



August 2021 newsletter

30th anniversary edition

Dear CGD Society member,

Welcome to the August 2021 edition of our newsletter. We hope you are keeping well as the world tries to return to some kind of normality.

This year marks our 30th anniversary as a registered charity supporting the CGD community. We started as a small patient group in 1998 and became a registered charity in 1991. Since then, we have evolved and adapted to the needs of individuals and families living with CGD.

In this newsletter we reflect on how our charity, formerly known as the CGD Research Trust, came about and how your donations have helped us to make a difference. We also take a moment to remember loved ones we have lost to CGD.

Three decades on from 1991, CGD remains a life-limiting, life-threatening, genetic disorder. Our work continues to raise awareness of the condition and to support affected individuals and families.

A message from our chair of trustees



Can we really be 30 years old? It's half a lifetime for me but, as a trustee, I am proud to be part of the journey. I hope you will agree that the CGD Society has delivered huge progress for the benefit of the CGD community worldwide.

I remember so clearly those early days as a young father, full of anxiety and fear as our boys were diagnosed with this unpronounceable and life-limiting rare disease. Thankfully, in my search for answers, I soon joined the irrepressible Paul Numan, Rosemarie Rymer (our tenacious volunteer fundraiser) and other parents, all of us searching for information, expertise and solutions for our loved ones.

So, where are we now, some 30 years later? I believe that our website has the best resources on CGD in the world. We have a specialist nurse working in the clinic, supported by a medical panel of expert clinicians. Bone marrow transplant offers a cure for many patients. (OK, so we didn't invent the internet or stem cell transplants but nonetheless this looks like awesome progress to me!)

We have so much more to do, however. We have new parents to advise on reproductive options, we have carrier mums who live with poorly understood autoimmune conditions, and we need genetic engineering in the clinic to deliver a safer curative option for all.

I will be 94 in another 30 years, but I am confident that by then, with your continued fundraising and support, we will have delivered our mission of a cure for all with CGD.

Best wishes,
Geoff Creamer, Chair

How it all began

Family support group

Our first family support group was held in 1988. The event was conceived by longstanding trustee Andrew Orchard after his son, Dan, was born with CGD. With little information on CGD available at that time – the internet was in its infancy – the support group provided an opportunity for families and individuals affected by CGD to contact each other and share information about the condition. Andrew would also update the group when information on the condition became available from University College Hospital (UCH) and other hospitals.

[Read full story from Andrew here](#)

A registered charity

Through the family support group, Andrew met Paul (Ocean) Numan. Paul's son was diagnosed with CGD, and it was Paul's vision to set up a registered charity with the aim of raising funds for research. Paul wrote the occasional newsletter for the family support group, which in July 1990 had 22 member families. In spring 1991, the charity was registered as the CGD Research Trust. It had total funds of £8.

[Read Ocean's story here](#)

What has been achieved?

Jeans for Genes Day



The main aim of the CGD Research Trust was to raise enough money to fund research into treatments and, ultimately, a cure for CGD. Realising that the charity needed to reach a wider audience to raise funds, Rosemarie Rymer, then a volunteer, came up with the Jeans for Genes Day campaign. The idea was to invite schools nationwide to take part in a non-uniform day on a particular date in exchange for a donation of £1 from each participating child and teacher.

The first two campaigns in 1992 and 1994 were headed by Rosemarie alongside volunteers and trustees from the CGD Research Trust. The 1992 campaign raised £50,000. Over the last 25 years, Jeans for Genes Day has raised over £45 million.

Jeans for Genes remains one of the main sources of income for the CGD Society. It also provides funds for vital support and equipment for families affected by other genetic disorders.

This year's Jeans for Genes takes place on 13–19 September. [Find out more here.](#)

You can also [read Rosemarie's story here.](#)

Research



Since 1997, our charity has invested nearly £3.5 million in research into CGD. Funding from the CGD Society supported the first proof-of-principle experiments, leading to clinical trials of gene therapy for CGD. This has attracted commercial interest in bringing gene therapy into mainstream medicine and will pave the way for the development of gene therapy as a treatment for the other forms of CGD.

We have also:

- provided funding to assist with the development of new methods to better diagnose the autosomal forms of CGD
- funded research into repurposing a drug, already used clinically to treat another condition, that was found to help fight infection and reduce inflammation in a CGD animal model; this work led to the start of clinical trials in CGD patients
- contributed towards 84 scientific articles published in highly regarded research journals
- forged international research collaborations between groups.

In 2002, our charity appointed Dr Susan Walsh as medical research officer. Susan was tasked with upgrading our grant-giving process to researchers. We were investing a lot of money in research in the early days, and Susan was visiting labs and consulting with researchers on how our grants were being used.

In 2010, the CGD Society started to put a lot of funding (over £1.2 million) into developing gene therapy for the X-linked form of CGD. Susan set up the Gene Therapy Advisory Committee to oversee a five-year programme of research at centres in London and Frankfurt. Find out more about Susan's work with us [here.](#)

Full details of the many research projects we have funded can be found [here.](#) We were able to fund these projects through monies raised from Jeans for Genes days and through your donations and fundraising.

Support



As well as funding research, our charity provides support and information to the CGD community around the world. Over the years we have tried to understand the needs of individuals with CGD, X-linked carriers and parents of children with CGD. It became apparent that these communities would benefit from the support of a dedicated specialist nurse.

In 2000, with money raised from Jeans for Genes Day, we were able to fund our first CGD clinical nurse specialist, Louise Morton. Louise was based at Great Ormond Street Hospital, London. In 2008, again with money raised from Jeans for Genes Day, we were also able to fund an adult nursing service. Marie Kirwan was based at Wythenshawe Hospital in Manchester and became a fundamental part of the care and support given to adults living with CGD. Unfortunately, owing to a lack of continued funding, we had to stop the adult nursing service.

Our current clinical nurse specialist, Helen Braggins, has been with the charity for 14 years and continues to provide advice and support for many families and individuals around the world. [Find out more about our nursing service here.](#)

Other support services provided include:

- an extensive range of guides and factsheets
- regular newsletters
- a telephone and email support line
- a comprehensive website
- a family support fund.

[Details of our support services can be found here.](#)

Family weekends and get-togethers



We have been able to bring together families and individuals from around the world at events as diverse as Halloween-themed family weekends and a ladies' day for X-linked carriers. Not only are our get-togethers an opportunity to share experiences and make new friends, but they also provide the chance to hear from CGD medical specialists on the latest treatments and developments.

COVID-19 meant that this year's family weekend could not go ahead, but we are hoping to plan some online activities to bring us together again and hope to hold our family weekend in 2022.

More information on some of our achievements over the last 30 years can be found [here.](#)

In memory



