DMD Pathfinders Annual Report April 2019 - March 2020

In September 2020 DMD Pathfinders became Pathfinders Neuromuscular Alliance. As this annual return refers to the period between April 2019-March 2020, it will refer to the charity as DMD Pathfinders and the charitable objects in place at the time of the reporting period.

Introduction

DMD Pathfinders is a user-led charity in England & Wales (reg. no. 1155884) and Scotland (no. SC045202) which was set up in 2014 to promote choice, control and quality of life for teenagers and adults with Duchenne Muscular Dystrophy in the UK.

It campaigns for improved standards of health and social care and provides advice, guidance and support to teenagers and adults with Duchenne Muscular Dystrophy on issues such as independent living, housing, employment and welfare rights.

About Duchenne Muscular Dystrophy

Duchenne is a fatal genetic muscle-wasting condition that affects 1 in 3500 male births and currently there is no cure. There are an estimated 650 people in the UK aged over 18 with Duchenne and many more with Duchenne-like types of dystrophy. In later stages, Duchenne leads to almost total paralysis, reliance on a ventilator to breathe and a need for round-the-clock-care.

Due to advances in medical care in the last few decades we are now living into our 20’s,30’s and 40’s, with extensive health, care and social needs.

We are an unforeseen generation, since we were not expected to still be alive and as a consequence, organisations and agencies that were originally created to advise and support our parents/carers, have been slow to respond to our needs.

The charitable objects of DMD Pathfinders as set out in its constitution are:

I. To advance the education of the general public, people with Duchenne Muscular Dystrophy and health & social care professionals in all areas relating to Duchenne Muscular Dystrophy

II. To promote and protect the physical and mental health of people with Duchenne Muscular Dystrophy in the United Kingdom through such means as are charitable by law

III. To promote social inclusion of people with Duchenne Muscular Dystrophy (a) by facilitating their involvement and participation in the planning and decision making structure of their communities and the care sup- port they receive, so that they can have equal rights and a voice and control over issues affecting their lives, and (b) by providing services including peer support, financial support to start a new business or enterprise, advice and guidance on welfare rights, health, housing and employment.

DMD Pathfinders has set further aims to realise these charitable objects:

I. To provide a voice for adults living with DMD. (Objects 1 & 3)

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

III. To provide information, advice and peer support to adults living with DMD. (Objects 2 & 3)

IV. To identify, promote, and develop best practice, innovative treatments and technologies for adults living with DMD. (Object 2)

V. To campaign and influence treatments for adults living with DMD 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 DMD. (Objects 1, 2 & 3)

VII. To increase awareness of adults living with DMD. (Object 1)

Reflections on the year

This year DMD Pathfinders has increased its outreach activities considerably and grown in staff capacity, membership and engagement with young people and adults with DMD. This is largely thanks to the Tudor Trust grant which has funded a development worker, a role which has been shared by two adults with DMD.

We have seen a number of successful events at colleges, hospices and other support venues, where we have continued to reach new young people and adults with DMD, raising awareness of our work and the support available. This year saw the expansion of regular online events to help tackle social isolation and the creation of new advice resources.

The end of this year was dominated by the outbreak of Covid-19 which has been a sign of difficult times ahead. In March, the charity has adapted and responded well to keep services operating and continue supporting adults with DMD.

How has DMD Pathfinders delivered on its core aims?

I. To provide a voice for adults living with DMD. (Objects 1 & 3)

Our CEO, development workers and trustees continued to provide the voice of adults with DMD in the work of other organizations and charities. This included Duchenne UK projects including a guide for parents of adolescents with DMD and the Hercules project to improve evidence and data to support pharmaceutical conditions. It also included contributions to the Action Duchenne conference.

The expansion of the trustee board has strengthened the voice of adults with DMD in DMD Pathfinders, as has the increase in member engagement. We continue to regularly survey our members, and a survey in January of what members are looking for from online provision has been invaluable in helping us to develop our online services.

The DMD 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. Over 2019-20 we increased the number of regular blog posts with regular contributions from our new development workers and trustees.

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

DMD Pathfinders continues to provide an online closed Facebook group for people living with DMD to raise issues in confidence. Total members remains around 350. This compares to 650 total adults with DMD living in the UK. We have also introduced new WhatsApp groups to help match up people with similar interests, increasing the number of online spaces where adults with DMD can share experiences, ideas and opinions.

III. To provide information, advice and peer support to adults living with DMD (Objects 2 & 3)

Throughout 2019-20, we ran a number of online peer support events to tackle social isolation, including games nights and pub quizzes. The events focused on building relationships between adults with DMD and allowing people to relax and be sociable, and proved very popular. This has helped bring new members into the organisation and has helped people to feel more comfortable approaching us for advice and support.

