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Help us, help families, across the world.

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Let's Connect

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Make a Donation

ring 20 
research & support

Information and Support services
Making connections, Supporting families

Why Donate

Give a little, help a lot...

Ring chromosome 20 syndrome [r(20) syndrome], is a rare form of epilepsy that is difficult to treat with frequent seizures often associated with cognitive decline and challenging behaviours impacting many aspects of daily life.

Ring20, the charity, provide information and support to individuals living with r(20), their families and healthcare professionals. Our services extend to anyone across the world, delivered by our team of volunteers.

Your donation ensures that we can continue to provide this support at no cost to affected families - one less burden for them in their complex lives.

Services we provide

- Helpline (phone, 1:1 video calls and email)
- Welcome Packs for new families
 - Latest information online: website, social media, eNews and print: leaflets/booklets
- Online group support calls
- Connecting families
- Patient advocacy



Ella's Story...

Three night time seizures and being bitten on my face is a far cry from Ella's former self! January 2013 marks the start of Ella's traumatic journey, her stay at Alder Hey Children's Hospital and Ella's subsequent r(20) diagnosis and we would like to share Ella's story of fight and determination with you...

After numerous visits to the hospital and months of assessments Ella was eventually diagnosed with epilepsy. A year on, Ella was back to her old self; seizures under control and enjoying life as a 6-year-old. Fast forward 5 years out of nowhere, she was back to square one, having 40-50 seizures a day. An admission to Warrington General hospital for overnight observation turned into a three month stay at Alder Hey children's hospital. Ella missed her first day at high school and regressed to a shell of her former self. Frequent seizures, behaviour and learning issues and wetting herself during the day and night. **Seizures ramped up to 80 a day.** Ella was eventually diagnosed with Ring Chromosome 20 Syndrome. Doctors believed it was unlikely Ella would ever get better.



Every day is a struggle; getting dressed; having medicine; just doing the things that we all take for granted. R(20) syndrome has had a huge impact on all of our lives; Will Ella ever leave home? Will she ever stop having seizures? - these are the questions that we ask ourselves daily.

Sadly Ella died as a result of her uncontrolled seizures in 2023, aged just 15.

HELP US, HELP CHILDREN LIKE ELLA

How to donate...

You can choose to donate as a regular contribution or one-off amount. The easiest way to donate is via our website (or use the QR code on the back of this leaflet) <https://ring20researchsupport.co.uk/donate/#donate>

Or you can visit our JustGiving page and select the Donate button at the top right:

<https://www.justgiving.com/ring20-researchsupport>

Donations can be made using a debit or credit card, via PayPal, or Google Pay. We accept any of the following currencies: CAD, AUD, EUR, GBP or USD.

We also accept bank transfers and cheques - contact us for further details via on how to do this:

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