



### May e-news

Dear CGD Society member,

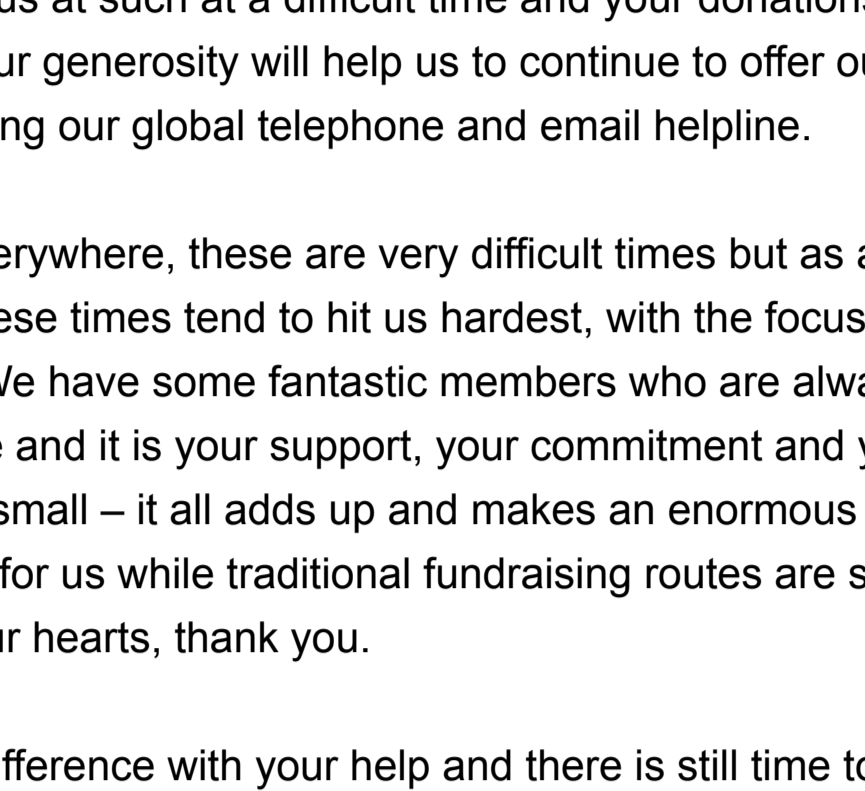
Welcome to our May edition and greetings to our newest members who have joined, with many of you living outside of the UK. Here you will find the latest news, events and developments within the CGD Society.

We have all been affected by the Coronavirus and our way of life has changed dramatically. We are aware of the impact this will have on individuals, families, carers and carriers affected by CGD. Some may have been in self isolation for some time now which can lead to feelings of loneliness and frustration which can be felt within other members of your household. Although we are all social distancing – you are not isolated or alone. We want you to know we are here for you.

As you may be aware, we have a dedicated page on the Coronavirus on our website featuring FAQs for families living with or affected by CGD. We've also included advice on your emotional wellbeing which lists some truly wonderful groups, projects and services out there who are specialised in this very area.

While we all get used to our new kind of 'normal', we have included a list of things to do and take part in during isolation for both children and adults. Please let us know of any other virtual activities you have found and we'll include them! We are definitely all in this together and any top tips, new virtual experiences and recommended sites are thoroughly welcomed!

Please visit our [dedicated Coronavirus page](#).



We would like to say a huge thank you to everyone including our non UK members that have so far responded to our Emergency Coronavirus Appeal by making donations or offering your time to help us continue as a charity.

Honestly, we can't thank you enough – we've are truly overwhelmed. You have been so generous at such a difficult time and your donations are very much appreciated. Your generosity will help us to continue to offer our many services, including our global telephone and email helpline.

For charities everywhere, these are very difficult times but as a small but vital organisation, these times tend to hit us hardest, with the focus being on the larger groups. We have some fantastic members who are always willing to help and donate and it is your support, your commitment and your donations – however big or small – it all adds up and makes an enormous difference. It is a huge challenge for us while traditional fundraising routes are suffering, so from the bottom of our hearts, thank you.

You make the difference with your help and there is still time to chip in by donating to [our emergency appeal on JustGiving](#).

We honestly couldn't do it without you.

Stay safe, keep well and we will get through this together.

