

December newsletter 2020



Dear CGD Society member,

Welcome to our December newsletter – our last of the year. As we head into the festive season and as 2021 approaches, it is a great opportunity to reflect and update you all on how we have been supporting the CGD community this year.

It has been a difficult year for us all. Nobody could have predicted a global pandemic that would turn the world upside down. Many have sadly lost loved ones, with many becoming seriously ill. Lockdowns were announced, shops, schools, colleges, universities and workplaces were closed. Handwashing, social distancing, face masks, vaccines, shielding the vulnerable and the latest COVID figures have dominated this year. Holidays were cancelled, get togethers postponed. 'Furlough', 'lockdown' and 'tiers' became part of our language. Some lost jobs, some were furloughed, others worked from home and Zoom calls became the 'go to' to connect with friends and family. The world turned virtual. But although we did our best to stay connected, no one could have predicted how much we would crave and miss hugs as we do now.

Throughout all this there have been flashes of human emotional that have brought joy to our lives, tears to our eyes and truly captured the beauty of the human spirit. Captain Tom, clapping for key workers, fundraising for our NHS and other charities and the world working together to create a much-needed vaccine. Not to mention all the home workouts thanks to Joe Wicks!

For us here at the CGD Society, we were lucky. Coronavirus has meant an exceptionally busy year, with many people contacting us seeking advice about shielding, their employment and their health concerns. Despite being a tiny team, we were able to keep offering our services and programmes, keeping everyone updated on the situation. We created a [COVID-19 information page on our website](#) to ensure we provided the best and clearest information we could. We hope we have eased some of your anxieties about COVID and have been of support when it is most needed.

Let us hope for a brighter new year for us all. Let us give thanks for the camaraderie, support and friendship our community provides. We send our thoughts to those who may struggle during this festive season and we hope you all have a restful, safe, healthy and Happy Christmas and New Year.

Best wishes,

Claire, Adelle, Helen, Susan and Trustees.

Latest news



Emergency medical information sheet

We are all too aware of the difficulties CGD patients face when being admitted to hospital in an emergency situation. CGD is so rare many Doctors and other health professionals may not be aware of the condition, the importance of immediate treatment and who to contact for advice. With this in mind and from a kind donation made from GammaUK, we have produced an Emergency Medical Information Sheet to present to medical teams in such situations. We hope this will help to alleviate some of the anxiety felt in an already stressful situation for both patient and doctor.

To receive copies of the leaflet please email us at hello@cgdsociety.org or call us on 0800 987 8988 or alternatively [download from our website](#). This is also available to our members outside of the UK.

COVID-19 vaccinations

The latest information regarding vaccines for the Coronavirus is emerging and changing all the time. The UK are the first country in the world to start the vaccination process using the Pfizer/BioNtech COVID – 19 vaccine. The first person to be vaccinated took place on the 8th December.

We have updated our COVID-19 information page to include [FAQS regarding vaccines](#). You can also keep updated on the latest vaccine news on the [UK Government website](#).

Christmas and COVID

As you are all aware the restrictions set in the UK will be changing for a short time to allow people to meet with family and friends over the festive season. Between the 23 and 27 December you can form a 'Christmas bubble' composed of people from no more than 3 households. Find out [all the rules and how to keep safe](#).

NHS launches 'long Covid' clinics to tackle persistent symptoms

The NHS will launch a network of more than 40 'long COVID' specialist clinics within weeks to help thousands of patients suffering debilitating effects of the virus months after being infected. [Find out more](#).

The importance of ventilation and Covid

As we all spend more time at home having good ventilation is important in keeping the spread of COVID down in your household.

[Watch this informative video to find out more](#)

Our team



You may recall Adelle started working for us part time from April of this year to support myself as the new Operations and Fundraising Manager and to drive forward our fundraising and marketing. Starting her role at a time when we were in the middle of a global pandemic was not ideal but Adelle has done a fantastic job in the time she has been with us and her enthusiasm to our cause is infectious. Here, I have asked Adelle her thoughts:

How have you found working for a rare disease charity?

It's been really interesting, humbling and challenging – all at the same time! I had looked at the website for information before my interview and learnt a little. The on the job learning and insight from Claire therefore was vital to my understanding. It's one thing to read about a symptom – it's entirely another thing to experience it.

I've been bowled away by the family's stories and journeys, their resilience & determination and the vital support the CGD Society offers – it feels like a little community looking out for each other – something I haven't experienced in other organisations I've worked for.

What challenges have you come across so far?

Joining the organisation in a pandemic was the first challenge but it really helped me settle into the team quickly. Dealing with an unknown & unprecedented situation for a rare disease charity meant that that I had to learn – and quick!

The biggest challenge this year is undoubtedly fundraising in a financially insecure global pandemic. Donations have dropped by 46% which equates to losing a decade in charitable donations. Charities are looking at having to make cuts to their services – or not developing essential programmes - at a time when they have never been needed more.

What do you enjoy the most about working for the CGD Society?

When you work for a small charity, you really see and feel the impact of your work. From the enquiries from the helpline to the feedback about Helen, we know exactly what our services and support means.

This is also the fuel which spurs me on as there are many other different programmes – like the family conference – which we would love to run again (COVID permitting). This is the reason why we have been trailing new fundraising, like the Facebook Auction and the Christmas e-Cards, to make these happen going forward.

