



December Newsletter 2019

Dear CGD Society member,

Welcome to our December newsletter. As we approach Christmas and the new year, it seems a fitting time to look back and highlight the ways in which your kind donations and fundraising in 2019 have made a difference to the CGD community. We rely heavily on individual donations, so your continued support is much appreciated by all the team.

This edition also includes an update on what we have been doing to raise awareness of CGD and the CGD Society, plus the latest news and some enquiries received by our helpline.

Whilst Christmas can be a happy time for many it is important to remember that for some Christmas can be a difficult time of the year. We send our thoughts to those who may struggle and we hope you all have a restful, healthy and happy Christmas and New Year.

Best wishes

Claire, Helen and Susan
The CGD Society team

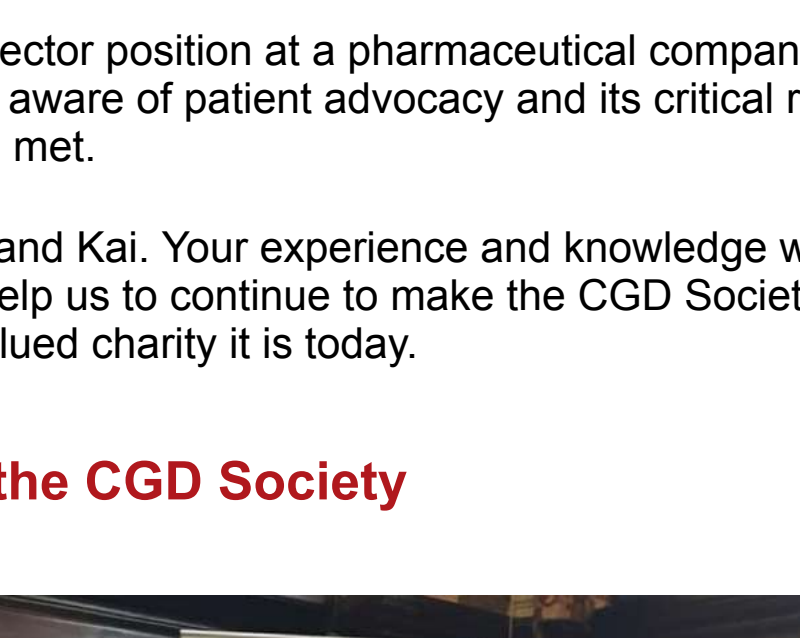
Latest news

Welcome to our new trustees

In October, we welcomed David Hannard and Chikai Lai as new members of our board of trustees.



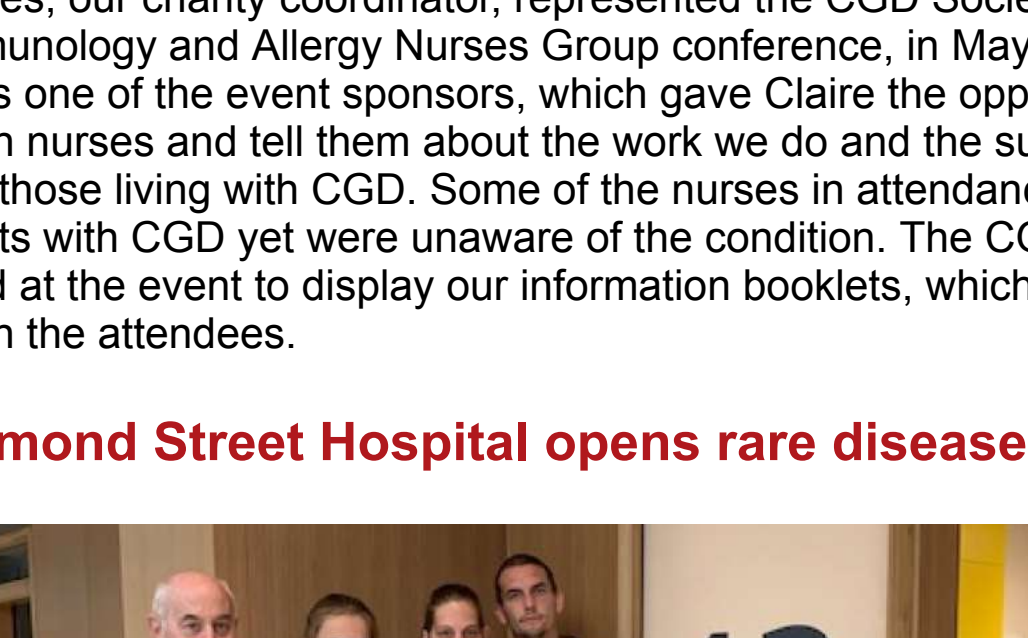
David's son was born in 2002 with X-linked CGD but wasn't diagnosed until the age of five. He had a successful bone marrow transplant in 2011. David is a serving officer in the Royal Air Force.



