

DMD Pathfinders Annual Report April 2018 - March 2019

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 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 support 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 has been a busy one and the charity has been growing at a steady pace, we have been developing as a team, raising money, earning more respect among professionals, charities and the community in general.

We must also remember those we have lost this year to Duchenne, this is something always in our minds, we fight to support and help adults with Duchenne live a better life, but the condition is still serious with no cure.

As a charity we try to remain positive and give other adults and their families inspiration and hope, but we all know people who are no longer with us, some close friends, we have suffered heartbreak and a lot of us have come close to not being here ourselves. This is why we do what we do, to make life as good as it can be for others and remind services, organisations and professionals not to forget us, a generation that was not expected to be here.



How has DMD Pathfinders delivered on its core aims?

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

Our CEO continued to provide the voice of adults with DMD into the strategic development of personalised care in NHS England, via the strategic coproduction group. The CEO has also represented the views of our users on the patient advisory board for Santhera pharmaceuticals as well as on DUK projects including designing a new wheelchair and the Hercules project to improve evidence and data to support pharmaceutical conditions.

Our CEO and trustees have also presented and joined discussions at the MDUK Adult North Star meeting, sharing their experiences as adults with DMD to identify and standardise best practice in clinical settings. Our CEO and trustees also contributed to the DUK DMD Hub project meeting to address the lack of treatments for adults being developed by pharmaceutical companies.

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. Following our website redesign, we have improved coordination between our different media channels, with more videos and blogs from adults with DMD.

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. We have sadly lost some members to DMD, as well as gaining new members, and overall membership is 350 members. This compares to 650 total adults with DMD living in the UK.

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

DMD Pathfinders provides a one-to-one advice service run by the CEO. Over the course of 2018-19 we provided advice to 30 adults with DMD and 10 parents in this way, on a wide range of issues including employing personal assistants, assistive technology and wheelchairs.

In June, DMD Pathfinders released our nutrition guide, a booklet providing detailed information, advice, case studies and quotes from adults with DMD about managing nutrition throughout adult life. The guide was produced in partnership with specialist clinicians including speech and language therapists, dieticians and gastrointestinal specialists, to ensure a balance between clinical recommendations and practical, experience-led advice on maintaining a healthy weight, dealing with changes in chewing and swallowing, managing feeding tubes, constipation and a range of other common issues. The guide has subsequently been translated into several different languages, has been distributed to adult DMD clinics around the country, and is available on our website. It has been very well received by the Duchenne community.

One parent of an adult with DMD commented:

This looks a brilliant 'go to' resource that I hope is incorporated into teen/ transition and adult care. We've muddled through a lot of this over the last year, hopefully this will provide more info and 'weight' for others to know what to look for/ what to expect/ when and where to seek help etc.

In July, DMD Pathfinders teamed up with the Neuromuscular Centre in Winsford, Cheshire, to run the NMD fest, a two-day event combining learning workshops and a social evening. This was an event entirely designed and run by those living with DMD and similar neuromuscular conditions and was a huge success. The event included presentations from no less than 14 different people with DMD and other neuromuscular conditions, sharing experiences of university, employment, housing and assistive technology. The event was attended by approximately 30 adults living with neuromuscular conditions and a further 20-30 supporters (carers, parents, non-disabled staff).



Also in July, our CEO Jon and co-chair Tyran met with young adults with DMD at Treloars College, to share their experiences of transition and living well as adults.



In November, DMD Pathfinders ran a range of sessions at the Action Duchenne conference on topics including travelling, nutrition, ventilation, assistive technology, managing a care team, going to university and finding a job. We also presented a highly popular panel session on relationships, with 4 adults with Duchenne sharing their varied experiences of dating, relationships and intimacy. In total 13 adults shared their experiences by presenting at our workshops, and for some was the first time they had engaged in one of our events.

Each session was live streamed via Facebook and received even more views than last year, with most sessions averaging 1,500-3,000 views. The relationship session was viewed by an amazing 5,400 people. As in previous years we received excellent feedback about our workshops at the conference.



In December, we launched our new website, which was generously funded by Duchenne UK. The website is a big improvement on our previous offer, and now features a knowledgebase, allowing us to add practical and useful information on a wide range of topics.

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

DMD Pathfinders ran a survey of adults with DMD to identify their knowledge, awareness and attitudes in regards to research for new treatments. The survey identified valuable information to help us identify, promote and develop innovative treatments for adults with DMD, including research priorities among adults as well as how clinical trials could be designed to meet the needs of adults with DMD. The survey was completed by 86 respondents, including both adults with DMD and carers or family members supporting an adult with the condition. This data has subsequently fed into ongoing work to influence the development of treatments (see section V.)

As part of our collaboration with Duchenne UK, we fed into their project to design a new wheelchair with Whizzkidz.

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)

In October, DMD Pathfinders and Duchenne UK ran a joint event of the DMD Hub project in Newcastle, exploring the potential for research to develop treatments for adults with DMD. Pharmaceutical companies and regulators were invited to discuss how emerging pharmacological treatments could benefit adults living with DMD.



The event identified significant barriers to developing treatments for adults, including established views among the pharmaceutical industry that running trials in adult patient groups were more complicated. The DMD hub event helped to place the issue of adults onto the agenda and raised awareness of the need for adult clinical trials, as well as sharing experiences from the two companies currently engaging with adults in the drug development process. The hub event provided a starting point for further engagement on this issue.

Throughout 2018-19, DMD Pathfinders continued to support Santhera to advance the drug development pipeline for Raxone, the only treatment currently available to adults, via the early access to medicines (EAMS) scheme.

