

Cure Myotonic Dystrophy UK Charity (CDM)

(CIO)

REPORT OF THE TRUSTEES: 6th April 2024 to 5th April 2025

The Trustees present their report together with the financial statements of the Charity for the year ended 5th April 2025.

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:

No change in period.

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 and grants.

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 2024-2025:

Research

- Attended the International Myotonic Dystrophy Consortium meeting, held every 2 years in a different country. This conference brings together worldwide researchers and clinicians to discuss new findings in the disease, potential new treatments, ongoing trials and best practice for patient care.

- Facilitated and funded attendance for a number of UK Clinicians to attend the International Myotonic Dystrophy Consortium in Nijmegen. Including facilitating presentation of posters and ongoing research to support the UK community.
- Co-Authored guidelines and papers for advancing Palliative and End of Life provision within the DM community.
- Submitted CureDM community research abstract to the International Myotonic Dystrophy Consortium (IDMC), worldwide scientific conference. Presented as a Poster during the event.
- Continued to update and publish 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.
- Supported 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.
- 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.
- Co-Authored research posters which were presented at worldwide scientific conferences.
- Supported and advised as DM specialist patient representatives on upcoming awareness video for the NHS. Facilitated real patients participation.
- 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: Completed a research paper on the support and events provided by different organisations within Euro-DyMA, presented a poster at the IDMC and published a booklet with full report.
- 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.
- Continued to collaborate 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.
- UK venues and landmarks lit up green to support the CureDM Charity and Awareness Day. Online awareness campaign and community support for the 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.
- 'Could it be Myotonic Dystrophy' posters dissemination to settings where patients may be seen. These are now used worldwide.
- Published 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 2024. A weekend at LEGOLAND WINDSOR.
- The event was fully funded by the Charity and catered to ❖ 157 attendees. ❖ 37 family groups. ❖ 41% of attendees living with DM. ❖ Over 1/3rd new family groups who have not attended a CureDM event before. ❖ Welcoming people living with CDM, DM1, DM2, Siblings, Parents, Caregivers and Grandparents. ❖ Travelling from all over the UK!
- Provided each attendee with opportunity for 1:1 support and handed out disease specific information materials.

- Xmas Polar Express Train ride – 2 full carriages: We are proud to have provided this event free of charge to 64 people from families living with Myotonic Dystrophy.
- Planned and organised an evening dinner/dance at The Deep (Hull, UK) – a total of 87 guests. CureDM provided free tickets for people living with DM.
- 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.
- Began the process of having MILES Mascots CE tested.
- 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.
- Continued with monitoring survey within the community, to identify and improve community satisfaction of services provided by the Charity.

Fundraising:

- Set up the TOGETHER CAMPAIGNS, with our first family fundraising on our behalf as 'TEAM TOBY' – this initiative is to increase funds into the Charity whilst giving other families a chance to raise awareness of their own experiences in their own way.
- 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.
- Organised and facilitated a team of 16 runners for Great North Run 2024, raising over £7600. 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.

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 provide peer support, family memories, form 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:

Events were reinstated to their fullest this year, with an increase in attendees and new families. CureDM are meticulous with planning and budgeting, and are delighted that income exceeded expenditure, keeping the Charity on even footing and living within its means. 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, taking into consideration restricted funds where necessary.

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

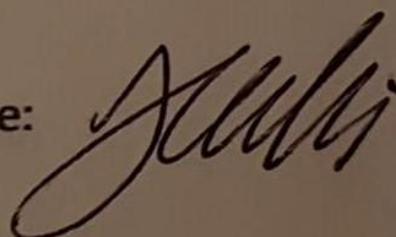
Signature:



Trustee 2

Name and date: Stephen Uncles

Signature:





CHARITY COMMISSION
FOR ENGLAND AND WALES

Cure Myotonic Dystrophy UK Charity (CDM)

1191217

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Receipts and payments accounts

For the period from	06/04/2024	To	05/04/2025
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Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Donations	26,794	2,500	-	29,294	-
Gift Aid	5,018	-	-	5,018	-
Community Events Refunds	-	-	-	-	-
Sponsorships/Grants	22,300	15,000	-	37,300	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	54,111	17,500	-	71,611	-
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	54,111	17,500	-	71,611	-
A3 Payments					
Fundraising & Community Events	40,919	-	-	40,919	-
Administration & Running Costs	6,202	-	-	6,202	-
Paypal & JustGiving Fees	1,029	-	-	1,029	-
Research Grants	-	-	-	-	-
Conferences	4,825	-	-	4,825	-
Advertising & Promotional Merchandise	4,517	-	-	4,517	-
Professional Fees	9,360	-	-	9,360	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	66,853	-	-	66,853	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	66,853	-	-	66,853	-
Net of receipts/(payments)	- 12,742	17,500	-	4,758	-
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	20,533	-	-	20,533	-
Cash funds this year end	7,791	17,500	-	25,291	-

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	6,383	17,500	-
	Paypal	1,408	-	-
		-	-	-
	Total cash funds	7,791	17,500	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-
		Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
		Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	
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

05/04/2025

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 05/04/2025.

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:

17/11/2025

Name:

Rebecca Rouse BSR Accountancy Ltd

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

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

Address:	15 Crakedale Road
	Winterton
	DN15 9UT

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.

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