Chikai holds a director position at a pharmaceutical company. Through his work, he became aware of patient advocacy and its critical role in ensuring patient needs are met.

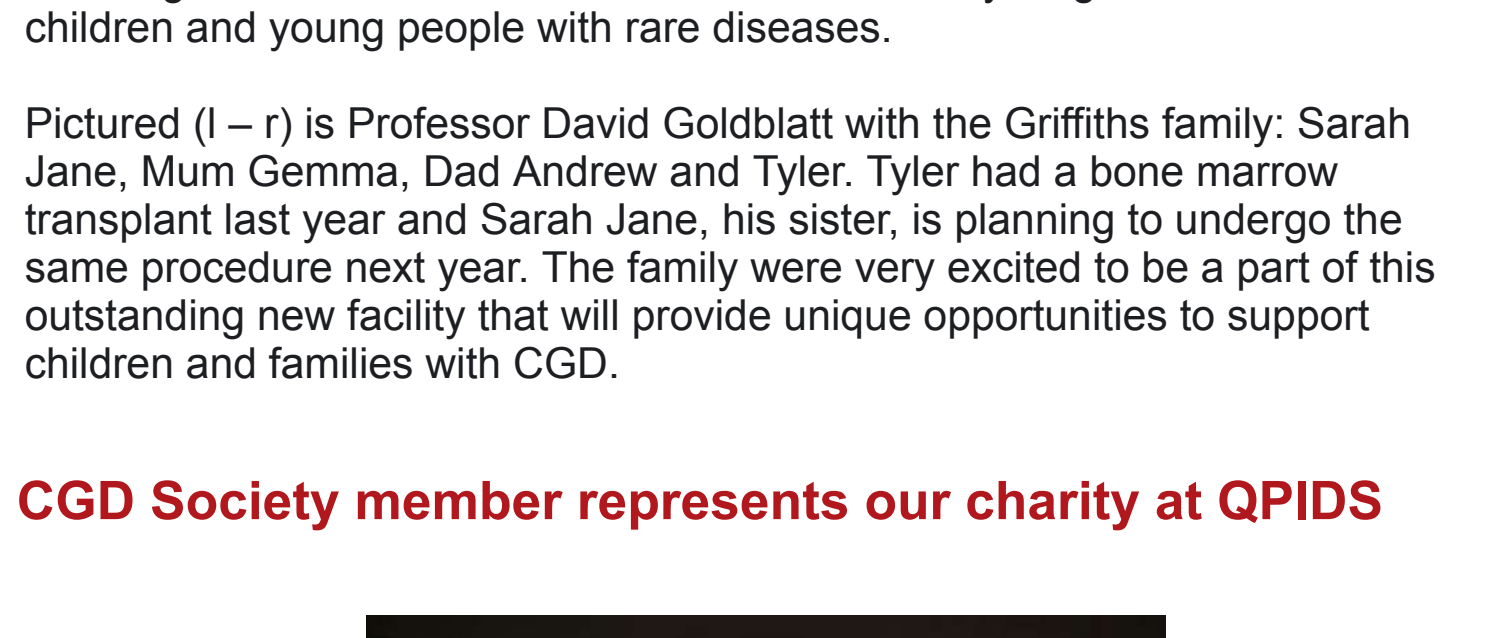
Welcome, David and Kai. Your experience and knowledge will benefit the CGD community and help us to continue to make the CGD Society the well-respected and valued charity it is today.

