Please contact newsletter@cmmd.uk with comments or suggestions.

June 2018 – Issue 2

Cure DM CIC- Raising funds for Congenital Myotonic Dystrophy Fight Fund & Families in Action

www.cmmd.uk @CMMDFightFund @CureDMCIC
@FightFund www.congenitalmyotonicdystrophy.co.uk

Well, I can't believe it has been a whole year since we started this newsletter – so much has happened in that time, but it has flown by. We are now CURE DM CIC – a community interest company which can now not only fund research via the CMMD Fight Fund, but we can also offer support and advice, organize and provide meet ups and gatherings for the DM community, and we have a snazzy charity shop and awareness base in North Lincolnshire! I could talk about it much more, but we have a whole newsletter to fill, so please take a look on our facebook pages or websites for more details.
Enjoy!

Congenital Myotonic Dystrophy Fight Fund

Muscular Dystrophy UK
Fighting muscle-wasting conditions

We are over the moon to announce:

Congenital Myotonic Dystrophy Fight Fund Grand Total is whopping

£91,904

(June 2018)

Thank you for supporting the Congenital Myotonic Dystrophy Fight Fund to raise awareness and funds for research.
Together we can beat CMMD!
www.cmmd.uk

Congenital Myotonic Dystrophy Fight Fund is a family fund associated with Muscular Dystrophy UK

All money raised by the family fund is ring-fenced according to their specification, the Fight Fund are dedicated to raising money for research and providing family support

How could you support us to support you?

- Tell people about us!
- Come to our events or join in with our campaigns.
- We can only run with the support of the community so donations and fundraising is vital to our success.
- Fundraise for us, and with us!
- Recommend us for corporate sponsorship or charitable grants.
- Visit our shop (in Brigg, North Lincolnshire and online)
- Donate to our shop – we accept clothes/toys/Books etc…

BREAKING NEWS!!!!

We are delighted to announce that the **Congenital Myotonic Dystrophy Fight Fund** has FULLY FUNDED its first research project – with Prof David Brook in Nottingham.

- The project will develop two new state-of-the-art techniques to study what is happening to the faulty genetic material in the cells. This will include a high-powered microscopy technique and a sophisticated sequencing technique to measure the amounts of faulty material in cells and tissues.
- Prof Brook's team has already created a few hundred possible treatments and tested them in cell culture to create a list of those with most potential. This project will check the best ones on the shortlist to see if any holds hope of treating Congenital Myotonic Dystrophy.
- For more on the project, visit http://www.musculardystrophyuk.org/grants/developing-tools-to-identify-effective-treatments-for-myotonic-dystrophy/

We couldn't have done this without the amazing support from you all. Thank you so much for making this happen. We are already on the way to building our pot for the next one…..!

Congenital Myotonic Dystrophy Fight Fund
CDM
Cure DM CIC
Funding Research ♥ Supporting Families ♥ Raising Awareness
CMD FAMILIES IN ACTION UK
www.congenitalmyotonicdystrophy.co.uk
@CMMDFIGHTFUND
@FIGHTFUND
www.cmmd.uk

2019 date: Saturday 20th July

Our new shop and awareness base!

In March this year we officially opened our doors to the Cure DM Awareness base in Brigg, North Lincolnshire. We planned it, set up the marquee, had yummy cakes made for us….and then the 'Beast from the East' showed up and snowed all over us. BUT, we didn't let it stop us, our saying was 'Myotonic Dystrophy doesn't stop for snow and neither will we'. We had a great day. We had a cheque presentation from Brigg Town Partnership, and were joined by Karl, Jemma, Michael and Ollie from Olly's Fund. (Karl is one of the Cure DM directors and runs Olly's fund as a family fund with MDUK to raise money for the Duchenne Breakthrough Fund)

The shop is not just another charity shop – we have a plethora of Myotonic Dystrophy related information, and also hold lots of information on other neuromuscular diseases and forms of MD. We are supported by MDUK and have plenty of leaflets, alert cards etc. This is all available for you to take away with you. Feel free to pop in for a chat and a brew. If we can't help you we can direct you to someone who can!

