

## Do you have, or know someone who has Ring Chromosome 20 Syndrome?

*If so we are looking for your support in connecting families and medical professionals in the UK and abroad.*

*You can use this leaflet and any of the media listed in this brochure to get connected with us.*

*The more we grow in support and knowledge, the stronger your voice will become to bring about change and identification of the need to engage and share more information about this rare disorder.*

### Contact us at:

For more information on membership use

<http://eepurl.com/RtyQP>

Or like us on our Facebook page:

Website: [ring20researchsupport.co.uk](http://ring20researchsupport.co.uk)

Facebook page: Ring20ReseachandSupportUK

Twitter: @ring20UK



[www.ring20researchsupport.co.uk](http://www.ring20researchsupport.co.uk)



## Do you have, or know someone who has Ring Chromosome 20 Syndrome?



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Registered Charity Number 1165651

## Ring20 Research and Support UK

### Who we are...



Allison Watson  
(Co-Founder)

Ring Chromosome 20 Syndrome is a rare epilepsy syndrome, affecting a very small number of people worldwide. The number of cases reported in literature is less than 100, though we suspect that there are many more cases diagnosed (or undiagnosed) with this extremely rare disease.

As a parent of a child with r(20) myself I wanted the mutual support of other families affected by the condition and to help raise funds for much needed research to try to find an effective treatment for this genetic disorder that causes intractable epilepsy. With the help of my colleague



Don Gordon  
(Co-Founder)

Don Gordon, with whom I have spent a number of years volunteering we have established a new charitable organization to do just that.

Ring20 Research and Support UK has been set up to support families, individuals and professionals who are affected by, or who come into contact with Ring Chromosome 20 Syndrome .

We operate from the UK (England) but are happy to extend our support to the many families affected by r(20) around the world and the health professionals that look after them.

We look forward to new members joining us in our mission. Use the following link to join our membership list: <http://eepurl.com/RtyQP>

### What we do....

Our mission is to raise funds for future research studies by way of member fundraising and seeking out opportunities for grants and/or corporate sponsorship.

We aim to represent r(20) patients and their families as a patient cohort to aid vital research, which may lead to im-proved quality of life and improved outcomes for those living with, or affected by r(20).

Membership provides a support network for our families to connect with each other in an otherwise isolated environment. We hope that by sharing experiences and knowledge we can help each other.

### How you can help...

To achieve our mission we need to identify as many r(20) families as possible, to offer them our support in response for their input; information sharing, experience of living with r(20), treatment options, fundraising and more.

We ask that all families, individuals and professionals that wish to engage with us become members, in order that they may jointly contribute to our cause, by virtue of time, money or information (no matter how large or small).

We are a new organization so welcome any fresh ideas and offers of support be it financial resource, or otherwise.

Membership is free and provides you with access to regular updates on our progress and activities and our patient sup-port group forums (one for families and one exclusively for individuals with the condition) both on Facebook:

#### Family Support Group Forum:

<https://www.facebook.com/groups/798475916833994/>

#### Patient Support Group Forum:

<https://www.facebook.com/groups/229551470569368/>

Our forums operate on an 'invite only' basis and operate as a closed group to protect the privacy of our families.

### Ring20 'on the map'...

We're in the process of plotting known cases of r(20) on a world map which we hope to share with medical professionals, researchers and families alike.

Link to Public map:

<http://tinyurl.com/kld2zny>



Are you on the map yet? If not, do get in touch so we can recognize you and where you are located. This will eventually lead to a worldwide resource and potential epidemiological study tracking the rate of incidence.

We also have a private version of the map exclusively available to our families who wish to share information with each other and find others to connect with.

