

CGD Society March news



Dear CGD Society member,

Welcome to our latest e-newsletter. We hope you are keeping well, and we hope that the onset of spring, with its blooming spring bulbs, longer days, and balmy sunshine (yes, it is sunny here in the UK sometimes) brings a little joy into your world.

Read on for our monthly news catch up. Please do not hesitate to get in touch if you have any questions or comments.

Latest news



England's Rare Disease Action Plan

England's first Rare Disease Action Plan has now been published. The action plan includes 16 commitments to further improve care, including faster diagnosis and supporting access to new treatments. This is a major step forward for the rare disease community in England and is very much welcomed by us all here at the CGD Society.

[Here](#) you will find full details of the plan.

Spring COVID-19 booster for England

The Government recently announced that care home residents, people aged 75 and over and those with a weakened immune system aged 12 and over will be invited to get a Spring COVID-19 booster. If you are listed to have the booster, the NHS will contact you and invite you to make a booking. For more information visit [here](#).

For those outside of the UK please follow the advice given by your medical teams.

The struggle to find a donor



Finding a suitable unrelated donor for a bone marrow transplant when you have mixed ethnicity can be extremely difficult. Little Ryan and Arend (L-R) are facing this tough situation.

Doctors treating Ryan, aged 4, from England have been searching for a suitable donor since he was diagnosed with CGD as a baby. Ryan's Mum, Hannah has been raising awareness of Ryan's plight and asking people to sign up to [UK | DKMS](#) to see if they could be a potential donor. You can read Ryan's story [here](#).

Little Arend, nine months old from Canada is also facing the same situation. Arend's Mum, Larisa, is of Latvian descent and husband Emil is from South Africa and there are no matches on the Canadian stem cell registry. She hopes that a Latvian expatriate or someone from the Netherlands, France or Germany might be able to help, given Emil's Afrikaner heritage. Read Arend's story [here](#).

We hope a donor is found for both boys soon.

UPDATE: Since the time of writing, we are pleased to announce that a donor has been found for Arend. [Read the full story here](#).

Membership survey 2022

We would like to thank everyone who recently completed our membership survey. We had an excellent response rate with 84 participants and 45% of those were from outside of the UK.

Your feedback has been insightful and will help us steer our charity forward. We will publish the findings in the next newsletter and on our website. The survey is now closed.

Our trustees meet again!



For the last 2 years, due to COVID-19, we have not been able to hold face to face trustee meetings but have instead relied on online meetings. This all changed when some of our trustees, along with Claire, our Operations and Fundraising Manager, got to meet each other once again at our latest trustee meeting held in London on the 12th of March.

The meeting was very productive, planning our charities strategy for this year, discussing ways to increase our support to those affected by CGD while reflecting on the membership survey. It was great to see everyone including our newest trustee Kultar who joined the board in January 2022. All trustees are volunteers and are the backbone of our charity. To find out more about our trustees click [here](#).

Join our team



Want to make a tangible positive difference to families and individuals affected by CGD and have fundraising and marketing experience? We are recruiting a Community Fundraiser and Marketing Lead to join our small and passionate team. If this is of interest to you or someone you know, please visit [we are hiring](#).

Support Us



With the cost of living rising, COVID cases increasing and the uncertainty in Ukraine we are all in for a bumpy ride. Our small charity is no exception. We have seen a decrease in donations over the last couple of months, which means we need your support more than ever.

It is so important that we are here to provide support, information, and advice to the CGD community. From making a small one-off donation to setting up a regular monthly donations there are many ways you may be able to help. Every time you donate or take part in a fundraising event you are making an enormous difference.

To find out ways you could support us visit [support us](#). You can make a donation, however big or small [here](#).

Thank you for taking the time to read our latest news. Wishing you all good health.

Claire, Helen, and Trustees



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