CURE MYOTONIC DYSTROPHY UK CHARITY (CDM)

England & Wales · Charity number 1191217

Details

Other names	CURE DM
Status	Registered
Legal form	CIO
Registered	2020-09-09
Register	View on the Charity Commission register

Contact

Address

Riverside View
Station Road
Whitton
Scunthorpe
DN15 9LR

Phone	07757030554
Email	curedm@outlook.com
Website	www.curedm.co.uk

Activities

Objects: THE OBJECTS 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.

Activities: 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; (b) making financial donations to support research into Myotonic Dystrophy;(c) raising awareness of Myotonic Dystrophy within the general public, medical and scientific community

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Other Charitable Activities
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability, Other Charitable Purposes
- **Who:** Children/young People, Elderly/old People, People With Disabilities, Other Charities Or Voluntary Bodies, The General Public/mankind

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-04-05	£71,611	£66,853	-	-
2024-04-05	£64,030	£78,232	-	-
2023-04-05	£52,013	£53,661	-	-
2022-04-05	£37,137	£17,505	-	-
2021-04-05	£19,596	£2,845	-	-

Trustees

Name	Role	Appointed
Peter Robert Ashley	Chair	2020-08-11
Dr Wendy Greenwood		2023-12-14
Emma-Jayne Ashley Mrs		2020-08-11
Liam Garwood		2023-01-04
Stephen Uncles		2020-08-11

CURE MYOTONIC DYSTROPHY UK CHARITY (CDM)

England & Wales - Charity number 1191217

Accounts

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 adaptions.
- 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.

<u>Appointment of Trustees:</u>
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.

<u>Trustee induction and training:</u>
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: EJAshley

Trustee 2
Name and date: Stephen Uncles

Signature:

CHARITY COMMISSION
FOR ENGLAND AND WALES

Cure Myotonic Dystrophy UK Charity (CDM)	1191217	CC16a

Receipts and payments accounts

For the period from	06/04/2024	**To**	05/04/2025

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	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

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
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 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.

CURE MYOTONIC DYSTROPHY UK CHARITY (CDM)

England & Wales - Charity number 1191217

Accounts

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

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
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 liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

	Signature	Print Name	Date of approval
Signed by one or two trustees on behalf of all the trustees			

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

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 adaptions.
- 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 20223, 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:
EJAshley

Trustee 2
Name and date: Stephen Uncles 19/07/2024

Signature:

CDM

Cure DM

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).

3. Patient access to specialist care

Data collection on access to specialist care revealed higher levels of referrals for patients in the congenital onset group, with fewer referrals in the early onset and late onset childhood groups respectively **Figure 6.**

Fig 6. Patient reported responses to the question: Have you EVER been seen by any of the following specialists?

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!**

www.curedm.co.uk
Reg.No.1191217

Events & Support

Calvert Trust

"Life changing!"

"Unbelievable weekend with amazing people!"

"Best time ever!"

CureDM hired the whole of the Calvert Trust in the beautiful English Lake District for 67 people - 20 families.

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!

"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.

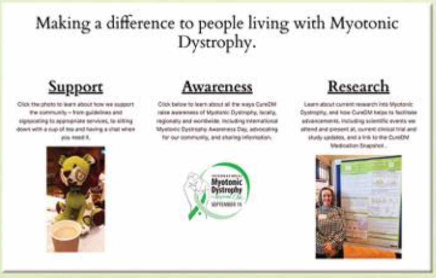
Our private Facebook group Cure Myotonic Dystrophy UK - Peer Support and events is the place for chat, news, discussion, and to ask questions of the community or to be signposted to further help. It's moderated by the Charity Trustees to ensure the hundreds of members can get, or give, support in a safe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

Join up today using the link on our FB page!

CureDM have a profile on X (Twitter), which is great for connecting with researchers and clinicians. In 2023 we launched on Instagram and we have a YouTube page with community videos!

@CureDMCharity

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

Awareness

Research

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.

THANK YOU!
Team CureDM
For fundraising and running
GNR 2023
And For Donating
£7451.43
It is very much appreciated!

