of fun and laughs, you don't have to be any quiz master either! I also spent a fabulous evening at the recent cocktail night with our party host Mitch. It was a great way to relax with friends over a few drinks as well as sharing some of our favourite cocktail recipes. I certainly enjoyed a good few, my captain's hat was certainly a hit with everyone! Many of us have found the social isolation really hard during this difficult time, these events are such an important lifeline as they are a great way to engage with some friendly faces." Mark, Midlothian

How has DMD Pathfinders delivered on its core aims?

I. To provide a voice for adults living with Muscular Dystrophy and related

conditions.

Our trustees and staff continued to provide a voice for adults with Muscular Dystrophy and related conditions in the work of other organizations and charities.

Our CEO has represented Pathfinders in a partnership with MDUK and a number of condition specific charities to advocate for issues related to the Covid 19 pandemic including access to vaccines, shielding guidance and support around health needs.

Pathfinders trustees and the CEO also contributed to news articles and shared our own resources around the impact of Covid-19 on people with DMD and other conditions. This included YouTube videos, a BBC News piece, newspaper articles and even appearance on a Japanese online TV show.

Pathfinders has continued to represent adults with DMD on a range of projects including Duchenne UK's DMD Care UK project, the Hercules project (which has included a range of quality-of-life and burden of illness research) and resource for parents of adolescents with DMD.

The expansion of the trustee board has strengthened the voice of adults with other muscle-weakening conditions in Pathfinders Neuromuscular Alliance.

We continue to regularly survey our members, and our annual survey of what matters to members has been invaluable in helping us to plan our work.

The Pathfinders blog on the website continues to provide an opportunity for adults with DMD to share their experiences and perspectives on issues they face in day-to-day life. In 2020-21 our blog has expanded significantly with a number of specific themes related to Covid 19.

II. To provide a forum for adults living with Muscular Dystrophy and related neuromuscular conditions to share experiences, ideas and opinions in complete confidence

Pathfinders Neuromuscular Alliance has set up a new Facebook group for all adults with muscle weakening conditions. Membership is currently at 200 members. In addition, we continue to host our Facebook group for people living with DMD to raise issues in confidence. Total members are currently around 250. We have also set up time-limited WhatsApp groups on specific topics and issues which have provided a forum for adults to share experiences.

Our Facebook and WhatsApp groups have been invaluable for the community in sharing information and experiences about shielding during the pandemic. This has allowed the community to learn from each other in adapting to the new situation.

III. To provide information, advice and peer support to adults living with Muscular Dystrophy and related neuromuscular conditions

Throughout 2020-21, we ran a regular online quiz (weekly, and then fortnightly after lockdown lifted). This has been highly popular and allowed our members to connect with each other over zoom during the challenging times.

We also ran a number of online social events, including a cocktail night, virtual afternoon tea and themed drop-in chats on disability and the media, games and reflective planning in the New Year. We also held a celebration and fundraising event for our co-founder Mark Chapman's 50th birthday (50 being an incredible milestone for someone living with DMD).

Pathfinders has run a number of information sessions during the year for the community, on wellbeing, nutrition, accessible gaming and planning for emergencies, as well as our summer mini-conference which included sessions on assistive technology and skills gained in lockdown.

During the year we have consistently published a new and improved monthly newsletter, featuring stories about people with muscle weakening conditions, information about opportunities to get involved in events and research, and a monthly honours award, honouring the contributions of community members.

Our engagement officer Cath has worked with 13 members of the community, supporting them to contribute blogs, stories and information to our website. This has included stories about how people have adapted to shielding and lockdown, and strategies for maintaining good mental health. Our Create: My Pandemic Story series shined a light on the creativity, productivity and positivity of our community during the lockdown.

Pathfinders has also taken part in events run by other organisations including Festival Spirit (an online festival experience aimed at disabled people), where our development worker Sanjeev ran a session on accessible gaming.

Our online relaunch event in October was also highly popular with 46 attendees. This was a groundbreaking event setting the future direction for Pathfinders, and provided a platform for us to engage with our new membership about their needs.

As our work has moved fully online, our social media presence has been increasingly important. Pathfinders has worked hard to significantly increase our social media activity, including creation of new and engaging content.

