Invitation to help get new therapy research up and running for rare conditions!

Are you affected by (or look after someone who has) a blood or immune disorder, a genetic eye condition, or an inherited neurodevelopmental condition?

We are a team of Oxford researchers and clinicians applying for funding to set up a new Centre of Excellence in Advanced Therapeutics. If successful, this could be an important advance for patients with rare genetic conditions.

We are keen to involve people affected by these conditions and their families, to get your insights and feedback into our research proposals. You are invited to a meeting about the proposals in Oxford, Friday 28 July, 10am – 1pm. You will be paid for your time, and reasonable travel expenses will be paid.

There is also the possibility of becoming a member of our research team in the longer term.

The research aims to use precise information about the genetic changes underlying each of these disorders in order to design new technologies that might correct or improve them. These technologies include so called 'gene editing' therapies.

If you are free and interested in participating, please email me at ronjon.chakraverty@ndcls.ox.ac.uk, and let us know whether your experience is as a patient or the family of someone affected. It would also be helpful to understand what condition you have experience of.

If the responses exceed available spots, we will be in touch to explain how we will select people to ensure a range of conditions and experiences are represented at the meeting.

If you cannot come to meeting in July, please still let us know if you are interested in being involved as there will be other meetings and events in the future.