ring 20
research & support

Ring20 Research & Support UK

Impact Report 2025/26

"Together, We're Changing the Story of Ring20"

www.ring20.org

A warm welcome from our CEO

Families living with Ring Chromosome 20 Syndrome often face uncertainty and isolation because the condition is so rare and so little is understood about it. No family should have to face that journey alone.

At Ring20 Research & Support UK, our mission is to ensure every family has somewhere to turn for trusted information, understanding and hope. By connecting families, providing practical support and driving the research agenda, we are working towards earlier diagnosis, better treatments and a brighter future for everyone affected by Ring20.

This year has marked an important turning point for our charity. Our commitment to research is beginning to deliver exciting progress, with new genomic studies using advanced long-read sequencing technologies now underway. We also launched our £80,000 Open Call Research Grant, attracting strong interest from researchers committed to advancing understanding of Ring Chromosome 20 Syndrome.

As our community grows, so too must our ability to support every family who reaches out to us. Over the past year, we have invested in both people and technology to strengthen our services. Our new Beacon CRM system is helping us welcome and support families more effectively, while the expertise of our Virtual PA, Susie, and professional bid writer, Kate, has strengthened our operations and funding capacity. These developments have enabled us to recruit our first part-time Families Liaison Officer and secure funding for a dedicated Communications Lead, ensuring families receive timely support and accessible, reliable information.

None of this would be possible without our remarkable volunteers. Our dedicated Trustee Board, International Scientific Advisory Board and Ring20 Champions generously contribute their expertise and time alongside work, caring responsibilities and family life. Their commitment is extraordinary and remains at the heart of everything we achieve.

We are equally grateful to every donor, fundraiser and pro bono supporter. Every donation, every fundraising challenge and every act of generosity helps us expand support for families and drive the research needed to change lives.

As a parent of a son living with Ring Chromosome 20 Syndrome, this mission is deeply personal. I share many of the same hopes and uncertainties as the families we support every day. It is both a privilege and a responsibility to lead Ring20, working alongside our volunteers, researchers, supporters and families to build a future where no one has to face this journey alone.

Allison

CEO

Watson

Promoting research, education and continuous support to end undiagnosed and misdiagnosed Ring20 epilepsy

Our Impact

Every family we support, every researcher we connect and every pound we invest brings us closer to earlier diagnosis, better treatments and a future where no one faces Ring Chromosome 20 Syndrome alone.

Our Year in Numbers

2025/26 at a glance

22

New families joined our community

14

Families participating in research

£80,000

Open Call Research Grant

17

International SAB members providing expertise

2

Research papers published

310

Newsletter subscribers

32

Webinar attendees

1

European rare disease award

213

Families in our global network

Our Community Shapes Everything We Do

Who are Ring20 Research and Support?

Ring20 Research & Support UK exists to ensure that no family faces Ring Chromosome 20 Syndrome alone. By supporting families, championing research and raising awareness, we are building a future where everyone affected by Ring20 has access to better support, greater understanding and new hope.

Our community is at the heart of everything we do.

By listening to the experiences of individuals and families living with Ring Chromosome 20 Syndrome, we ensure our support, resources and research reflect what matters most to those we serve. Throughout the year, feedback gathered through conversations, surveys, webinars, events and our online community helped shape our priorities and future plans.

Every story shared and every voice heard helps us build a stronger charity—one that is led by lived experience, responds to changing needs and works towards a better future for everyone affected by Ring20.

> ***"Every story shared strengthens our understanding, informs our work and brings us one step closer to a future where every person affected by Ring20 feels understood, supported and heard."***

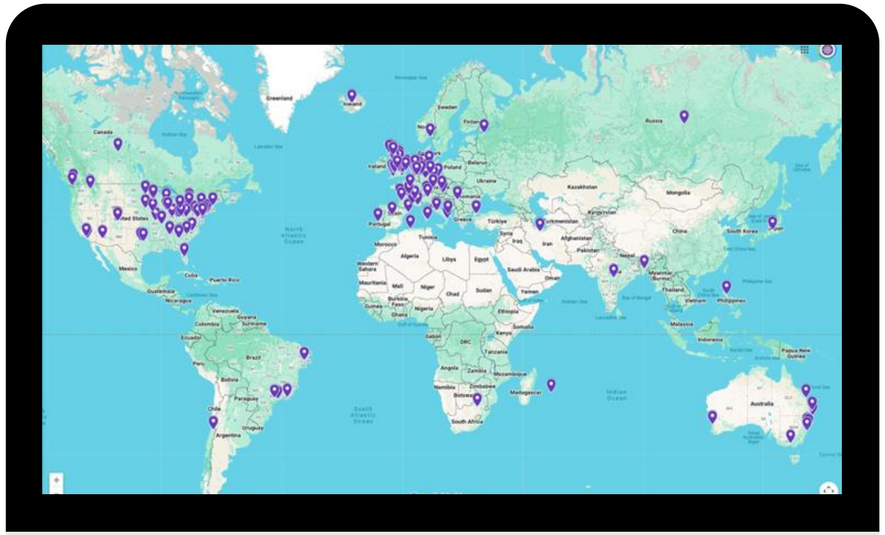
Supporting Families: UK-based with global reach & impact