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

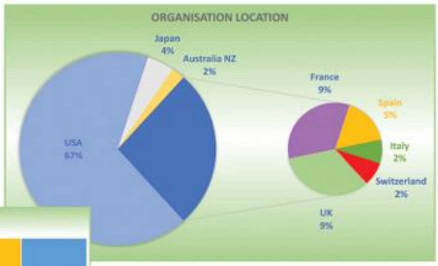
♥ producing videos, published via social media & our YouTube page - www.youtube.com/@CureDMCharity

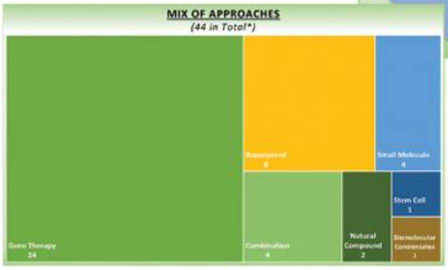
Facilitating Research

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 familiy and new oportunities. 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

Accounts

CHARITY COMMISSION
FOR ENGLAND AND WALES

Cure Myotonic Dystrophy UK Charity (CDM)	**1191217**	**CC16a**

Receipts and payments accounts

For the period from	06/04/2022	**To**	05/04/2023

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	29,914	-	-	29,914	-
Gift Aid	2,801	-	-	2,801	-
Community Events Refunds	823	-	-	823	-
Sponsorships/Grants	18,475	-	-	18,475	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
***Sub total** (Gross income for AR)*	52,013	-	-	52,013	-
A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	52,013	-	-	52,013	-
A3 Payments					
Community Events	28,534	-	-	28,534	-
Administration & Running Costs	11,888	-	-	11,888	-
Paypal & JustGiving Fees	871	-	-	871	-
Research Grants	6,270	-	-	6,270	-
Conferences	319	-	-	319	-
Advertising & Promotional Merchandise	3,557	-	-	3,557	-
Professional Fees	2,222	-	-	2,222	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	53,661	-	-	53,661	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	53,661	-	-	53,661	-
Net of receipts/(payments)	- 1,649	-	-	- 1,649	-
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	36,383	-	-	36,383	-
Cash funds this year end	34,734	-	-	34,734	-

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	34,734	-	-
			-	-
		-	-	-
	Total cash funds	34,734	-	-

(agree balances with receipts and payments account(s)) OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
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 liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

	Signature	Print Name	Date of approval
Signed by one or two trustees on behalf of all the trustees	EJAshley	E.J. ASHLEY	6-10-23
		P. ASHLEY	06/10/'23

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 05/04/2023 **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 05/04/2023.

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:** 02/10/2023

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

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 2022 to 5th April 2023

The Trustees present their report together with the financial statements of the Charity for the year ended 5th April 2023.

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, Dr Alison Kay (all sitting as first trustees). Liam Garwood and Tamsyn Tait (as of 4th Jan 2023).

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 annual AGM (which is the main source of future Charity planning).

Services were maintained in the following areas:
The return to in person events, consultations, and conferences. Discussions between all stakeholders were held in person, and via continued utilisation of virtual meetings.

For the period April 2022-2023:

Research

- Presented CureDM Posters at worldwide scientific conferences, raising the profile of congenital and childhood onset Myotonic Dystrophy (DM) in the UK.
- Submitted an abstract and presented a poster at the International Myotonic Dystrophy Consortium (IDMC), worldwide scientific conference in Japan (virtually).
- Co-authored DM papers and posters on Patient preferences, DM1, DM2 and CDM.
- UK DM Data continued to be gathered via ongoing community questionnaire.
- 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.

- Patient representative supporting the ILAP application process within MHRA, SMC, AWMSG and NICE.
- Advised on DM relevant study protocol/design as patient representatives on numerous ongoing research projects, including direct meetings with organisations 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.
- Steering committee member for the UK Myotonic Dystrophy Patient registry.
- 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 PEoLC 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.
- Provided grants to the UK DM Patient Registry.
- Provided grants to researchers to support attendance and research presentation at Neurology conferences.
- Reviewed and agreed to co-fund UK Natural history study into Adults with Congenital Myotonic Dystrophy (next year's accounts)

Awareness:

- Joint founders of the INTERNATIONAL MYOTONIC DYSTROPHY AWARENESS DAY.
- Continued to promote the awareness day and collaboration throughout the year.
- Member of steering committee for the DM Global Alliance.
- Designed 'could it be Myotonic Dystrophy' posters for dissemination to all settings where patients may be seen. These are now used worldwide.
- 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.
- Regularly updating website with accurate, DM specific, information and advice.
- Social media pages including public Charity pages and dedicated private peer support pages, allowing patients and families with DM to connect in private.
- Moderates worldwide social media pages for DM1, DM2 and CDM.
- Advocates for families with DM in charitable, social, and medical settings.
- Attended several online medical, research and support conferences including World Orphan Drug Congress, MDUK, MDF, Genetic Alliance, Eurordis, Euro-Dyma, IMI, WMS, Treat-NMD, CNMD and other rare disease communities.
- Presented at some of the above conferences and manned CureDM information stands.
- Raised the profile of Myotonic Dystrophy in Rare disease, Neuromuscular, Pharma and Muscular Dystrophy focused collaborations.