DMD Pathfinders continues to provide an advice service for adults with DMD and their families. Over the year we provided advice to 25 adults with DMD and 8 parents online, on issues including employment, sex and relationships and assistive technology.

In September DMD Pathfinders held an outreach event at Helen House hospice in Oxford, where we met with young adults with DMD and spoke about DMD Pathfinders, keeping active, mental health and finding employment, and answered questions from the young people about living with Duchenne.

In September we also attended the steering group meeting for the Duchenne UK project to create a DMD folder for parents of adolescents with DMD. We have since contributed staff and trustee time to help develop the project which is continuing into 2020-21, when we hope to see publication of the final book.

In October we joined the Neuromuscular Centre (NMC) in Cheshire at their Game Changers Fest. Our development worker Mitch spoke about his journey with Duchenne and overcoming the negative assumptions and expectations he faced from professionals growing up.

In November DMD Pathfinders took part in the teen event at Children's Hospice South West Charlton farm, talking about DMD Pathfinders, answering questions from the young people and joining them in some board games.

In November DMD Pathfinders also joined Action Duchenne at their international conference, with DMD Pathfinders members presenting a whole day of workshops and information sessions on living as an adult with DMD. Sessions included finding employment, recruiting a PA, getting your own home and research for adults. All the conference videos were live streamed and later shared on our YouTube channel, with each workshop being viewed by 400-500 people.

In December DMD Pathfinders held its Christmas party at Helen House hospice in Oxford. We had an excellent day with fun and games and a Christmas dinner. Less about delivering information and more about bringing people together to have a good time. It's easy to feel a bit isolated at times and these social get-togethers are just as important for health and well-being as providing information and advice.

In March, in the early days of the Covid-19 pandemic DMD Pathfinders worked hard to keep its members informed and prepared in regards to the virus. This included sharing important updates about the introduction of shielding and the use of PPE for carers, as well as tips and advice from adults with DMD and other conditions about how to stay safe.

IV. To identify, promote, and develop best practice, innovative treatments and technologies for adults living with DMD. (Object 2)

DMD Pathfinders collaborated with Parent Project Muscular Dystrophy in the US on an international survey of people living with DMD to understand the provision of treatments, attitudes to research, and services available. Thanks to DMD Pathfinders, adults with DMD in the UK were well represented in the survey which will provide valuable insight and assessment of need in the community. We eagerly await the results which will be released in 2020 and will inform our strategic plan.

This year saw the completion of the Living Life to the Fullest project, which used a unique combination of creative arts, storytelling and in-depth interviews to capture the attitudes and perspectives of young people living with life limiting conditions. The project produced a summary of findings with valuable insights into how young people wanted to be supported and what was important in their lives, and how they want to talk about issues such as death and dying. This will inform our own work and help us to raise awareness of best practice when supporting young people with DMD.

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

Following the ending of funding for the adult research campaign, we have continued to look for further funding and avenues to campaign and influence treatments for DMD. We have continued to work with Duchenne UK on the Hercules project to build tools for the pharmaceutical industry to better evidence the impacts of new treatments. This has included sharing the adult experience of DMD to better develop new quality-of-life measures and burden of disease economic models.

DMD Pathfinders also provided consultancy input to Santhera Pharmaceuticals in the development of idebenone, including a presentation by our CEO to an internal staff training event in July and involvement of our CEO and development workers in a patient focus group in November to better support the company to understand patient needs related to respiratory failure.

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

In June DMD Pathfinders attended the latest meeting of the Adult North Star Project, involving the development of standardised care in adult DMD clinics. We continue to represent the voice of adults within this project.

In 2019-20 DMD Pathfinders spearheaded a campaign to improve access to rail travel, launching the Campaign for Level Boarding which brought together disabled people, rail engineers and parliamentarians to work towards the introduction of level boarding across the

UK rail network. This campaign aims to improve the experience of rail travel for adults with DMD to enable them to better access travel for work, health and leisure. The campaign has established a clear ask and developed information materials, and had begun to gain traction on social media and with some MPs, before entering a hiatus with the introduction of Covid 19 lockdown. We look forward to resuming the campaign in 2020-21.

As part of the rail access campaign DMD Pathfinders also took part in the first ever Step Free Tube Challenge in partnership with Transport for All. The challenge raised money for Pathfinders and awareness of the challenges faced by adults with DMD and other disabled people using the London tube. We collaborated with Transport for London (TfL) to arrange senior managers to accompany our CEO on the challenge, which provided valuable feedback to the organisation to make improvements to how they supported disabled passengers.

