CGDSociety
Supporting families affected by chronic granulomatous disorder

# February e-news

Welcome to this February edition of the CGD Society e-news and a warm hello to all our new members!

## Latest news

### The UK Rare Disease Framework

The UK government and the 3 devolved administrations have published the first UK strategy for rare diseases. The UK Rare Disease framework aims to ensure that the lives of people with rare diseases continues to improve.

This is a really important step to improving the lives for those with a rare disease and is welcomed by all at the CGD Society.

Read more here

### Charity-funded research at risk

The outbreak of COVID has had a devastating impact on medical research charities. The pandemic has disrupted clinical trials, put an end to mass fundraising events, closed charity shops and has forced charities to cut funding for research.

The Association of Medical Research Charities (AMRC) and it's 153 members (of which CGD Society is one) are campaigning for the Government to step in and provide vital financial support.

For more information and how you can get involved to show your support, click here

### CGD Association of America X-linked carrier survey : calling all our US members!

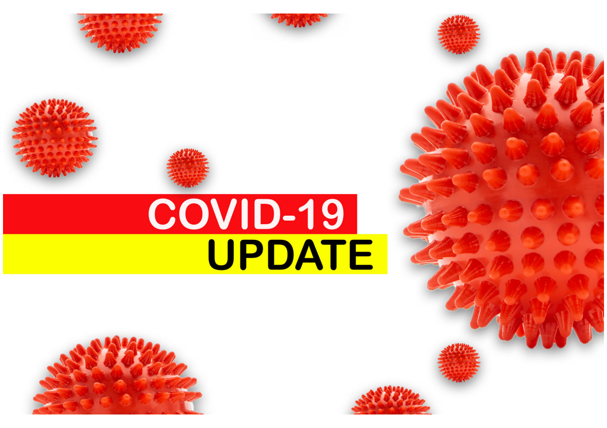
Through collaboration with the Primary Immune Deficiency Treatment Consortium, the CGD Association of America has developed a survey for X-linked female CGD carriers.

Dr. Jennifer Leiding is the Primary Investigator (PI) of the study, and the survey has been approved through the University of South Florida Institutional Review Board (IRB #001208). Through this survey, they aim to determine the medical problems and access to health care that these girls and women face.

The survey takes about 30 minutes to complete, and it can be paused as well as returned to for completion. **THIS SURVEY IS OPEN TO OUR USA MEMBERS ONLY SO PLEASE DO TAKE PART.**

Click here to take part

### COVID updates for the CGD Community



**A large-scale trial of nebulised interferon beta has started**. Early findings suggested the treatment may reduce the chance of a COVID-19 patient in hospital developing severe disease - such as requiring ventilation - by almost 80%. Read more here.

**Two drugs called tocilizumab and sarilumab prove effective in reducing death rate from COVID**. The drugs are anti-inflammatory and can cut deaths by a quarter in patients who are sickest with COVID. As well as saving more lives, the treatments speed up patients' recovery and reduce the length of time that critically-ill patients need to spend in intensive care by about a week. Read more here.

**A third COVID vaccine has been approved.** The Moderna vaccine, made by the US company Moderna, is a messenger RNA vaccine like the Pfizer one, which is already being offered on the NHS.

The UK has ordered an extra 10 million doses of this vaccine, but supplies are not expected to arrive until spring. It requires temperatures of around -20C for shipping - similar to that of a normal freezer. Read more here.

**Public Health England (PHE) study shows that past COVID-19 infection provides some immunity but people may still carry and transmit virus.** Between 18 June and 24 November, scientists detected 44 potential reinfections (2 'probable' and 42 'possible' reinfections) out of 6,614 participants who had tested positive for antibodies. This represents an 83% rate of protection from reinfection. The protection against reinfection lasts for about 5 months. BUT early evidence from the next stage of the study suggests that some of these individuals carry high levels of virus and could continue to transmit the virus to others. It is therefore crucial that everyone continues to follow the rules and stays at home, even if they have previously had COVID-19, to prevent spreading the virus to others. Past COVID-19 infection provides some immunity but people may still carry and transmit virus - GOV.UK (www.gov.uk).

To keep up to date with the latest advice and support regarding COVID-19 please visit our website.

## Living with CGD - Your stories

We realise that sharing experiences and stories on life with CGD can have a positive impact on others. You can sometimes feel isolated and unsure if what you are feeling and going through is 'normal' for CGD. This is also true for x-linked carriers, parents and carers.

We would like to introduce you to Michael and his own amazing story. Michael has kindly shared his and his family's story and we'd like to thank him for this and wish him all the best on his BMT journey.

Click here to read all about Michael

Would you like to share your story with the community? We would especially like to hear from X-linked carriers. You do not need to use your name and how much you want to share with us is entirely up to you. Please email us or call us on 0800 987 8988. Thank you.

## Your fundraising

Run, Beth, run!

Good luck and a huge thank you goes to the lovely Beth who has taken on the daunting challenge of training herself to be able to run 10K (quite an achievement anyway but Beth has set herself the task to do it in just 4 weeks).

Beth sadly lost her mother to CGD when she was very young. We are really touched that Beth has decided to take on this challenge to raise money for CGD Society and can really appreciate the impact of losing her Mum has had on both Beth and her family. We are sure Beth's Mum would be very proud of her daughter – just like we are here.

She has set herself a target to raise £200 but has already reached an incredible £429. If you would like to support Beth by making a donation or sending a supportive message, please visit her Just Giving page

### Many drops make an ocean

We would like to send a big thank you to everyone who has donated, set up a Facebook Birthday button, donated while shopping online or shared and liked our social media pages so far this year. We truly understand the difficulties people are facing right now so we are really touched by the generosity shown to our cause. Like so many other charities, COVID-19 has devastated our fundraising and we are fighting hard to keep our services going.

Your support really does make the difference.

Every time you use something like Amazon Smile or Easyfundraising, it's another step towards us being able to continue to provide our programmes. When you sign up for regular giving, you enable us to plan for the year ahead, anticipating what services may be needed more and allocate funds accordingly. When you run, skip, hop, bike and gather family & friends to support your fundraising activities and sponsored events, we make huge strides towards our main goal – a cure for all with CGD.

Put simply, we couldn't do any of this without you.

We are passionate about our CGD community and want to ensure that we continue to be the leading source of information and support for individuals and families affected by CGD. If you'd like to get involved with us and support out work – please take a look at our website for some ideas or make a donation online.

Thank you for taking the time to read our latest e-news and if you would like to feature in future editions or could volunteer your time, then please email us or telephone: 0800 987 8988

Best wishes,

Claire, Adelle, Helen and Susan

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