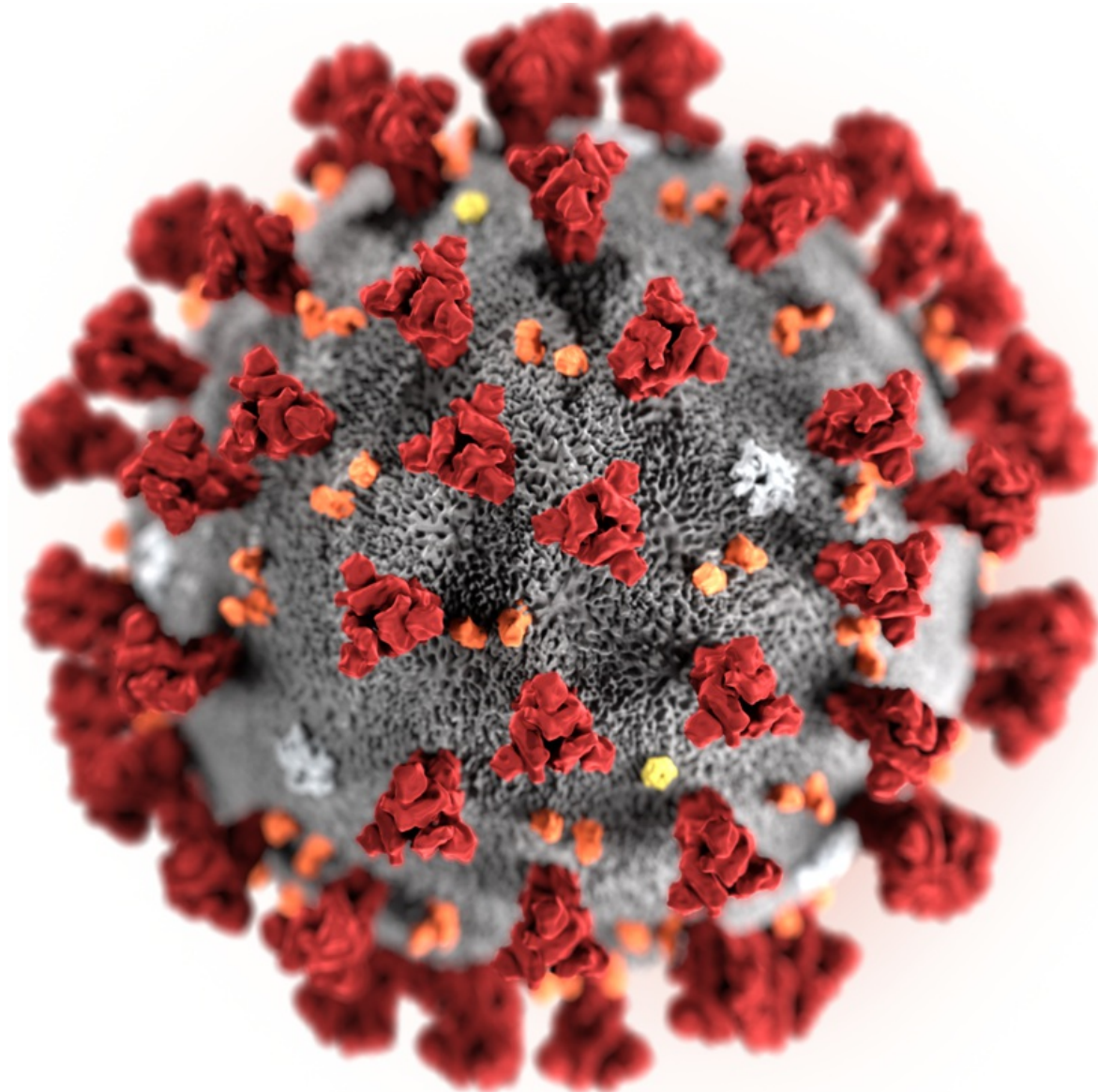


## June e-news

Dear CGD Society member,

Welcome to our June edition and a huge welcome to our new members who have recently joined us.

