

September e-news

Dear CGD Society member,

Welcome to this September issue and we would like to send a warm welcome to any new members who have recently joined the charity.

Latest news

Back to school



Although some children have returned to school already, the start of the Autumn term after a long summer break can be a little daunting at the best of times. Going back after having months away from the classroom during a pandemic may understandably lead to feelings of anxiety and uncertainty for both parents and children.

With this in mind, we have updated [our dedicated COVID-19 information page](#) with the latest advice on returning to full time education at school, college, or University.

Important research update - International study of BMT outcomes



The largest study ever conducted on the success rate of bone marrow transplants (BMT) for CGD finds excellent outcomes. Chair of Trustees, Geoff Creamer, says on this very important piece of research – *“The use of BMT for CGD patients has transformed many lives providing the option of a potential cure. However, it is not without risk, so for families making this decision, they rely on good quality data, particularly for older patients where fewer have been treated and where the protocol is trickier. This report is excellent news for our members and their clinicians. The results, from a large body of data, are very encouraging and will provide a great basis for those affected to decide how to proceed. BMT is not for everyone, but this report demonstrates that where it can be used, it is effective and with relatively low risk. This confirms that many CGD patients now have a reliable curative option which is great news”*

[Read more on the research.](#)

The UK national flu immunisation programme 2020-2021 update



As you know it is very important for those living with CGD to have the flu vaccination each year. Public health England have expanded this year's programme in light of COVID-19.

[Find out more.](#)

How can you help?

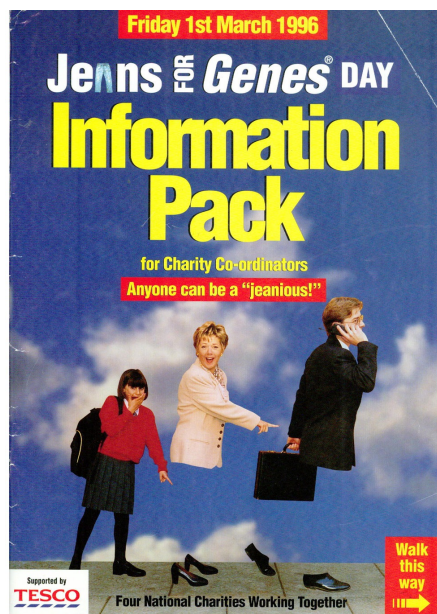
Once again, we would like to thank each and every one of you who have made donations or have taken part in fundraising events so far this year. Like many other charities we are struggling with the drop in income due to COVID-19. Every donation, however big or small does make such a difference and will allow us to continue as a charity. So how can you help? Read on ...

Jeans for Genes Day - 14th to 20th September 2020



2020 is the 25th year that Jeans for Genes Day has been raising funds to help children affected by some of the most serious and life-threatening genetic disorders.

Jeans for Genes Day has raised over £45million in its first 25 years.



Since its origination from CGD Society (then known as the CGD Research Trust) back in the beginning, Jeans for Genes has swept through the UK, covering everything it sees in a beautiful blue denim hue!

This fund and awareness raiser for genetic disorders in the UK is the largest of its kind and motivates schools, colleges, companies and communities to grab their denim and do good on the week in 14-20 September.

We take a fond look back at how it all started with words from the originator of the fundraiser herself – Rosemarie Rymer

Who came up with idea for Jeans for Genes? It was February 1992 and an amazing lady called Rosemary had a bright idea in the early hours of the morning, following a fundraising dinner for a new and very important charity, the

CGD Research Trust. She called her idea 'Jeans for Genes' – they would invite schools nationwide to wear jeans to school on a particular day in exchange for a donation of 50p. Rosemary said "the basic idea of a non-uniform day was slightly 'old-hat' but it had the vital ingredients of being simple to organise and easy to take part. The 'new' ingredient was the fact that children and students everywhere would be doing the same thing simultaneously.

Persistence and determination to keep going, come what may, was just part of the reason for the campaigns huge success. Following the 1992 and 1994 campaign's the CGD Research Trust offered Rosemarie Rymer a job to run the first joint Appeal, working firstly with the Primary ImmunoDeficiency Association (PiA), The Society for Mucopolysaccharide Diseases (MPS) and subsequently with Great Ormond Street Children's Hospital (GOSCH).

