



ring 20
research & support 



@Ring20ResearchandSupportUK



@ring20epilepsy



@Ring20UK



@ring20-research-support-uk



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Let's Connect

Phone

+44 (0) 7385 292797

Website

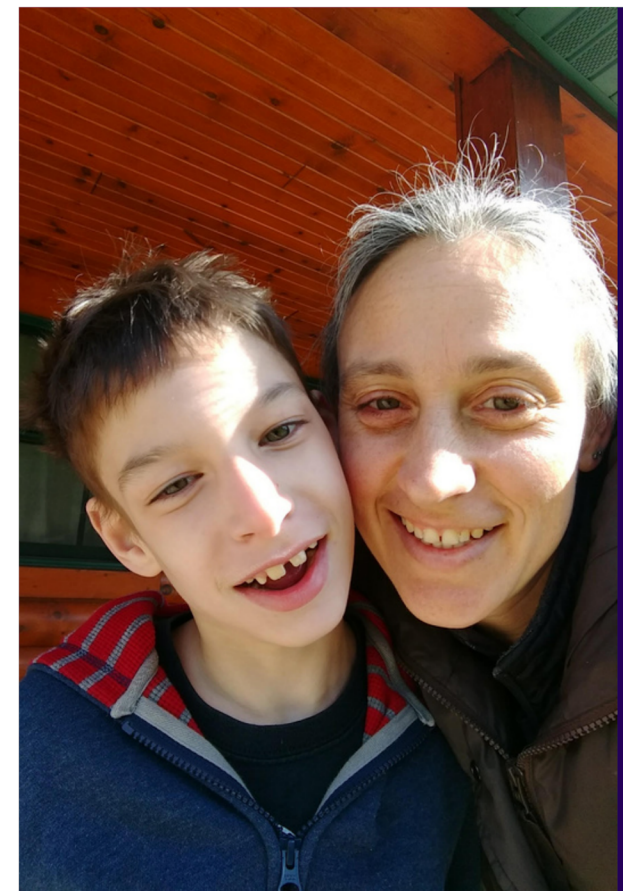
www.ring20researchsupport.co.uk

Email

ring20@ring20researchsupport.co.uk

Consent and Data Protection

The information you provide will be treated with the utmost confidentiality and used exclusively for research purposes. Your privacy will be protected, and no names will be used to ensure confidentiality and to comply with ethical guidelines. Please note that participation in this study is completely voluntary, and you have the right to withdraw at any time without providing a reason.



Research Study:
Living with r(20)

ring 20
research & support 

Information and Support services
Making connections, Supporting families

Patient Survey: Living with Ring Chromosome 20

Why participate...

We want to hear from as many families as possible about what living with r(20) is really like.

This is in addition to the planned Natural History Study with Glasgow Children's Hospital because:

- We are solely focusing on the patient family perspective (not medical records).
- We want to know what impact an r(20) diagnosis has on individuals and families.

The information that you provide will help to inform future research studies in r(20).

By collecting experiences directly from individuals or their parents/caregivers we want to see if your experiences can add any new knowledge to what has been documented about living with r(20).

Am I eligible...

The study is open to all individuals and their families who are living with a ring chromosome 20 worldwide.

Some of our Ring20 Champions will be able to help conduct interviews in other languages including: French, Dutch, Italian, Portuguese, Japanese, Spanish.

Will this benefit me...

The knowledge gained from this study will serve to raise awareness among the wider population and potentially improve support and care for individuals affected by this rare condition.

What will I have to do...

1. Tell us you'd like to take part: ring20researchsupport.co.uk/patient_survey/
2. Agree a date/time for your online interview.
3. Prepare by thinking about how r(20) has impacted your child/you.

Interviews will be arranged during **August and September 2023.**

Topics we will cover include:

Your journey to Diagnosis

Genetic testing

Medications and other treatments

Seizures, Behaviour and other symptoms

Education and Lifestyle

Personal Impact

What will happen after.....

We aim to publish a new research paper on living with r(20) based on the findings of this study. Ring20 will be ably supported in the data collection and analysis by colleagues at Newcastle University, UK. By sharing your insights, you will contribute to the comprehensive understanding of the challenges, impacts, and other aspects associated with a Ring Chromosome 20 diagnosis.

Any questions...

If you have any questions regarding the research study, please contact our team at ring20@ring20researchsupport.co.uk or your designated [Ring20 Champion](#). We will be more than happy to address any concerns or provide additional information.

All experiences are welcomed...there are no wrong answers!