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 October, DMD Pathfinders contributed to the meeting of the Muscular Dystrophy UK Adult North Star Project, to introduce consistent reporting and clinical guidelines for adult DMD clinics. Throughout October and November we also met with other DMD charities including Action Duchenne, Duchenne UK and MDUK trailblazers to identify opportunities for further collaboration to improve care and support for adults with DMD.

In Scotland, throughout 2018-19, our chair of trustees Mark Chapman attended a number of cross-party groups at the Scottish Parliament, helped to secure a debate in the Scottish Parliament on powerchair football, and contributed to the Social Security experience panels examining the benefit system in Scotland. These contributions were vital in influencing care and support for adults with DMD in Scotland.

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

In April, our CEO was the focus of an article on Pharmaphorum, an online news resource for the pharmaceutical industry, as part of a series looking at the needs of the Duchenne community. The article highlighted the value of peer support and showcased the work of DMD Pathfinders supporting adults living with DMD.

In May, DMD Pathfinders featured on ITV Meridian, a regional TV news programme in the South of England. The report was focused around the fundraising rally organised by our co-chair Tyran, and provided an excellent opportunity to raise awareness of the work of the charity and the needs of adults living with DMD.



In July, DMD Pathfinders released a video on YouTube showcasing our work providing peer support, information and advice, which has been used at a range of events to provide a useful introduction to the charity. It continues to raise awareness of our work via our website and social media.

In November, we began 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.

In December our CEO presented to a meeting of Catabasis, a pharmaceutical company developing a treatment for DMD. Our CEO shared his experience as an adult with DMD and spoke about the changing needs of adults with DMD over their lives. This was a valuable opportunity to raise awareness.

Financial review

Tyran Hawthorn: Gib or Bust rally

A massive thank you to our co-chair Tyran and his family, who raised a huge £5,568 (£5,178 in 2018-19) with the Gib or Bust rally they participated in, in aid of DMD Pathfinders. The rally involved three generations of Tyran's family racing from Cornwall to Gibraltar, in a cheap banger. We are delighted to say they made it!



Erskine Stewart's Melville Schools

We are absolutely delighted with the pupils from Erskine Stewart's Melville Schools who raised a whopping £1,722.96 for DMD Pathfinders in May. Our Chair Mark Chapman visited the school personally to express our sincere thanks and answer some great questions the children had about DMD.

Belfast Half Marathon

A huge thank you to Kevin Mc Bride and Neal Alexander who completed the Belfast Half Marathon on 23rd September, 2018 to raise £478.05 for DMD Pathfinders. We are incredibly grateful and will ensure this money goes to support and empower adults living with DMD.

Overall financial position

Our direct fundraising income increased significantly on the previous year, from £4,300 to £9,349, largely due to the successful Rally fundraiser. We continue to face a challenge of encouraging more of our supporters to fundraise for us, and this remains an area we need to continue to focus on.

During 2018-19 DMD Pathfinders received two major grants, including the second year of the grant (£19,000) from PTC Therapeutics to support a volunteer programme and development of information and advice resources. The second grant was received in March, the first instalment of a very significant £90,000 grant from the Tudor trust over the next three years, to fund a part-time development worker to grow the work of the charity.

DMD Pathfinders has therefore been successful in meeting the two key aims identified past year, bringing in a second member of staff and increasing fundraising donations. Moving into 2019-20 the main challenge for the charity is to cover its core costs, particularly the employment costs of the CEO, in order to ensure it can make the most of the development worker project.

The financial focus of our strategic plan next year is to significantly increase our community fundraising income, to provide core stability for the organisation.

Plans for the Future

2018-19 was an incredibly successful year which saw us run a number of very popular and impactful events, and continue to influence and shape the agenda of treatments, care and support for adults with DMD. Our activities were very successful in raising awareness of DMD in adulthood.

The success in securing a grant from the Tudor Trust at the end of the year will have a big impact on the future of DMD Pathfinders. It will significantly boost our capacity, freeing up our CEO to develop new project ideas and increase fundraising income into the organisation, while continuing to deliver the successful events, advice and information the charity has become known for.

We have already completed the recruitment process and have one development worker in place, with another due to start in April (operating on a job-share basis). Both are adults with DMD and offer great potential in increasing the impact of our work.

Our strategic plan for 2019-20 was developed in consultation with our users, staff and all of the trustees, identifying how we can make the most of this new capacity. The charity has agreed that its focus will be on tackling social isolation, using innovative approaches including online events, as well as social days, outreach events and one-to-one mentoring.

Over the last year we have seen a greater success in our volunteering programme, by focusing on engaging users in specific one-off tasks, rather than ongoing volunteering roles. We continue to learn how best to engage our users, who are often hard to reach and need prompting to engage with our work. We will focus more intently on one-to-one engagements and building personal, supportive relationships with our users in order to best engage them.

Our Board of Trustees:

Our trustees for the 2018-19 year were:

Mark Chapman, Co-Chair (resigned & reelected on 05/12/19)

Tyran Hawthorn, Co-Chair (resigned & reelected on 05/12/19, then resigned 30/03/19)

John Ashby, Trustee

Alan John Pockley, Trustee

Ryan Worth, Trustee

Celine Barry, Trustee

Daniel Baker, Trustee

Jonathan Gilmour, Trustee

Ravi Mehta, Trustee (resigned 05/12/19)

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.

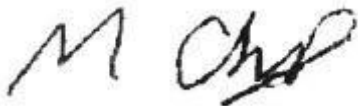
Membership of the CIO is open to anyone living with Duchenne Muscular Dystrophy who is interested in furthering its purposes, as well as people living with conditions with a similar presentation to Duchenne Muscular Dystrophy at the discretion of the trustees.

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:



Name: Mark Chapman

Position: Chair of the Board of Trustees

Date: 03/10/2019