The development workers and engagement officer have worked hard to engage and interact with members of our community on social media, with an average of 24 interactions per week. Our engagement officer brought in an additional 112 members into the community who were previously unknown to Pathfinders.

In many cases, these interactions have involved the provision of advice on shielding, vaccinations, PA recruitment, housing and care packages.

Pathfinders has used its website, newsletter and social media channels to share important information about changing advice and information relating to the Covid-19 pandemic and shielding.

In December, Pathfinders began an online skills project, funded by PTC Therapeutics, to skill up young people with DMD to deliver online events, as well as running sessions for parents to support them in encouraging their young people with DMD to become more independent. Our first online event on accessible gaming was run by two young people with DMD and was highly popular and very well received. Both young people involved in running the first event have gone on to volunteer and/or work for Pathfinders. This project will continue into next year, working with young people to run online events.

Our CEO has worked closely with Duchenne UK on the ongoing development of the DMD folder for parents of adolescents with DMD. This has included research and writing work for many of the chapters. The reference resource is due to be published in September 2021 as a joint effort by Duchenne UK and Pathfinders neuromuscular Alliance.

IV. To identify, promote, and develop best practice, innovative treatments and technologies for adults living with Muscular

Dystrophy and related neuromuscular conditions.

Pathfinders met on a number of occasions with Cure Duchenne and became a member of the Power of Voice coalition, working on improving the effectiveness of voice recognition technology.

Pathfinders has been successful in securing a grant from PTC Therapeutics to conduct a research study into quality of life for adults with DMD during and after transition to adulthood. This project is due to start in April 2021.

Pathfinders has also secured funding from Duchenne UK to carry out research on housing accessibility and independent living. This research project will also start in April 2021.

V. To campaign and influence treatments for adults living with Muscular Dystrophy and related neuromuscular conditions within health and local authorities, government, relevant professionals, disability organisations and charities.

Pathfinders continued to support Santhera with their submission to NICE for the extension of the early access to medicines scheme for Raxone. Unfortunately development of this treatment ceased later in the year due to lack of functional effectiveness reported by Santhera.

Pathfinders continue to work closely with Duchenne UK on the Hercules project, contributing to a burden of illness study, to better inform how the benefits of new treatments are calculated during the drug development process. We also met with the DMD hub in Newcastle to discuss how we could support the provision of clinical trials for adults with DMD.

VI. To work with health and local authorities, government, disability organisations and charities in improving care, support and services for adults living with Muscular Dystrophy and related neuromuscular conditions.

Pathfinders Neuromuscular Alliance has worked with a range of different service providers this year to help them understand the concerns of the neuromuscular community during Covid 19, and to help them think about how they would resume services. We have had 197 interactions with 128 different service providers.

We were able to support one particular hospice by connecting some of our adult members with a young person and their hospice transition worker over a video call. Our adult role models discussed where their life had taken them and their experiences and answered questions from all involved.

Pathfinders also hosted the first Duchenne Adults Working Group, bringing together a range of charities, professionals and adults with DMD to coordinate work on improving quality-of-life and research for adults with DMD. This represents a significant change for Pathfinders, becoming proactive rather than reactive in coordinating a range of organisations and their work with adults with DMD. Our intention is to introduce similar models of working within the other condition-specific communities we now support.

Pathfinders has also worked with one of its members, Rhys, to campaign for Personal Health Budgets to be introduced in Wales. We supported Rhys to contact the Welsh health minister. Unfortunately the response indicates that campaign still has a way to go to highlight the need for Personal Health Budgets.

VII. To increase awareness of adults living with Muscular Dystrophy and related neuromuscular conditions.

In April, our celebration of our co-founder Mark Chapman's 50th birthday was featured on STV in Scotland, raising awareness of adults with DMD.

Throughout the first part of the year Pathfinders produced a number of video podcasts on YouTube, with a group of adults with Duchenne Muscular Dystrophy discussing a range of issues, such as sex and relationships, music and disability in movies.

Pathfinders also created a video series of DMD Profiles, profiling the lives of several adults with DMD, for the purposes of raising awareness among the community of the diverse lives of people with DMD.