Please contact newsletter@cmmd.uk with comments or suggestions.

In our last newsletter we spoke about the AMO-02 drug trial for Adults with Congenital and Juvenile onset Myotonic Dystrophy. This stage trial has now completed with **POSITIVE RESULTS.**

-Patients showed significant improvements in cognitive function, levels of fatigue and ability to perform daily tasks

- Treatment shown to be safe and well tolerated

"These significant data are an important step in the development of AMO-02 as a potentially safe and effective treatment option for many patients living with congenital and childhood onset myotonic dystrophy type 1," **said Michael Snape, MD, chief executive officer of AMO Pharma.** "We look forward to advancing the clinical development program for AMO-02 and are grateful to the clinicians, caregivers and patients who participated in this landmark trial."

We are looking forward to the next stage – which is set to begin in Newcastle, USA and Canada for children between the ages of 6-16 very soon. We are very excited for the future of this trial and will be updating our website as more info is received.

SAVE THE DATE: 14th JULY 2018

Our 2nd International Myotonic Dystrophy Awareness day!

We are having a group meet up at Butlins in Skegness to celebrate International Myotonic Dystrophy Awareness Day! If you would like to join us in our DM Families gathering, please contact us for more details.

Cure DM CIC will be gifting day tickets ordered in advance, and also if you come for the weekend we will be able to help with a donation towards your stay.

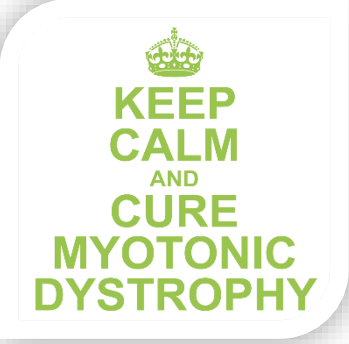
On the day, please change your profile pic on FB/Twitter and ask all your friends and family to do the same.

For more details on how you can get involved, keep an eye on our Facebook page and website.

Mud Run for Muscles!

Rachael Davey wanted to do something to support Cure DM. She has known 18 year old Dregan since he was in infant school, and has been a great friend to the family throughout the years, and through diagnosis of Congenital Myotonic Dystrophy. Not to do things by half - she decided not only would she do a 10k run for muscles, but she would do it through MUD and over showjumping obstacles. Somehow, she also managed to persuade Dregans step-dad Pete to join in, and they raised an amazing £265….and got very muddy!

If you would like to do a fundraising activity for us, let us know and we can support you with a fundraising pack.



Ongoing Fundraising Campaigns:

Bonus Ball Lotto - Join in to be in with the chance of taking home a cash prize every month! (Facebook @CureDMCIC)

Easyfundraising - Earn donations for us EVERY time you shop online - simple and FREE!
Easyfundraising.org.uk/causes/CureDMCIC

Easyfundraising.org.uk/causes/cmmdfightfund

Donate to Cure DM for free with Paypal for Charity - 100% is received - NO FEES!
paypal.com/uk/fundraiser/charity/2328314

Justgiving - Fundraise for research for The Fight Fund, or simply donate on our dedicated page:
Justgiving.com/campaigns/charity/muscular-dystrophy/cmmd-fight-fund

Awareness day Collage by Liam Murray.

In the Spotlight

IDMC-11

In September, Pete and Emma went to the International Myotonic Dystrophy Consortium in San Francisco. It was a worldwide scientific gathering where all the Myotonic Dystrophy research is presented over a week, by the leading scientists and researchers. It was an amazing event and it really hammered home how much the worldwide community is working together to understand this condition. One of the highlights for us was the French Registry which showed that Congenital Myotonic Dystrophy inherited from the father isn't as rare as our clinicians still believe. It showed a 13% inheritance rate. This is more in keeping with our experience and as it is something we feel very strongly about we were overjoyed to see it recognised. We were very pleased to meet the Japanese Myotonic Dystrophy Support group while we were there, and hope to keep in touch. We are big believers in working together and supporting each other. Miles of course came with us and was a big hit too!