22 new families joined our community in 2025/6

As the UK's dedicated Ring20 charity, we provide specialist support to families across the UK while working alongside an international network of families, clinicians and researchers.

We reduce isolation by connecting families who may otherwise never meet another person living with Ring Chromosome 20 Syndrome. We provide trusted, evidence-based information that helps families navigate diagnosis, education, healthcare and everyday life.

Our global case maps highlight the worldwide reach of Ring20, strengthening collaboration, advancing research and reminding every family that they are part of a connected community. Together, we are bringing families together, wherever they are in the world.



"I found out about you [Ring20] when I started Googleing about this disorder. It is certainly the most comprehensive and helpful resource I've found on r(20). I can't express my gratitude enough."

Driving Research Forward

This year marked a significant milestone as Ring20 Research & Support UK moved from supporting research to actively driving it. Every new discovery brings us closer to earlier diagnosis, more effective treatments and, ultimately, better lives for people living with Ring Chromosome 20 Syndrome.

Alongside strengthening existing collaborations, we established new research partnerships, launched our largest-ever research funding call and continued to champion the priorities identified by Ring20 families. These achievements have only been possible thanks to the generosity of our supporters and the determination of our community to accelerate progress.

Genomic Research

Our partnership with Illumina on the UNRAVEL project continues to explore the underlying genetics of Ring Chromosome 20 Syndrome. While the blood samples provided by our community have proved beyond the capabilities of current short-read sequencing technologies, this work has helped define the next phase of our research strategy.

Building on this foundation, our advocacy has led to an exciting collaboration with **Oxford Nanopore Technologies** and the **Genetics Team at Birmingham Women's and Children's NHS Foundation Trust**, led by **Dr Hannah Titheradge**, with support from **Professor Andrew Beggs** at the University of Birmingham.

Using advanced long-read sequencing, the team is analysing blood samples from people living with Ring20 to better understand how the ring chromosome forms and whether these genetic changes explain the symptoms experienced by individuals with the condition.

If successful, this work could establish a new NHS diagnostic pathway using long-read sequencing—an approach with the potential to benefit not only Ring20 but other rare ring chromosome disorders worldwide. Ultimately, identifying the precise genetic mechanisms underlying Ring20 could reveal new targets for precision medicines and more personalised treatments.

Ring20 Research Grant – Open Call

This year we relaunched our £80,000 Ring20 Research Grant through an Open Call for applications. The response exceeded expectations, attracting high-quality proposals from researchers committed to improving outcomes for people living with Ring20.

Following rigorous review by our International Scientific Advisory Board, a successful applicant has been selected and is awaiting final ethics approval before the project is announced. We hope this pilot study will generate vital new knowledge, stimulate further research and provide the evidence needed to secure larger-scale funding in the future.

A special thank you to: Gowling for pro bono legal support in developing our Research Study T&Cs

GOWLING WLG

> ***"We bring together families, clinicians, scientists and industry partners to accelerate research that would otherwise not happen."***

14 FAMILIES CONTRIBUTED TO PUBLISHED RESEARCH

32 ATTENDEES RESEARCH WEBINAR

None of this research would be possible without our Ring20 families and supporters. Through fundraising, donations and an unwavering belief that better answers are possible, you are helping to build the evidence that will shape tomorrow's diagnosis, treatments and care.

Influencing Healthcare

Our Mission & Expertise

Research is at the heart of Ring20 Research & Support UK's mission, and one of our greatest strengths is the guidance and expertise provided by our 17-member international Scientific Advisory Board (SAB).

Bringing together leading clinicians, researchers and scientists from across the world, our Scientific Advisory Board provides expert oversight of the charity's research priorities, ensuring that every project we support is informed by the latest scientific knowledge and driven by the needs of people living with Ring Chromosome 20 Syndrome.

