



CHARITY COMMISSION
FOR ENGLAND AND WALES

Cure Myotonic Dystrophy UK Charity (CDM)

1191217

Receipts and payments accounts

CC16a

For the period
from

06/04/2023

To

05/04/2024

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 | | | | | |
| Donations | 18,957 | 5,000 | - | 23,957 | - |
| Gift Aid | 3,706 | - | - | 3,706 | - |
| Community Events Refunds | 288 | - | - | 288 | - |
| Sponsorships/Grants | 28,579 | 7,500 | - | 36,079 | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| Sub total (Gross income for AR) | 51,530 | 12,500 | - | 64,030 | - |
| A2 Asset and investment sales, (see table). | | | | | |
| | - | - | - | - | - |
| | - | - | - | - | - |
| Sub total | - | - | - | - | - |
| Total receipts | 51,530 | 12,500 | - | 64,030 | - |
| A3 Payments | | | | | |
| Fundraising & Community Events | 31,683 | - | - | 31,683 | - |
| Administration & Running Costs | 16,215 | - | - | 16,215 | - |
| Paypal & JustGiving Fees | 896 | - | - | 896 | - |
| Research Grants | 16,040 | - | - | 16,040 | - |
| Conferences | - | - | - | - | - |
| Advertising & Promotional Merchandise | 4,173 | - | - | 4,173 | - |
| Professional Fees | 9,225 | - | - | 9,225 | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| Sub total | 78,232 | - | - | 78,232 | - |
| A4 Asset and investment purchases, (see table) | | | | | |
| | - | - | - | - | - |
| | - | - | - | - | - |
| Sub total | - | - | - | - | - |
| Total payments | 78,232 | - | - | 78,232 | - |
| Net of receipts/(payments) | - 26,701 | 12,500 | - | - 14,201 | - |
| A5 Transfers between funds | - | - | - | - | - |
| A6 Cash funds last year end | 34,734 | - | - | 34,734 | - |
| Cash funds this year end | 8,033 | 12,500 | - | 20,533 | - |

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 | Bank Account | 8,033 | 12,500 | - |
| | | | - | - |
| | | - | - | - |
| | Total cash funds | 8,033 | 12,500 | - |
| | (agree balances with receipts and payments account(s)) | OK | OK | OK |
| B2 Other monetary assets | Details | Unrestricted funds to nearest £ | Restricted funds to nearest £ | Endowment funds to nearest £ |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| 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) |
| | | | - | |
| | | | - | |
| | | | - | |
| | | | - | |
| Signed by one or two trustees on behalf of all the trustees | Signature | Print Name | Date of approval | |
| | | | | |
| | | | | |



CHARITY COMMISSION
FOR ENGLAND AND WALES

Independent examiner's report on the accounts

Section A

Independent Examiner's Report

Report to the trustees

Charity Name
Cure Myotonic Dystrophy UK Charity (CDM)

**On accounts for the year
ended**

05/04/2024

Charity no
(if any)

1191217

Set out on pages

1 & 2

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity for the year ended 05/04/2024.

**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 Act 2011.

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the 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 which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

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.

Signed:

Date:

01/07/2024

Name:

Rebecca Rouse T/As BSR Accountancy

Relevant professional
qualification(s) or body
(if any):

Chartered Institute of Management Accountants (CIMA)
CGMA, ACMA, MIP

Address:

15 Crakedale Road

| |
|-----------|
| Winterton |
|-----------|

| |
|----------|
| DN15 9UT |
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Section B**Disclosure**

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

| |
|--|
| |
|--|

Cure Myotonic Dystrophy UK Charity (CDM)

(CIO)

REPORT OF THE TRUSTEES: 6th April 2023 to 5th April 2024

The Trustees present their report together with the financial statements of the Charity for the year ended 5th April 2024.

Reference and Administrative Details:

Charity Number: 1191217

Registered Address: c/o Riverside View, Station Rd, Whitton, North Lincs, DN15 9LR

Directors and Trustees:

The currently registered Trustees are:

Emma-Jayne Ashley, Peter Ashley (Chair), Stephen Uncles (all sitting as first trustees).

