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

June 2017 – Issue 1 – Welcome to the Fight!

Congenital Myotonic Dystrophy Fight Fund & Families in Action

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

Welcome to our first newsletter. We will be using this opportunity every 6 months to keep you up to date with what we've been up to, what we have planned, and what is going on in the world of CDM.

Let us introduce ourselves. We are The Congenital Myotonic Dystrophy Fight Fund, and Families in Action Group. Joined together to raise awareness of this complex condition. We raise funds for research which will hopefully lead to treatments and one day a cure for our loved ones. The Families group aims to bring people together for fun days, providing family support and a safe community in which we can talk freely about anything and everything. Thank you for being involved, we hope you enjoy our updates and would love to hear from you!

Emma-Jayne, Sarah, Kathy, Linda and Sian
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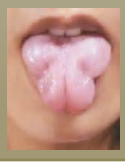
What is Myotonia in Myotonic Dystrophy?

Imagine shaking hands and not being able to let go. This is one of the examples given in Myotonia. The muscles seize up and can not release, often taking a few seconds to minutes. Mostly seen in the hand, but also happens inside the legs (often causing pain at night when trying to relax for sleep), feet, face, throat and interestingly, the tongue. This is mostly an adult onset symptom, children will start to show Myotonia as the condition progresses. There are medications which can help ease the symptoms, such as Carbamazepine, Mexilitine, Baclofen and Lamotrigine. **Speak to your Neurologist.**

Fun Fact - An easy way to diagnose Myotonic Dystrophy is by gently tapping the tongue.
Many professionals still don't know this, and many patients don't realise it happens to them!

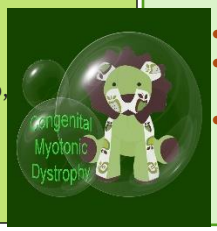


SAVE THE DATE: 30th JULY 2017

Our 1st ever International Myotonic Dystrophy Awareness day!

Families certainly are In Action, and we would love you to help us in this campaign. The date has been set to coincide with a FIA meetup in Birmingham. Please change your profile pic on FB/Twitter and ask all your friends and family to do the same. The main aim of this campaign is to spread awareness. If we can encourage fundraising activities for The Fight Fund on that day too, it would be an added bonus! Look here for more details on how you can get involved:

facebook.com/events/227107824471097



We are often asked "How can we help?" There are so many ways you could join in, here are a few ideas…

- Spread the Word.
- Donate/Regular Giving
- Come to our events or join in with our campaigns.
- Buy our stuff!
- Fundraise for us, and pull friends and family in.
- Recommend us for corporate sponsorship or charitable grants.

A selection of upcoming Events

July 15 - Black Tie Charity Fun Casino Dinner and Dance. Blackpool Hilton.

October 7 - Charity Fashion Show evening. Park Club, Cleveleys.

October 28 - Casino Royale Charity Ball. **Holiday Inn**, Segensworth.

We have many more events planned throughout the year - please check our website or Facebook pages for more details.

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

Briony has just completed the TIDEGLUSIB drug trial in Newcastle (info below). She was very brave, and quite misses going to see the team now. It was an enjoyable experience for Briony, and on one week she got to spend an evening with Dregan (below). The beginning of a budding friendship! This trial is open to people with Congenital/Childhood onset DM, where symptoms were present before the age of 12, with or without diagnosis.

Why do we need to support clinical trials if we can?

This is a very important trial and they still need a handful of people to sign up. Only once this stage is finished can the next one can begin. The **ONLY** people who can test these medications are the people who meet the strict criteria, and that means us and our loved ones. Without the support and commitment from the Myotonic Dystrophy community, potential medication may never be available. We need to speed this up as much as possible so it can help **THIS** generation. **PLEASE** spread the word and if you can take part. Not everyone is eligible, but if you feel you could help, please contact:

Nikoletta.nikolenko@newcastle.ac.uk

Thank you to Briony and everyone involved.

Do you have Myotonic Dystrophy Type 1?

Do you want to make a difference?

By Signing up to the UK Patient Registry you can do just that

The registry can direct you to clinical trials and research results (such as new treatments) that might be of specific interest to you. In addition, by registering you are helping researchers obtain precise data about the prevalence of Myotonic Dystrophy, which could be of benefit to all affected patients

www.dm-registry.org/uk

TREAT-NMD Neuromuscular Network

To help advance the research and development of treatment, therapies and care for all those diagnosed with myotonic dystrophy.

Upcoming conferences, come and say hello if you see us there, we don't bite!

MDSG Info day, Nottingham, June 24th.

MDF/IDMC Conference, San Fransisco, USA, Sept 7-9 (We have been invited to have a Fight Fund stand and Emma and Pete will be there, we are looking forward to meeting our USA family!)

MDUK AGM and Annual Conference, Birmingham - Oct 7th

In the Spotlight

Peter and Loretta run London Marathon!

On April 23rd, thousands of people ran London Marathon for Charity, and we had the wonderful Peter and Loretta, who ran for us! Peter had been struggling with injuries for the months leading up to the race, but his determination to 'use his muscles for those who can't' was unwavering. They both ran, and earned their medals!

(And ended up on crutches!)

To date they have raised an astounding **£1342** for our Charity.

Justgiving.com/fundraising/Peter-English2

Thank you so much for your support!

If you would like to join our team in 2018, or know someone who is interested, please email: emma@cmmd.uk

Ongoing Fundraising Campaigns:

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

Hug a Tree - In memory of her sister Chantelle, Alisha has started this lovely campaign to spread love and awareness.
Justgiving.com/fundraising/Hug-A-Tree-For-CMMD

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

Justgiving - Fundraise on our behalf, or simply donate on our dedicated page:
Justgiving.com/campaigns/charity/muscular-dystrophy/cmmd-fight-fund

Regular Giving - you can set up a regular gift donation to support the Fund here:
www2.muscular-dystrophy.org/donation/congenital-myotonic-dystrophy-fight-fund-dd-form

In the Spotlight

What's Josh been up to?

Dr Johnson (pictured) is leading the TREAT_CDM research in Utah, USA. Josh is now in his 4th year of taking part in the research, which is following and documenting to progression of CDM, to find valid endpoint markers which can be used for future clinical trials. This is vital research which will provide insight into the condition, so when a drug is identified, we will be able to see if it successfully changes its expected course of over time.

Josh has just returned from Utah in May, and is set to go again in 6 months' time, for repeat observations. You can read more on this ongoing Natural History Study, by visiting the following page:
https://clinicaltrials.gov/ct2/show/NCT03059264

Thank you to Sarah and Josh for the dedication you are showing in supporting this research.

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