Impact & Publications

During 2025/26, members of our Scientific Advisory Board continued to make significant contributions to the global understanding of Ring20, publishing two important peer-reviewed research papers. These included the international study exploring the use of **Vagus Nerve Stimulation (VNS)** in people living with Ring20 Syndrome, together with a landmark study describing the clinical characteristics of 47 individuals with Ring20 Syndrome from a specialist epilepsy centre in Tokyo, Japan.

Active research studies

Work continues towards publishing our Ring20 Patient Reported Impact Study with data collected from member families in 2023. The follow-on Me & r(20) study is also being written up. We anticipate submission for publication of these studies in 2026/27 bringing new evidence on the impact of living with r(20) syndrome.

Board Contribution

These publications add to the growing evidence base for this ultra-rare condition, helping clinicians to better understand diagnosis, treatment and long-term care while informing future research priorities around the world.

A Dedicated Partnership

Together, these partnerships ensure that Ring20 Research & Support UK continues to punch above its weight—connecting empotrennting families, clinicians.
Our Scientific Advisory Board is far more than a group of advisors. Throughout the year they worked alongside the charity, sharing expertise, presenting research updates to families, reviewing opportunities and strengthening international collaboration. In September 2025, we were also delighted to hold our first in-person Scientific Advisory Board meeting, bringing together nine members to shape the future direction of Ring20 research. and researchers to accelerate discoveries that have the potential to improve lives.

Accelerating Discoveries

Together, these partnerships ensure that Ring20 Research & Support UK continues to punch above its weight—connecting empowering families, clinicians and researchers to accelerate discoveries that have the potential to improve lives.

17
Advisory Board Members

2
Research Papers Published

14
Families in Research

200
Total cases reported in the literature

213
Families supported

1
Shared Ambition

International Recognition

01 EURORDIS Black Pearl Award

CEO Allison Watson received the prestigious EURORDIS Black Pearl Volunteer Award, recognising extraordinary dedication to the rare disease community and leadership in advancing Ring20 syndrome support internationally.

02 Meaning for Families & Funders

This award validates the vital work carried out for Ring20 families worldwide, boosting confidence among funders and reinforcing Ring20 Research & Support UK as a credible, impactful organisation in rare disease advocacy.

03 A Milestone for Rare Disease

Recognition at a European level elevates Ring20's profile among researchers, policymakers and partner organisations, strengthening collaboration and amplifying the voice of families living with Ring20 syndrome globally.

Fundraising

Our supporters go above and beyond to raise vital funds for Ring20 Research & Support UK. From athletic challenges to corporate partnerships and trust funding, every contribution helps us continue our mission.

Community

Louise Nyakoojo - Everest Base Camp, May 2025
Carl Darby - Triathlon, Uppingham, June 2025

Corporates

Corporate partners supporting Ring20 through team challenges, matched giving and sponsored events throughout the year.
Steve Gardiner, Listers - Half Iron-Man, Majorca, May 2025

Trusts

The Frank Litchfield General Charitable Trust
Gilly's
POSTCODE PLACES TRUST

Funding secured our first Families Liaison Officer, ensuring newly diagnosed families receive earlier support, better information and a dedicated point of contact when they need it most.

"I am so grateful for the people who get out and raise funds for our awesome Ring20 Research and Support network! This organization feels like home, it feels like family, an organization and group of people who truly understand our lives with a Ring20 family member. Every single donation is so important, and I am thankful for it!"

Thank you to every individual, company and trust that supports our work. Together, we are making a difference.

Building a Stronger, Connected Community

Growing Our Reach

Living with an ultra-rare condition can often feel isolating. That's why investing in better communication has become one of Ring20 Research & Support UK's highest priorities.

During 2025/26, funding from Postcode Places Trust and The National Lottery Awards for All enabled us to strengthen our capacity and lay the foundations for long-term growth. This investment will allow us to provide more personalised family support, expand our digital communications and ensure more families can access trusted information when they need it most.

At the same time, we continued to grow our digital community through regular newsletters, social media and new online resources, helping families stay connected, informed and supported wherever they live.

2025/26 Highlights

- 📩 310 newsletter subscribers
- 👨‍👩‍👧‍👦 22 new families welcomed
- 📱 Growing social media across all platforms
- 🎥 New video content launched
- 💜 Automated Welcome Packs

Looking Ahead to 2026/27

Our investment in digital communications will help us:

- Reach more newly diagnosed families
- Share research in accessible ways
- Increase awareness of Ring20
- Strengthen engagement with healthcare professionals
- Grow our online community
- Better measure our impact through improved analytics

Together, these developments will help ensure that no family faces Ring20 alone.

