

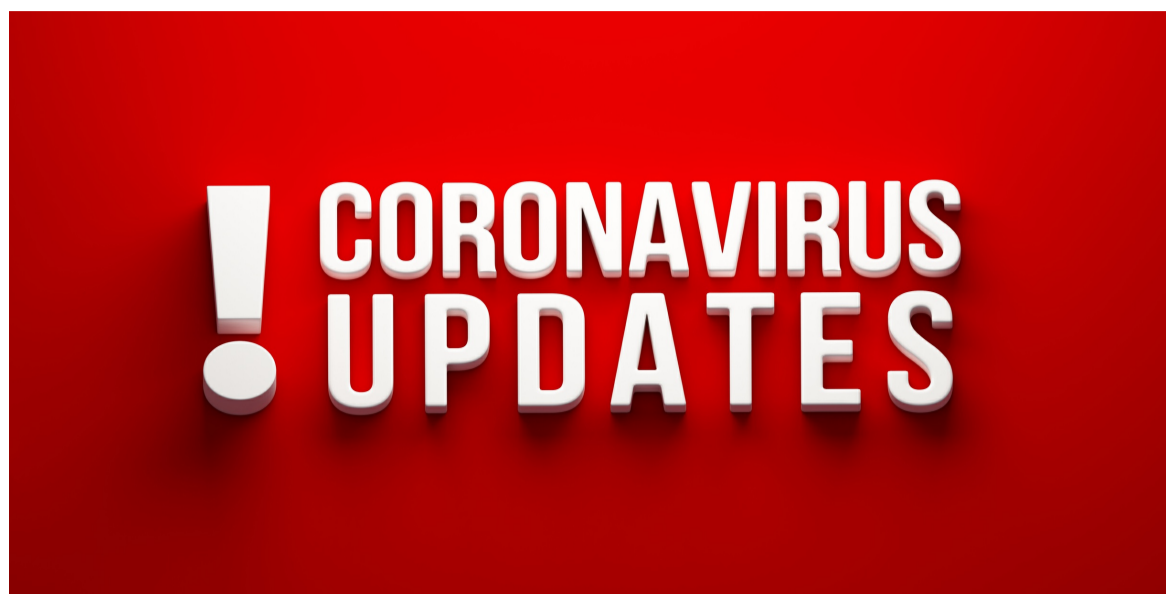
August e-news

Dear CGD Society member,

Welcome to this latest edition. We hope you are well and keeping safe.

Latest news

COVID-19 Update



The coronavirus vaccine (ChAdOx1 nCoV-19) being developed University of Oxford appears safe and triggers an immune response. The trials have involved 1,077 people and showed antibody and T-cells responses that can fight coronavirus. However, it is too soon to know if the vaccine offers a protection against COVID infection. [Read more here](#).

Monitoring ongoing health problems after COVID-19

NHS England is launching a new service for people with ongoing health problems after having coronavirus to help deal with the sometimes-longer term impact of having had COVID-19. "Your Covid Recovery" will be an online portal for people in England to access tutorials, contact healthcare workers and track their progress. The web portal will be launched later this month and will only be accessible via a personal log-in and will be available to virus patients who had to be treated in hospital, as well as to those who managed their illness at home. [Read more here](#).

Interferon beta treatment for COVID-19

The preliminary results of a clinical trial suggest that interferon beta reduces the number of COVID-19 patients needing intensive care. The new drug called Synairgen is a special formulation of interferon beta delivered directly to the airways via a nebuliser, which delivers the drug via an aerosol.

The trial, part of the ACCORD scheme of COVID trials, involved just over 100 participants with the drug showing a 79% reduction in disease severity. Although these are promising results the full data set has yet to be peer reviewed and published. [Read more here](#).

Fifi the llama and nanobodies

Scientists at the UK's Rosalind Franklin Institute have used the specially evolved antibodies from a llama called Fifi to make an immune-boosting therapy to fight COVID. The development has been [published in Nature Structural and Molecular Biology](#). The work involved "engineering" llama antibodies, which are smaller and more simply structured than the antibodies in human blood. That size and structure means they can be "redesigned" in the lab to form 'nanobodies' that can be used to neutralise COVID-19. [Read more here](#).

What a great name for a llama!

Wearing face coverings

As we move towards the compulsory wearing of face coverings in shops and other confined public spaces [this useful guide gives you all the do's and don'ts](#)

GP systems and COVID

COVID-19 test results are now being automatically sent to GP systems as well as being communicated to the individual, giving GPs visibility of which of their patients have had COVID-19 tests and whether they have tested positive or negative. [Read more here](#).