Liam Garwood and Tamsyn Tait (as of 4th Jan 2023).

Dr Wendy Greenwood (as of 14th Dec 2023)

Retired Trustee:

Dr Alison Kay (Sept 2020 to January 2024)

There must be at least three (3) charity trustees. If the number falls below this minimum, the remaining trustee or trustees may act only to call a meeting of the charity trustees or appoint a new charity trustee. Apart from the first charity trustees, every trustee must be appointed for a term of three years by a resolution passed at a properly convened meeting of the charity trustees.

Objectives, Activities, Achievements and Performance:

The objectives of the CIO are:

To preserve and protect good health among, and relieve the needs of, people living with Myotonic Dystrophy, their families and carers, in particular but not exclusively by:

- (a) providing information, help and support to such people and their families and carers;*
- (b) making financial donations to support organisations and individuals carrying out research into Myotonic Dystrophy, the useful results of which will be published for public benefit; and*
- (c) raising awareness of Myotonic Dystrophy within the general public, medical and scientific communities.*

Raising funds is always high on our priority list. Financial income for this period came from donations and fundraising, the community, sponsorships, grants, and donations from CureDM Ventures CIC.

The Board of Trustees have regular updates/meetings, and an AGM (which is the main source of future Charity planning).

Services were maintained in the following areas:

In person events, consultations, and conferences. Discussions between all stakeholders were held in person, via email and online resources, and via continued utilisation of virtual meetings.

For the period April 2023-2024:

Research

- Produced and published CureDM Medication Snapshot – a view of research currently ongoing for Myotonic Dystrophy on a global scale. Updated regularly and

shared with all stakeholders to keep the community up to date with the fast-paced movement of current research.

- Co-Authored guidelines and paper in the British Medical Journal for advancing Palliative and End of Life provision within the DM community.
- Agreed to an increase in grant funding to the UK DM Patient Registry, facilitating access to research and current and upcoming clinical trials for the DM community.
- Steering committee member for the UK Myotonic Dystrophy Patient registry.
- Co-funded UK Natural history study into Adults with Congenital Myotonic Dystrophy – CARE-CDM
- Invited specialists, funded and organised attendance for a number of UK Clinicians to attend the International Myotonic Dystrophy Consortium in Nijmegen (April 2024, planning throughout this financial year).
- Attended international conference as Patient Representatives on TREAT-NMD (TGDOC) Myotonic Dystrophy sub-group – worldwide group representing DM patients in research and patient registry collaboration.
- Updated and re-circulated UK Charity community questionnaire to enable an up-to-date vision on DM in the UK.
- Submitted CureDM community research abstract to the International Myotonic Dystrophy Consortium (IDMC), worldwide scientific conference, to be held in 2024 in Nijmegen.
- Co-Authored research posters which were presented at worldwide scientific conferences.
- Supported and advised as DM specialist patient representatives on upcoming awareness videos to be released UK wide in 2025.
- Founding members of Euro-DyMA, an international collaboration of European DM support groups. Euro-DyMA meet regularly online and in person to facilitate research and to define and meet the un-met needs of the DM Community.
- Social Task Force Lead: working with European support groups to produce a research paper on the support and events provided by different organisations within Euro-DyMA.
- Took part in the Euro-DyMA Scientific Advisory Board meeting, ‘Pharma Day’ and AGM.
- Consulted on potential upcoming new worldwide trials, studies and natural history studies for DM1 and CDM. Regular meetings and member of patient representative committees.
- Patient representative for the ILAP application process within MHRA, SMC, AWMSG and NICE.
- Continued to advise on DM relevant study protocol/design as patient representatives on numerous ongoing research projects, including direct meetings with organisations and companies working towards clinical trials for potential new treatments in the UK, and DM natural history studies. Vital to find treatments and therapies for those living with Myotonic Dystrophy.
- Using our Subject Matter expertise in Myotonic Dystrophy to provide input, advice and support to wider Neuromuscular committees and panels.
- Patient representatives for upcoming potential research studies and clinical trials, advising on the complexity of DM/CDM.
- Collaborated with clinicians and researchers to produce disease specific guidelines and advice. Notably Palliative and End of Life Care for DM1.
- Attended and presented at carefully selected worldwide scientific, medical, and clinical conferences (online and in person).