Support:

- Re-started face to face meetings in July 2022 with a Families Day event at Alton Towers, supporting 20 families and over 70 participants.
- Facilitated group events at Disney on Ice in Nov/Dec 2023, in 3 venues around the UK, for 16 families living with Myotonic Dystrophy.

- 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.
- Produced ‘medical need for space’ and ‘please give me space’ cards and badges for the community re-entering public as pandemic measures reduced.
- Supported individuals and families with day to day, benefits, healthcare, and quality of life issues.
- Successfully supported community members in applying for disability benefits and home adaptions.
- Continued to provide ‘Miles’ mascots to children with CDM to promote friendship and support.
- Commissioned a “life-sized” ‘Miles’ mascot costume to help with engagement at face-to-face community and fund-raising events.
- 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.
- Supports work in advancing Palliative and End of Life provision for the DM community.

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).
- We continued to receive generous donations from people fundraising on our behalf.
- In memory donations received.
- CureDM trustees organised and ran with the team for Great North Run 2022 raising over £9600.

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 2022/2023 Impact Report was published and is attached to this Trustee report.

Stakeholders:

- Charity stakeholders are those affected by Myotonic Dystrophy, their families and carers, 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 and social media.
- When deciding on future peer support get-togethers, the 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.
- Strategic or significant financial decisions, such as activities or proposals for research funding, are made following consultation with all trustees, who all have significant 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 and encourage the sharing of knowledge to improve day to day quality of life.

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.

Future Plans:
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, 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 and resulting downturn in donations received 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 to ensure adequate funding is available for the 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:

Trustees are appointed by the 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: EMMA-JAYNE ASHLEY.
Name and date: 06.10.2023.

JAshley.

Trustee 2: P. ASHLEY
Name and date: 06/10/23

March 2023

A Snapshot of What We Got Up To This Year...!

Cure DM
Support ♥ Awareness ♥ Research

CureDM is a small yet mighty collective of families, carers, loved ones and special individuals. We would like to thank everyone who makes CureDM charity what it is.

We've seen our donations almost double in 2022 / 23 and our expenditure has increased to reflect this. This simply wouldn't have been possible without your support! We would like to sincerely give thanks to those whose efforts, contributions, and donations – big and small- make up the CureDM community.

Thank You!

All the Trustees on our panel have the unique perspective of being parents and carergivers to a child / young adult diagnosed with Congenital Myotonic Dystrophy or a similar neuromuscular condition...

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

Peter Ashley
Trustee & Chair
Dad to Dregan
(CDM)

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

Dr. Ali Kay
Trustee
Mum to Bertie
(Ullrich CMD)

In 2022 we gave a warm welcome to two new additions to the CureDM Trustees…

Tamsyn Tate
Trustee
Mum to Daisy
(CDM & DM1)

"I am really excited to join the CureDM team. My two-year-old daughter's diagnosis of CDM1 and my own subsequent diagnosis of DM1 means I can relate to those who have the condition whilst caring for a child with the severe form. With a career as a Marketing Manager, I'm hoping I can help raise the charity's profile and ultimately awareness for the disease. I am also keen to support others through their journey."

"I'm delighted to be joining the CureDM team. My one-year-old son was diagnosed with CDM shortly after birth along with my wife (DM1). The news came as a huge shock, as it does for many families. I look forward to contributing to the charity's fantastic work in community support, as well as raising awareness within the science and medical community to move towards effective treatment."

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

(Learn more about the team by visiting our web site)

Ongoing Support

This year, like every year, we make efforts to let children and their families, carers and guardians know we are thinking of them and follow their journeys as much as possible. We try to offer emotional support and informative advice whenever we can. Many of the CureDM community face daily challenges such as the shock of diagnosis, illness, and often being in hospital. We hope, through our network, we can help support one another and let you know you are not alone.

