

April e-news

Dear CGD Society member,

Welcome to our latest e-news. We hope you are all keeping well as we head into the easing of lockdown here in the UK.

Latest news

Covid-19

Step one of the UK Government roadmap out of lockdown has begun. From 29 March, the 'stay at home' rule ends - and up to 6 people or 2 households can meet outside. Shielding also ends 31st March. To find the full details, including the easing of lockdown in Scotland, Wales and Northern Island then [click here to find out more](#).

Your wellbeing through the pandemic



We have all faced challenges over the past year and many of us will need time to adjust to the easing of lockdown, especially for those that have been shielding. It is important to be kind to yourself and take things at your own pace. The Samaritans have put together some resources to help with your mental health at this time - [click here to find out more](#).

Reflections on a pandemic year



We were delighted to learn Tuesday Gale was recently interviewed by Stylist magazine about the pandemic 12 months on. Tuesday has P47 autosomal recessive CGD and has been shielding for the majority of the last year.

[Read Tuesday's article](#).

Easter opening hours

The CGD Society will be closed Friday 2 – Monday 5 April inclusive. We will back to normal working hours Tuesday the 6 April.

Our CGD Clinical Nurse Specialist Helen Braggins will also be on leave Friday 2 – Monday 5 April inclusive and will return to normal working hours Tuesday 6 April.

If you require urgent support during the Easter holidays then please [visit our website](#) for more information.

Life with CGD



Some of you will know Simon Bostic. Simon has CGD and made history by becoming the first person in the world to have a Bone Marrow Transplant from an unrelated donor. That was 48 years ago. Simon's story was recently featured in the Daily Express newspaper. His story is powerful and reminds us of how remarkable and resilient Simon continues to be.

[Read Simon's story](#).

CGD Society 30th year

As some of you are aware, this year marks 30 years that CGD Society, formally known as CGD Research Trust, has been supporting the CGD community both in the UK and overseas. We continue to be the only charity in the UK providing support services and care to X-linked carriers, children and adults living with CGD and the wider family.

One of our most valued support services is our UK based CGD Clinical Nurse Specialist, Helen Braggins. Did you know that CGD Society fund our nursing service? This is only made possible from your donations and fundraising activities and the income generated by our annual fundraiser Jeans for Genes Day. Simply put, without donations we would not have a nursing service.



As part of our 30th celebrations we would like to highlight our nursing service and how this service has supported you and the difference it has made. From previous nurses to our specialist nurse today, Helen Braggins, if you have been supported in any way, we would love to hear from you whether you are in the UK or overseas.

We are looking for people to provide a small quote about how important our nursing service is and how it has helped you in the past. This will also help us going forward when trying to apply for funding so we can continue providing this vital support.

Your quote does not have to be too long. Here is an example from the lovely Griffiths family:

"Helen is a fantastic lady - so kind and caring she has helped us as a family so much. Without the help, care and support we have received from Helen, I don't think us, as a family, would have been able to get through half the stuff we have.

She is always happy to help with anything big or small and is always there when you need some advice, support or even a cry. She isn't just a nurse she is a friend and we absolutely love her"

Please [email us](#) with your quotes. These will feature in our 30th page on the website and our social media pages. We would also love a picture of yourselves or you family to go with your quote. All consent forms will be sent to you.

Calling all runners, walkers and joggers



We have some exciting news to announce.... As part of our 30th celebrations we have secured 5 places to take part in this year's virtual London Marathon!

Taking place Sunday 3 October 2021, the event is open to anyone that wishes to take part. Last years virtual event was a huge success and we would love for you to take part and raise much needed funds for us here at CGD Society. The great news is you do not have to run the whole 26.2 miles, you can jog or walk or mix it up with both. So if you or someone you know would love to be part of this big event and at the same time make a difference to the lives of people living with CGD then [more details can be found here](#).

Your fundraising

Rare Disease Day and homemade prizes



We want to send a huge thank you to the team at Costello Medical who held a virtual raffle in aid of Rare Disease Day and decided to donate the £410 they raised to us here at CGD Society. The team made the prizes themselves which was such a nice touch and our Operations and Fundraising Manager, Claire got to attend the virtual event and speak about the work of the charity and the support we provide.

We think the team did a great job in raising such a large amount and the prizes looked amazing. Thank you again to you all.

[Find out more about Costello Medical.](#)

Rosey's 100 hats

During lockdown Rosey Wilkins has been keeping herself occupied by doing lots of knitting. With her grandson Phileas due to be admitted to hospital for a Bone Marrow Transplant for CGD, Rosey decided to put her knitting skills to good use by setting a target of knitting 100 hats for preschool children to raise money for CGD Society. Rosey has given herself until the end of June to complete her knitting challenge.

I think you will agree from the above picture Rosey is doing a grand job and has already raised over £4,000 for us. Her target was to raise £1,000! This is just amazing.

Thank you Rosey for thinking of us and we wish Phileas and his family well in their BMT journey. You can [visit Rosey's Justgiving page here](#).

Thank you for taking the time to read our latest e-news and we wish you all a safe and enjoyable Easter break.

Best wishes,

Claire, Adelle, Susan and Helen.



Sponsored by a grant from Orchard Therapeutics



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