

March e-news

Dear CGD Society member

Welcome to the March edition of our e-news. Heading into Spring, with its lighter nights and spring bulbs blooming, seems to lift some of the gloom winter leaves behind. This is especially true this year with the hope the Covid vaccine rollout now gives us.

We understand it has been a tough time for us all but especially for those that have been shielding throughout this pandemic. Sometimes it has seemed never ending but with scientists around the world working together and producing much needed vaccines we now have hope that life can return to some kind of normality for us all.

Latest news



CGD Society

Supporting families affected by chronic granulomatous disorder

CGD Society 30th year

This year marks 30 years of our charity providing information and support to individuals and families affected by Chronic Granulomatous Disorder. Starting from a small patient group back in 1991 the charity has come on leaps and bounds over the past 30 years, improving and adapting to the needs of our community.

We will be celebrating this momentous occasion throughout the year so keep watch on our social media platforms, website and our monthly e-news.

As part of our celebrations, we want to hear from you, our supporters both here in the UK and overseas, on how we have supported you. From using our informative website, contacting us through our helpline, financial support or information and support through our Clinical Nurse Specialist both past and present, we would love to hear from you. You could provide a small quote, a short video from your phone or share with us your CGD or carrier story. Please contact Claire and Adelle on 0800 987 8988 or send us an email at hello@cgdsociety.org. We know that sharing with others helps with those feelings of isolation many feel when living with a rare condition. We look forward to hearing from you.

Covid-19

On the 22 February the UK government announced the roadmap for easing Lockdown restrictions in England. We have collated this latest information in the [Covid-19 pages on our website](#).

A Fathers story on his family's journey with CGD



Miguel Sancho, from the USA, is an Emmy Award-winning television producer and has written a book titled *More Than You Can Handle*. In the book, Miguel describes with honesty and humor how his struggle to cope with his son Sebastian's illness derails his career, strains his marriage, and even gets his family evicted from a Ronald McDonald House. Sebastian eventually receives a life-saving stem-cell transplant at Duke University Hospital in North Carolina, and the journey to get there brings the whole family into the heart of the rare-disease community.

Miguel's wife, Felicia Morton, is Executive Director for The CGD Association of America.

The book is due for release in the US on March 2nd, 2021 and in the UK on March 4th you can purchase a copy here: [More Than You Can Handle](#).

Your support

It is true when we say that without your support we simply would not be here as a charity. We receive no government funding and so rely on donations, fundraising, grants and income from our annual [Jeans for Genes Day](#) to enable us to support our CGD community both here in the UK and overseas.

We are always truly grateful for any donations we receive and would like to thank everyone who has supported us over the years in this way. We would also like to acknowledge donations made in memory of loved ones lost. We are so touched that at such an emotionally difficult time people want to support us. Please know that your kind donations, made in memory, really do help those affected by CGD.



We would especially like to thank Ronnie Campbell for the very kind and generous donations he has made to the charity over the last few months. Ronnie's little grandson Max who lives in Singapore with his parents received a Bone Marrow Transplant for CGD before his 1st birthday. Max's dad, Ronnie's son, was the donor for Max.

The family have had their ups and downs during Max's BMT journey but Ronnie reports that "Max is continuing to make good progress and thanks to the greatly improved Covid situation in Singapore is enjoying playing outside. He looks, to all intents and purposes, like any other healthy 18-month-old baby, walking and beginning to talk."

Ronnie's donations have amounted to £1,300 and will go towards helping us continue supporting those affected with CGD, Carriers and their families.

Once again Ronnie, thank you and I am sure you will agree with me when I say this photo of Max is just super cute!

[Donations can be made online here.](#)

The CGD Association of America and Remember the Girls

Claire, our Fundraising and Operations Manager, has been in contact with two charities in the USA, The CGD Association of America and Remember the Girls discussing ways in which to collaborate for the benefit of our communities.

Felicia, Executive Director at CGDAA and Taylor Kane, founder of Remember the Girls have been working on a U.S X-linked female carrier guide. In recognition of using some information provided by our own X-linked guide, the two charities made a very kind and generous donation of £1,065 towards our work at the CGD Society.

Thank you once again ladies. We look forward to future collaborations to help spread the word on CGD and X-linked carriers.

You can find out more about both organisations by visiting their websites:

- [CGDAA](#)
- [Remember the Girls](#)

Thank you for taking the time to read our latest e-news. If you would like to appear in future editions or would like to support us in our 30th year, then please do call us on 0800 987 8988 or email hello@cgd-society.org

Best wishes,

Claire, Adelle, Helen and Susan



Sponsored by a grant from Orchard Therapeutics



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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