> *"CureDM has been a lifeline of hope and reassurance to us. Getting the shock diagnosis, we didn't know where to turn for information and found so little positive information out there. The charity has really helped our understanding and made us feel more hopeful for the future."*

Events of 2022

Families Day - Alton Towers - July

We were able to organise an incredible family day to give families affected by CDM the opportunity to enjoy the theme park with minimal cost to them. This also gave families, carers, and guardians across the UK the opportunity to meet face-to-face and offer a safe space to connect with others familiar with the issues of caring for children affected by CDM. We received lots of lovely feedback about how much fun the attendees had and what a positive experience it was.

If you attended Alton Towers this year you may have seen a friendly, somewhat cuddly character in the form of Miles the Mascot. We hope you enjoyed this new addition to our team. Watch out for him at our future events!

"What a fantastic experience for our daughter to meet with so many other children who share her condition. She's only met two other children who have this condition…

…I wish this charity had existed 11 years ago when we collected her from hospital…This charity is a wealth of knowledge on this condition and bringing us together is very special."

Disney On Ice - Sheffield, Birmingham, London - December

We were also able to offer a Winter family event this year. We secured spaces at three venues, offering 55 people the chance to enjoy a family trip to watch Disney on Ice live at Birmingham, Sheffield, or London with minimal personal cost to the families. It was lovely to be able to give the families another chance to meet up. For some it was the first time attending one of our events. We hope those who could make it made some unforgettable memories for the festive season! It was so successful that we are repeating the offer in 2023 - contact us if you are interested!

"[CureDM} has been a constant source of support and knowledge over the past year when the children have been ill, or I have had questions or concerns."

"We have really enjoyed and benefitted from the two meet ups (both Alton Towers in the Summer and Disney on Ice in December) where we got to meet many other families with children who have the same condition as my two...

...That for me is the best part as it has allowed me to build a network of support of other muns / dads who may be going through similar...This gives me hope and reassurance, knowing I am not alone!

Research

At last, 3 potential systemic treatments are in clinical trials (AMO Pharma, Avidity and Dyne) and more are on the way!

CureDM are working with the companies to make sure the trials measure what is important to us, that they are not too much of a burden, and are safe. We are also working with the UK regulatory bodies to speed up the approval process and make them available to everyone as soon as possible. Please get in touch if you'd like to know more or to be involved!

MDUK announced in 2022 that Dr.Chris Turner at UCL will be leading a natural history study of adults with Congenital DM1 (symptoms from birth). The study will give us information to further improve care and also provide data for clinical trials.

Members of CureDM advocated for this study and we are proud to be part-funding it.

We have been involved in producing a number of abstracts and posters that have been presented at conferences by CureDM, TREAT-NMD, and the UK DM Patient Registry (which we also part-fund) to explain to clinicians and researchers the real-world experiences of the people that actually live with Myotonic Dystrophy.

Thank you for the hundreds of responses to our ongoing survey that allowed this to happen!

Congenital and Childhood Myotonic Dystrophy Type 1 in the UK

Nikolenko Nikoletta[1], Ashley Emma-Jayne[2]

[1]National Hospital for Neurology and Neurosurgery, Queen Square, UCLH NHS Foundation Trust, UK

[2]Cure Myotonic Dystrophy UK Charity

Introduction

Aim

To identify the epidemiology and clinical characteristics of DM1 patients within the UK

Methods

Results

Conclusion

References

Acknowledgements and Contact

Raising Awareness

Shining a light on Myotonic Dystrophy, especially the Congenital form, is crucial. Here are some of examples how we spread the word this year:

Celebrating International DM Awareness Day:

Social media came into its own, especially Facebook and Twitter, where many in the UK community and beyond showed support by changing their profile pictures, sharing information on the disease, upcoming trials, and posting personal stories. The national mourning of the Queen meant landmarks that were planned to light up green on the 15th of September were purple in respect for the monarchy. They have, however, all said they'll light up for us in 2023!

Growing Our Strong Online Presence:

As well as the CureDM web site, this year we added Instagram to our continuous, strong online presence on social media, helping us to share any news and breakthroughs. Our private, UK only, Facebook group continued to grow. It is only for those living with DM, focusing on peer support and day to day living.

www.curedm.co.uk

Attending Conferences:

This year we got back to face-to-face conferences in the UK, Belgium, Italy and Canada and also presented at the prestigius IDMC. These allowed us to connect with the leading medical and scientific professionals, raising the profile of DM on a big stage.

