



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) <i>We have engaged on matters of policy, including those around the COVID-19 pandemic, housing, and access to treatments for Spinal Muscular Atrophy</i> 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) <i>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</i>

		<i>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.</i> To provide information, advice and peer support to adults living with Muscular Dystrophy and related neuromuscular conditions. (Objects 1.2 & 1.3) <i>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.</i> To identify, promote, and develop best practice, innovative treatments and technologies for adults living with Muscular Dystrophy and related neuromuscular conditions. (Object 1.2) <i>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:</i> <i>–scoping review of social care and support priorities for young people with neuromuscular conditions, University of York</i> <i>--chaplaincy services and spiritual care of children, young people and parents facing end of life, University of York</i> <i>–attitudes towards treatment of DMD, Newcastle University</i> <i>–sexual functioning and fertility in DMD, Newcastle University</i> <i>– assistive Technology, University College London</i> <i>– supporting genders project, University of Northumbria</i> <i>– Bone health for patients with DMD, University of Glasgow</i> <i>– supporting the functioning of Pfizer patient boards</i> 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) <i>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.</i> 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) <i>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.</i> To increase awareness of adults living with Muscular Dystrophy and related neuromuscular conditions. (Object 1.1)
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		<i>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.</i>
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 <i>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.</i> PTC Research <i>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.</i> Uplift <i>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.</i> Skills for Care Employer Training <i>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.</i> Skills for Care PA Training <i>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.</i> Core Work <i>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.</i>
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		
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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.
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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 <i>Improving our governance</i> 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. <i>Demonstrating our impact</i> 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. <i>Expanding our membership</i> 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
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		improved our outreach, and we are almost ready to launch our new member sign-up process. <i>Aligning our branding</i> 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. <i>Securing financial sustainability</i> 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 <i>Setting up campaigns and events</i> 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 <i>Crafting for Change</i>, 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. <i>Crafting for Change</i> 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
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		fundraising event, which again we felt privileged to be the recipients of support from. <i>Continuing our projects</i> 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. <i>Offering information, advice, and support</i> 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. <i>Raising awareness</i> We have delivered two <i>What It's Like</i> 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. <i>Engaging members and organisations</i> 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 <i>Crippling Breath</i> 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

[illegible]

Name of trustees holding title to property belonging to the charity

[illegible]

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



Receipts and payments accounts

CC16a

For the period from	06/04/2022	To	05/04/2023
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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
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
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)
	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	29/08/2023
			Vicky Mozley	30/08/2023