Best wishes,

Claire, Adelle, Susan, Helen and trustees.

### Latest News

#### Welcome to the new members of our team



Jayne Nicol joined the trustee board in January 2020 to become our newest trustee. Jayne is a registered nurse and solicitor specialising in medical law. She was an in-house solicitor for several London teaching hospitals before spending 10 years living and working in the developing world in the charitable and medical sectors. She has a special interest in palliative care and life limiting conditions and currently works as a hospice nurse.



At the start of April 2020, we welcomed Adelle Scott to our team as our Fundraising and Marketing Officer. Adelle will be working from home part time to support myself, Claire Jeffries, as I have successfully been promoted to the Operations and Fundraising Manager. I am so happy to have Adelle working along side me and she has a wealth of experience and an endless supply of enthusiasm for our cause. I am sure you will be speaking to Adelle very soon. Here is what Adelle has to say:

*Hello all - I'm Adelle Scott and I'm beyond excited to be joining The CGD Society as Marketing & Fundraiser Officer.*

*Professionally, I have worked in the NGO sector for over 20 years in total, with experience and track record in designing, developing and delivering high impact communication, fundraising and marketing strategies.*

*Over my career, I have been responsible for a diverse range of charitable activity from the creation, management & delivery of integrated CRM strategies to devising and driving new fundraising and income streams. I have built volunteer programmes with a 95% retention rate and co-created global product fundraising marketing campaigns, along with commercial content and in-store communications for 3,000 stores in over 60 countries.*

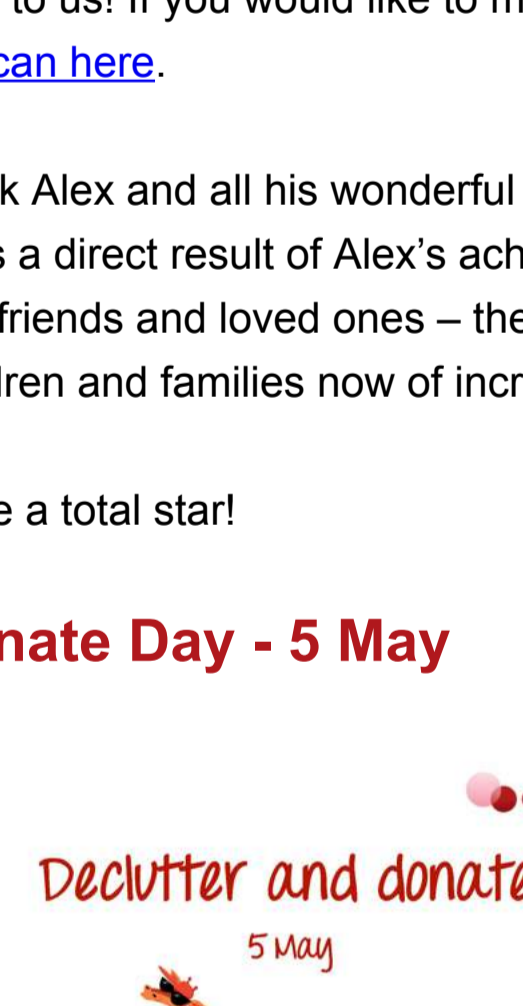
*I'm passionate about communication and storytelling – as an Aunt to some pretty incredible (but discerning nephews and nieces), I know the power of a targeted message to the right audience, delivering it creatively whilst engaging, educating and empowering the listener!*

*Positive social change totally ignites me; I am as committed to assisting extraordinary charities and organisations as I was when I joined the sector as a mere youngster. I am inspired daily by the people whose stories touch and drive my desire to make things just a little bit better.*

*I am also looking forward to working with Claire and the team at CGD Society on all the charities activities and events and can't wait to meet/hear from you all in the days to come!*

Welcome Jayne and Adelle. 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.

### Rare Disease Day 2020



To mark this year's Rare Disease Day, 29th February, myself and Simon Bostic, who has CGD, were invited to speak at the London Office of Orchard Therapeutics, a biotechnology company who are developing a Gene Therapy treatment for CGD.

Simon spoke candidly about his life with CGD and how this has affected his mental wellbeing.

