

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 adaptations.

- 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:

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 the Trustees to prepare 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 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
		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	