

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:

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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 adaptations.
- 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	-
Gift 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
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	



CHARITY COMMISSION
FOR ENGLAND AND WALES

Independent examiner's report on the accounts

Section A

Independent Examiner's Report

Report to the trustees/
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

Responsibilities and
basis of report

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

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.