

## CGD Society February News

Dear CGD Society member,

Welcome to this February 2022 edition of our latest news. We would also like to send a warm welcome to new members who have recently joined us.

### Latest news

#### Rare Disease Day 2022

**I SUPPORT  
RARE DISEASE DAY  
28 FEBRUARY 2022**  
#RAREDISEASEDAY RAREDISEASEDAY.ORG



This year's Rare Disease Day is on the 28th of this month. This annual campaign raises awareness and generates change for the 300 million people worldwide living with a rare disease, their families, and their carers.

Thousands of events in over 100 countries will be taking place to mark this occasion. If you are taking part in an event or if you would like to share any photos of you and your family to help us raise awareness of CGD, then please do contact Claire at [hello@cgdsociety.org](mailto:hello@cgdsociety.org). We would be delighted to share your lovely photos on our social media platforms leading up to Rare Disease Day.

You can also share your story and experience of living with a rare disease with Rare Disease UK by taking part in their rare repository. [Find out more here.](#)

To find out more about the Rare Disease Day campaign [click here.](#)

#### Speaking at the Westminster Health Forum



### Case Study – The Challenges of CGD



Chronic Granulomatous Disorder is a rare, inherited, life-limiting immune disorder, where children and adults get frequent bacterial and fungal infections, which can be serious and life-threatening<sup>1</sup>

#### Diagnosis

It can take years to reach a correct diagnosis, with misdiagnoses such as Crohn's disease leading to inappropriate treatments



#### Awareness Among Healthcare Professionals

Lack of awareness can lead to life-threatening decisions to not admit patients who could be experiencing a serious infection<sup>2</sup>



#### Coordination of Care

Lack of communication and collaboration between medical teams has a detrimental effect on patient health and mental wellbeing



#### Access to Specialist Care, Treatments and Drugs

Despite national guidelines,<sup>3</sup> some patients are still being denied access to dedicated, specialist centres that can offer bone marrow transplants



1. CGD Society. About CGD > CGD – The Basics. Available at <https://cgdsociety.org/about-cgd/cgd-the-basics/>. Last accessed 21.01.2022; 2. Rare Revolution. CGD Society: History and Development. Available at <https://edition.pagesuite-professional.co.uk/html5/reader/stage/default.aspx?localhost=true&pubname=Redid-01d6b6fa-8962-45a5-8195-6b81c2af6316&num=51>. Last accessed 24.01.22; 3. NHS England. P01: Blood and Marrow Transplantation. Available at <https://www.england.nhs.uk/commissioning/spec-services/psc-org/blood-and-infection-prowe-692/>. Last accessed 25.01.22; With thanks to Claire Jeffries, Operations and Fundraising Manager at the CGD Society and Helen Braggins, CGD Clinical Nurse Specialist.

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On Monday the 31st of January 2022, our trustee, Annabel Griffiths, gave a presentation at the online Westminster Health Forum policy conference discussing priorities for rare disease research, diagnosis, and care in the UK.

Annabel, who is Head of Rare Diseases at Costello Medical, spoke about CGD and the difficulties faced by patients when diagnosed, awareness of CGD amongst medical professionals, coordination of care and access to specialist treatments.

Well done Annabel and thank you for your continued support in raising awareness of CGD.

#### Covid-19 Vaccines

The UK has approved a fifth Covid-19 vaccine developed by US company Novavax, which offers up to 89% protection against Covid illness.

[Found out more here.](#)

#### UK Rare Disease Framework

The UK Rare Disease Framework lists the priorities and underlying strategic themes that detail how the UK will address the challenges faced by those living with rare diseases.

It will ensure that the lives of people living with rare diseases continue to improve. It will work across the 4 nations of the United Kingdom to ensure that rare disease patients receive the best possible care, building on the commitments in the UK Strategy for Rare Diseases and major advances in the diagnosis and treatment of rare diseases. This framework will develop positive change in how we diagnose, treat and care for patients with a rare disease.

The UK Rare Diseases Framework outlines 4 high-level priorities for rare diseases in the UK over the next 5 years:

- helping patients get a final diagnosis faster
- increasing awareness of rare diseases among healthcare professionals
- better coordination of care
- improving access to specialist care, treatments, and drugs

England's National Action Plan is due to be published on Rare Disease Day. More news to follow in our March newsletter.

You can find out [full details here.](#)

#### Your Opinion Matters



As a small charity with limited resources, we always strive to provide the best support and information to the CGD community here in the UK and around the world. You may be aware that our charity has been providing this support for 30 years.

Every year, trustees and staff meet to discuss and reflect on the charities previous year's successes and challenges to help us plan future activities whilst considering the funds available to us. The needs of the CGD community are the driving force in any decisions made by the board of trustees, so we would like to hear from you.

We have created a CGD Society member survey that gives you the opportunity to give your feedback on our charity in 2022. Amongst the things we want your feedback on are: the support services we provide, how we respond to your enquiries, our current website and if there any improvements we can make in supporting you. If you receive our survey, we would love to hear your feedback.

The survey is anonymous, so there is no need to give your name and it should take no more than 10 minutes to complete. Please see our [privacy policy as stated on our website](#).

If you would like to find out more about this survey, please contact Claire at [hello@cgd-society.org](mailto:hello@cgd-society.org).

Thank you.

## Join Us and Make a Difference



We are currently recruiting up to five new volunteer trustees to join the board of our charity. This is a fantastic opportunity for new and experienced trustees looking to make a real difference and grow their skills in the charity sector. You would be working alongside experienced board members who will support you in the role and necessary training will be provided.

To find out more and how to apply [click here](#).

## How You Can Support Us



From asking friends to donate in honour of your birthday to taking on a marathon, there are many ways you, your family, and friends can raise funds for our charity. Without your donations and fundraising we would be unable to support the CGD community.

Look at some of the ways [you can support us](#). Claire will fully support and encourage you with any of your fundraising activities or ideas. Please do contact Claire at [hello@cgd-society.org](mailto:hello@cgd-society.org) to discuss further. She would love to hear from you!

Thank you for taking the time to read this February edition. Wishing you all good health.

Best wishes,

Claire, Helen and trustees



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Call us on: [0800 987 8988](tel:08009878988)

Email us at: [hello@cgd-society.org](mailto:hello@cgd-society.org)

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

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