CGD Society April news

Dear CGD Society member,

We hope you are keeping safe and well. Please read on to find out our latest news and updates.

If you have any news you would like to share with us and would like to be featured in future news updates, please contact Claire at hello@cgdsociety.org or call free on 0800 987 8988.

Latest news

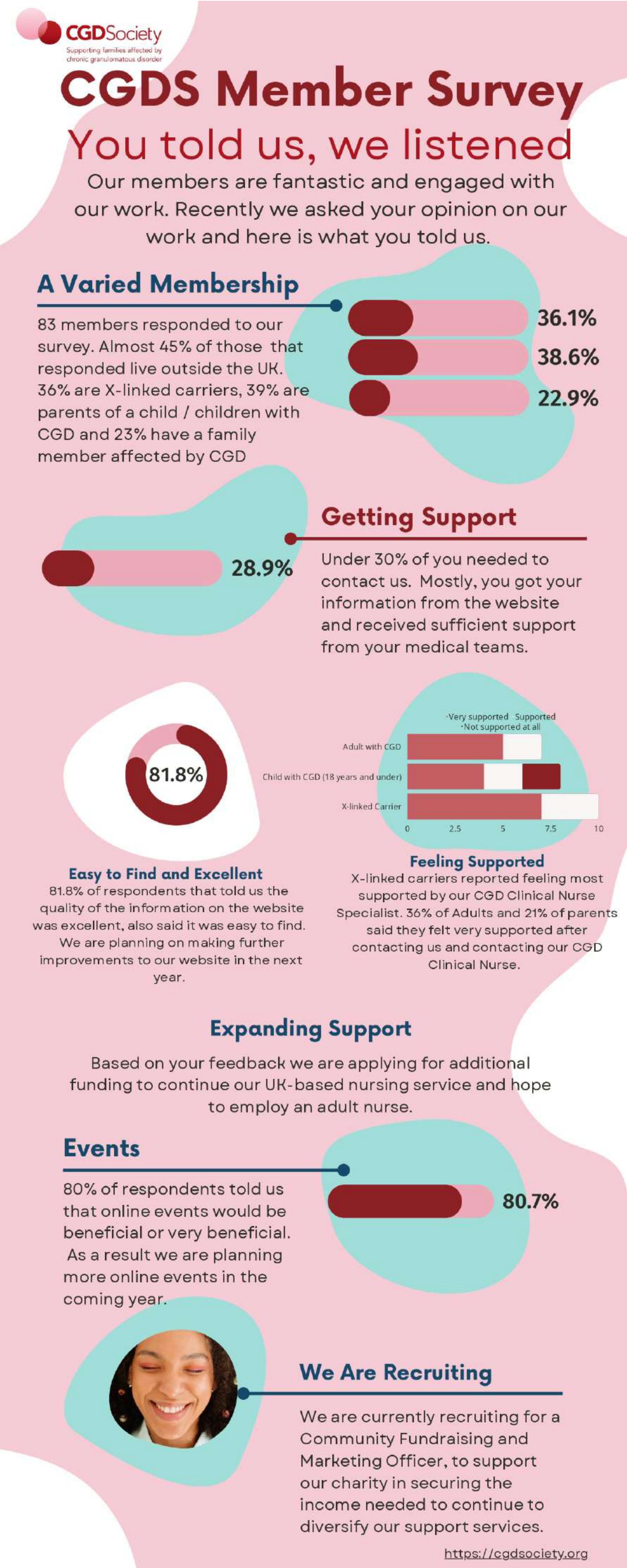
Membership survey

In February we asked you, our members to complete our member survey 2022. The aim of the survey was to gain feedback on how well our charity is providing support, areas we can improve on and to provide evidence when applying for funding to increase our services.

Who responded?

84 people responded to the survey. Of these almost 45% live outside of the UK. 39% of respondents were a parent of a child/children with CGD, 27% of those have a child/children over the age of 18.

Key findings



CGDS Member Survey

You told us, we listened

Our members are fantastic and engaged with our work. Recently we asked your opinion on our work and here is what you told us.

A Varied Membership

83 members responded to our survey. Almost 45% of those that responded live outside the UK. 36% are X-linked carriers, 39% are parents of a child / children with CGD and 23% have a family member affected by CGD

Getting Support

Under 30% of you needed to contact us. Mostly, you got your information from the website and received sufficient support from your medical teams.

Easy to Find and Excellent

81.8% of respondents that told us the quality of the information on the website was excellent, also said it was easy to find. We are planning on making further improvements to our website in the next year.

Feeling Supported

X-linked carriers reported feeling most supported by our CGD Clinical Nurse Specialist. 36% of Adults and 21% of parents said they felt very supported after contacting us and contacting our CGD Clinical Nurse.

Expanding Support

Based on your feedback we are applying for additional funding to continue our UK-based nursing service and hope to employ an adult nurse.

Events

80% of respondents told us that online events would be beneficial or very beneficial. As a result we are planning more online events in the coming year.

