

June e-news

Dear CGD Society member,

Welcome to CGD Society's latest e-News. We hope you have all been keeping well as we, hopefully, get back to some kind of normality.

Latest news

COVID-19



The UK government have announced the vaccine rollout is now available to ALL UK adults, with the over 18s recently added to the list. This is a major step forward in helping to protect those that are vulnerable and towards the final easing of current restrictions. To find out more visit [the NHS website for Covid-19 vaccinations](#).

Our CGD Clinical Nurse Specialist, Helen, informs us that the take up of the vaccine for those with CGD and X-linked carriers has been good so far, but it is important to emphasise that unless medically advised not to, the CGD community in the UK should have the vaccine.

Funding success



We are pleased to announce that our application to The Charities Aid Foundation (CAF) for their Patient Organisations Recovery Fund was successful and we have been awarded a grant of £17,893. This grant will go towards funding our CGD Clinical Nurse Specialist, Helen Braggins, for this year. As you may be aware, our nursing service is funded entirely by us through your donations and income from our annual fundraiser [Jeans for Genes Day](#).

This is a difficult time for many charities, including ourselves, and being awarded this grant is a tremendous help. That being said, we still have a long way to go to secure full funding for our nursing service, so every donation and fundraising event helps.

Meet our new volunteer



Let us introduce you to Annabel Griffiths. This month Annabel joins us at the CGD Society as a part-time volunteer until the end of July.

Ordinarily Annabel works for a healthcare consultancy called [Costello Medical](#), which provides scientific support to companies and organisations that are developing medical treatments. Annabel leads a team that specialises in rare diseases and is really looking forward to learning more about CGD.

During a sabbatical from her day job, Annabel will be working alongside Claire and Adelle to look into fundraising efforts for our 30th anniversary, as well as helping us better understand mental health needs in the CGD community.

The rest of her time is currently being spent keeping her new puppy Wilson out of trouble! Welcome to the team Annabel, we are enjoying working with you.

Your stories



As a charity we recognise that X-linked CGD female carriers have their own health and emotional needs. Therefore, we have a dedicated page on our website for carriers. Our CGD Clinical Nurse Specialist also provides advice and support. Our information for carriers [can be found here](#).

Please [read Carly Koncuk's carrier journey](#) and how this has had an impact on her families lives.

Thank you for sharing this with us Carly, it is so important to share experiences to help others. Please contact us if you would like to tell us your story at hello@cgdsociety.org

30 years



As you may be aware, this year marks our 30th year as a charity. This is a major milestone and we are really excited to celebrate it with you. To recognise how we have been supporting the CGD community over those 30 years, we have

been showcasing our achievements through our social media platforms and [our website](#). Please take a look and comment or share.

This year would also have been our Family Conference weekend but due to the pandemic we are sadly unable to hold this popular event. However, we are going to be hosting an online birthday Mingle and Bingo night in July. This is a great opportunity for us all to meet up again, to pour yourself a beverage of your choice and have a bit of fun playing a few games of bingo. We have some great prizes for you to win. If you would like to find out more, please email Claire at hello@cgdsociety.org We hope to see you there!

Your fundraising

So far this year we have been overwhelmed by people's generosity from donations and fundraising events. We are truly touched that you have wanted to support our work and please know that every donation and event helps us in continuing to provide support and advice to the CGD community both here in the UK and overseas.

Here are a few shoutouts to our fabulous fundraisers!

Best foot forward



A huge well done and thank you goes to Bonnie Burgess-Biggerstaff and family for raising over £11,000 so far! Bonnie, her sisters, Emily and Amy and mum Mary-Rose took on the challenge of 10,000 steps in May. They finished their challenge in style, posing with our CGD Society t-shirts.

Bonnie's two sons, Ben and Bobby were diagnosed with CGD in July 2020 when they were six and five years old, respectively. Thank you so much again and we wish both Ben and Bobby well on their CGD journey.

Making a splash



Our very own CGD Clinical Nurse Specialist, Helen Braggins, decided to take on a challenge – to swim 30K in June at her local swimming baths. We can proudly announce that Helen has now completed her challenge and raised over £1,000 so far. However, it seems Helen doesn't want to rest on just 30K, she has now decided to increase this to 50K by the end of June! Way to go Helen.

Show your support for Helen by visiting [her JustGiving page](#).

Feeling the burn

Skye Holmes contacted us as both her brother and sister have CGD, and she wanted to take on a challenge of 100 squats a day in June. Skye is hoping to raise awareness of CGD and help us raise funds to achieve our vision... A cure for all with CGD. Skye has just informed us that she is going to continue her challenge throughout July too! Wow, Skye must have legs of steel!

Skye is doing a great job so far and has raised £73, her target is £100. Let's see if we can [help Skye reach her target](#).

It's a save



Noah, who attends Willesborough Junior School, is doing a great job of being goalkeeper and facing 1,000 penalties. Noah's school friend Dimitrios received a bone marrow transplant (BMT) last year for CGD and because Dimitrios has been so brave, Noah wanted to do something for his friend.

The challenge started on the 19th of June with the final penalty taking place on the 26th of June. Half of the money raised will go to CGD Society with the other half going to the Willesborough Junior School Fundraisers. So far Noah has managed to raise over £1,000.

You are doing a sterling job Noah and I'm sure you would do a better job in a penalty shoot out than the England team!

Thank you for taking the time to read this latest edition of our e-News. Please do contact us if you require any information or support or if you would like to support us in some way.

Best wishes,

Claire, Adelle, Helen and trustees



Sponsored by a grant from Orchard Therapeutics



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