Financial review

This year has represented further growth for the charity, with additional funding being secured from a wider range of grants.

The ongoing Tudor trust project funding (£30,000 this year) has allowed us to continue employing development workers who have significantly improved our outreach and engagement. Next year will be the final year of the Tudor trust funding.

Although our larger lottery bid was put on hold due to Covid-19, we were successful in securing a grant for £24,689 from the National Lottery to cover core costs and engagement work related to the Covid-19 pandemic. This allowed us to take on an engagement officer who has had a tremendous impact on the charity's activities, and allowed us to provide a range of advice, information and peer support for our members. It also funded the ongoing costs of our CEO, giving stability to the charity at a turbulent time.

A project grant of £22,100 from PTC Therapeutics has allowed us to extend the work of the engagement officer, within a more specific project around skilling up young people. This will fund work up to December 2021.

As such, most of our funding continues to come from grants. This has meant that the impacts of reduced fundraising activity across the sector have not significantly affected our work.

We have been successful in securing two additional grants, one from PTC Therapeutics and one from Duchenne UK, which will start at the beginning of the next financial year. This will allow us to take on additional staff and run new projects.

Our community fundraising income of £4,149 has seen a modest increase since last year, but remains relatively low. Our efforts to increase fundraising have been delayed due to the Covid 19 pandemic. Community fundraising remains an area in urgent need of additional development for Pathfinders in the future, as the financial impacts of the pandemic begin to decrease.

Our financial position remains relatively strong with good prospects for retaining our core services and staff and bringing in new staff and projects. Given the difficult context of the wider sector, this is a significant achievement.

Securing most of our core costs as part of project grants has resulted in some capacity limits in

carrying out core activities such as fundraising, networking and office management. This is an area that needs to be addressed by increasing unrestricted funding in the future.

Pathfinders aims to create a unrestricted reserves fund equivalent to 3 months operating costs for the CEO and the equivalent of 2 full-time posts. This will be achieved through increasing fundraising and consultancy income.

Plans for the Future

Our strategic plan for 2021-22 was developed in consultation with our users, staff and all of the trustees, reflecting our transformation to Pathfinders neuromuscular Alliance. It sets out priorities for Pathfinders in improving how we measure and report on impact, ensure good governance, improve organisation and increase fundraising in order to make the charity more sustainable.

In terms of our activities, the plan sets out actions to increase engagement and generate referrals from other organisations, increase the range of information resources, create infrastructure to manage campaign work and continue to provide the range of events we have offered over the last year.

The next financial year will be the last of our regular grant from the Tudor Trust. As such we will be focused on exploring additional sources of funding to continue the work of Pathfinders. We anticipate submitting a range of bids for project and core costs grants to secure our ongoing operation, as well as significantly boosting fundraising income.

We believe our decision to transform DMD Pathfinders to Pathfinders Neuromuscular Alliance has significantly strengthened the charity, widening our user base and community. This has both allowed us to increase our impact as well as given us a stronger base of members and volunteers who are able to support our work. The relatively seamless transition is a credit to our staff and trustees, both new and existing, and has allowed us to endure the Covid-19 pandemic and emerge stronger. We are excited to explore the new opportunities that our transformation offers in the future.

Our Board of Trustees:

Our trustees for the 2020-21 year were:

Jonathan Gilmour, Trustee (resigned 14/05/2020)
Alan John Pockley, Trustee (resigned 19/06/2020)
Celine Barry, Trustee (resigned 01/09/2020)
Phillip Carroll, trustee (resigned 04/09/2020)
Sanjeev Mann, trustee (resigned 07/09/2020)
Robert Watkins, trustee (resigned 17/09/2020)
Benjamin James, trustee (resigned 23/11/2020)
Mark Chapman, Co-Chair (resigned 21/11/2020)
John Ashby, Trustee
Ryan Worth, Trustee
Daniel Baker, Co-Chair
Kerry Thompson, trustee (co-opted 21/11/2020, resigned 20/01/2021)
Bryan Purdue (co-opted 21/11/2020)
Sarah Rose (co-opted 21/11/2020)
Lucy Watts, Co-Chair (co-opted 21/11/2020)
Fi Anderson (co-opted 21/11/2020)

Michaela Hollywood (co-opted 21/11/2020)

About Pathfinders:

Pathfinders Neuromuscular Alliance is a charitable incorporated organisation (CIO) with an "association model" constitution, as an organisation with voting members other than its charity trustees. The constitution was agreed on 5 February 2014.