Showcasing the CGD Society



Claire Jeffries, our charity coordinator, represented the CGD Society at the annual Immunology and Allergy Nurses Group conference, in May. The CGD Society was one of the event sponsors, which gave Claire the opportunity to engage with nurses and tell them about the work we do and the support we provide for those living with CGD. Some of the nurses in attendance looked after patients with CGD yet were unaware of the condition. The CGD Society had a stand at the event to display our information booklets, which proved popular with the attendees.

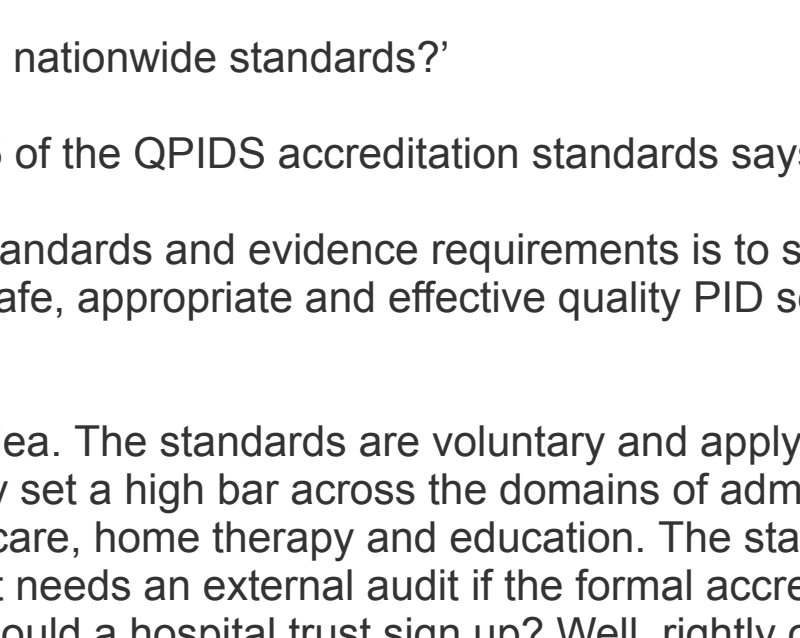
Great Ormond Street Hospital opens rare disease centre



The immunology team at Great Ormond Street Hospital welcomed their first family, the Griffiths family, to the new outpatient facility at the Zayed Centre for Research into Rare Disease in Children. This world-leading centre of excellence will tackle some of the most challenging scientific questions, enabling scientists and clinicians to more accurately diagnose, treat and cure children and young people with rare diseases.

Pictured (l-r) is Professor David Goldblatt with the Griffiths family: Sarah Jane, Mum Gemma, Dad Andrew and Tyler. Tyler has a bone marrow transplant last year and Sarah Jane, his sister, is planning to undergo the same procedure next year. The family were very excited to be a part of this outstanding new facility that will provide unique opportunities to support children and families with CGD.

CGD Society member represents our charity at QPIDS



We asked Simon Bostic to represent us at the Royal College of Physicians to help review the Quality in Primary Immunodeficiency Services (QPIDS) accreditation standards. Simon was diagnosed with CGD at birth and became the first person in the world to survive a bone marrow transplant from an unrelated donor. Simon reports on the events of the day.

