



## Living longer, healthier fulfilling lives...

It's possible to achieve remarkable things with Duchenne Muscular Dystrophy (DMD)

With the right help and support we can travel around the world, gain a PhD, become a published author, graphic designer, music promoter...

## THE SKY'S THE LIMIT!

We are DMD Pathfinders, a user-led organisation and our mission is to improve quality of life for teenagers and adults with DMD in the UK.



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## **DMD Pathfinders Impact Report April 2016 - March 2017**

### **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 with 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:**

1. 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
2. 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
3. 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 en-

terprise, 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)

## **Reflecting on the last year**

The 2016-17 year saw the conclusion of the Action Duchenne Takin' Charge project, which provided the springboard for the creation of DMD Pathfinders. Up until it ended in September 2016, DMD Pathfinders members and trustees continued to contribute to the programme of events in this project. Our Leadership Camp in September 2016 marked a turning point, with the baton being clearly passed on to adults with DMD to continue the work that Takin Charge had started.

With the appointment of our CEO in October 2016, DMD Pathfinders gained significant capacity to deliver our charitable objectives. This has led to improved relationships with other charities and organisations to achieve shared aims, increased membership and engagement of adults, and a higher profile for the organization. It has also allowed us to tighten up on effective management and good governance.

In the 2016-17 year we completed our Mentoring Plus project, the lottery funded project which saw us skill up young adults to use social media in a professional capacity and provide mentoring support to young people with

DMD. While we are sad to see the project come to a close, the impacts of this project are clearly evident in the organisations' new-found reach, and the improved engagement and skill-set amongst our members who accessed this development opportunity.

As of March 2017, significant progress has been made but there is still a lot of work to do. We look forward to another productive year ahead.

## **What have we done to achieve our core aims?**

### **I. To provide a voice for adults living with DMD.**

#### **September 2016: "Into the Future" Leadership Camp**

The "Into the Future" Duchenne Leadership Camp was held at Hereward College, Coventry. The Leadership Camp was run as a joint venture between Action Duchenne and DMD Pathfinders.

It was a fantastic weekend which marked the end of the Lottery funded Takin' Charge Transition project and was designed to inspire, challenge and support young people with DMD to move forward as leaders within the Duchenne Community through DMD Pathfinders.



DMD Pathfinders trustees and members played an active part in the event, promoting it to members, facilitating sessions and leading the discussions. The older trustees with DMD also played a mentoring role to young people throughout the leadership camp.

It was also supported by Martyn Sibley from the brilliant Disability Horizons, who spoke about his journey into leadership and encouraged many of the

young adults with Duchenne to explore the issues important to them going into the future and dare to think big!

Colin Rainey from Radio Active 101 (based at the University of East London), through his recording of interviews and sound bites, captured the passion, feelings of empowerment and sense of direction for the future that developed over the weekend.

The young people who attended the event left feeling very positive about their aspirations for the future and with enthusiasm to continue the work of identifying and addressing barriers through DMD Pathfinders. DMD Pathfinders left the event with clear ideas about what young people with DMD wanted from the charity and a clear set of goals for the future, as well as an army of volunteers.

### **Scottish Roundtable meeting: February 2017**

In February, DMD Pathfinders was pleased to join Action Duchenne's Scottish Roundtable meeting in February 2017 to explore interesting research updates and information about the growth in clinical trials. DMD Pathfinders represented the voices of adults who were asking that that trials are relevant and available to them.



### **UPPMD Conference (United Parent Projects for Muscular Dystrophy): February 2017**

UPPMD is an international network of parent-led charities working to support families of people with Duchenne and drive research into a cure. In February, our CEO presented to the annual conference in Rome via video link, providing the voice of adults with DMD to this conference for the first time. The

presentation helped to build links with potential partner charities, and DMD Pathfinders looks forward to working with UPPMD in the future.



**II. To provide a forum for adults living with DMD to share experiences, ideas and opinions in complete confidence.**

**DMD Pathfinders Facebook group**

DMD Pathfinders continues to provide an online closed Facebook group for people living with DMD to raise issues of concern to them in confidence. It now has over 350 members. Through this group, DMD Pathfinders have collated evidence of the extent of need within the Adult DMD Community, which will inform the activities of DMD Pathfinders moving forward. A key need that has been identified is for greater information on nutrition and feeding tubes. DMD Pathfinders will convene a working group on the issue in April 2017 with the intention of producing a guide next year.

