

## December newsletter 2021



Welcome to our end of year newsletter. As we head into the festive season and as 2022 approaches, we thought we would take this opportunity to look back over the last year. Yet again Covid has dominated our lives this year. With restrictions being imposed then lifted, hospital appointments being cancelled and rescheduled, travel being hindered and the loss of loved ones, it has been a difficult year for many. However, we are in a much better situation with the roll out of vaccines that have saved many lives and helped to protect many from serious illness. We also saw many restrictions lifted over the summer, not that we had much summer weather here in the UK!

At the time of writing this, we find ourselves facing a new variant of Covid, Omicron. We advise all those in the UK with CGD and x-linked carriers to have the booster vaccine offered if you have not already done so. For those outside of the UK, please follow the guidelines from your country and your medical team.

It has been a busy year for us here at the charity with many changes taking place, however, we have continued to work hard in providing support and information to the CGD community here in the UK and around the world. Read on to find out more.

I, Helen our CGD clinical nurse specialist and our trustees would like to send our thoughts to those who will struggle this festive season and we hope you have a restful, safe, healthy and happy Christmas and new year.

Claire Jeffries,  
Operations and Fundraising Manager

### Support over the holidays

Our charity will be closed over the holiday season from the 23rd of December and will re-open on the 4th of January. Claire will be monitoring emails intermittently.

Our CGD Clinical Nurse Specialist, Helen, will NOT be contactable from 15:00 on 24th December until 8am on 5th of January.

If you require medical advice or treatment during the holidays, please [visit our website](#) to find more information.

Helen has asked us to remind those on regular medication to make sure you order enough medication to cover the holiday season.

### A message from our Chair of Trustees



It is with great sadness that I must report the death in tragic circumstances of our founder and talisman Paul (Ocean) Numan.

Paul, whose son Andrew had CGD, founded this charity in 1991. His enthusiasm for our cause was infectious and persuaded me and other parents to become trustees. He created the early newsletters himself using his marketing flair and charisma to engage the few CGD experts that we could find to join our mission.

The following year we ran the first Jeans for Genes campaign on a shoestring, but Paul recognised that it needed a bigger voice, so he engineered the partnership with Great Ormond Street hospital and two other charities that lasted for 15 years and provided the income that transformed our prospects. He also had the wisdom to register the trademark from which we still earn a licence fee today. This campaign funded over £3m of research and provided the foundation of our worldwide network that supports so many CGD families today. This is a wonderful legacy for this inspirational man.

Paul returned to his native New Zealand a few years ago following Andrew's death from complications during his BMT. Although I never visited him there, I understand that he lived close to the sea which is perhaps why he adopted the name 'Ocean'. It is especially sad therefore that we heard that he drowned while pursuing one of his favourite pastimes, swimming near his home, on September 20th. The Covid lockdown has made accurate information hard to come by, so we do not know the exact circumstances but for those of us who knew him, and were so motivated by him, this was devastating news.

Paul was proud to be our Honorary President. We spoke a couple of times a year and reflected on how far this charity has come. I will miss his kiwi accent, his irreverent humour but above all his dedication to our cause which remained so close to his heart. Such a sad loss for us and especially his family.

Geoff Creamer, Chair

### Latest news



#### Covid latest

As mentioned, the world is now facing the new variant, Omicron. The UK government for England have announced plan B and the urgency to have the booster vaccine. For full information for England, Northern Island, Scotland and Wales please visit [Coronavirus \(COVID-19\): guidance and support - GOV.UK](#).

For those outside of the UK please do follow guidelines for where you live.

#### Bring your voice to NHS specialised services

NHS England and NHS Improvement is recruiting Patient Public Voice (PPV) partners to groups with responsibility for commissioning specialised services.



PPV partners play a crucial role in specialised services and are represented across all aspects of our work. These voices ensure the views of patients, carers and the public are at the heart of all we do.

Roles on these groups attract an involvement fee for the time and expertise appointed candidates bring.

We are recruiting for PPV partners in three areas of work:

- Blood and Infection Programme of Care Board
- Cancer Programme of Care Board
- Rare Diseases Advisory Group

For full information about the roles, [see here](#).

The closing date for applications is 16 January 2022.

## One Father's story

Miguel Sancho is the father to Sebastian, who was diagnosed with CGD in 2012 at five months old. Miguel has recently published a book called "More Than You Can Handle: A Rare Disease, A Family in Crisis, and the Cutting-Edge Medicine That Cured the Incurable", where he talks candidly about his experience as a "CGD Dad".

The story is told from Miguel's perspective and reflects on Sebastian's diagnosis and successful stem cell transplant. Miguel's gives his point of view on how as a family they survived it all, with his marriage, and sanity intact. It reminds us of the stress "CGD Dads" can be under and how they can navigate it with the right support.

You can purchase a copy of the book [here](#).

## Raising awareness of CGD



On Wednesday, 17th November, Claire, our Operations and Fundraising Manager, visited Cambridge University to give a lecture to MPhil students on CGD, our charity and her own personal story of losing her child to CGD. Claire also spoke about the many challenges faced by families and individuals who are affected by a rare disease.

It is never easy for Claire to speak about her story but raising awareness is something she is passionate about and it is so important.



On Monday, 1st November Claire, and Helen, our CGD Nurse Specialist represented our charity at the UK PIN conference in Sheffield. The conference is over 2 days and was attended by consultants, trainees, nurses, and scientists involved in the healthcare of patients with primary immunodeficiencies, or in research into these diseases.

## How your donations and fundraising have supported the CGD community this year



It has been a challenging year. Along with COVID we have been running the charity for the last few months on low resources with Claire managing the day to day running of the charity by herself. Our annual Jeans for Genes fundraising event, which helps fund some of our support services has been hit hard by the pandemic with a decrease in donations.

We have been working hard behind the scenes this year to ensure we are here for the CGD community and it is with thanks to you, our supporters, through your donations and fundraising for the CGD Society that this year we have been able to:

- Provide support and information on COVID through our helplines, website and CGD clinical nurse specialist.
- Continue our telephone and email helpline, which has enabled us to offer support and guidance to 100 people with 27 of those being outside of the UK.
- Raise awareness of CGD through attendance of a conference, attending virtual workshops with other rare disease charities and through our social media platforms.
- Continue the provision of our CGD clinical nurse specialist, Helen Braggins, who provides direct support to paediatrics and adults with CGD, X-linked carriers and the wider family.
- Provide financial support to 11 UK families through our family support fund.
- Provide prepayment prescription certificates to 16 people in the UK.
- Buy gifts and comforts for children who have had a long hospital stay.
- Help fund a psychology service for PID patients at University Hospitals Birmingham, England.

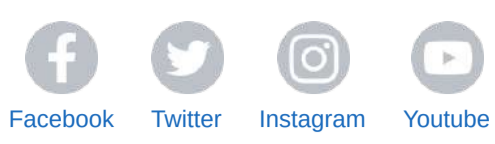


We have had some fantastic fundraisers and donations this year. From completing 10,000 steps a day in May, penalty shoot outs, knitting 100 adorable hats to a swim for life you have all been amazing and your efforts and donations have been deeply appreciated.

Without your donations and fundraising we would not be here to support the CGD community. Please consider donating, however big or small your donation

you will be making a difference. To find out how you can support us and donate please [visit our website](#).

Thank you.



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