Setting the standard

Living with a rare disease, such as CGD, whether as sufferer or carer, is enough of a challenge without having to cope with the variable knowledge and standards that exist in the care and treatment of people with primary immunodeficiency (PID). So, I was delighted to be asked to help review the QPIDS accreditation standards. The scheme, created in 2000 following an audit of PID services across the country, was designed to improve and optimise the care of patients with PID, wherever they presented themselves for treatment.

‘What? There are nationwide standards?’

Well, yes. Page 5 of the QPIDS accreditation standards says:

‘The aim of the standards and evidence requirements is to support the achievement of safe, appropriate and effective quality PID services in the United Kingdom.’

It's a wonderful idea. The standards are voluntary and apply to hospitals with a PID service. They set a high bar across the domains of administration, staffing, facilities, clinical care, home therapy and education. The standard itself can be self-assessed but needs an external audit if the formal accreditation is to be awarded. Why should a hospital trust sign up? Well, rightly or wrongly, in a complex world of competing markets within the NHS, it is to their advantage to do so for funding reasons, and the standard is viewed favourably by local Clinical Commissioning Groups.

The patient meeting was a great chance to meet representatives of other charities supporting PIDs and to share experiences about what it is like to be a patient with a rare disease that no doctor has ever heard of (apart from your specialist!). Many of you will recognise how difficult it can be (outside known centres of excellence in PID) to get what you need, and it can be a frightening and infuriating experience being admitted to hospital. We talked about the serious emotional strain on patients and carers and how little provision there is for mental health support for PID sufferers compared with, say, cancer patients. Our diseases are just as debilitating, and sufferers have to cope for years with deteriorating bodies. I have since discovered that the Royal Free in London is the only specialist PID service that has a full-time psychologist.

As a result, a number of patient-centred themes were written into the standard. So, next time you see your specialist, ask them if their service does, or intends to, adopt the standard. Hopefully they will know what you are referring to!

Frequently asked questions

Q. I would like to have a real Christmas tree this year, but I am a little wary. What are the things I need to take into consideration?

A. Having a tree is an important part of Christmas for many families. Family's with CGD often ask about having a real tree. It would be advisable if you have small children who will want to play around the tree to consider an artificial tree.

Real trees are best suited to an environment where they are not likely to be disturbed.

Best advice if in doubt have an artificial tree.

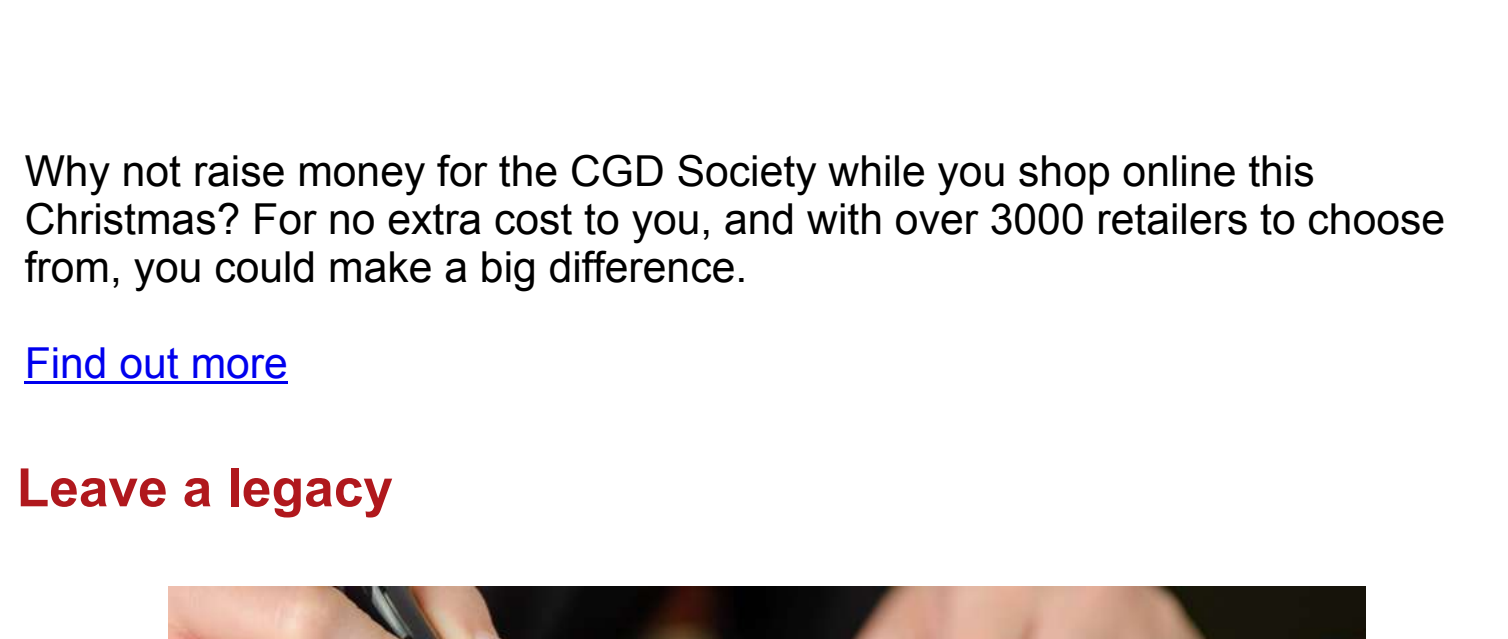
Q. I live in the United States and have just been diagnosed with CGD at the age of 32. My primary care physician is unfamiliar with the disorder. Is there a list of CGD specialists working in the United States?