Taking Part in Webinars:

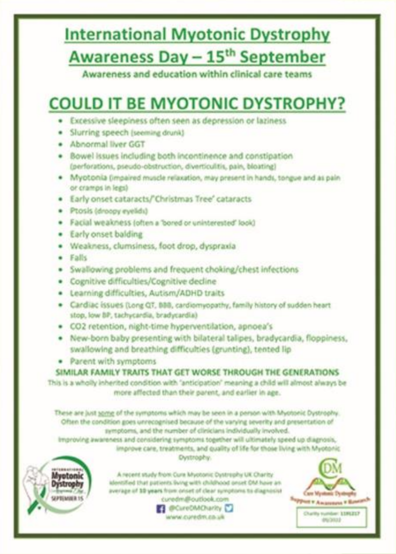
In 2022/2023 we attended online conferences based in the UK, across Europe, Japan and the USA. As with in-person conferences, these webinars allow the exchange of medical advances in the field of neuromuscular disease and create collaborations that raise the profile and accelerate awareness of Myotonic Dystrophy.

Presenting the importance of patient preferences in webinars for ISPOR (Professional Society for Health Economics and Outcomes Research) and representing the community in online conferences is vital for keeping DM relevant in the eyes of the researchers.

Contacting Professionals:

We increased our efforts to make positive contact with medical professionals to bring recognition and further their understanding of the disease, to speed up diagnosis and implement the necessary care to their patients living with Myotonic Dystrophy earlier rather than later. Being members of Euro-DyMA (Federation of European DM Associations) and other DM specific associations enables us to bring meaningful discussion and collaboration to the very start of any project, making sure work is relevant for the community we represent.

This year we created a "Could it be Myotonic Dystrophy?" poster that has been distributed to clinicans and sent around the world. This can be downloaded from our website or please contact us for copies.



International Myotonic Dystrophy Awareness Day – 15th September

Awareness and education within clinical care teams

COULD IT BE MYOTONIC DYSTROPHY?

- Excessive sleepiness often seen as depression or laziness
- Slurring speech (seeming drunk)
- Abnormal liver GGT
- Bowel issues including both incontinence and constipation (perforations, pseudo-obstruction, diverticulitis, pain, bloating)
- Myotonia (impaired muscle relaxation, may present in hands, tongue and as pain or cramps in legs)
- Early onset cataracts/'Christmas Tree' cataracts
- Ptosis (droopy eyelids)
- Facial weakness (often a 'bored or uninterested' look)
- Early onset balding
- Weakness, clumsiness, foot drop, dyspraxia
- Falls
- Swallowing problems and frequent choking/chest infections
- Cognitive difficulties/Cognitive decline
- Learning difficulties, Autism/ADHD traits
- Cardiac issues (Long QT, BBB, cardiomyopathy, family history of sudden heart stop, low BP, tachycardia, bradycardia)
- CO2 retention, night-time hyperventilation, apnoea's
- New-born baby presenting with bilateral talipes, bradycardia, floppiness, swallowing and breathing difficulties (grunting), tented lip
- Parent with symptoms

SIMILAR FAMILY TRAITS THAT GET WORSE THROUGH THE GENERATIONS

This is a wholly inherited condition with 'anticipation' meaning a child will almost always be more affected than their parent, and earlier in age.

These are just some of the symptoms which may be seen in a person with Myotonic Dystrophy. Often the condition goes unrecognised because of the varying severity and presentation of symptoms, and the number of clinicians individually involved. Improving awareness and considering symptoms together will ultimately speed up diagnosis, improve care, treatments, and quality of life for those living with Myotonic Dystrophy.

A recent study from Cure Myotonic Dystrophy UK Charity identified that patients living with childhood onset DM have an average of 10 years from onset of clear symptoms to diagnosis

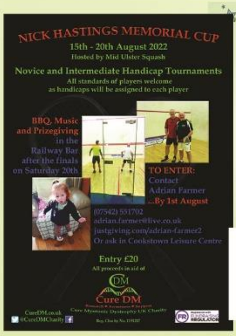
curedm@outlook.com

@CureDMCharity

www.curedm.co.uk

Raising Funds!

None of this would happen without the generous organisations that provide us with grants and, of course, the many amazing people that volunteer for us and selflessly raise the much needed money! You are fabulous!



