CGD Society August news

Dear CGD Society member,

Welcome to our August news updates. We would like to send a warm welcome to our new members who have recently joined us. As always, if you have any news you would like us to include in future newsletters, please do contact Claire or Niamh at hello@cgdsociety.org

Latest news

A new research study to see if restoring the bacteria in the gut can help with colitis in CGD

Chronic granulomatous disease (CGD) can be associated with inflammation in the gut (colitis) and studies show that changes in your gut bacteria (microbiome) may contribute to this. Many people with CGD colitis take steroids and other medications to help. However, long term use of these medications can cause side effects or do not completely cure these issues. Dr. Suchitra Hourigan at the National Institute of Allergy and Infectious Diseases (NIAID) in the National Institutes of Health (NIH) is looking for new ways to treat CGD colitis. Her team is testing fecal microbiota transplantation or FMT (placing good bacteria from donor stool into the intestine of a person with CGD) to restore the microbiome and treat CGD colitis. This research is the first study looking at FMT to see if restoring the gut microbiome reduces symptoms of colitis in patients with CGD. FMT is often used to treat a bacterial infection called *Clostridioides difficile (C. diff)*. FMT has also been studied with other types of colitis not related to CGD, such as Crohn's disease and ulcerative colitis. FMT may lead to less inflammation and may therefore be a novel treatment for CGD patients.

For more information please click here.

Suchitra Hourigan, MD
Chief, Clinical Microbiome Unit
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Suchitra Hourigan, M.D. | NIH: National Institute of Allergy and Infectious Diseases

Psychology service

Some of you may recall that we are part funding an Immunology Psychology Service at University Hospitals Birmingham NHS Foundation Trust. This service is being provided from the Heartlands Hospital site on Tuesdays and Wednesdays by Dr Nicola Wilson (Clinical Psychologist) from Birmingham and Solihull Mental Health Foundation Trust and will be provided for three years.

It is intended to provide specialist psychological support and therapy for patients living with immunodeficiency and hereditary angioedema, and to support the wider Immunology Team in their ongoing delivery of psychologically informed care.

You can read the first year's report on this new service here.

Online community BMT (Bone Marrow Transplant) chat

We were due to hold the next virtual get together on the 21st of June with the topic being BMT (bone marrow transplant) but due to staff sickness we had to cancel the event. I am pleased to announce that we have a new date to hold this online event which is Thursday 15th September 7pm – 8pm BST. This is open to anyone who is considering this treatment option, who is in line for a BMT or anyone who has been, or had a child, go through this process. If you would like to join us, please email Claire at hello@cgdsociety.org

Freddy's wishes and memories

As a charity supporting those affected by CGD, it is important that we share stories of families and individuals to help raise awareness and to provide support, even if those stories are distressing. Please do remember that each person's journey with CGD is different and no two cases are the same.

Kirsty has set up a JustGiving page to give her child, little Freddy, the chance to have his dreams come true. Freddy is facing many challenges now with his battle with CGD and Kirsty and the family have been told by doctors to make this year a time for making memories as they are unsure how much longer Freddy's kidneys will be able to function.

This is such a tough time for all the family so if you could help Freddy live his dreams then please do donate here. Our charity will be donating money raised from our Family Support Fund. If anyone can help Freddy meet Captain America, then please let us know! Now that put a smile on Freddy's face!

Our wonderful supporters

The CGD community has been busy supporting us recently, doing so in a variety of ways!

What have our supporters been getting up to?

First off, Ian and his friends at his local Vintage Sports Car Club celebrated their annual barbeque in July where they raised an amazing £725 for our charity. Ian, along with VSCC member, David, and his two sons with CGD, raised the money in style surrounded by their special vintage cars.

Meanwhile Nev took on the massive 25km Peak District Challenge in July, bringing awareness of CGD. Nev, had a BMT for CGD back in 2007 but sadly Nev's sister passed away in 2000 due to complications from a series of issues. Nev completely smashed his fundraising target of £500, raising £1,318 for our charity!

We are so grateful to our supporters for coming together and taking on impressive feats to spread awareness and help our charity support the CGD community.

Upcoming supporter events

Chris is preparing to complete Ride Across Britain in September, where he will cycle 980 miles in 10 days, from Land's End at the tip of Cornwall to John O'Groats at the top of Scotland – wow! He is taking on this "mega challenge" in memory of his cousin, Daniel, who sadly passed away last year and whose family has been supported by the CGD Society for many years. You can help him reach his fundraising target here.

We will be in the London Marathon this year! Kate is taking on this iconic marathon at the beginning of October in support of her friend's son, Albie, who has CGD and their family's amazing strength and courage. If you would like to support Kate's fundraiser, you can donate here.

We wish Chris and Kate the best of luck in their final weeks of preparation, and will be rooting for them as they complete their challenges and raise vital funds.

How can you get involved?

The rare disease community is coming together for the Butterfly Run, on Sunday 25th September at the Olympic Park in London. Created by Cure EB, the Butterfly Run is a celebration of inclusivity, with races and entertainment for everyone including face painting, balloon modelling and much more. People of all abilities will unite to run, walk, wheel, or whatever you can do to complete a 1k, 5k or 10k race, supporting your rare disease charity of choice. Signing up is only £5-£20 depending on age and distance, and it is free for adults running alongside their child to support them. If you are interested in taking part for the CGD Society, you can find out more and sign up here, and let us know so we can support you along the way!

Help us to help you

There are many ways that you can get involved in supporting the work we do for the CGD community. From volunteering your time to shopping online, every little bit of support from you will help our small charity in continuing the support and information we provide to so many.

Online shopping

Are you an avid online shopper? Find out how you can raise money for us as you shop, at no extra cost to you, through Amazon and 4,000 other shopping sites here.

Facebook Birthday Fundraisers

Is your birthday coming up? Are you looking for a straightforward way to give back and feel good for your birthday?

You can use your birthday to support the CGD community by creating a Facebook Birthday Fundraiser! It is simple, free and our charity receives 100% of the donations. Just go on Facebook to 'Community Settings', 'Fundraisers' and search for CGD Society as your chosen charity.

Our charity lottery

Join our charity lottery through One Lottery for the chance to win up to £25,000 each week! If you sign up before Saturday 27th August, you also join the chance of winning free fruit and veg home delivery for a year. You can find out more and sign up here.

Support that keeps on giving

Would you like to give continued support to the CGD community? We really value any donation we receive, but regular monthly donations go the extra mile for continuing to help those with CGD. Find out how to make singular or monthly donations for our CGD community.

Thank you for taking the time to read our latest news update. Wishing you all good health.

Best wishes,

Claire, Niamh, Helen and trustees

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