Families Driving Discovery

Powered by People

Throughout 2025/26, our volunteers Ian, Laura and Kallif, together with our outgoing/incoming interns from Aston University Elin and Aavani, brought valuable skills, enthusiasm and fresh perspectives to the team. Alongside them, our Ring20 Champions played a vital role by sharing their experiences, raising awareness and encouraging families to become involved.

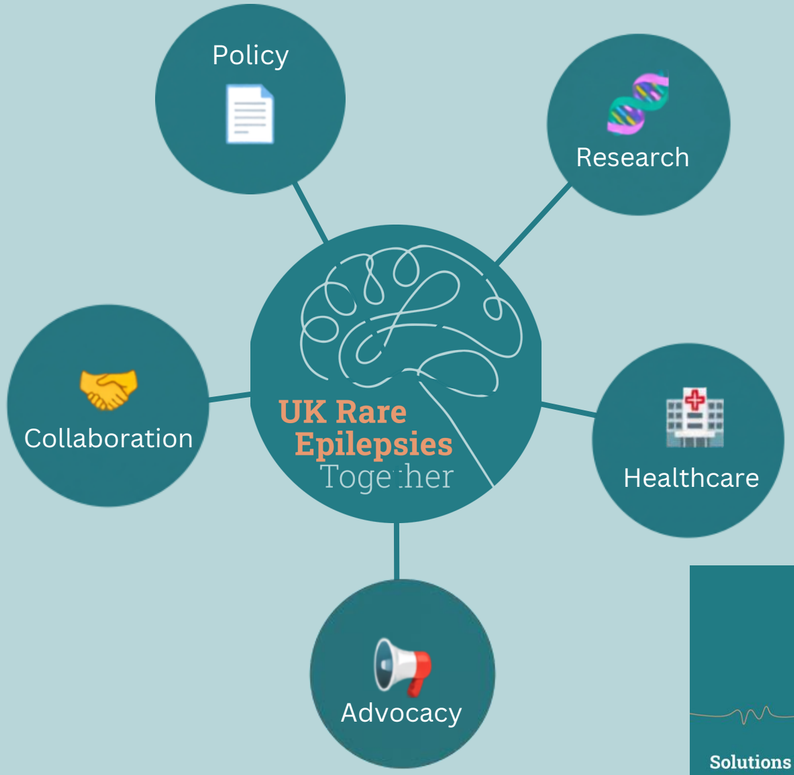
Together, they helped ensure that the voices of people living with Ring20 remained at the heart of every stage of the project.

UK Rare Epilepsies Together (UKRET)

About UK Rare Epilepsies Together (UKRET)

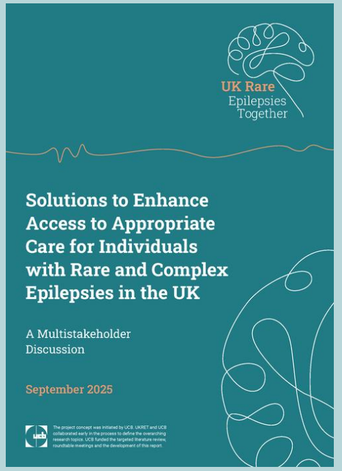
Founded by our CEO, Allison Watson, the UK Rare Epilepsies Together network (UKRET) brings together clinicians, researchers/academics, pharma/industry, payers and policymakers to drive improvements in access to diagnosis, treatment and care for people living with rare and complex epilepsies across the UK.

By combining clinical expertise with the lived experiences of families, UKRET is helping to build the evidence needed to influence national healthcare policy and improve outcomes for everyone affected.



Stronger Together: Collaborating for Greater Impact

At Ring20 Research & Support UK, we believe that collaboration is one of the most powerful ways to create lasting change. Whilst our mission is to support individuals and families affected by Ring Chromosome 20 Syndrome, we recognise that many of the challenges faced by those living with rare and complex epilepsies are shared across conditions.
That is why we are proud to play an active role within UK Rare Epilepsy Together (UKRET), working alongside other patient organisations, clinicians and researchers to share knowledge, influence policy and strengthen the collective voice of the rare epilepsy community.
By collaborating rather than working in isolation, we can help drive more equitable access to information, support, research and healthcare for everyone living with rare and complex epilepsies. This approach extends our impact beyond Ring20, ensuring that our experience, knowledge and advocacy contribute to wider improvements across the rare disease landscape.



Read our **Case for Change** white paper style report here

Together, we are building stronger partnerships, creating shared opportunities and working towards a future where no family is disadvantaged because their condition is rare.
Working together to improve outcomes for rare and complex epilepsies

Our Trustees

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RARE REVOLUTION MAGAZINE
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