There is still time to sign up and get involved – in whatever way you can [click on the link](#) and join in today!

Social Fundraising



Did you know that Facebook helps you celebrate your birthday with your nearest and dearest with a charity donation?

Birthday fundraisers are a meaningful way of celebrating this special day and are great for those who are struggling to know what to buy you!

Two weeks before your birthday, you will see a message from Facebook in your newsfeed, giving you the option to make a fundraiser for your birthday.

Select the cause you care about (we believe you'll find it named as CGD Society!) and put in an amount you'd like to raise. Then you personalise it with your story and why you've chosen us and add a pic. Simply press create and send this out to all your family and friends, offering them a way to celebrate years of wonderful you while benefitting a cause close to your heart!

We get a notification when you choose us and are able to thank all your supporters for their kind gift directly. Their support means that our services continue and we can aim for our goal for a cure for all with CGD.

It's the gift that keeps on giving, [join us on Facebook](#).

Sporty fundraising - Go virtual



COVID has hit the charitable world pretty hard this year.

Studies from the Institute of Fundraising show that 92% of all charities reported a fall in income during lockdown and 91% of all charities have had to cancel events.

On a small charity scale like ours, only one in five small charities were able to provide normal services because of the pandemic.

We were extremely lucky to be one of those five and are so thankful to the donations, the fundraised income and events run by our supporters to continue our work.

However, we are still navigating choppy charity waters and we still need your help – more than ever before. We are still in need of people to get involved with fundraising to 'walk, ride, run or skip their talk' for CGD.

Traditional fundraising events have taken an online form, to ensure that charities can continued to be supported in these difficult times and here's a few ways you can get involved with fundraising for the services – like Helen – provided by The CGD Society.

Great North Run Reimagined (Virtual North Run 2020)

Date: 13 September

Entry: free

Distance: 13.1 miles

The Great North Run is the biggest half marathon in the UK and the World with over 57000 runners taking part in the famous 13.1 mile UK half marathon. Be part of the re-imagined virtual run, while fundraising for CGD Society!

[Click here to sign up.](#)

Edinburgh Marathon Festival (EMF 2020 Virtual Challenge)

Date: Complete your challenge before 31 December

Entry: dependent on distance running

Distance: from 5k & Junior 5k to Marathon

Entry benefits include:

- Can complete it over your own time
- Wicking finisher's t-shirt
- Finisher medal & keyring charm
- Finisher presentation pack
- Personalised finisher certificate
- Downloadable training plans
- Personalised Event Number & Information Pack

The first Edinburgh Marathon Festival Virtual Challenge with multiple distances to choose from. It's your challenge and your rules – complete your challenge in one day or over multiple days!

[Click here to sign up.](#)

Virtual Virgin Money London Marathon

Date: 4 October

Entry: available from Wed 26 Aug - £20 entrance fee

Distance: 26.2 miles

Entry benefits include:

- It's the 40th London Marathon – be part of history!
- Finisher Medal
- New Balance finisher T-Shirt

It's the spirit of the London Marathon in its 40th year – just in your own

surroundings! Take part in the 'mother' of all Marathons and benefit The CGD Society at the same time!

[Click here to sign up.](#)

Fundraise while you shop online

If you are not the sporty kind but would like to help us – do you know that you can help support CGD Society from your own home by doing very little other than your usual shopping?

As more of us use online shopping, this is a brilliant way to help your favourite charity (us!) at the same time AND at no cost to you.

HOW TO.... USE EASYFUNDRAISING



Before shopping, click on easyfundraising.org.uk and THEN search for your required retailer. Click shop now and shop as you normally would – there is no extra cost to you. The retailer will then give us a donation for you shopping – it's really that easy!!

HOW TO.... USE AMAZONSMILES



Visit [AmazonSmile](#) and choose us as your selected charity! Then just order whatever you've got to buy and Amazon will donate to our charity, again, free of charge to you. On this site, you are able to see how much you personally have generated for your charity so every time you need to buy something, we get something too– how lovely is that!

Thank you for taking the time to read this latest addition of CGD news.

Sending you all best wishes and good health,

Claire and Adelle



Sponsored by a grant from Orchard Therapeutics



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