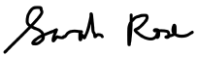
Membership of the CIO is open to anyone living with Muscular Dystrophy or related neuromuscular conditions who is interested in furthering its purposes.

At each annual general meeting one third of the charity trustees shall retire from office. These trustee vacancies are appointed by decision of the members at the annual general meeting. Charity trustees may decide to appoint a new charity trustee at any time outside of an AGM. A person so appointed by the charity trustees shall retire at the conclusion of the next annual general meeting. There are no limits on the number of terms a trustee may serve, if reappointed by members.

Declaration:

The trustees declare that they have approved the trustees report above. In preparing this report, the trustees declare that they have had regard to the guidance issued by the Charity Commission on public benefit.

Signed on behalf of the charity's trustees:



Name: Sarah Rose
Position: Co-Chair of the Board of Trustees
Date: 15/10/21

CHARITY COMMISSION FOR ENGLAND AND WALES

Charity Name	No (if any)
Pathfinders Neuromuscular Alliance	1155884

Receipts and payments accounts

CC16a

For the period from	Period start date	To	Period end date
	6/4/2020		5/4/2021

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Grants	-	78,789	-	78,789	23,800
Fundraising (donations)	4,149	-	-	4,149	2,393
Reimbursements	3,651	-	-	3,651	1,325
Consultancy	-	-	-	-	1,386
Fundraising (events)	-	-	-	-	-
***Sub total**(Gross income for AR)*	7,800	78,789	-	86,589	28,904
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	7,800	78,789	-	86,589	28,904
A3 Payments					
Insurance, governance and digital	-	2,693	-	2,693	2,470
Office costs, equipment and stationery	172	3,329	-	3,500	763
Promotional activity	-	168	-	168	393
Employment costs	9,821	39,598	-	49,419	39,531
Volunteer and staff expenses	726	303	-	1,030	1,393
Bank interest and charges	69	-	-	69	72
Payment and transaction costs	-	-	-	-	-
Project/Event costs	134	220	-	354	293
Fundraising costs	-	-	-	-	126
Sub total	10,921	46,311	-	57,232	45,041
A4 Asset and investment purchases, (see table)					
	-	-	-	-	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	10,921	46,311	-	57,232	45,041
Net of receipts/(payments)	- 3,121	32,478	-	29,357	- 16,137
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	41,069	4	-	41,073	57,210
Cash funds this year end	37,952	32,478	-	70,430	41,073

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds		37,952	32,478	-
		-	-	-
		-	-	-
	Total cash funds	37,952	32,478	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

B2 Other monetary assets

Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-

B3 Investment assets

Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
		-	-
		-	-
		-	-
		-	-
		-	-

B4 Assets retained for the charity's own use

Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-

B5 Liabilities

Details	Fund to which liability relates	Amount due (optional)	When due (optional)
		-	
		-	
		-	
		-	
		-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
Sarah Rose	Sarah Rose	18/10/2021

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF PATHFINDERS NEUROMUSCULAR ALLIANCE

I report to the trustees on my examination of the accounts of Pathfinders Neuromuscular Alliance ('the charity') for the year ended 5 April 2021.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 (the '2005 Act'), the Charities Accounts (Scotland) Regulations 2006 (as amended), and the Charities Act 2011 ('the 2011 Act'). You are satisfied that your charity is not required by charity law to be audited and have chosen instead to have an independent examination.

I report in respect of my examination of the Trust's accounts carried out under section 44 (1) (c) of the 2005 Act and section 145 of the 2011 Act. In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and all applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 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 as required by Section 44 (1) (a) of the 2005 Act and Regulation 4 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and section 130 of the 2011 Act; or
2. the accounts do not accord with those records; and
3. the accounts do not comply with the accounting requirements of Regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

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.

Mr J P Foxwell FCCA FCIE
independent-examiner.net

39 Enfield Road, Poole, BH15 3LJ

Date: 21 November 2021