- Ongoing European Patient Advocacy Group representative on the European Reference Network (ERN) for neuromuscular diseases.
- Chair provides representation on the MDUK Lay Research Panel as DM patient expert.
- Ongoing representation as DM patient expert in the SIMPATHIC drug repurposing project.

Awareness:

- Joint founders of the INTERNATIONAL MYOTONIC DYSTROPHY AWARENESS DAY on Sept 15th each year.
- Over 40 UK venues and landmarks lit up green to support the CureDM Charity and Awareness Day.
- Continued to promote the awareness day and collaboration throughout the year.
- Member of steering committee for the DM Global Alliance.
- Bi-monthly Global Alliance (online) meetings with worldwide support groups and organisations. Global collaboration to raise awareness and bringing all communities, scientific, research, patients, and pharma, together.
- Produced Charity videos raising awareness of the condition and the work we do, celebrating the community, distributed through social media and on the Charity YouTube page.
- Supported schools/families in providing student education and raising DM awareness for Rare Disease Day 2024. Video can be seen here: <https://youtu.be/cKEWm7AJcrU?si=oWQShCkCnAnKb4TL>
- Provided information for university education conference on DM for Rare Diseases for students and clinicians, for Rare Disease Day 2024.
- Attended and held information stall at the Myotonic Dystrophy Foundation annual conference in Washington, USA. Presented information and posters on UK Charity and support. Met with many families living with DM and made worldwide connections.
- Supported worldwide awareness of DM by joining the MDF in advocating for funding for research at Capitol Hill, taking part in meetings with senators and giving the global experience of families living with rare diseases.
- 'Could it be Myotonic Dystrophy' posters dissemination to settings where patients may be seen. These are now used worldwide.
- Began work on new CureDM website, providing accurate, DM specific, information and advice.
- Active social media pages include public Charity pages and dedicated private peer support pages, allowing patients and families with DM to connect in private.
- Expanded LinkedIn presence and established a CureDM page, increased network of clinicians, researchers and organisations with an interest in DM.
- Moderated and supported worldwide social media pages for DM1, DM2 and CDM.
- Advocated for families with DM in charitable, social, and medical settings.
- Attended several face-to-face and online medical, research and support conferences and meetings. Including World Orphan Drug Congress, MDSG, MDUK, MDF, MDA, Genetic Alliance, Eurordis, Euro-Dyma, World Muscle Society (WMS,) European Reference Network (ERN), Treat-NMD, and other rare disease communities.
- Presented at some of the above conferences and manned CureDM information stands.

- Co-authored, submitted and were accepted for a number of abstracts for the IDMC in April 2024, showing international collaboration and raising awareness of DM in the UK, including the work we do with other worldwide support groups, Pharma and within the Charity.
- Raised the profile of Myotonic Dystrophy in Rare disease, Neuromuscular, Pharma and Muscular Dystrophy focused collaborations.

Support:

- Planned, funded and organised the annual Families Day event in July 2023. A full activity weekend at The Calvert Trust. Video to event can be seen here: <https://youtu.be/8YsPHdSePXc?si=1ubcE3w5-SowJ1Bk>
- The event was fully funded by the Charity and catered to 20 families, filling the venue with 67 attendees. Participants included people from all over the UK, living with CDM, DM1 and DM2.
- Held a mini conference at the family's weekend, provided 1:1 support and information materials.
- Facilitated group event at Disney on Ice in Dec 2023, including a group 'after party' gathering with food and activities after the show. We are proud to have provided this event free of charge to 50 people (13 families) living with Myotonic Dystrophy.
- Planned and organised community event at The Deep – taking place in next accounting period (May 2024).
- Funded and successfully supported application of a number of disability cards for the community – allowing them to access benefits outside of the Charity.
- Delivered support, advice, and assistance virtually and in person to the Myotonic Dystrophy community, dealing with the queries or passing them on to an appropriate person or organisation.
- Supported individuals and families with day to day, benefits, healthcare, and quality of life concerns and applications.
- Successfully supported community members in applying for genetic testing, disability benefits and home adaptations.
- Continued to provide 'Miles' mascots to children with CDM to promote friendship and support.
- Supporting community members by providing information and advice to enable them to advocate for themselves and loved ones in medical situations.
- Supported families dealing with the devastating effects of the condition, including during bereavement of loved ones.
- Initiated monitoring survey within the community, to identify and improve community satisfaction of services provided.

Fundraising:

- Fundraising events included online campaigns and personal fundraisers/donations.
- Grants and sponsorships were received to support conference attendance, admin support and the running costs of the charity, enabling us to use personal donations for community support and facilitating research (ringfenced if specified).
- Successfully received sponsorship to build on community events, enabling the Charity to offer more provision to a wider audience.
- We continued to receive generous donations from people fundraising on our behalf.
- In memory donations received.
- CureDM Trustees organised and fundraised as a team for the Dundee KiltWalk – meeting with families in Scotland affected by Myotonic Dystrophy.

- Organised and facilitated a team of 13 runners for Great North Run 2023, raising over £7500. Supported by Charity trustees and volunteers during the event.

News and information:

The charity facilitates a private social media group, and a public charity page on Facebook. Also utilising Twitter, LinkedIn, and Instagram accounts. CureDM have a YouTube page to share community videos and charity presentations. These are platforms for sharing articles, peer support, sharing experiences and ideas. Information is shared on research progress and other matters impacting families of disabled children and adults. There is also a website used to keep families up to date with news and events.

The 2023/2024 Impact Report is attached to this Trustee report.

Stakeholders:

- Charity stakeholders are those living with Myotonic Dystrophy, their families and caregivers, those involved in running the Charity, volunteers and those fundraising or raising awareness, the clinicians, researchers and drug developers that engage with and benefit from our work.
- Support, events, and fundraising opportunities are proposed and discussed by stakeholders. Consultations take place regularly in meetings with families, during business meetings and conferences and online via e-mail, the Trustee messenger group, and social media.
- Future peer support get-togethers, activities, meet up plans, venues, dates, and itineraries are planned around consultation with the potential users themselves. Plans are made to include as many people as possible, whilst making efforts to reduce attendee bias and ensure those who have not been able to attend previously are accommodated.
- Day-to-day decisions are made with consultation between trustees, volunteers, and community members as required.
- Strategic or significant financial decisions, such as activities or proposals for research funding, are made following consultation with all trustees, who all have significant experience (personal and professional) knowledge and experience of the conditions, support for others, charitable work, and fundraising.
- Research/Grant funding requests are approved following consultation with the trustees to determine the most appropriate use of funds.

Events:

The charity endeavours to facilitate social events where families can enjoy a relaxed atmosphere whilst sharing their experiences. Events are aimed to facilitate peer support, family memories, forming peer friendships, and encourage the sharing of knowledge to improve day to day quality of life. Events include education to support the community and enable them to advocate for themselves, whilst keeping all stakeholders updated on upcoming advances in healthcare and potential treatments.

Review of Public Benefit:

In setting out the objectives and planning activities, the Trustees have carefully considered the Charity Commission's general guidance on public benefit. Face to face events were reinstated with provision in place to keep community members as safe as possible after the COVID-19 pandemic. Whilst Covid-19 is mostly managed in day-to-day life, the DM community is vulnerable to this and other respiratory infections, so careful planning is undertaken at all stages.

Future:

CureDM continually strives to expand services to meet growing demand, in a planned and financially prudent way, ensuring all projects stand on a sound financial footing and that the Charity moves forward and grows, but does so responsibly.