What accomplishments over the last few months are you most proud of?

Joining a lovely team and playing a part in its success. It sounds like a cliché but real teamwork – from Claire, to Helen, to Susan to the Trustees that makes it all work. I am grateful for the opportunity to play my part.

What have you learnt about CGD and the impact it has on people's lives?

From an organisational point of view, it does more than offer information and assistance – it becomes like a trusted family member – there to support, clarify, care and assist. There's a wealth of expertise and experience within the organisation that means our services offered are practical and clear but are delivered with compassion, understanding and empathy.

From my position behind the scenes, I am in awe of the frontline work done by Helen and Claire supporting the lives of many families across the UK and also working on many global enquiries that come in via our website.

Although small in size, CGD Society plays a very significant part in the families lives it supports and this gives me that inner glow of contentment and the determination to do more in my role so we can offer more, in the future.

Thank you, Adelle for sharing with us your insights and thoughts and thank you for working so hard over the last few months.

Your fundraising and donations

We would like to say a huge thank you to all those that have made donations, either through regular giving or one-off donations, held or took part in a fundraising challenge and to those who took part in Jeans for Genes Day this year. We have been overwhelmed by people's generosity and support in such difficult circumstances. THANK YOU SO MUCH.

At the start of the pandemic, we set up an Emergency funds appeal asking for donations to help us continue the support services we provide the CGD community in the UK and worldwide. We want to thank once again those who donated to this appeal. The amount raised so far is an incredible **£3,247**. To donate please visit [our JustGiving page](#).



We want to send special thanks to Alex Whitfield for taking on the 2.6 virtual challenge back in April. Alex ran lengths of his garden for 2 hours and 36 minutes and raised an impressive **£2,545** for us. Well done again Alex, you did a fantastic job.



A special thank also goes out to Shona Munro. Shona completed a virtual 60k run in 30 days back in August and raised an amazing **£170** for us. Well done Shona, we know you did lots of training for this and your dedication and hard work is very much appreciated.

We would also like to thank everybody that took part in our virtual Halloween costume competition and our Facebook live auction. The auction was a huge success raising **£365**. Adelle did a sterling job sourcing some lovely items to auction off and it was a source of great online fun.

CGD Society virtual Christmas Cards



If you haven't sent cards yet but would like to send a special 'Christmas Goodwill Delivery' to family & friends – why not send one of our digital Christmas cards. Not only are they environmentally friendly but it is a unique way of sending seasons greetings in what has been a 'unique' year. You can choose from 6 designs and all monies raised will go to helping us support the CGD community.

Donate while you shop

There is still time for that last minute online Christmas shop and donate to us at the same time, free of charge! Shop via Amazon Smile or Easy fundraising and make a difference. Full details on how to sign up [can be found here](#).

Jeans for Genes Day



As you are aware our annual fundraiser Jeans for Genes Day is an event started by our charity, then known as CGD Research Trust. It was a simple but great idea, wear jeans for the day at work or school and donate to support children with a genetic disorder. That was 25 years ago and the event has grown and evolved over the years.

This year's event took place 14 – 20 September and you could choose a day to take part. Even though many had to go virtual we still received great support. From Zoom Jean wearing office meetings, people buying the limited Bugs Bunny T-shirt, blue cupcake making, shaving their hair off to children being able to wear Jeans for the day at school the total raised so far is a colossal **£380,000**. Thank you to everyone who took part and a big thank you to the team who have worked hard to make this year's campaign possible. Well done!

Our support this year



We have been working hard behind the scenes this year to ensure we are here for the CGD community at such a difficult time and it is with thanks to those who have made donations, fundraised or made a regular donation that this year we have been able to:

- Provided support through the COVID crisis creating and regularly updating a COVID-19 information page on the website
- Continue our telephone and email helpline, which has enabled us to offer support and guidance for COVID-19 and other concerns to 82 people, 28 of whom were from overseas
- Raised awareness and increased our social media following by posting regular news updates and information through all our social media channels
- Gained 120 new CGD Society members, 53 from the UK and 66 from outside of the UK
- Continue the provision of our Clinical Nurse Specialist, Helen Braggins for both paediatric and adult care
- Provide financial support to 8 UK families through our family support fund
- Provide Prepayment Prescription Certificates to 20 people in the UK
- Update our guides and resources for patients, carers and medical professionals
- Produced an Emergency medical information sheet for families and individuals
- Buy gifts and comforts for children who have had a long hospital stay
- Held a virtual information display table at the ESID 2020 conference
- We successfully secured a grant from Orchard Therapeutics for one year's publications of our monthly e Newsletters , to keep you updated with the latest news and the charity's activities
- Recruited Adelle our Marketing and Fundraising Officer to support Claire and drive forward our marketing and fundraising

Our vision is a cure for all with CGD and our mission is to continue to inform and support the CGD community.

We want to expand our support services to offer mental health support, hold family days, raise awareness and support x-linked carriers and to continue our reach to the wider community. With your continued support we aim to achieve this.

YOU are at the heart of everything we do. If you would like to get involved as a volunteer, have any fundraising ideas or would like to share your story, please contact us at hello@cgdsociety.org



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Sponsored by a grant from Orchard Therapeutics



Call us on: **0800 987 8988**

Email us at: **hello@cgdsociety.org**

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

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