

# RUNNING FOR UNIQUE

## MEET OUR 2016 LONDON MARATHON TEAM



SUNIL DUGGAL

"I am running the London Marathon for my daughter, Marigold, who has trisomy 3q11 mosaicism. Unique has been a real lifeline to us as a family and we have found support and friendship through it.

The challenge of running the marathon is a daunting one but being able to do it for our little girl is all the motivation that I could ever need!"



SAM ROOME

I will be running for my daughter Tilly and specifically Unique. Since Tilly was diagnosed with a rare chromosome deletion in 2014, we finally had an answer to the quirksiness that is Tilly. But there is so little information on this area that without the support of Unique we would have felt completely isolated.

Unique connect and support families across the globe. Suddenly you are not the only parent with this specific deletion in the country but part of a global support network with access to information to support the various stages you will go through as a family.



MICK PARKER

"Hi, I'm Mick Parker. I've been a Consultant Clinical Geneticist at Sheffield Children's Hospital for 13 years. Many of the children I see have conditions for which the Unique Support Group offer invaluable, independent information and contact opportunities. I have previously attended Unique Family Conferences as an Expert Adviser and in 2012 I ran the Berlin Marathon for Unique. I have recently helped to write a Unique Patient Information leaflet for the SYNGAP1 gene, which is one of the more common genes recently identified as causing intellectual disability, through studies such as the DDD Study. I am privileged to continue to work with Unique and be part of their 2016 London Marathon team."



JANET HULLEY

I have been trying a few years to take part in this fantastic event - the London Marathon, this year I have finally got a place. OK, I'm bricking it, but at the same time really, really pleased.

Our Molly has a chromosome disorder, she has in technical terms "1 p 36 deletion" which results, in practical terms, in her having very severe learning difficulties.

I will do my very best to finish the run in a respectable time (no promises!) I would appreciate any support and donations you can make ... thank you everyone.



AMY JOHNSON

"Unique has provided incredible support to the family of my oldest friend from school, Samantha Roome, whose daughter Tilly has a rare chromosome disorder. The advice and help the charity has given in helping them to understand this little understood condition has been vital and so I'm running the Marathon to help Unique continue to provide support. I work for Sky who have agreed to match anything I raise up to £300."



SALLY WATT

"I have decided to run the London Marathon inspired by my nephew, Jack, who has a rare chromosome disorder (he is 49XXXXY). He means the world to me and is a true inspiration, he has gone through so much and the thought of his cheeky face will keep me running!

Families really need specialised support and we are truly grateful to Unique for offering some of this and linking families together. I hope what I can raise will help and make a little bit of difference.

If you'd like to show your support for the Unique London Marathon Runners, you can sponsor them by donating on our website <http://www.rarechromo.co.uk/html/DonateNow.asp> and select London Marathon from the drop down box.

Unique wishes all of our runners the very best of luck and would once again like to say a big thank you for supporting us.