Frequently asked questions

Q. Do I have to wear a mask if I have breathing problems?

A. If you have a lung condition that makes you breathless **and find wearing a face covering makes you feel too breathless**, the governments in all nations have said you don't have to wear one, whatever the situation. We also know that many bus and train companies are offering their own exemption card which you can print and take with you or have said customers using their service will not need to prove they're exempt. For example:

- [Arriva exemption card](#)
- [First Bus/First Group exemption card](#)
- [Nexus journey assistance card](#)
- [Stagecoach face covering journey assistance card](#)
- [Transport for London exemption card](#)

Do get in touch with your transport provider in advance of your journey to discuss your options

Q. Is there any information on how to buy a mask that has been certified/approved to say it is of a good standard?

A. At present there isn't a standard, but the idea is that face coverings are there to protect others, not you, so the main thing is that they are washable to make them practical and economical and that they cover your mouth and nose. They can be made from tightly woven cotton fabric and T shirt material and you can find various patterns and instructions by searching on the web. [These are the Government's guidelines](#). Make sure you wash your hands before putting them on and taking them off. Cloth coverings should be washed often, and disposable masks disposed of responsibly.

Q. I've been advised to stop shielding my child. Is it safe?

A. This is the advice from Great Ormond Street Hospital: 'Very few children develop severe symptoms of COVID-19, even if they have an underlying health condition. The latest guidance from the Government suggests that most children and young people no longer need to shield, if they follow national guideline for social distancing and handwashing. There is a need to protect those who may be extremely vulnerable to the virus, but we also know that we need to protect children and young people from the negative impact of unnecessary shielding. If you have received a letter or text stating your child no longer needs to shield, you should feel comfortable taking this advice'.

Human X chromosome research



Researchers gain more insight into the human X chromosome through genome sequencing. The Nature paper study authors at the University of Carolina, Santa Cruz, chose to complete the X chromosome sequence, due to its link with a range of x-linked disorders including Chronic Granulomatous Disorder. [Read more here.](#)

Recent newsletter survey



We would once again like to thank those of you who took the time to complete the short survey we sent out regarding our monthly newsletters. We wanted your feedback to help us understand the value they provide, what content is important to you and to help us seek funding to be able to continue offering this vital support service.

We had an excellent response providing us with some really good feedback.

- We received 55 responses, 58% from the UK and 42% outside of the UK.
- Our newsletters were rated 4.12 out of 5 on how informative they are.
- Over 30% felt the newsletters supported them by providing the latest medical treatments and advances on CGD.
- Over 30% felt supported by reading shared stories and experiences from those living with CGD.
- The majority would like us to feature more real-life stories and to provide more advice and stories from X-linked carriers.

From your valuable feedback I am pleased to announce that Orchard Therapeutics have kindly agreed to sponsor the publication of our monthly newsletters for one year. Orchard Therapeutics are focused on treating rare, genetic disorders and have held a trial gene therapy drug for X-linked CGD.

We would like to thank the team at Orchard Therapeutics for agreeing to sponsor our newsletters and ensuring continued communication to our members and the wider CGD community.

Please do [get in contact by email](#) if you would like to share your story with the community.

How can you help?

We would once again like to thank those that have kindly donated, took part in fundraising or shared our social media posts to help us get through this difficult time. We still have a long way to go and we just could not do it without you, our supporters.

Here are a few ideas where you can help. Remember to keep reposting and sharing our social media to help raise awareness of CGD and the CGD Society.

Prudential MyRideLondon - Save the UK's Charities



"Life is like a bicycle, in order to keep your balance, you must move forward"

We really have seen a dramatic fall in our income so far this year because of the pandemic. With the cancellation of many fundraising events, including this year's Prudential Ride London, the Team at Virgin Money Giving have decided to hold a [MyRideLondon virtual event](#) taking place on the 15-16th August 2020 to help save UK's charities.

[All you need to do is to sign up](#). It's FREE, choose one of four challenges for all ages and abilities, which you can do on a route of your choice, wherever you are in the world. You can then set up your fundraising page for the CGD Society. You don't have to do this on a bicycle, so dig out your skateboards, roller skates, scooter or anything else you may have and get signed up! Thank you.

Jeans for Genes Day 14-20 September 2020



Our annual fundraising denim packed Jeans for Genes Day is fast approaching. From Monday the 14th to Sunday the 20th September we would love to see you taking part by signing up for your free fundraising pack, wearing your double denim, baking denim coloured cupcakes or getting your child's school or your work place involved. This can all be done virtually to reflect our changing times.

This year marks 25 years of Jeans for Genes Day so look out for various celebrations to mark the occasion. You can also celebrate by purchasing our limited addition Bugsy Bunny t-shirt. [Find out more.](#)

Thank you for taking the time to read this latest edition.

Wishing you all good health,

Claire and Adelle



Sponsored by a grant from Orchard Therapeutics



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If you do not wish to receive any further emails, [unsubscribe.](#)