A. If you let us know where in the United States you live, we can locate a suitable specialist and centre. There are two resources that may be helpful to you. These are the [IDF physician finder](#) and the Jeffrey Modell Foundation tool ['Find an expert immunologist'](#). The CGD Society's [Guide for Medical Professionals](#) will also help your primary care physician to understand more about your condition and its treatment.

Q. I know CGD is hereditary but I don't really understand the genetics of it and the implications if I want to start a family. Can you help?

A. [This webpage](#) explains how CGD is inherited and our [Guide for Patients and Families](#) offers advice on family planning.

Your fundraising



All of us at the CGD Society would like to thank everyone who has donated, fundraised or made a regular donation this year. We have seen some amazing efforts and achievements that have helped us raise over £20,000 this financial year.

This year, your kind generosity has helped us to:

- launch our new, fantastic [website](#)
- provide financial support to eight UK families through our Family Support Fund
- buy gifts and comforts for children who have had a long hospital stay
- update our guides and resources for patients, carers and medical professionals
- send monthly eNewsletters to you, our members, to keep you updated with the latest news and the charity's activities
- sponsor two events: the Immunology and Patient Education Symposium at the Royal Free Hospital and the Immunology and Allergy Nurses Group Conference in Leicester
- continue our telephone and email helpline, which has enabled us to offer support and advice to 37 people, 13 of whom are from overseas

If you would like to help us reach our fundraising target for this financial year and continue to offer support and information to the CGD community, then here are some things you could do:

Prudential RideLondon 2020

We have charity places for Prudential RideLondon 2020. This event is a 100-mile cycle ride from Surrey to London on closed roads.

[More information and to find out how to enter](#)

easyfundraising

Why not raise money for the CGD Society while you shop online this Christmas? For no extra cost to you, and with over 3000 retailers to choose from, you could make a big difference.

[Find out more](#)

Leave a legacy

Leaving a gift in your will to the CGD Society could make all the difference and may give you deep satisfaction knowing your support will live on in the future. Your donation can be as small or as large as you like.

[Find out more](#)

I hope you enjoyed reading this edition. If you would like to feature in future news updates, then please contact Claire at hello@cgdsociety.org

Call us on: 0800 987 8988

Email us at: hello@cgdsociety.org

Write to us at: CGD Society, PO Box 454, Dartford, DA1 9PE

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