NICK HASTINGS MEMORIAL CUP

15th - 20th August 2022

Hosted by Mid Ulster Squash

Novice and Intermediate Handicap Tournaments

All standards of players welcome as handicaps will be assigned to each player

BBQ, Music and Prizegiving in the Railway Bar after the finals on Saturday 20th

TO ENTER: Contact Adrian Farmer ...By 1st August

(07542) 551702

adrian.farmer@live.co.uk

justgiving.com/adrian-farmer2

Or ask in Cookstown Leisure Centre

Entry £20

All proceeds in aid of

Cure DM

CureDM.co.uk

@CureDMCharity

Cure DM

THANK YOU!

Lisa Canterbury

For

Supporting us via your 3 Peaks Challenge

YOU ARE AMAZING!!!!

And For Donating £1953.83 (plus £365.01 Gift Aid!)

Totalling £2318.84

It is very much appreciated!

Thank You!

For more information on CureDM and what we are doing behind the scenes, you can keep up to date on our social media pages, visit our website, or e-mail us at curedm@outlook.com

Accounts

Cure Myotonic Dystrophy UK Charity (CDM)
(CIO)
REPORT OF THE TRUSTEES: 6th April 2021 to 5th April 2022

The Trustees present their report together with the financial statements of the Charity for the year ended 5th April 2022.

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), Karl Kibble, Stephen Uncles and Dr Alison Kay. All are first trustees.

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 charitable company 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. Due to Covid-19, many events and fundraising activities had to be cancelled this year. Financial income has come from donations and fundraising, from the community and donations from Cure DM Ventures CIC. The Board of Trustees have regular updates/meetings and an annual AGM, which are the main source of future Charity planning.

Services were maintained in the following areas:
Due to the ongoing Covid-19 Pandemic, most consultations, conferences, and discussions between all stakeholders were held virtually and/or via email. We hope that in person meetings can begin very soon. In the period April 2021-2022: -

Research
Presented Cure DM Posters at scientific conferences (EAP and MRC), raising the profile of congenital and childhood onset DM in the UK.

- UK DM Data continues to be gathered via ongoing community questionnaire.

- Founding members of Euro-Dyma, an international collaboration of European support groups, facilitating research and focusing on un-met needs of the DM Community.
- Patient representative supporting the ILAP application process within MHRA, SMC, AWMSG and NICE.
- Advising on DM relevant study protocol/design as patient representatives on numerous ongoing research projects. Vital to find treatments and therapies for those living with Myotonic Dystrophy
- Patient representatives for upcoming potential research studies and clinical trials, liaising directly with pharma to advise on the complexity of DM/CDM.
- Collaborated with clinicians and researchers to produce disease specific guidelines and advice.
- Attended scientific, medical and clinical conferences online and in person
- Attended European Reference Network (ERN) for Neuromuscular Diseases.

Awareness:

- Instrumental in setting up the INTERNATIONAL MYOTONIC DYSTROPHY AWARENESS DAY.
- 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.
- Regularly updating website with accurate, DM specific, information and advice.
- Social media pages including public Charity pages and dedicated secret peer support pages, allowing patients and families with DM to connect in private.
- Advocated for families with DM in charitable, social and medical settings.
- Attended several online medical, research and support conferences including: World Orphan Drug Congress, MDUK, MDF, Genetic Alliance, Eurordis, Euro-Dyma, IMI, and other rare disease communities.
- Raised the profile of Myotonic Dystrophy in Rare disease, Neuromuscular, Pharma and Muscular Dystrophy focused collaborations.
- Represented DM and attended the parliamentary cross party muscle group.

Support:

- Delivered support, advice, and assistance virtually to the Myotonic Dystrophy community, dealing with the queries or passing them on to an appropriate person or organisation.
- Provided support packages for children affected by Congenital Myotonic Dystrophy, and who continued to shield due to the pandemic.
- Produced ‘medical need for space’ and ‘please give me space’ cards and badges for the community re-entering public as pandemic measures reduced.
- Supported individuals and families with day to day, benefits, healthcare and quality of life issues.

- Successfully supported community members in applying for disability benefits and home adaptions.
- Sent ‘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.
- The COVID pandemic has meant many in person meet-ups were postponed.

Fundraising:

- Most fundraising events were postponed due to the Covid Pandemic
- We continued to receive generous donations from people fundraising on our behalf.
- In memory donations received.
- Cure DM organised a team for Great North Run 2021.

