

About Ring20

Who we are...

Ring20 Research and Support (Ring20) is a support group for families established in 2014. We are based in the UK but our reach is worldwide.

Our key goal is to provide support for individuals, families and healthcare professionals who are affected by, or who come into contact with Ring Chromosome 20 Syndrome, r(20) syndrome – a rare epilepsy syndrome.

r(20) syndrome is an ultra-rare disease with difficult to treat symptoms including seizures and sometimes cognitive decline and behaviour disorder.

Our vision is to promote research, education and continuous support surrounding undiagnosed and misdiagnosed r(20) epilepsy.



What we do...

- **Supporting Families**

We provide a wide range of services to support your needs. We understand that receiving a diagnosis of r(20) syndrome can be difficult to understand and deal with, so you may have many questions. Whilst we do not give medical advice on treatments, we are here to provide you with lots of information about r(20) syndrome, including what it's all about, what to expect and where to get help!

You are welcome to phone or email us. We have online group chats, 1:1 video calls, or you can even attend one of our events in-person. We understand that everyone will have a different experience and will be on a different stage of their own r(20) journey, which is why Ring20 is here for you every step of the way.

- **Promoting Research**

Research is important to furthering our knowledge of r(20) syndrome and how the lives of those affected can be improved. This is done through finding more effective treatments and understanding how the needs of the individual and their families can be best supported.

Ring20 is active in raising awareness of r(20) syndrome working with researchers, neurologists and pharma companies, as well as exhibiting and speaking at conferences and events globally to help educate those who need it or those who are curious. We are continuously seeking partners from across the globe to collaborate with us and to help identify new opportunities for research and funds to help get basic research projects started.

Get Information...

You can find a wealth of information on our website with auto translation in many different languages. If you want to know more about r(20) syndrome take a look here:

www.ring20researchsupport.co.uk

This is also where you can sign up to our mailing list. Once signed up, we will contact you to see how we can help you further and issue you with a free Welcome Pack.





ring 20
research & support



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@ring20epilepsy



@Ring20UK



@ring20-research-support-uk



@ring20researchandsupportuk73



Let's Connect

Phone

+44 (0) 7385 292797

Website

www.ring20researchsupport.co.uk

Email

ring20@ring20researchsupport.co.uk

Ring20 Community

Many families find talking to others in a similar situation very helpful and comforting. We are more than happy to help connect you with other families in the Ring20 community to simply listen, chat or share experiences for mutual support.

There are lots of ways to connect...

- join the conversation through one of our private chat forums
- connect with other families via our Ring20 map
- come along to one of our online or in-person events.

You choose what's right for you.



Support for
Families

ring 20
research & support



Information and Support services
Making connections, Supporting families