DMD Pathfinders also presented evidence to the London Assembly Transport Committee regarding the experience of disabled people travel in London. DMD Pathfinders specifically raised a number of issues with information provided to disabled passengers, which led to a number of changes (e.g. including the accessible Thameslink core network on the London transport map). We also contributed to wider feedback along with a number of other disability organisations to inform the overall transport strategy

In November our development worker Mitch presented to the South-West Neuromuscular Operational Delivery Network, sharing his experience of living with DMD and accessing adult services with clinicians and health professionals working in the south-west area. This information sharing network provided a valuable opportunity to share patient experiences with clinicians in order to improve the quality of care.

VII. To increase awareness of adults living with DMD. (Object1)

Throughout the year DMD Pathfinders has produced a number of videos to raise awareness of adults living with DMD, including a series on relationships, highlighting the different experiences of adults with DMD in finding romantic relationships.

In February for Rare Disease Day our CEO featured in the Rare Revolution Magazine, a special edition on Duchenne to raise awareness of the condition and the individuals, organisations and professionals supporting adults with DMD and the development of treatments.

DMD Pathfinders also contributed to a documentary film currently in production, highlighting the journey from child to adult with DMD, and the opportunities and challenges faced by people living with DMD. We look forward to seeing the release of the film set for 2020.

In 2019-20 we continued our monthly social media roundup series, coordinated by our trustee Daniel Baker, summarising our monthly activity to share with our users. Monthly roundup posts typically have a reach of 500 people and raise awareness of what our trustees, staff and volunteers are involved with.

Financial review

This year represents significant growth for the charity, which is somewhat disguised by the Tudor Trust grant funding for this year being received in March 2019 and therefore shown in the previous set of accounts. We have seen a growth in income and expenditure as well as staff capacity, which has been reflected in increasing engagement with adults with DMD, and a stronger overall profile.

The majority of our funding continues to come from grants, with a relatively small amount of community fundraising and income from consultancy work. This included the final instalments of grants to fund our work on the Living Life to the Fullest project from the University of Sheffield, comprising £10,800 this year.

Unfortunately we haven't been able to deliver the increase in community fundraising income we were hoping for this year, however two successful fundraising events contributed to a total direct fundraising income of £2,363 this year. We also secured a £3,000 grant from the Foyle foundation which has helped us to cover our core costs and meet our overall objectives.

The Tudor trust grant of £30,000 per year for three years has provided some stability until 2022, providing space for us to increase our community impact and engagement, laying the groundwork for significantly increasing our community fundraising. The development of fundraising income remains a key focus of our strategic plan for 2020-21.

Our financial position remains relatively strong with the employment costs of the CEO secured for a further 12 months, however funding beyond this will require new grants and community fundraising in 2020-21, which is currently uncertain due to the impact of Covid-19.

Plans for the Future

2019-20 has seen a significant increase in the number of adults with DMD we have been able to support, with more events both in person and online. This has led to greater community engagement and awareness of the charity. New additions to the staff team and trustee board (all adults with DMD) have also helped to diversify the profile of the charity, so it has started to be perceived as a truly community-led initiative rather than simply the work of our chair of trustees and CEO.

The role of the development worker (funded by the Tudor trust) has been critical in boosting staff capacity and allowing us to support more adults with DMD. It has also been invaluable in allowing us to provide employment opportunities for adults with DMD and to support our staff in their professional development. This has laid the groundwork for further expansion and increasing impacts in the community in the future.

Our strategic plan for 2020-21 was developed in consultation with our users, staff and all of the trustees, to build on the successes of the previous year and expand our events and developed new advice resources, capitalising on the increasing number of members and more organised approaches to working with them. This included running more face-to-face events and developing a project to build skills among young adults with DMD using residential training events. The outbreak of Covid-19 has forced a significant rethink of the plan and will require ongoing adaptation and innovation.

We believe the charity is well placed to adapt and innovate to the changes ahead, with some stability of funding for the next 1-2 years, and well-established procedures for remote working by staff and provision of online services (e.g. events and advice). It remains to be seen what impact the pandemic will have on the charity and the wider sector, but we will continue to prioritise meeting the needs of adults with DMD as they develop.

Our Board of Trustees:

Our trustees for the 2019-20 year were:

About Pathfinders:

DMD Pathfinders 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 Duchenne Muscular Dystrophy who is interested in furthering its purposes, as well as people living with conditions with a similar presentation to Duchenne Muscular Dystrophy at the discretion of the trustees.

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:

M Chap

Name: Mark Chapman
Position: Chair of the Board of Trustees
Date: 21/10/20