Income/Expenditure:

The restrictions necessitated by the Covid-19 pandemic and the vulnerability of the community/families caused a delay in planned social/peer support activities (days out, holidays etc.), normally at the core of the Charity's work. Careful planning allowed these events to begin again in 2022/23, showing as an increase in expenditure for this financial period.

It is the belief of the Charity that funds should be used to fulfil the charitable aims as available, and not to accrue a large unused credit which could otherwise be used to benefit the community we serve.

Investment powers and policy:

The CIO has power to do anything which is calculated to further its Objects or is conducive or incidental to doing so, as laid out in the Constitution.

Reserves policy:

The state of the economy means sufficient reserves may need be held to ensure the future running of the charity. There is no policy to date in place dictating reserve amounts. The Trustees carefully monitor the finances throughout the accounting year to ensure adequate funding is available for continuation of services and financial obligations.

Structure, Governance and Management Governing Document:

Cure Myotonic Dystrophy UK Charity (CDM) is a registered charity (charity number 1191217), which achieved registered charity status on 9 September 2020.

The CIO is governed by Constitution of Charitable Incorporated Organisation (Foundation Structure).

The CIO is registered with the Fundraising Regulator.

Appointment of Trustees:

New Trustees are appointed by current board of Trustees at the Annual General Meeting, in accordance with the Charity's Constitution. No external bodies have the right to appoint Trustees.

Trustee induction and training:

New Trustees are introduced to the operations of the organisation and are given information on the responsibilities of being a Trustee as well as copies of the Constitution. Training is provided to Trustee's as required.

The board of Trustees meet regularly and administer the CIO. The charity has no employees. The Trustees are responsible for all decisions.

Trustees' responsibilities require preparation of financial statements that give a true and fair view of the state of affairs of the CIO, at the end of the financial year, and of its surplus or deficit for the financial year.

In doing so the Trustees are required to:


- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities SORP (statement of recommended practice)
- make judgements and estimates that are reasonable and prudent
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements
- prepare the financial statements on the going concern basis.

The Trustees are responsible for maintaining accounting records which disclose with reasonable accuracy at any time the financial position of the CIO. The Trustees are also responsible for safeguarding the assets of the Charity, taking reasonable steps for the prevention and detection of fraud and other irregularities.

Signed by two trustees on behalf of all trustees:

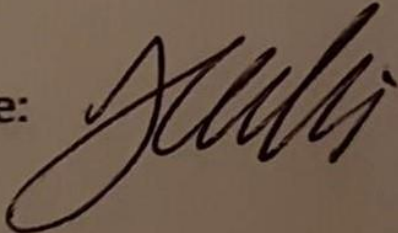
Trustee 1

Name and date: Emma-Jayne Ashley 19/07/2024

Signature: 

Trustee 2

Name and date: Stephen Uncles 19/07/2024

Signature: 

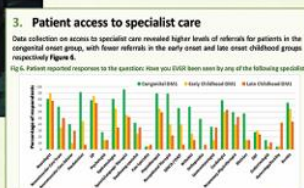


Support ♥ Awareness ♥ Research
Cure Myotonic Dystrophy UK Charity



2023/24 Snapshot - What We Got Up To This Year!

CureDM is a very active registered Charity with a mighty community of families, caregivers, loved ones and amazing individuals. We exist to support everyone affected by Myotonic Dystrophy (DM1 & DM2).



Thanks to our amazing donors, this year our income increased again by over 20%, enabling us to grow our activities and provide:

- ♥ more Fun & Adventurous Events
- ♥ more Personal Support
- ♥ more Expertise to Progress New Treatments
- ♥ more Care Guidelines & Research Posters
- ♥ more Awareness of Myotonic Dystrophy

The Trustees (and Miles) would like to give a BIG "Thank You!" to everyone whose hard work, donations and encouragement make it all possible!

"Thank You!"





Events & Support

Calvert Trust

"Life changing!"

"Unbelievable weekend with amazing people!"

Great videos on !



4 days of making friends, uplifting, emotional, challenging and rewarding activities, information, support, awards, fun and dancing! None of us will ever forget!



