CGD Society
Supporting families affected by chronic granulomatous disorder

September e-news

Dear CGD Society member,

Welcome to our latest e-news and a huge welcome to those who have recently joined as a member. We hope you have all been keeping well.

Latest news

Sepsis Awareness Day

September 13th marked sepsis awareness day. Sepsis happens when the body's immune system goes into overdrive in response to an infection. It is often referred to as septicaemia or blood poisoning.

Everybody is potentially at risk of developing sepsis from minor infections, such as a bacterial throat infection. However, people with CGD and other causes of a weakened immune system (e.g., no spleen or immune suppressant treatment) are more at risk.

If picked up early, it can be relatively easy to treat but if treatment is delayed it can progress to septic shock. We have a dedicated page on our website on what to look out for and what to do if sepsis is suspected.

Click here for more information.

Flu Immunisation

The flu is unpleasant for anyone but if you have CGD, it can lead to further problems.

People with the condition can fight the flu virus normally. But having flu may lead to nasty bacterial pneumonia and this can be more severe for people who have CGD.

Annual flu jabs are recommended for older people and those with medical conditions, including CGD and immune deficiencies. Carriers of X-CGD should also have the immunisation. Please see our dedicated page on the flu vaccine. Members from the UK can also visit the government website for up to date information on the flu vaccine for 2021-2022 click here.

Farewell and thank you

It is with much sadness that we announce Adelle Scott, our Marketing and Fundraising Officer and Trustee, Davina Grey have now left our charity. We would like to thank them both for their hard work and commitment given to our small charity and we wish them well in their future. They will be missed.

We are currently looking at our staffing levels and resources according to our budget. In the meantime, Claire, our Operations and Fundraising Manager is working on all aspects of the day to day running of the charity by herself, including the production of our newsletters so please be aware that it may take a little longer than usual to respond to your enquiries.

Volunteering opportunities

To support Claire and the services we provide while we address our staffing levels, there is an opportunity to volunteer for us. Currently we have two volunteering vacancies available. We would love to hear from you or someone you know who may be able to support us and in turn support our CGD community.

To find out more please visit here.

Please contact Claire at hello@cgdsociety.org

Welcome

We would like to send a warm welcome to Annabel Griffiths who has recently joined our charity as a trustee. Annabel provides a wealth of information and experience as head of Rare Diseases at Costello Medical and is a mentor for Claire.

Learn more about Annabel here.

We look forward to working with you Annabel!

Your stories and fundraising

Driving to victory

We would like to send our congratulations to Ellis Rogers on coming 1st and 3rd racing his stoxcart in Formula Stoxcart at Birmingham Wheels raceway on Saturday July 31st.

Ellis has CGD and follows in the footsteps of his late brother Josh who sadly passed away with CGD in 2018. Josh, as is Ellis, was a huge fan of stock car racing winning many races in his CGD Society covered car. Ellis now races in the same car.

Ellis and Josh's parents Lisa and Chris told us the following *"The photo of Ellis was taken at a racetrack called Birmingham Wheels raceway on Saturday July 31st. Ellis has only just restarted racing again this year due to the pandemic and our reluctance to let him partake until now. He started his racing in 2019 with a few meetings just to see if he actually liked doing it and to see if he wanted to follow in his brothers' footsteps.*

He races in a formula called stoxkarts which are custom built cars based around go kart chassis. At any one time he could be racing against 25-40 drivers on a 300-yard oval racing circuit. The racing is run to a highly professional standard with strict safety rules for the driver and for tracks to be raced at. He races mainly at Birmingham wheels which is our local track but racing takes place all over the country from Scotland right down to the south of England. Sadly, we don't have any tracks in Wales. I personally have watched stock car racing for over 40 years, and it's been brilliant as a family to watch firstly Josh and now Ellis partake in a sport which has given us so many great memories and allowed us to meet lots of wonderful people. Josh won his first ever race back in April 2015 at the same track Birmingham wheels, and now roll forward Ellis has won his first race in July 2021. The pride, joy, and shear emotion on both occasions was something I wish everybody could experience. When you see what CGD patients suffer with, and how they deal with their lives in silence it makes it all the more worthwhile."

Thank you, Lisa, Chris and Ellis, for sharing this meaningful achievement with us. Well done Ellis, I'm sure you will win many more trophies!

London Marathon 2021

We would like to say a huge thank you to Nick Strong who is taking part in this year's virtual London Marathon for us in memory of his friend Daniel who sadly lost his battle with CGD recently. Daniel and his family are well known to our charity and we are touched that Nick has decided to take on this challenge which takes place on the 3rd October.

Please visit Nick's Just Giving page or share this post to show your support. Good luck Nick!

Jeans for Genes

This month marks our annual fundraiser Jeans for Genes. This is a week when schools, places of work and individuals kit themselves out in denim and donate to do so. Many events took place this year, 13 – 19 September, and it was great to see so many people taking part after what has been a difficult year and a half for us all. From making blue cupcakes to school children decorating old pairs of jeans, every donation and event will help those living with rare genetic disorders.

You can still make a donation here.

Thank you for taking the time to read our latest news. Please do contact us if you have any queries or if you can support us in any way.

Best wishes,

Claire, Helen and trustees

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Sponsored by a grant from Orchard Therapeutics

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