We Are Recruiting

We are currently recruiting for a Community Fundraising and Marketing Officer, to support our charity in securing the income needed to continue to diversify our support services.

https://cgdsociety.org

Some of the key findings from the survey can be found in the above infographic. They include:

- 82% of respondents told us the quality of the information on the website was excellent and easy to find. We are planning on making further improvements to our website in the next year.
- Fewer than 30% of you needed to contact us. Mostly, you got your information from the website and received sufficient support from your medical teams.
- 80% of respondents told us that online events would be beneficial or very beneficial. As a result, we are planning more online events in the coming year.

A full report on the survey will be published soon and will be uploaded onto our website. We were truly overwhelmed by the response rate and really value your comments and suggestions.

The results from this survey formed a key part in this year's strategy meeting held last month, which was attended by trustees and our Operations and Fundraising Manager, Claire. We listened to your feedback and put together an achievable strategy that will lead the charities objectives for this year as we look to continue and improve support for those affected by CGD.

This meeting also provided the opportunity for the team to meet face to face after 2 years of online meetings. Online really is different from meeting physically and the meeting was a great success. Below we hear from some of our trustees:

Andrew Orchard says: *"Our strategy meeting highlight was seeing the team face to face for the first time in 2 years including meeting our newest trustees in person for the very first time. Like many businesses, we have had to change our mode of working and while Zoom meetings will continue to have their place, our physical get-together was both enjoyable and productive. We concluded by setting ourselves some challenging tasks for the next few years, some of which* *are already in motion, with the overall aim of improving the lives of those affected by CGD."*

Geoff Creamer reports: *"It was a privilege to get together in person after 2 years of Zoom meetings and especially to meet three new trustees for the first time. We had a constructive day revisiting our strategy in conjunction with the survey results and other inputs to develop a set of goals for the new financial year which look challenging but achievable."*

Annabel Griffiths says: *"The meeting was a great opportunity to reflect on the achievements of the CGD Society over the last year and learn from our members about what they would most like to see next from us. It was really exciting to set our ambitious objectives and priorities for this next stage, and I look forward to working with staff and trustees to make these goals a reality."*

Kultar Shahi says: *"It was a pleasure to be able to meet (nearly) all trustees in person in my first official board meeting as part of CGD Society. The meeting was very productive as it enabled us to review the issues affecting the charity and CGD patients, and then decide the best way to start addressing these over the coming year."*

Thank you to everyone who completed the survey.

Online coffee and a chat

We are hoping to put together the next family conference as soon as we can but with covid still part of our lives and some travel restrictions in place this will not take place until next year at least. However, the survey results informed us that people would like to take part in online events.

Join us online for our first coffee (or beverage of your choice) and chat with our CGD Clinical Nurse Specialist, Helen Braggins and Operations and Fundraising Manager, Claire Jeffries. Taking place via Zoom on the 24th of May at 7pm-8pm BST this is a chance to finally get together and find out how you are doing. It also provides the opportunity for you to discuss any concerns you may have regarding health and wellbeing with Helen.

This will be on a first come first serve basis and numbers will be limited to 12 people. Of course, the whole family are welcome to join in if you are one of the 12. To join us please email Claire at hello@cgdsociety.org who will provide you with the Zoom invitation.

We cannot wait to see you and to organise more online events so that everyone has the opportunity to take part.

New drugs to fight superbugs

Antimicrobial resistance is a major issue which threatens to set modern medicine back to the pre-antibiotic era. Two new medications, cefiderocol and ceftazidime with avibactam, which fight drug-resistant superbugs could soon become available to NHS patients in England. Approved in draft guidelines from the National Institute for Health and Care Excellence (NICE), these two drugs will help patients with risky urinary tract infections, pneumonia and sepsis.

Full details can be found here.

World PI Week

World PI Week
TEST • DIAGNOSE • TREAT

World PI Week offers an opportunity to inform and educate health policymakers, schools and families, and the general public about primary immunodeficiencies (PI) to drive the earliest possible diagnosis and optimal treatment. This year's world primary immunodeficiency week, 22nd – 29th April, focuses on the importance of access to healthcare. To find out more information please visit this link.

Your health records

We advise you to check your health records with your GP to make sure all medications and alerts on your CGD status are up to date. This is especially true for x-linked carriers. If you have not made your GP aware of your carrier status, you could be missing out on treatment and care. We are aware that many GPs have little knowledge of CGD so it may be worth asking them to put our emergency medical information sheet in your records, so GPs and other medical teams have easy access to it. You can find this sheet here.

We need your support

We have seen a fall in donations and fundraising in the last couple of months. With families and individuals facing a significant increase in the cost of living we know times are tough so we would be extremely grateful for your support. If you can, please help us continue delivering valued activities and services by making a small donation, fundraising, buying a One Lottery ticket or taking part in the many other ways you can support us. You can find more details here. Thank you!

We hope you enjoyed reading our latest news. If you have any questions, please get in touch. We would love to hear from you.

Thank you for taking the time to read our latest news. Wishing you all good health.

Claire, Helen, and Trustees

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