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:

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