### Coronavirus latest advice



As we are all trying to live with the 'new normal' and get through this pandemic as best we can, we wanted to reassure you that we are still updating our website and social media platforms with the latest updates on the Coronavirus as and when we receive them. With the UK government easing the current lockdown and with the slight easing of lock down for those that are shielding you may have many questions and concerns. Please find the [latest guidance and advice here](#).

If you are a non UK member then it is important that you follow the current advice for your country and any advice given by your specialist.

It is not an easy time for many and some may decide that it is better for themselves and their family to remain shielding until the government reviews the current guidance. With this in mind, we have included some of [your isolation stories](#) that we hope are relatable. Thank you to the Tolentino family and the Stockwell family for sharing your stories. If you would like to share your isolation stories with us then please do [email us](#).

### Newsletter survey



I would like to thank everyone who took part in the newsletter survey. We received a really good response and you provided us with such great feedback about our current newsletters. Not only will this help us when putting together future editions, your feedback will also help us in trying to gain funding so that we are able to continue providing our monthly newsletters. If you have not completed the survey yet, then please do. It should take no longer than 5 minutes to complete. [The survey can be found here](#) and the closing date to complete this will be Tuesday the 16th June.

### Living with CGD



Following on from the feedback you provided by taking part in the survey it has become clear that many of you benefit from articles in our newsletters relating to relevant updates on the latest medical treatments and advances on CGD. It is also clear that many X-linked carriers would like to see information on any recent or future studies.

Research moves very slowly and no new treatments for CGD are emerging at this current time. Our Technical Director, Susan Walsh, regularly consults with our medical panel regarding any new studies that may be taking place. All the carrier studies that have taken place to date [can be found on our website](#). Here you will also find many other areas of resource relating to long term treatments, information for children and young people and many guides and resources. We will of course keep you updated with any new updates on treatments and advances as and when we receive them.

You have also given us feedback that reading individual life stories on living with CGD and being a X-linked carrier adds real benefit and helps you feel part of a community. We are starting to add 'Your Stories' as a feature on our website.



Here you can [read Aydin's story](#) as told by his mum Carly.

We know that such stories can really help with the feeling of isolation that is so often associated when living with a rare disorder and we are keen to hear from anyone that is willing to share their story. You do not have to give your name and we can protect the identity of anyone involved. We would also like to hear from our overseas members on life as a carrier or what it is like to live with CGD where you are. If you would like to take part then please do [email both myself and Adelle](#). Thank you.

## Fundraising



At the end of May, it was confirmed that due to the Coronavirus the 2020 Prudential RideLondon festival of cycling was cancelled. All participants and charities that brought places for 2020 will be refunded their entry fee in full.

## Emergency coronavirus appeal

It is with heartfelt thanks we report back that our Emergency Coronavirus Appeal raised over £4,500 during May & June.

When our traditional fundraising income avenues looked bleak in those first initial weeks, you came forward with your support and stood shoulder to shoulder with us - we could not have been prouder and more thankful to our CGD community.

We still have a long way to go and with fundraising avenues still uncertain, we still need your unwavering and continued support at this difficult time. [There is still time to donate](#). However big or small your donation, it will make a world of difference.

## Covid and fundraising events

Due to the current uncertainty around coronavirus and social distancing, all major fundraising events have been postponed. As soon as we receive updates and information on rearranged times, we will keep you in the loop.

The loss of these fundraising avenues has significantly impacted predicted income for our programmes. We will keep you abreast of all opportunities to help with fundraising for CGD over the course of the year.

In the meantime, you can support us when you shop online. Signing up to Easyfundraising is quick and easy to do and there is no extra cost to you. With over 300 retailers to choose from, every time you make a purchase a percentage will be donated to us. [Sign up here](#).

Thank you for taking the time to read our latest news update. Wishing you all good health and we hope you stay safe.

Best wishes,

**Claire and Adelle**



**Call us on: 0800 987 8988**

**Email us at: [hello@cgdsociety.org](mailto:hello@cgdsociety.org)**

**Write to us at: CGD Society, PO Box 454, Dartford, DA1 9PE**

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