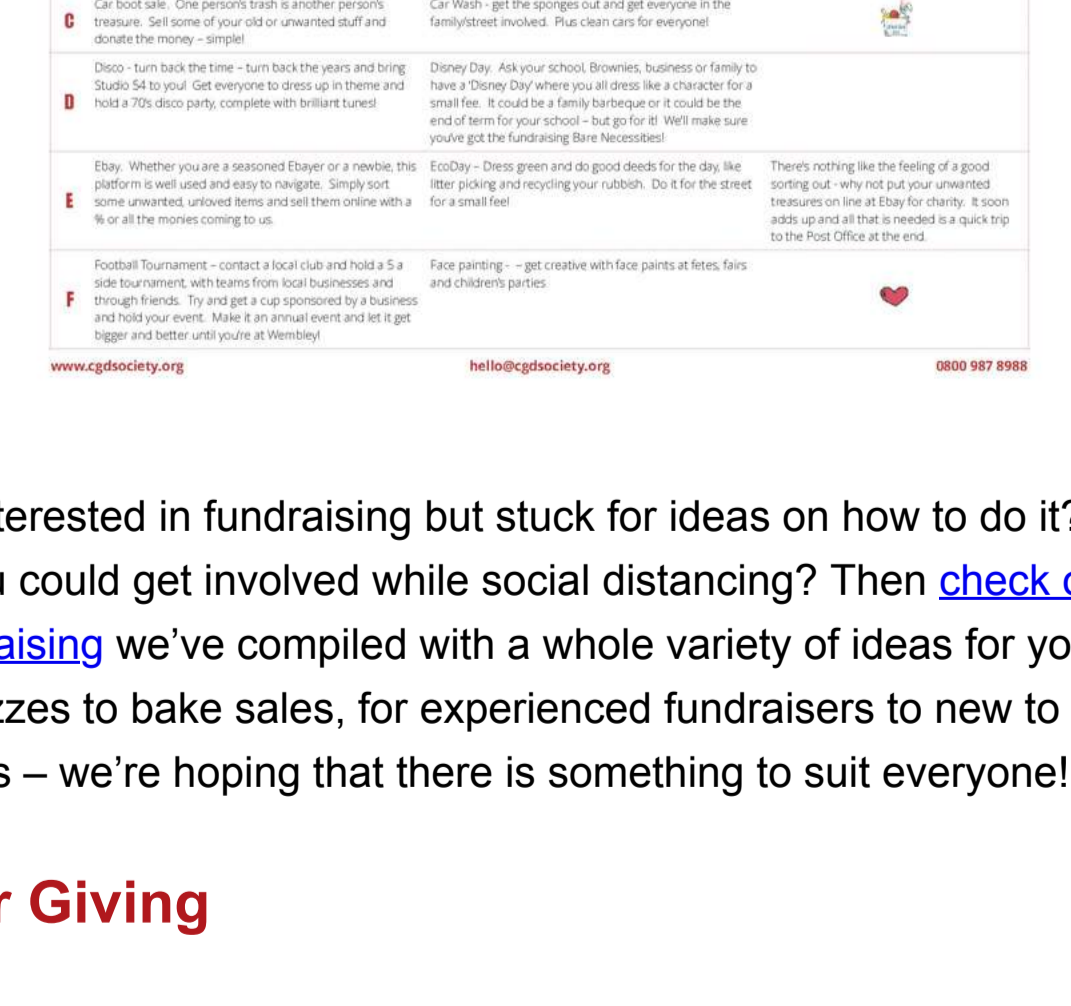
I got the opportunity to speak about the CGD Society, the work we do, the support we provide the CGD community and about my experience with CGD. It was a successful day and the team at Orchard Therapeutics made us feel very welcome. We would also like to thank those who made a donation to our charity, it is very much appreciated.

### FAQs on the Coronavirus

I am sure there are many questions you may still have regarding this pandemic, so we have put many of your [frequently asked questions](#) together on our website

We hope you find this informative and please do [contact us by email](#) or call 0800 987 8988 if you do need support at this time.

