



CHARITY COMMISSION
FOR ENGLAND AND WALES

Cure Myotonic Dystrophy UK Charity (CDM)

1191217

Receipts and payments accounts

CC16a

For the period
from

06/04/2022

To

05/04/2023

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	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

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

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	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

P. Ashley
P. Ashley

E. J. ASHLEY
P. ASHLEY

6-10-23
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

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, AWMSC 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 PEOC 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 adaptations.
- 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 Trustees 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.

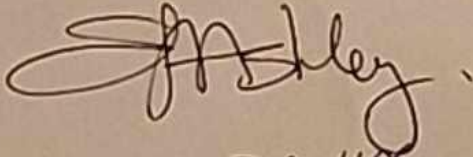
In doing so the Trustees are required to:

- 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-JAINE ASHLEY
Name and date: 06.10.2023



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



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

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 mums / 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.

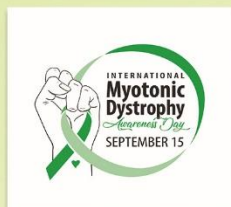
We have been involved in producing a number of abstracts and posters that have been presented at conferences by CureDM, TREAT-NMD, and the UK DM Patient Registry (which we also part-fund) to explain to clinicians and researchers the real-world experiences of the people that actually live with Myotonic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

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



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:

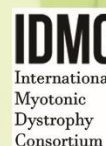
As well as the CureDM web site, this year we added Instagram to our continuous, strong online presence on social media, helping us to share any news and breakthroughs. Our private, UK only, Facebook group continued to grow. It is only for those living with DM, focusing on peer support and day to day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

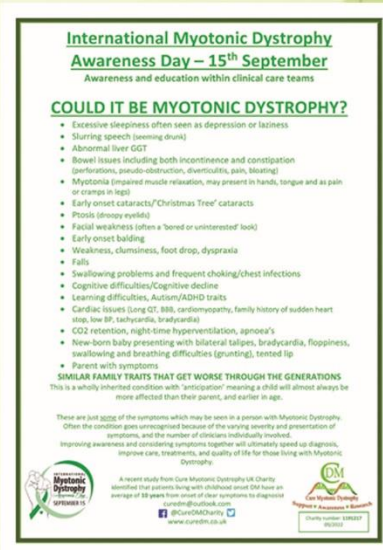
In 2022/2023 we attended online conferences based in the UK, across Europe, Japan and the USA. As with in-person conferences, these webinars allow the exchange of medical advances in the field of neuromuscular disease and create collaborations that raise the profile and accelerate awareness of Myotonic 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 clinicians and sent around the world. This can be downloaded from our website or please contact us for copies.



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!



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

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