"Best time ever!"



"Anyone want to borrow Steven for a couple of days to give my ears a rest? He's STILL telling me all about his weekend!"



Disney On Ice

Back by popular demand, CureDM visited Disney on Ice! This year over 50 people - 13 families converged on Birmingham for a dazzling show followed by food and a party!

We've all had times of feeling isolated when living day to day with DM. This year we expanded our support, offering safe places to connect.

Memorable community events connect people who understand how you feel. Our frequently updated Facebook page and Messenger are our main points of contact and sources of information. They are free, easy to access, and the fastest way to stay in touch.



Our private Facebook group **Cure Myotonic Dystrophy UK - Peer Support and events** is the place for chat, news, discussion, and to ask questions of the community or to be signposted to further help. It's moderated by the Charity Trustees to ensure the hundreds of members can get, or give, support in a safe environment that can't be seen by the wider public. Join up today using the link on our FB page!

Throughout the year we've been planning and building a new, more up-to-date, informative, and easier to navigate web site for launch in 2024!

Making a difference to people living with Myotonic Dystrophy.

Support

Click the photo to learn about how we support the community - from guidelines and signposting to appropriate services, to sitting down with a cup of tea and having a chat when you need it.



Awareness

Click below to learn about all the ways CureDM raise awareness of Myotonic Dystrophy, locally, nationally and worldwide, including international Myotonic Dystrophy Awareness Day, advocating for our community, and sharing information.



Research

Learn about current research into Myotonic Dystrophy, and how CureDM helps to facilitate advancement, including recently securing an award and present at current clinical and study updates, and a link to the CureDM Medication Register.



We invest a lot of time in e-mail threads with community members, doctors and researchers. A message to curedm@outlook.com will be replied to as soon as possible by the best person for your query.



Fundraising

We would like to thank EVERYONE for each and every penny you raise, we simply wouldn't be here to advocate for this community without your incredible generosity and support! Every donation goes to Providing Support, Raising Awareness and Facilitating Research for the UK DM community.



This year we claimed £3,706 in Gift Aid! UK tax payer? Tick the box! - it makes a real difference!

Of course, huge thanks for the grants and sponsorships! These funds allow us to organise bigger and better events and to be at the critical conferences to keep up to date, to advocate and raise the profile of DM.

Huge thanks to all our amazing individual donors and fundraisers - you are such an inspiration!

We would like to express our grateful thanks to these organisations for their generous contributions toward making this event happen!

Special thanks to...

- The Uncles Family - Lego
- The Tait / Lawson Family - Quiz night
- The KAY Family - Kind Support
- The Dixon Family - Sports Hall Activities
- The Garwood Family - Prizes & Gifts
- The Shields Family - Party Games & Prizes
- The Davies family - Cakes!

If you can help with fundraising, holding an event, gaining grants or sponsorships, or in any way at all, please contact us. None of this work can happen without our generous supporters.

THANK YOU!

Awareness



How can we all help?

If every person who reads this goes away and tells one person about Myotonic Dystrophy, then we are all raising awareness!

Whenever we talk about things that we don't see a lot, we are helping to spread awareness and make it a little less scary.

That makes it easier for families like ours, who sometimes need more help to do things that seem 'normal' to others.



Awareness in healthcare is everything. It means more people being diagnosed faster, getting the care we need, and easier access to more treatments!

Our work this year included:

- ♥ founding membership of the new Global Alliance steering committee for International DM Awareness Day - 15th September
(CureDM jointly founded day which now includes the alliance of over 50 organisations around the world!)
- ♥ increasing work with UK & European neuromuscular & rare disease networks
- ♥ developing our LinkedIn network to raise awareness in researchers, pharmaceutical companies & clinicians
- ♥ stands & attendance at bigger, key scientific conferences
- ♥ lobbying Senators & Representatives on Capitol Hill with the MDF for awareness & more research funding to benefit the worldwide DM community
- ♥ working on more Care Guidelines
- ♥ creating research posters for specialist conferences
- ♥ producing videos, published via social media & our YouTube page - www.youtube.com/@CureDMCharity



