



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) <i>As well as the above, we have</i> • 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 <i>Smart Suit</i> 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
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		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
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		content that will be returning to the website, further developing a “magazine” section of it, and expect to finalise this summer 2024.
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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
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		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

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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				

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

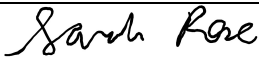
Other optional information

N/A

Declarations

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

Signed on behalf of the charity’s trustees

Signatures		
Full name(s)	SARAH ROSE Sarah Rose (Dec 20, 2024, 1:32pm)	Andrew Tunks Andrew Tunks (Dec 20, 2024, 1:51pm)
Position (e.g., Secretary, Chair, etc.)	Chair of Trustees	Trustee
Date	20 Dec 2024	20 Dec 2024



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
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
			SAH ROSE	20 Dec 2024
		Andrew Tunks (Dec 21, 2024, 1:32pm)	Andrew Tunks	20 Dec 2024

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