CGDSociety
Supporting families affected by chronic granulomatous disorder

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Hello from the CGD Society

Welcome to our latest newsletter, and greetings to our new members from the UK and overseas. In this edition you will find synopses of research findings, Q&As, your fundraising stories and details of how I have been promoting the CGD Society to raise awareness of the work we do in supporting families and individuals living with the disorder.

Our annual Jeans for Genes Day has a twist this year! You can choose when to hold your event and wear denim for the day to raise funds for children with genetic disorders. You may be aware that Jeans for Genes Day was created by the CGD Society over 20 years ago and most of the Society's activity is funded from money raised on Jeans for Genes Day. You can read more in the fundraising section.

I have been charity coordinator for over a year now and am thoroughly enjoying working for the CGD Society. Some of you may know that I lost my only son, Kade, to CGD eight years ago and I felt it was time to give something back to the charity that was a great support to us. Over the last year I have made some big changes that have brought us closer to you, our members. I have met some amazing families and individuals, and I want to thank you all for your kind words of encouragement and continued support.

Please get in touch with me athello@cgdsociety.org if you have any fundraising ideas, if you would like to take part in one of the fundraising events mentioned later in this newsletter or if you would like to share your story and be featured in our next edition.

Best wishes

Claire
Charity Coordinator

Latest news

Immunology Patient and Family Education Symposium

Our Clinical Nurse Specialist Helen Braggins and I attended the Immunology Patient and Family Educational Symposium on 17 March 2019 at the Royal Free Hospital, London. Immunology patients from the Royal Free were invited to attend the symposium, which featured presentations on various topics, including infections and treatments, research studies, bone marrow transplantation and gene therapy.

The CGD Society was one of the event’s sponsors and we were there to speak with attendees and to give out information materials on CGD. The symposium was a great success and provided a platform for us to raise awareness of CGD and the services our charity provides.

Pictured here, L–R, Helen Braggins, CGD patient Umera Ahmed and Claire Jeffries.

Website update

We are excited to announce that work is underway to give the CGD Society website a fresher look and to make it easier to navigate. The website will be updated with the latest news and will include new photos and members’ stories. The work has been made possible thanks to the many donations from and the money raised by our members and the CGD community. We will keep you posted on our progress and let you know when the new site goes live.

How would you like your photo to be hanging in a swanky London office?

The CGD Society is working with Orchard Therapeutics, a biotech company dedicated to transforming the lives of patients with rare diseases through innovative gene therapies. Orchard Therapeutics are keen to get to know the CGD community better; they want their employees and investors to appreciate the challenges faced by those affected by the condition.

The CGD Society are looking for a family/individual affected by X-linked CGD and a family/individual affected by p47 autosomal recessive CGD, who live in the UK home counties or London and are willing to be photographed by a professional photographer at their home or in the surrounding area.
Find out more.

Going on holiday

If you are organising your summer holiday and affected by CGD, then there may be a few things that you need to consider. You will also need to buy travel insurance. Information on going on holiday and insurance matters is available on our website.
Visit our website for further information.

Report on 20 years of CGD transplant experience shows excellent survival rates

Research on long-term outcomes for children with CGD treated by haematopoietic stem cell transplant (HSCT) has been published in a letter sent to the editor of the prestigious journal, *Blood*. The results, from Newcastle's Great North Children's Hospital supra-regional transplant centre, underline the use of HSCT as a safe and curative treatment for CGD.
Visit our website for further information.

Quality of life issues in X-linked CGD carriers

Results of the first study into the quality of life of X-linked CGD carriers (XL-carriers) have been published in the *Journal of Clinical Immunology*. The results show that high levels of anxiety and significantly reduced quality of life are associated with this carrier status.
Visit our website for further information.

UK adult BMT success for CGD patients emphasises the need for transplants to be done in Highly specialised centres

Data expected to change the clinical management of adult primary immunodeficiency (PID) patients was published earlier this year in the journal, *Blood*. The publication reports on the largest series in the world to date of adult PID patients who have undergone bone marrow transplant (haematopoietic stem cell transplant; HSCT).
Visit our website for further information.

Bereavement support

Nothing can prepare you for what you are experiencing if you have lost a loved one to CGD. Grief can last for years, not weeks or months. Its duration is different for everybody – because everyone is different. We have a section devoted to bereavement support on our website. Here you will find information on organisations that can help and support you and your family in what is a very difficult time.
Visit our website for further information.

Fundraising

We rely heavily on individual donors and fundraisers in order to continue the support we provide to the CGD community, both here in the UK and abroad. There are many ways you can get involved, from entering this year's Big Fun Run (see below) to holding an event yourself. You can find out more on our website.

Visit our website for further information.

We have spaces in this year's Big Fun Run. The Big Fun Run is a series of 5k untimed runs staged throughout the UK from June to October. It really is great fun for all the family.

Find out more.

Your fundraising

A hair-shaving experience

A huge well done and thank you to Sunita, Devi, Paul, Jay and their families and friends who had their heads shaved or their hair cut very short to raise funds for the CGD Society. Sunita and seven family members who took part have raised over £6,000 so far. The hair was donated to the Little Princess Trust, an organisation that makes wigs for children affected by hair loss as a result of cancer treatment or other conditions.

There were also contributions from Sunita's colleagues and the staff and children at Buckhurst Hill Community Primary School. Sunita's colleagues held a dress-down day and raffle, raising £225. Buckhurst Hill Community Primary School held a non-uniform day and organised a collection.

Sunita and Jay's son Raylen is currently in Great Ormond Street Hospital receiving a BMT for his CGD. We all wish Raylen well and hope he makes a full recovery soon.

One tough mudder

Good luck to Aaron Williams and his friends, seen here L–R: Aaron, Callum and Jack, who are taking part in July's Tough Mudder Urban Bristol for the CGD Society. Aaron received a successful BMT for his CGD and wanted to give something back to the CGD Society.

Read Aaron’s story and make a donation on his JustGiving page.

A cycling challenge

We would also like to say good luck to our trustee Jane Docherty and her friend, Marco Maddalena, who are taking part in this year’s Prudential Ride London on 4 August. Ride London is a gruelling 100-mile cycle ride from the beautiful Surrey countryside to The Mall in London. We will be there on the day to cheer them on and offer our congratulations at the finishing line.

Frequently asked questions

Q My son has CGD and vapes (uses an e-cigarette). Is this OK?
A The safety of e-cigarette products for the general population is still under debate but our medical advice is that any type of smoking is not recommended for people affected by CGD.

Q We live in Israel and have two children affected by CGD. We have been told that we have two options for a cure: bone marrow transplantation (BMT) and gene therapy. We are a bit confused about what these options are and would like some clarity, so we can decide what to do. Can you help?
A We have lots of information on our website about BMT and gene therapy, which we recommend you read. This information will help you ask the right questions of your medical team when they advise on the best way forward for your children’s CGD and individual associated health problems.

Q My daughter is considering a BMT for her CGD. I know this can be a risky procedure and I don’t know what questions we should be asking. Can you advise?
A To help patients and their parents research which centres have the

necessary experience in BMT for CGD, we have put together a list of questions that we recommend you ask before considering a BMT at a particular centre. These questions are in the leaflet *Key questions to ask about BMT*.

Q Do you have any information on CGD that I might be able to pass on to my GP? She is very interested in finding out more about my condition.
A We have just updated our guide for medical professionals, which explains CGD and its health implications. If you would like a copy, you can either download it from the website or obtain a paper copy from Claire at hello@cgdsociety.org

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