

July e-news

Dear CGD Society member,

Welcome to our July edition. We hope you are well and keeping safe as we continue to live in this new 'normal'.

Latest news

COVID-19

The COVID – 19 information pages on our website are continually updated to inform you of the latest guidance and information. With the UK government easing the shielding guidance we are aware that many of you may have questions or concerns. We also understand that some will feel anxious about entering the outside world.

Here you will find the latest guidance and some of our [tips for looking after your mental health](#) during this easing of lockdown.

We have also [updated our Frequently Asked Questions](#) page on COVID – 19. Here you will find a comprehensive list of FAQ's that cover areas such as testing, the latest research and potential treatments to Mental well-being.

Shielding stories



We would like to once again thank our [members who have shared their shielding stories](#) with us. It was also lovely to hear from one of our members from the US. We are aware that we have a large non-UK community so it was really informative to see how lockdown has been for them. Being away from family and friends and not being able to enjoy the outside has been extremely difficult for many. We hope these stories are relatable to you.

If you'd like to share your lockdown and shielding experience with us, [please email us](#).



On a little lighter note for lockdown we asked our Technical Director, Dr Susan Walsh, for her personal reflections during lockdown and what she has personally learnt about herself, during this period. Here is what she said.

"Self-awareness is a wonderful thing and although I have always suspected it, I can officially confirm I am a hoarder.

Having time to spare at home, as most of us have, I decided to start a clear out of a few cupboards and found a stash of old spectacles - 12 pairs and 16 spec cases.

Some of the specs had only one branch arm working, one pair had gaffer tape in the middle holding the frame together (shame on me), and others were fully functional but from a bygone era when I was very much younger. These specs still looked good on me but could I see anything clearly – no. And it was at this point the song by Cher popped into my mind 'If (I) eye could turn back time' (apologies, it really did as that's how my brain works).

Unfortunately, the rejuvenation of my eyesight is never going to happen, so I'll be back to my local Specsavers when it reopens, (other retail outlets are available), to add my vintage collection to their recycling box.

Conclusion, I have turned into my Great Auntie Rachel and Uncle Arthur, who after they passed away, drawers full of NHS specs and dentures were found. These were free on the NHS at the time (many decades ago) and obviously my dear Aunt and Uncle were good 'customers'. The good news, I still have my own teeth.

I will end with - after a disastrous first attempt at cutting my partner's hair and making a botched job of a second go I have been instructed to do an online hair cutting course. Nothing like expanding your skill set at a time like this. Who knows I could be the next Vidal Sassoon – now that comment really dates me!"

Thank you SO much Susan for sharing - we love your personal insight!

Your CGD stories



We know how important and helpful it is for many of you to be able to read about other people's lives living with CGD. We have two stories from our members, Aydin's as told by his Mum, Carly and we have Alex's Creamers story. From the challenges they have had to overcome, to recovering from a Bone Marrow Transplant [we hope you find these stories relatable](#)

We are very keen to feature more stories, especially those from X-Linked carriers and those who have not had a BMT. We would also like to feature stories by video. If you would like to be featured in next months newsletter and on our website, then please do [get in touch](#).

Fundraising

Shona Munro - 60k in 31 days



Thank you shout out to Shona who is fundraising for us here at CGD Society by running a virtual 60k in 31 days! Shona is no stranger to fundraising for CGD Society having completed the Stamford Santa Run twice, in support of her partner Josh who is recovering from recently receiving a BMT. In these uncertain times, the donations we receive from fundraising events has really dropped so we really appreciate you going the extra K for us Shona!

If you can, please show your support for Shona [by visiting her Just Giving page](#) and leaving a donation or a message of support for her. Go Shona! We are behind you all the way!

easyfundraising - help out while you checkout!



Fancy donating to CGD Society without it costing you a penny? Then read on! Easyfundraising is the UK's biggest fundraising site. It's simple to use and it's free. All you need to do is [register with easyfundraising](#) and it takes you through the very simple steps. By shopping through their website as a starting point, they then coordinate with all the retailers there to make a small donation to our cause, just to say 'thank you' really!

There are over 3,500+ retailers including the big names like John Lewis, M & S, Expedia, Amazon, eBay, all the major supermarkets – plus a wide range of smaller and more niche online shops and stores.

And the best news? There is no catch. Whatever you buy costs exactly the same as if you would have visited the retailer site directly. They do not take any financial information from you as all your transactions are with the retailer. Plus, they will not sell your information or spam you – and it doesn't cost you or us a penny.

An average person can easily raise over £100 per year – imagine if all the CGD community, friends and family used it – we'd receive a much needed boost to our funds at no cost to anyone!! [Check it out](#) at and let the online, no cost to anyone fundraising begin!

Jeans for Genes 2020



Are you ready for a demin-packed week of opportunities this year? From Monday 14th to Sunday 20th September, there is a whole menu of ideas and ways you can get involved with this fundraiser for children with genetic conditions in the UK.

[Check out all the amazing ideas and resources available for this year's event](#)

Or perhaps you like your support a little more wearable? Well, this year limited edition merchandise is solid 24 carrot gold featuring the world's most charismatic rabbit – Bugs Bunny himself!

This year sees a wonderful collaboration between Warner Brothers UK, Kingston School of Art and Jeans for Genes to bring a stylish merchandise range which will look perfect with your favourite jeans! As well as T-shirts for the adults there is also a range of sizes for the little ones.

Interested? Then head to [the only place you can pick up this incredible merchandise](#) and order yours today!

Thank you for taking the time to read this latest edition.

Best wishes,

Claire and Adelle



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