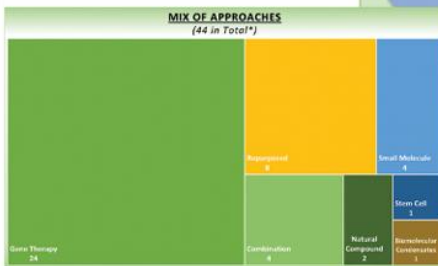
Facilitating Research

April '23/'24

This year we increased our engagement with those undertaking new research into treatments, with clinicians increasing knowledge of DM to improve clinical and social care, and with organisations developing much-needed registries. This included:

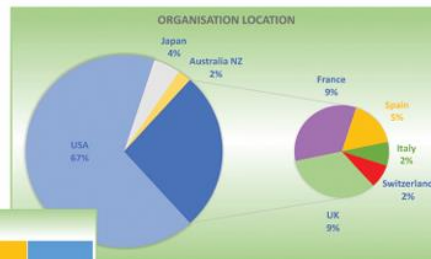
- ♥ updating and circulating the CureDM Community Survey to show the patient perspective
- ♥ co-authoring the Palliative and End of Life provision (PEoLC) in DM
- ♥ creating and co-authoring 8 posters for the IDMC conference in April '24
- ♥ increasing UK Patient Registry funding and encouraging better communication with patients
- ♥ being patient representatives at the TREAT-NMD TGDOC registry collaboration conference
- ♥ co-funding CARE-CDM, the UK natural history study for Adults living with Congenital DM
- ♥ helping to develop an upcoming international study of Children with Congenital DM
- ♥ being patient representatives in the large European SIMPATHIC drug repurposing project
- ♥ completing the first Euro-DyMA Social Task Force projects on community engagement and unmet social needs

In 2023 we created a comprehensive horizon scan of potential new treatments being developed around the world...



...from investigating promising ideas in labs, to clinical trials being evaluated in people. This year saw the first gene therapy trial in the UK!

(Info. as of March 2024) Please contact us if you would like more information.



For the first time there is real hope of systemic treatments for Myotonic Dystrophy! CureDM are in touch with all companies that are developing clinical trials, from informal meetings to in-depth workshops & meetings with the MHRA & other regulators.

We are also reaching out to those earlier in development to encourage them to consider the patient perspective as soon as possible.

If you are interested in learning more about trials, please contact us for more information.

Meet the CureDM Team...

All our Trustees have families affected by Myotonic Dystrophy. Each has a unique and varied personal journey of living with DM and diverse professional and wider life experience.



Emma-Jayne Ashley
Founding Trustee
Mum to Dregan (CDM)



Peter Ashley
Trustee & Chair
Dad to Dregan (CDM)



Stephen Uncles
Trustee
Dad to Matthew & husband to Paula (CDM & DM1)



Tamsyn Tait
Trustee
Mum to Daisy (CDM & DM1)



Liam Garwood
Trustee
Dad to Louie, husband to Bayley (CDM & DM1)



Wendy Greenwood, PhD
Trustee
Mum & Wife (CDM & DM1)



This year Dr. Alison Kay stepped down as Trustee to focus on her family and new opportunities. Ali has been an integral part of the charity from the onset as a founding member of the board and her wise perspective was always valued. We wish her all the very best and hope to see her at one of our community events soon!

A warm welcome to Wendy!

"I am delighted to be joining the Cure DM board of trustees. I am a scientist working in clinical development for a rare disease focused pharmaceutical company, but my main motivation for joining the team is because my husband has DM1 and I see the challenges he faces due to the disease on a day to day basis. We are currently seeing a rapid evolution in the development of therapies for both DM1 and DM2. My husband and I have three young sons, and I'm hopeful for us, and for the thousands of families like us, that the next few years will bring treatments with the potential for substantial benefit to the community."

Learn more about the team by visiting our website - www.curedm.co.uk