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

---

**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 cannot 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!

---

**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.

---

**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

---

CMMD Fight Fund is a Family Fund with Muscular Dystrophy UK
Registered Charity No. 205395 Scottish Registered Charity No. SC039445
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 beginni

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.

We Need You!

**Tideguslib Drug Trial**

- **Phase I** - Assess the safety of the drug in healthy individuals
- **Phase II** - Assess the safety of the drug in individuals with DM Type 1
- **Phase III** - Trial of the drug in more people (younger, older, less able) with DM Type 1

![Tideguslib Drug Trial](Image)

If you are in the U.K. and between 18 and 45 years old and experienced symptoms (with or without diagnosis) before the age of 12, you may be able to be involved in this trial. The trial is being held in Newcastle and you will be required to travel every 2 weeks for 10 weeks but all expenses are paid.

More information is here www.ana-pharma.com and clinicaltrials.gov
Or contact Dr. Nikoletta Nikolenko on 0191 222 8168 or email:
Nikoletta.nikolenko@newcastle.ac.uk

This is the first and only clinical trial involving a company and a new drug to take place in Europe for DM Type 1.

**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

Upcoming conferences, come and say hello if you see us there, we don’t bite!
MDUk AGM and Annual Conference, Birmingham - Oct 7th
MDG Info day, Nottingham, June 24th.
MDF/IDMC Conference, San Francisco, 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!)

Ongoing Fundraising Campaigns:

- **Bonus Ball Lottery** - 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

CMMD Fight Fund is a Family Fund with Muscular Dystrophy UK
Registered Charity No. 205395 Scottish Registered Charity No. SC039445

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.