

November enews

Dear CGD Society member,

Welcome to our November edition, featuring news and your fundraising stories.

Research funded by the CGD Society



Researchers at the University Children's Hospital Zurich, Switzerland, have developed a promising new low-cost and fast method of diagnosing p47phox CGD. The work, published in the journal *Molecular Therapy – Methods & Clinical Development*, was part-funded with a grant in 2016 from the CGD Society.

[Find out more.](#)

World Antibiotic Awareness Week



As part of preparations for the 2019 World Antibiotic Awareness Week this November, a group of senior leaders from across the health system, including NHS England and NHS Improvement, has co-signed a letter that reminds commissioners and providers alike of their responsibility to avoid the further emergence and spread of antibiotic resistance.

[Find out more.](#)

Department of Health and Social Care

Give your opinion on the key challenges facing the rare disease community in the UK. Patients, families, carers, medical professionals specialising in rare diseases, GPs, clinical academics and industry experts are invited to take part in this Department of Health and Social Care survey.

[Access the survey here.](#)

Share your story



We would like to feature on our website your stories about living with CGD, being a carer or an X-linked carrier. We would also like to hear from members who have had a BMT or gene therapy and find out how this treatment has impacted on your life. Whether you share your journey to diagnosis, details of the treatments you receive or your top tips for living life to the full, sharing your story about how CGD affects your everyday life can help others who may be experiencing the same thing.

If you would be willing to share your story with others, then we would very much like to hear from you. We will always change the names in your story to protect the identity of individuals, if requested.

If you would like to contribute a story, then please contact Claire Jeffries at hello@cgdsociety.org.

Fundraising

We really do have great supporters who are willing to take on challenges to help us continue supporting families and individuals living with CGD. Here we say thank you to just some of those supporters.



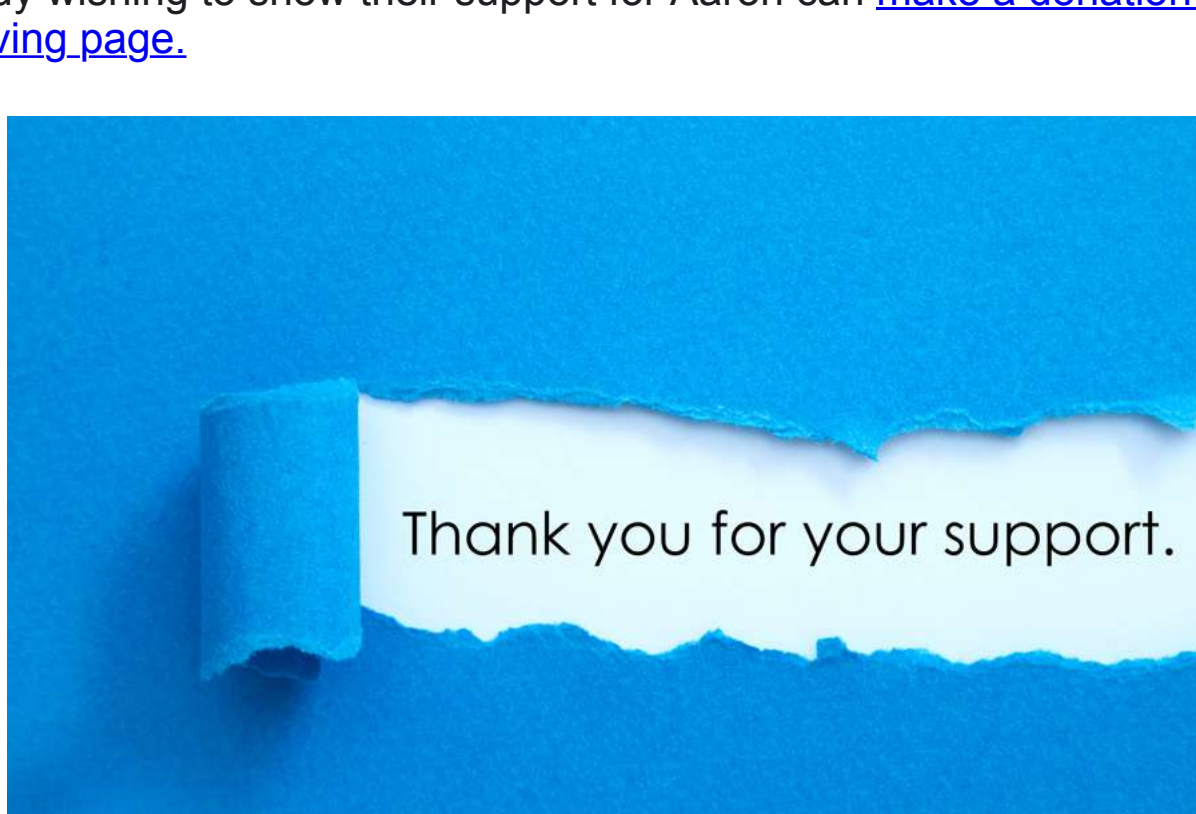
Huge congratulations to Ronja and Dom for completing the Cardiff Half Marathon on 6 October, in aid of the CGD Society. Ronja and Dom ran in memory of Josh Rogers. Dom finished in 1 hour 56 minutes and Ronja finished in 2 hours 20 minutes. They have so far raised an impressive £597.50. Thank you, Ronja and Dom, your fundraising is very much appreciated.



We would also like to say a big thank you and well done to Rob and Rachel Fisher who completed the 5k Big Fun Run on 19 October at Crystal Palace, London. So far, they have raised a fantastic £460. Thank you for taking part, Rob and Rachel, and for raising so much money for the CGD Society.



Aaron Williams and his friend have signed up to take part in the Cardiff Trail Half Marathon on 10 November. You may remember Aaron and his friends completed the Tough Mudder 5k Urban Bristol on 6 July and raised over £500. Aaron has also completed a successful BMT for CGD nearly two years ago. Good luck, Aaron. Anybody wishing to show their support for Aaron can [make a donation on his JustGiving page.](#)



A huge thank you to everybody who has made a donation, held a fundraiser, completed a sporting challenge or helped us to spread the word about CGD. So far this year, your generosity has made it possible for us to provide financial support to six UK families, through our Family Support Fund. These families have either experienced a long hospital stay in order to receive treatment for CGD or had a child undergo BMT, requiring the family to take time off work and move close to the hospital. We are so grateful because #YouMadeItHappen.

I hope you enjoyed reading this edition. If you would like to feature in future news updates, then please contact me at hello@cgdsociety.org

With best wishes,

Claire Jeffries

Charity Coordinator



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