### **III. To provide information, advice and peer support to adults living with DMD.**

#### **Action Duchenne International Conference: November 2016**

DMD Pathfinders ran a number our conference sessions at the Action Duchenne conference in London in November, targeted towards young people and adults with DMD and their families. This was the first time DMD Pathfinders was responsible for the content and coordination of conference sessions, in previous years having contributed to the opening session and Takin' Charge sessions, coordinated by Action Duchenne



The conference was a very successful debut for DMD Pathfinders, and received very positive feedback from conference delegates. Conference sessions provided a means to deliver information and advice to young people and adults with DMD directly on a range of topics. DMD Pathfinders directly

delivered seven conference sessions on topics such as living well and independently, preventative care, sex and relationships, having carers who aren't your parents, adult health and well-being, transition to adulthood and a respiratory focus group.

### **Accessible Gaming webinar: February 2017**

As part of the Mentoring Plus project, DMD Pathfinders piloted a webinar format as a way of reaching young people and adults with DMD to provide information, advice and peer support. In February, Deciphia CIC was commissioned by DMD Pathfinders to provide training on running webinars to several DMD Pathfinders staff and volunteers.



The first webinar was run on accessible gaming and included contributions from 4 DMD Pathfinders staff and volunteers living with DMD. This included DMD Pathfinders volunteers sharing their experiences and responding to live questions as a way of mentoring younger people on key issues in their lives. The webinar was viewed 130 times and was subsequently uploaded onto YouTube.

### **Individual advocacy support: 2016-17**

Advocacy, information and advice has been provided on an ad hoc basis to individuals who contact us, with the main emphasis being on signposting to relevant services. This reflects a lack of funding for the organisation to meet advocacy needs in the community.

DMD Pathfinders focused its own limited resources on providing one-to-one advocacy support for a small number of adults living with DMD. Support was focused on obtaining a care package, and included the provision of advice, writing of supporting statements, and contacting local decision makers on behalf of adults with DMD. The support was well received and all the adults

with DMD were subsequently able to access care packages that better met their needs.

**IV. To identify, promote, and develop best practice, innovative treatments and technologies for adults living with DMD.**

**Technology Event Scotland: October 2016**

DMD Pathfinders hosted a great collaborative event with the Eileen McCallum Trust, bringing information and support on assistive technology to people living with DMD. Over 35 people, adults with DMD, their parents/PAs/carers as well as a range of professionals specialising in assistive technology, gathered in Edinburgh to get an update on assistive technology to support young people and adults with DMD.



## **NAIDEX 2017**

Four DMD Pathfinders' trustees attended the Naidex exhibition in March, the National exhibition in Birmingham showcasing a wide range of equipment for disabled people. We identified equipment and technology that could be beneficial for adults with DMD, and produced a short film documenting the day and showcasing what we found for our members.



## **Launching the Adult Research Project: March 2017**

In March DMD Pathfinders was proud to launch an Adult Research Campaign, funded by Duchenne UK, who have commissioned DMD Pathfinders to coordinate a campaign pushing for new treatments for DMD to be made available to adults. The project aims to increase the understanding of how treatments currently in the pipeline for DMD might impact on adults with DMD, to better understand how treatments can be made available to adults, and to raise awareness of adults with DMD among pharmaceutical companies. The project will run for two years and will be managed through a joint Duchenne UK & DMD Pathfinders working group.

**V. To campaign and influence treatments for adults living with DMD within health and local authorities, government, relevant professionals, disability organisations and charities.**

**APPG on Exondys 51: November 2016**

DMD Pathfinders attended the All Party Parliamentary Group on Exondys 51, which focused on the next steps and future assessment processes for Exondys 51 (eteplirsen) following approval by the USA regulator, the Food and Drug Administration. The session heard contributions from Sarepta (the pharmaceutical company producing Exondys 51) as well as representatives from NICE and NHS England. Jon Hastie, CEO, contributed to the discussion, asking representatives on the panel about whether adults would be able to access the treatment. This provided useful information on the need for trials in adults, which subsequently informed the adult research campaign.

**Scotland Cross Party Group on Muscular Dystrophy**

Mark Chapman, Chair represented DMD Pathfinders at the Cross Party Group on Muscular Dystrophy, chaired by Jackie Baillie MSP, in the Scottish Parliament, on 15<sup>th</sup> June 2016, 9th November 2016 and 1st March 2017. The views of adults were heard on a range of issues that included discussions on: Access to Translarna in Scotland and developments on Exondys 51; The use of physiotherapy in managing your condition; Specialist respiratory care provision for people with muscle-wasting conditions; Access to suitable hospice and respite provision for young disabled adults; Adult social care funding and the new 'Integration Joint Boards' that integrate NHS and social care

**Duchenne UK Economic Modelling Workshop: January 2017**

Jon Hastie, CEO represented DMD Pathfinders and adults with DMD in this Duchenne UK initiative to bring together pharmaceutical companies to better address the evidence requirements of NICE when submitting new treatments for approval. We are pushing for treatments to target adults, and establishing the benefit of treatments for adults is one part of this campaign.