News and information:

The charity facilitates a private social media group, and a public charity page on Facebook. These are platforms for sharing articles, peer support, sharing experiences and ideas. Information is shared on research progress and other matters impacting on families of disabled children and adults. There is also a website and a Twitter account – used to keep families up to date with news and events.

Stakeholders:

- The stakeholders are those affected by Myotonic Dystrophy, their families and carers, those involved in running the Charity, volunteers and those fundraising or raising awareness.
- Support, events, and fundraising opportunities are proposed and discussed by all stakeholders. Consultations take place regularly in meetings with families, during business meetings and conferences and online via e-mail and social media. (Online due to COVID)
- When deciding on future peer support get-togethers, the 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 sure 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.
- Strategic or significant financial decisions, such as activities or proposals for research funding, are made following consultation with all trustees, who all have significant knowledge and experience of the conditions, support for others, charitable work and fundraising.
- Research funding is 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 and ideas. Events this year were cancelled due to the Covid-19 pandemic.

Review of Public Benefit:
In setting out our objectives and planning our activities, the Trustees have given careful consideration to the Charity Commission's general guidance on public benefit, and cancelled face to face events until it is safe.

Future Plans:
We continually strive to expand our 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.
The restrictions necessitated by the Covid-19 pandemic and the vulnerability of our community/families caused us to delay planned social/peer support activities (days out, holidays etc.), normally at the core of our work, which has reduced our expenditure.

Income/Expenditure:
The excess of income over expenditure in the year amounted to £19,632 (this is our first full-year accounting period.

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 and resulting downturn in donations received means sufficient reserves may need be held. There is no policy in place dictating reserve amounts. The Trustees carefully monitor this area to ensure adequate funding is available for the 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:
Trustees are appointed by the 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:

Trustee 2:
Name and date:

CHARITY COMMISSION
FOR ENGLAND AND WALES

Cure Myotonic Dystrophy Charity (CDM)	No (if any)

Receipts and payments accounts

CC16a

For the period from	06/04/2021	**To**	05/04/2022

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	28,964	-	-	28,964	-
Giftt Aid	2,787	-	-	2,787	-
Community Event refunds	5,386	-	-	5,386	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total *(Gross income for AR)*	37,137	-	-	37,137	-
A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	37,137	-	-	37,137	-
A3 Payments					
Community Events	1,896	-	-	1,896	-
Administration costs	2,066	-	-	2,066	-
Paypal fees	684	-	-	684	-
Research Grants	6,102	-	-	6,102	-
Conferences	277	-	-	277	-
Event Cancellation Refunds	4,724	-	-	4,724	-
Advertising & Promotioin	1,756	-	-	1,756	-
		-	-		-
	-	-	-	-	-
Sub total	17,505	-	-	17,505	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	17,505	-	-	17,505	-
Net of receipts/(payments)	19,632	-	-	19,632	-
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	16,751	-	-	16,751	-
Cash funds this year end	36,383	-	-	36,383	-

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	35,577	-	-
	Paypal Account	806	-	-
		-	-	-
	Total cash funds	**36,383**	**-**	**-**
	(agree balances with receipts and payments account(s))	OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
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 liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	

	Signature	Print Name	Date of approval
Signed by one or two trustees on behalf of all the trustees			

CHARITY COMMISSION
FOR ENGLAND AND WALES

Independent examiner's report on the accounts

Section A Independent Examiner's Report

Report to the trustees/ members of	Charity Name Cure Myotonic Dystrophy Charity (CDM)

On accounts for the year ended	5th April 2022	**Charity no (if any)**	1191217

Set out on pages	1 and 2

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 05/04/2022.

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 ("the Act").

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 (other than that disclosed below *) 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.

* *Please delete the words in the brackets if they do not apply.*

Signed:

Date: 29/06/2022

Name: DAVID GLOSSOP

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

Address: 53 Irwin Road, Blyton

Gainsborough, Lincolnshire
DN21 3LS

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.

Accounts

Cure Myotonic Dystrophy UK Charity(CDM)
(CIO)
REPORT OF THE TRUSTEES: 9th September 2020 to 5th April 2021

The Trustees present their report together with the financial statements of the Charity for the year ended 5th April 2021.

Reference and Administrative Details:

Charity Number: 1191217

Registered Office: 15 Chapel Court, Brigg, North Lincs, DN20 8JZ

Directors and Trustees: The currently registered Trustees are Emma-Jayne Ashley, Peter Ashley (Chair), Karl Kibble, Stephen Uncles and Dr Alison Kay. All are first trustees.