### Your fundraising

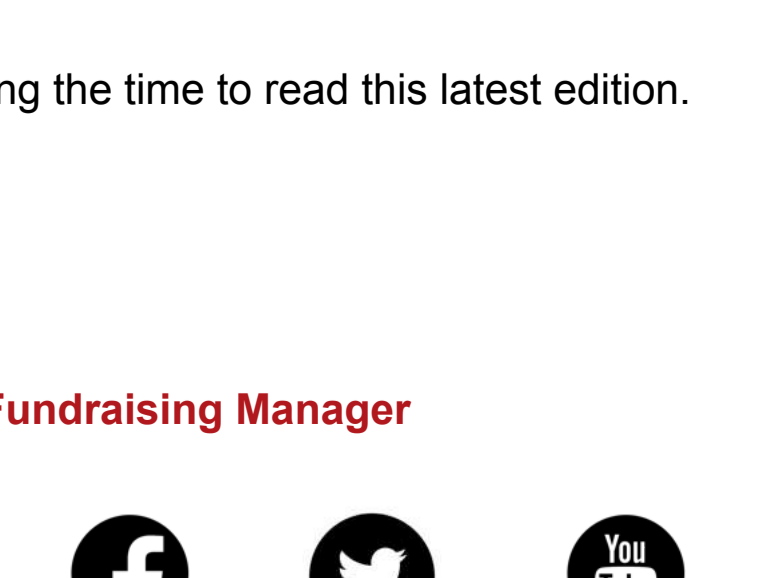


Huge trumpet thank you fanfares to the wonderful Alex who took part in the 2.6 Challenge for us, running lengths of his garden for 2 hours 36 minutes, all to benefit the CGD Society. Alex has – to date - raised over £2,000 but also ran a challenge within a challenge asking donors to guess how many lengths he ran during this time – bearing in mind his garden is 8 meters long! The total amount of lengths run was 1,705 and not content with running for two hours in the sun, Alex also doubled the donation of the correct guess – incredible commitment and support to us! If you would like to make a [donation towards Alex's achievement you can here](#).

We'd like to publicly thank Alex and all his wonderful supporters for this incredible fundraiser – as a direct result of Alex's achievement and all that love and support from family, friends and loved ones – the money raise will allow us to be there for more children and families now of increased need.

Thank you Alex – you are a total star!

### Declutter and Donate Day - 5 May



In support of global fundraising day #GivingTuesdayNow, we are challenging our UK supporters to get involved and #DeclutterAndDonate on Tuesday 5 May. This fundraiser doesn't cost you a penny, it's minimal effort AND you get nice, clean rooms too!

[World of Books Group](#) and [Virgin Money Giving](#) launched a partnership last month to provide an alternative way for supporters to support charities by turning their unwanted books, games, DVDs and CDs into cash for good causes, and have now launched a campaign to promote the idea in the run up to [Giving Tuesday Now](#).

The service is provided by [Ziffit](#), a free app and website to sell unwanted books, CDs, DVDs, Blu-rays and games for cash.

Without leaving your homes, you can scan the barcode on their unwanted books and media through the Ziffit app or enter the details manually online and get a cash value which they can then pass, via Virgin Money Giving, directly to a charity of your choice (which we are kind of hoping will be us, it should be said!!). All the funds raised, including Gift Aid where applicable, will go to your chosen charity. The service is free and goods can be collected by a Ziffit courier service.

So, what are you waiting for? Get rummaging, sorting and get decluttering and donating today!

### A-Z Fundraising



Are you interested in fundraising but stuck for ideas on how to do it? Thinking of how you could get involved while social distancing? Then [check out our new A-Z Fundraising](#) we've compiled with a whole variety of ideas for you from online quizzes to bake sales, for experienced fundraisers to new to the game fundraisers – we're hoping that there is something to suit everyone!

### Regular Giving



Every pound makes a difference.

If you would prefer to make a regular donation or contribution to help ensure our vital services continue, please visit [our website](#) and select your preferred giving avenue.

And thank you. It really does mean the world knowing you are on our side to help us, not just at this difficult time but every day. Together, we will achieve our goal for a cure for all with CGD and until then, we will continue to offer information, support and advice for individuals and families living with and affected by CGD – wherever they are in the world.

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

Best wishes,

Claire Jeffries

Operations and Fundraising Manager



Call us on: 0800 987 8988

Email us at: [hello@cgdsociety.org](mailto:hello@cgdsociety.org)

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

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