**V. To work with health and local authorities, government, disability organisations and charities in improving care, support and services for adults living with DMD**

**MDUK Adult North Star Network: March 2017**

DMD Pathfinders attended the first meeting of the Adult North Star Network project, being delivered by Muscular Dystrophy UK. This project aims to improve and standardise clinic assessments and standards of care across specialist clinics for adults with DMD. Ravi Mehta, trustee of DMD Pathfinders and Jon Hastie, CEO, contributed extensively to the session, bringing the perspective of adults with DMD into the discussions. This included highlighting the importance of issues such as social isolation, psychology, self-management and peer support. DMD Pathfinders will continue to be actively involved in this project as it develops.

**NHS England Personalisation: March 2017**

In March DMD Pathfinders CEO Jon Hastie was appointed to the Strategic Coproduction Group on the Integrated Personal Commissioning programme at NHS England. This group informs the strategic development of IPC and Personal Health Budgets throughout England. This appointment provides a key point of influence for DMD Pathfinders in the development of personalisation in health and social care in England. As many adults with DMD access continuing healthcare as they get older, this programme is of particular interest in terms of improving care, support and services.

## **VI. To increase awareness of adults living with DMD.**

### **The Radio 4 'Listening Project'**

On the 20th April, Mark Chapman, Chair of DMD Pathfinders recorded a conversation for the Radio 4 'Listening Project' with Jack Ebanks from the 'Takin Charge' project.

The 'Listening Project' is a collaboration with the British Library to capture the nation in conversation and build a unique picture of our lives today which will be preserved for future generations.

There is a **30 year** difference between Mark and Jack and in the conversation they discuss their experiences and thoughts on the different journeys they have been on and what is important to them.



### **Social Media**

The Mentoring Plus project supported training for adults with DMD in using social media in a professional capacity, with a focus on blogs, Facebook, Twitter and webinars. This has led to a significant increase in the number of posts and followers, and the level of engagement with the community. All of the work of DMD Pathfinders on the facebook group, website, social media, attendance at conferences and lobbies has increased awareness of the needs of adults living with DMD.

The website was revamped in October 2016 to coordinate with a new website host and movement to WordPress.org for greater functionality. The focus was on a clean, efficient design allowing for contribution by multiple users.

Blogs: 13 blogs from a range of contributors were uploaded to the website in the 2016-17 year.

Twitter followers as of April 2017: 670 (+130 or 24% up from 2015-16)

Facebook page likes as of April 2017: 1089 (+302 or 38% up from 2015-16)

As part of a fundraising challenge, CEO of DMD Pathfinders Jon Hastie provided daily video blogs recording the progress of his 28 day fundraising challenge. During the daily vlogs Jon talked about a wide range of issues affecting adults with DMD to raise greater awareness of the condition.

DMD Pathfinders staff and trustees have regularly contributed to social media content run by Muscle Owl, an online content producer for the neuromuscular community. Muscle Owl videos use an online talk-show format and DMD Pathfinders have contributed sessions on a wide range of topics including life expectancy, assistive technology, independent living, carers and personal assistants and accessing care packages.

### **Living Life to the Fullest Grant**

DMD Pathfinders was delighted to be part of a successful grant application to the Economic and Social Research Council (ESRC) which is being coordinated by the University of Sheffield. The grant is for a new research project that will let children and young people with life limiting or life threatening conditions tell their own life stories through the arts. Their works will then be used to help raise visibility and awareness of how children and young people see themselves. As a community partner to the project, DMD Pathfinders looks forward to participating in the project as a way of raising awareness of teenagers and young adults with DMD and the issues they face in their lives. The project will launch in April 2017.

## **Financial Review**

Fundraising: DMD Pathfinders raised £8,101 in direct donations and from fundraising events during 2016-17.

### **Brendan Casey: ‘The Crazy Mohawk Challenge’**

Brendan raised an amazing £2,000 for DMD Pathfinders in December 2016, by having his hair styled into a Mohawk. Anyone who knows Brendan and how precious he is about his hairstyle knows this wasn’t easy!

