CGDSociety
Supporting families affected by chronic granulomatous disorder

October e-news

Dear CGD Society member,

Welcome to the latest news from the CGD society. We are now in autumn which means, pumpkins, darker nights and flu season. It is more important than ever to get your flu vaccine this year with the prevalence of COVID-19. In fact, in the UK, you can have your flu vaccine at the same time as your booster covid vaccine. We are advising all those in the UK who have received an invitation to have a booster jab to book an appointment and have it done. More information can be found here. If you are outside of the UK please consult with your medical team.

Latest news

Psychology service

It is with thanks from your donations, fundraising and support that we have part funded a three-year psychology service for PID patients (Primary Immunodeficiency Disorders, this includes CGD) at University Hospitals Birmingham, England.

The current service is for patients of the UHB immunology service only. The team will be looking to evaluate how psychology support can be made more widely available, since it is not going to be possible for every centre with CGD or other PID patients to have a dedicated clinical psychology service.

Dr Nicola Wilson, Clinical Psychologist (pictured), said *"We know that living with long term health conditions and conditions which affect the immune system can impact upon people's emotional wellbeing in many ways, so it is a wonderful opportunity to be able to offer a service to help patients with this aspect of living with their condition."*

The new service is intended to provide specialist psychological support and therapy for patients living with immunodeficiency and hereditary angioedema, and to support the wider Immunology Team in their ongoing delivery of psychologically informed care.

Dr Aarn Huissoon, Clinical Lead for Immunology and Allergy at the Trust, said: *"We're really pleased to finally have this service available for our patients. Nicola will be working closely with the team and colleagues around the country to ensure that our patients benefit as much as possible from her expertise. We're very grateful for generous sponsorship from a number of patient organisations that has helped to make this possible"*

We want to thank the team at Birmingham for all the hard work in establishing this new service and thank you to you, our supporters. Without your donations we could not have help fund a service that is much needed

Know your health records

For those in the UK it is now much easier to gain access to your GP health records. You will need to download the NHS App on your smartphone or tablet. The app allows you to do things such as get your NHS covid pass, book GP appointments and view your health record. You can securely access your GP health record to see information like your allergies and your current and past medicines. If your GP surgery has given you access to your detailed medical record, you can also see information like test results and details of your consultations. Please visit NHS App - NHS for more information.

We advise you to check your health records with your GP to make sure all medications and alerts on your CGD statues are up to date. This is especially true for x-linked carriers. If you have not made your GP aware of your carrier statues you could be missing out on treatment and care. We are aware that many GPs have little knowledge of CGD so it may be worth asking them to put our emergency medical information sheet in your records, so GPs and other medical teams have easy access to it. You can find this sheet here.

Raising awareness

We are delighted to be featured in Rare Revolutions Autumn online magazine. The theme for this edition is Future of Rare and we were given the opportunity to raise awareness of CGD, our charity and our CGD clinical nurse specialist, Helen Braggins. We wanted to highlight the support Helen provides, how she is funded and why it is so important we continue to fund this vital service. You can read our full article here on pages 59,60 and 61.

Your fundraising

We would like to say a huge well done and thank you to Nick Strong for running the London Marathon on the 3rd October and raising an impressive £2,974 for our charity. Nick was running in memory of his good friend Daniel Mills who sadly passed away recently after a long battle with CGD.

Nick ran the race in a time of 3 hours 35 and reported that the second half of the race was particularly difficult as his knee became very painful.

Well done Nick you did a great job in memory of Daniel who is loved and remembered by so many. Your contribution will help us in continuing the vital support we provide the CGD community in the UK and around the world.

Ways to support us and make a difference

Volunteering

As you may be aware, we are a very small charity with no central office and with limited staffing. We are currently in the process of reviewing our staffing levels and resources to ensure we are delivering the best support to those who need it.

Claire Jeffries, our Fundraising and Operations Manager is currently working alone in running the day-to-day activities for the charity. As such we are looking for volunteers to support Claire and the charity in delivering its objectives for the next few months. If you have a passion for wanting to make a difference to the lives of those affected by CGD and want to help our small charity in some way then please do visit our website here to find out how you can volunteer for us.

Become a trustee

TRUSTEES' WEEK

HAVE YOU EVER THOUGHT OF BECOMIING A TRUSTEE?

We have vacancies on the CGDS Board and would like to hear from anyone interested to join us.

Although we need people with particular skills or experience, if you additionally have a personal link to CGD as a carrier or as affected individual you can bring so much more to the board.

Full details on becoming a trustee and the skills and experience we are currently looking for can be found here. We will also be recruiting externally throughout November. Coincidentally, November 1st to 5th is Trustees Week so you should hear plenty more about the virtues of a trusteeship!

If you wish to apply or just want to talk about it, drop a line to recruitment@cgdsociety.org and I will follow it up.

With thanks,

Geoff Creamer, Chair

Fundraise and donations

Fundraising for any charity can seem a little daunting and you may not know where to start. You may think fundraising means organising a big event for which you do not have the time or experience. There are lots of ways you can fundraise and donate and in turn support those with CGD that doesn't take a lot of time. From online shopping, playing the lottery to holding a fundraising event there are many ways you can support us. To find out more visit our website here.

The other option is regular giving. Setting up a monthly donation however much you can afford, is a simple and effective way of giving. It could be as easy as donating the amount of your takeaway coffee 2 days a week. Every regular donation, however big or small, helps us in continuing to provide our vital support services. Find out how you can set up a regular donation here.

Thank you for taking the time to read this latest edition. We would love to hear from you so please do get in touch if you have any fundraising suggestions or would like to share your CGD story with us. Contact Claire at hello@cgdsociety.org

Best wishes,

Claire, Helen and trustees

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Sponsored by a grant from Orchard Therapeutics

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