

September enews

Jeans for Genes Day 2019



You still have time to sign up your school or workplace to take part in this year's Jeans for Genes day. This year you can choose your denim day from Monday the 16th – Friday the 20th September. To celebrate the day and raise funds you could wear denim from top to toe, bake blue cupcakes or even dye your hair blue! Whatever you decide to do you will be making a big difference to the lives of children living with a genetic disorder. You can find out more on where your fundraising goes and what [difference you can make here](#).

Jeans for Genes Day is also the main source of income for the CGD Society. The CGD Society receives a fee for the use of the Jeans for Genes trademark and it is this income, as well as from individual fundraisers and donors, that funds our support services and research programme.

Please [sign up today](#) to receive your free fundraising pack.

Your fundraising



We would like to say thank you and congratulations to Marco Maddalena for taking on the challenge of the Prudential Ride London on the 4th August. This is a gruelling 100-mile cycle ride and Marco finished in an impressive time of 5 hours and 37 minutes.



We would also like once again to thank Sunita Devi-Paul and her family and friends who had their heads shaved or their hair cut very short to raise funds for the CGD Society. Sunita and seven family members who took part have raised over £6,000 so far. Sunita's son Raylen has just recently received a BMT and is making great progress in his recovery. We can not thank you enough Sunita.

Good luck goes to both Rachel and Robert Fisher who are taking part in the Big Fun Run on the 19th October at Crystal Palace Park London to raise money for us. We are so pleased that you are taking part and we can not wait to see the photos of the day! We will keep you posted on their progress.

There are still places available for the Big Fun Run if you would like to take part. The run takes place in various locations throughout the UK and the locations left that you can take part in are:

- 1) Maidstone on Saturday 14th September
- 2) Dartford Sunday 15th September
- 3) London Crytsal Palace Park Saturday 19th October

4) London Victoria Park Sunday 20th October

[Find out more.](#)

Latest news

The CGD Society has added its logo and support to Genetic Alliance UK in its endorsement of newborn screening for rare conditions. This could potentially have positive outcomes in the early treatment of conditions such as CGD.

You can [read the full patient charter here](#)

As mentioned in our July newsletter we are currently in the process of updating our website. This is a very exciting time for the CGD Society so we are looking forward to sharing it with you when it goes live. Date yet to be confirmed. Would you like to be on our new website?

We want to feature relatable stories from our members describing life with CGD. You could be a carrier, relative, carer, pre or post BMT. It can sometimes help others to know they are not alone which can give some comfort.

If you are lucky enough to travel or go on an annual holiday and have CGD we would also like to hear about your adventures. We know holidays can sometimes be difficult for those living with CGD but you may have some tips or ideas that you would like to share.

We would like to hear from any of our members, UK or overseas so please do get in touch with Claire at claire.jeffries@cgdsociety.org if you want to take part

I hope you have all had a great summer. After a chilly and wet UK August, let's hope for a better start to Autumn.

Claire
Charity Coordinator



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