Brendan said: “I wanted to fundraise for DMD Pathfinders because I am one of very few adults with DMD in Northern Ireland. There are not many people I can ask about things that worry or concern me about my condition as I get older. DMD Pathfinders have given me such a lot of great support and advice as well as inspired me to do things I never thought I would. They are the only organisation set up by adults with DMD for adults with DMD and that has made all the difference. Me and my family wanted to let them know how much we appreciate the support they give”



### **Jon Hastie: 28 Miles in 28 Days: The Cold Hand Challenge**

Jon raised £3,705 in February 2017 by travelling 1 mile a day in his wheelchair for 28 days, choosing the coldest month to add an additional challenge. Jon also used the event to raise awareness of DMD through regular video blogs.

Jon said: “I’ve endured the cold, rain, wind, bumpy pavements, fatigue and even a fever to do a mile a day in my powered chair. It’s a big deal when you

need a ventilator to breathe and struggle to even hold a pen. However, I've received tremendous support and smashed my first few fundraising targets. Along with other adults living with Duchenne, I have been involved with projects supporting young people to prepare for adulthood for the last five years. Adults with this condition are now an unexpected generation. The care hasn't kept up and people often have no information or support to live their lives. We know that when the right support is in place, adults with Duchenne can have great quality of life. That's why I am proud to support the work of DMD Pathfinders".



### **Overall financial position**

During the 2016-17 year, DMD Pathfinders continued to raise money to support its work, both through direct donations and securing grants from Duchenne UK, both a one-off grant to support its core aims and a two-year project grant for an adult research campaign. This provided enough funding to employ a part-time CEO in October 2016 in accordance with our business plan to help move the charity forward and develop a more sustainable footing for the organization. DMD Pathfinders has begun to incur greater expenditure as a result of taking on staff and following the completion of the Action Duchenne Takin Charge project (which previously met most of the event costs involved in our activity). But the overall financial picture is one of positive growth and plans are in place to boost direct fundraising and bring in new streams of revenue over the 2017-18 year.

Due to our low overheads, limited financial assets, and need for funding to be focused on projects to develop the charity, the trustees have opted to maintain a zero reserves policy. This is reviewed on an annual basis and it is the intention of the trustees to build up reserves in the future.

## **Plans for the Future**

DMD Pathfinders has developed considerably over the last year and there is a noticeable shift in the DMD community towards a greater recognition of the needs of adults and the importance of engaging with adults with DMD. With improved medical care and the reality of more people with Duchenne living into adulthood, the role of a charity for adults with Duchenne run by adults with Duchenne is even more crucial.

As in previous years, the focus for future work is to continue to deliver on our core aims as well as to build the skills of people involved in the organization so as to be sustainable in the future. With a new CEO in place, DMD Pathfinders now has a far greater capacity to do this, enabling new conversations to be held with key partner organisations, new projects to be set up and more adults with DMD to be brought into the organization.

During the 2016-17 year the organisation will develop a strategic plan for meeting its charitable objectives, which will set out in a more coherent format the short and long-term priorities for DMD Pathfinders. As a user led organisation this process will involve extensive engagement with adults with DMD to agree the plan and the result of this exercise is not yet known.

## **Our Board of Trustees:**

Our trustees for the 2016-17 year were:

Mark Chapman, Chair  
Jon Hastie, Trustee (resigned 07/10/16)  
Robert Watson, Trustee (deceased 24/03/17)  
John Ashby, Trustee  
Alan John Pockley, Trustee  
Ryan Worth, Trustee  
Celine Barry, Trustee  
Mithun Soul, Trustee  
Farhan Mian, Trustee (resigned 10/11/2016)  
Vivek Gohil (co-opted 08/12/16)  
Daniel Baker (co-opted 12/12/16)

## **About Pathfinders:**

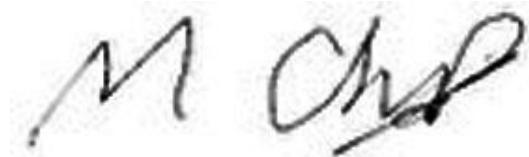
DMD Pathfinders is a charitable incorporated organisation (CIO) with an "association model" constitution, as an organisation with voting members other than its charity trustees. The constitution was agreed on 5 February 2014. Membership of the CIO is open to anyone living with Duchenne Muscular Dystrophy 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:

A handwritten signature in black ink, appearing to read "Mark Chapman".

Name: Mark Chapman  
Position: Chair of the Board of Trustees  
Date: 23/11/2017