

## JOIN THE RING20 MAP

We plot known cases of r(20) on a map, so you can see if there are families affected living nearer to you. All cases are plotted anonymously on the PUBLIC map, in general locations. You can request to join the map by scanning the QR code or using the link below:



<https://ring20researchsupport.co.uk/families/global-patient-map/>

Please note you need a gmail address to participate in the PRIVATE map. Maps are updated online monthly with any new cases.



@Ring20ResearchandSupportUK



@ring20epilepsy



@Ring20UK



@ring20-research-support-uk



@ring20researchandsupportuk73



## Let's Connect

### Phone

+44 (0) 7385 292797

### Website

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

### Email

[ring20@ring20researchsupport.co.uk](mailto:ring20@ring20researchsupport.co.uk)



## Connecting r(20) Families



# Ring20 Support Services

## Making Connections

At Ring20 we recognise that having an ultra-rare diagnosis like r(20) can be a frightening experience and that you will have lots of questions!

That's why we provide a safe and welcoming community to help you on your journey. Families tell us that connecting with others relieves feelings of isolation and helps them find practical solutions to cope in everyday life. Peer support can be a lifeline, where medicine doesn't have the answers...YET!

## How can I meet others?

### • Join our Facebook group

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

Separate to our public facing Facebook page (where we post Ring20 general news updates) our private **Ring20 Families Support Group** on Facebook allows you to ask questions to other r(20) families and share your experiences of living with r(20), in confidence. Facebook offers auto-translation of all posts, so language is no longer a barrier to connecting!

You must complete a form to obtain access to the group here: <http://eepurl.com/iEh5pE>

### • Attend an in-person event:

Given the rarity of r(20) it is not feasible for Ring20 to arrange regular in-person events as families are widely dispersed across the world.

Occasionally we host in-person events such as:

- Family Conferences
- Workshops
- Informal picnics/events

Look out for announcements on our social media, eNews and website for upcoming events.

## Online Chat Groups

### • Coffee and Chat

One of our popular events is **Coffee and Chat**, accessible via regular scheduled video calls. These online group chats offer a safe space to connect with other r(20) families for mutual support - reminding you that you are not alone. We are trying to extend these calls to cover specific regions/time zones/languages. Come join the conversation!



### • Step Into The Ring

Individuals who are 18 and above and living with an r(20) diagnosis can join our **Step Into The Ring** virtual chat group sessions. These provide a chance to talk and share experiences without parents, or caregivers. Calls run on a regular basis and we occasionally organise fun, special events including quizzes or guest speakers. (calls conducted in English)

Contact one of our team members for more information:  
Dale - [dale@ring20researchsupport.co.uk](mailto:dale@ring20researchsupport.co.uk)  
Khalif - [support@ring20researchsupport.co.uk](mailto:support@ring20researchsupport.co.uk)

Check our website, eNews or socials for our next calls:  
<https://ring20researchsupport.co.uk/families/coffee-chat/>

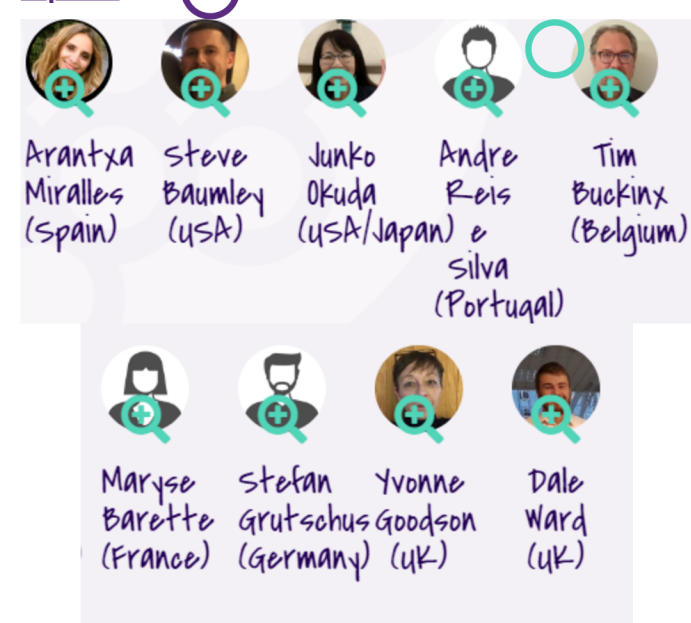
## Find your Champion

Our Ring20 Champions are a single direct point of contact for families in their own country and native language. Champions have **local knowledge** to help you access and navigate support. We have Ring20 Champions in several different locations around the world.

Our Champions meet regularly online helping to bring the voice of our families to the table, so that Ring20 can continuously strive to adapt our support and information services to meet YOUR needs, when and how YOU want services to be delivered.

Find your Ring20 Champion on our website:

<https://ring20researchsupport.co.uk/unravel/#champions>



If you would like to be connected with your Ring20 Champion, or if you would like to become a Ring20 Champion for your local r(20) community, please get in contact;

[ring20@ring20researchsupport.co.uk](mailto:ring20@ring20researchsupport.co.uk)