

CGD Society June news



Hello and welcome to the latest news from the CGD Society. As always, if you have any news you would like us to include in future newsletters, please do contact Claire or Niamh at Hello@cgdsociety.org

Latest news



A new member of the team



Let us introduce you to Niamh who joined us in May as our new Community Fundraising and Marketing Officer. Niamh will be working with Claire on developing a community fundraising strategy that will be engaging and fun to inspire people to fundraise and donate to our cause. Niamh will also be creating and producing marketing content for our social media and newsletters to increase awareness and to strengthen connections within the rare disease community and potential supporters. You can find out [more about Niamh here](#).

If you would like more information on fundraising, then please contact Niamh at events@cgdsociety.org. I know Niamh would love to hear from you!

Help shape a research study

If you are a parent or a carer of a child with CGD you can take part in an important research study.

Genetic Alliance UK is collaborating with researchers at Great Ormond Street Hospital and others, on a new research study evaluating rapid exome sequencing for critically ill children. Rapid exome sequencing is a rapid tool that will look for a genetic cause for a child's medical condition when a child is seriously ill. The research is needed to make sure that this new NHS service benefits patients, supports parents and can be accessed equally by everyone.

The survey for the study [can be found here](#).

Virtual get togethers



On the 24th May we held our first virtual get together. This was an opportunity to meet online and speak with Helen about any health concerns and a chance to see one another after such a long time. Thank you for those that attended, and we hope you found it beneficial. It was lovely to see some new and familiar faces.

We were due to hold the next virtual get together on the 21st of June with the topic being BMT (bone marrow transplant) but due to staff sickness we had to cancel the event. This was open to anyone who is considering this treatment option, who is in line for a BMT or anyone who has been, or had a child, go through this process. Please look out for an announcement for a new date to hold this event and we hope you can join us.

Going on holiday



For some going on holiday can be stressful enough with remembering your passport or if you have packed your toothbrush but it can be even more stressful when you must pack your medications or plan in case you become unwell on holiday. Please read our helpful guide for going on holiday which gives you tips on how to stay healthy and ways you can plan ahead. You can [access the guide here](#).

Our wonderful supporters



A huge well done to Emma Wormull who has been walking, running and jogging 100 miles in May. This was to mark the 5th anniversary of her son Mason's successful bone marrow transplant and Emma has managed to raise £210. Her target was £100 so Emma has done a wonderful job.

Well done Emma. Your fundraising will be making a positive difference to those affected by CGD.

Help us to help you



There are many ways that you can get involved in supporting the work we do for the CGD community. From volunteering your time to shopping online, every little bit of support from you will help our small charity in continuing the support and information we provide to so many.

Please [visit this page](#) on our website to find out how you can help. We are aware that things are difficult with the cost of living crisis so any support you can offer is genuinely appreciated.

If you would like to volunteer your time, then please contact Claire at hello@cgd-society.org It would be particularly helpful to know if you are willing to contact others who are seeking support especially if they are newly diagnosed. We are all aware how lonely living with CGD can be and how difficult it can be being an x-lined carrier.

Thank you for taking the time to read our latest news and we wish you all good health and that you enjoy the summer season.

Best wishes,

Claire, Niamh, Helen, and trustees



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Call us on: [0800 987 8988](tel:08009878988)

Email us at: hello@cgd-society.org

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

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