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 charitable company 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. Due to Covid-19, many events and fund-raising activities had to be cancelled this year. Financial income has come from donations and fundraising, from the community and donations from Cure DM Ventures CIC.

Services were maintained in the following areas:

In the period Sept 2020 to April 2021, the charity has: -

- Delivered support, advice and assistance virtually, dealing with the queries or passing them on to an appropriate person or organisation.
- Provided support packages for children affected by Congenital Myotonic Dystrophy, and who were shielding due to the pandemic.
- Supported individuals and families with day to day, benefit, and quality of life issues.
- Successfully supported community members in applying for disability benefits and home adaptions.

- Sent ‘Miles’ mascots to children with CDM to promote friendship and support.
- Continued with websites and online presence via social media. 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.
- Consulted on numerous ongoing research projects. Vital to find treatments and therapies for those living with Myotonic Dystrophy.
- Advocated for families with DM in charitable, social and medical settings.
- Attended several online medical, research and support Conferences.
- Raised the profile of Myotonic Dystrophy in Rare disease, Neuromuscular, Pharma and Muscular Dystrophy focused collaborations.
- Collaborated with clinicians and researchers to produce disease specific guidelines and advice
- The COVID pandemic has meant face to face meet-ups were not possible.
- Most fundraising events were postponed due to the Covid Pandemic, although we continued to receive generous donations from people fundraising on our behalf.

News and information:

The charity has been preparing a private social media group, and a public charity page on Facebook. These are platforms for sharing articles, peer support, sharing experiences and ideas. Information is shared on research progress and other matters impacting on families of disabled children and adults. There is also a website and a Twitter account – used to keep families up to date with news and events.

Stakeholders:

- The stakeholders are those affected by Myotonic Dystrophy, their families and carers, those involved in running the Charity, volunteers and those fundraising or raising awareness.
- Support, events, and fundraising opportunities are proposed and discussed by all stakeholders. Consultations take place regularly in meetings with families, during business meetings and conferences and online via e-mail and social media. (Online due to COVID)
- When deciding on future peer support get-togethers, the 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 sure 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.
- Strategic or significant financial decisions, such as activities or proposals for research funding, are made following consultation with all trustees, who all have significant knowledge and experience of the conditions, support for others, charitable work and fundraising.
- Research funding is 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 and ideas. Events this year were cancelled due to the Covid-19 pandemic. Review of Public Benefit In setting out our objectives and planning our activities, the Trustees have given careful consideration to the Charity Commission's general guidance on public benefit, and cancelled face to face events until it is safe.

Future Plans:

We continually strive to expand our 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.
The restrictions necessitated by the Covid-19 pandemic and the vulnerability of our community/families caused us to delay planned social/peer support activities (days out, holidays etc.), normally at the core of our work, which has reduced our expenditure.

Income/Expenditure:

The excess of income over expenditure in the year amounted to £16,751 (this is our first accounting period.

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 and resulting downturn in donations received means sufficient reserves may need be held. There is no policy in place dictating reserve amounts. The Trustees carefully monitor this area to ensure adequate funding is available for the continuation of services and financial obligations.

Structure, Governance and Management Governing Document:

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In doing so the Trustees are required to:
- select suitable accounting policies and then apply them consistently
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- 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:

Trustee 2:

Name and date:

CHARITY COMMISSION
FOR ENGLAND AND WALES

Cure Myotonic Dystrophy UK Charity (CDM)	1191217

Receipts and payments accounts

CC16a

For the period from	09-Sep-20	**To**	05-Apr-21

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	17,192	-	-	17,192	-
Event contributions	2,404	-	-	2,404	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total *(Gross income for AR)*	19,596	-	-	19,596	-
A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	19,596	-	-	19,596	-
A3 Payments					
Community events	1,443	-	-	1,443	-
Fundraising	1,230	-	-	1,230	-
Administration costs	68	-	-	68	-
Bereavement support	52	-	-	52	-
Paypal fees	52	-	-	52	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	2,845	-	-	2,845	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	2,845	-	-	2,845	-
Net of receipts/(payments)	16,751	-	-	16,751	-
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	16,751	-	-	16,751	-

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	16,751	-	-
		-	-	-
		-	-	-
	Total cash funds	**16,751**	**-**	**-**
	(agree balances with receipts and payments account(s))	OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
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 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