2026 Ring 20 USA Newsletter

This marks our third full year as a nonprofit organization, and our fourth year for funding purposes. ALL that we have accomplished is a result of the gifts from friends and active supporters of our organization.



Highlights for 2026

We published another paper in Epilepsia – our hope is that more articles in the scientific journals will bring more attention to physicians who are treating epilepsy. The paper we published is attached here:

Establishing consensus diagnostic criteria for ring chromosome 20 syndrome: A modified electronic Delphi consensus study - Sánchez-Feliciano - Epilepsia - Wiley Online Library

These are the key points of the paper:

- The objective of this study was to achieve consensus on the clinical and diagnostic features of ring chromosome 20 syndrome.
- In this two-round modified electronic Delphi study of 12 international experts in Round 1 and 11 in Round 2, consensus was achieved for 25 clinical and 19 diagnostic statements.

- Experts agreed that karyotype analysis is required for diagnosis and that characteristic electroencephalographic findings and recurrent nonconvulsive status epilepticus are core diagnostic features.
- These consensus criteria provide a practical framework to improve recognition of ring chromosome 20 syndrome and reduce diagnostic delay in patients with drug-resistant epilepsy.

We attended two meetings since our last newsletter: in December 2025 we attended the American Epilepsy Society meeting where we made many great contacts and put together a plan for developing research in the near term. Dr. James was appointed to the Epilepsy Leadership Council and attended a meeting as well. We also joined the Rare Epilepsy Network and helped man a booth at the meeting.

In October 2026, Dr. James and his family went to the Ring 20 Families Conference in the United Kingdom where Dr. James was one of the speakers. The photo above is from that meeting. During the scientific day session the following things were discussed:

1. Understanding the ring – how the ring forms, what new genetic tests are revealing, and how Ring 20 can be better recognized and diagnosed.
2. Learning from lived experience – what we know about seizures, behavior, safety, treatment, and everyday life – and how families' experiences the impact study, and patient registry are guiding future research and care.
3. Building a path to better treatments – finding better ways to measure Ring 20, exploring how genetics may support safer use of medicines, developing laboratory models to understand the condition, and preparing for future clinical trials.
4. Research priorities were agreed upon, with plans for the short term (1-2 years) and medium term (3-5 years).

Finally, in 2026 we teamed up with the Strong Brave Hopeful Foundation (a nonprofit dedicated to supporting children and families facing epilepsy and rare neurological conditions) to fund a 2 year research program at the Children's Hospital of Pennsylvania which is a Ring Chromosome 20 long read sequencing project (they will apply a complementary set of advanced long-read sequencing technologies to generate the first complete, chromosome-scale genome assemblies of ring chromosome 20). We are excited to take this first step in trying to understand the underlying biology of ring 20.

Treasurer's Report

In 2025, we received over $50,000 in donations - this was made possible by a few donors double matching other donations ($1 in donations was matched by an additional $2 in other donations). We also were awarded the Guidestar Silver Seal of

Transparency – demonstrating our disclosure of information to prospective donors. For donations in 2026, we will again have a group of donors that will match donations for Ring 20 epilepsy research.

Becca James: A Best Friend's Perspective

Nearly 40 years of friendship, resilience, and hope

By Becca's best friend of nearly 40 years

A Friendship That Began in Childhood

When Becca James and I became friends at around seven or eight years old, we spent our days running around soccer fields, swimming in pools and the ocean, exploring creeks, and hiking through the woods. Becca was athletic, bright, and intelligent. She ran circles around me on the soccer field and swam faster than I did on the swim team. Back then, neither of us could have imagined the challenges that would become part of her life.

Today, we have shared nearly 40 years of friendship. Ring 20 has affected many aspects of Becca's life, but it has never defined all that she is or changed the importance of our bond.

Learning About Becca's Absences

One of my earliest memories of Becca's seizures was during a family walk in the woods. She suddenly stared into space and didn't respond when we called her name. She seemed unaware of what was happening around her. We came to call these episodes her "absences." They did not always look like the seizures people typically imagine. They could last seconds, minutes, or sometimes much longer, and they could begin with or without warning.

During an episode, Becca might be quiet and unresponsive, or she might become restless, frustrated, defensive, or agitated. As a child, she understandably struggled with the unpredictability and lack of control. Over time, I learned that her frustration wasn't personal; she was dealing with something she couldn't simply stop.

Becca and her family pursued many appointments, tests, medications, and other approaches to manage her condition. She also had a vagus nerve stimulation device implanted in her chest, with a magnet on a bracelet used in an effort to help manage seizure activity. Sometimes it seemed to help, and sometimes it didn't. I learned that supporting someone does not always mean being able to fix what is happening. Often, it means staying present and offering patience and understanding.

What Becca Has Taught Me

Becca has taught me to listen carefully, pay attention to body language, and give people the time they need to express themselves. Her comprehension and communication can vary: sometimes she shares her knowledge and ideas with ease, while at other times she may need more time or support. People

who don't know her well can underestimate her abilities if they judge her by one moment or one conversation. I wish everyone would take the time to see the whole person.

As a veterinarian, I have a deep connection with animals, but Becca's special way of connecting with animals and children is uniquely her own. She also loves God, her family and friends, movies, and music. And when it comes to movie and music trivia, she will always win!

Becca has reminded me to be grateful for abilities I might otherwise take for granted. She has taught me that friendship isn't about having all the answers. It's about showing up, listening, learning, and standing beside someone through difficult times.

A Wedding Memory—and an Unbreakable Circle

One of my most cherished memories is having Becca as a bridesmaid at my wedding. The night before, she took it upon herself to interrogate my soon-to-be husband to make sure he was good enough to take care of her best friend. She wanted to know that I would be loved and cared for as I deserved. At one point, my husband and I looked at each other with tears in our eyes. We both understood that her questions came from a place of deep love, loyalty, and protectiveness.

When I think of a ring, I think of a circle with no beginning and no end—a symbol of commitment, strength, and an enduring bond. That is what my friendship with Becca means to me. Our friendship has lasted through childhood, life's milestones, and the challenges Ring 20 has brought. It is a circle I hope will always remain unbroken.

Breaking the Ring of Ring 20

While I want our circle of friendship to remain unbroken, I want us to break the circle of Ring 20. I hope continued research will lead to a better understanding of the disorder, improved support, more effective treatments, and ultimately a cure.

Becca is bright, beautiful, intelligent, loving, and special in ways no diagnosis can capture. Ring 20 is part of her story, but it is not the whole story. She deserves to be recognized for her personality, gifts, relationships, and potential—not simply through the lens of a medical condition.

I'm grateful for the nearly 40 years of friendship Becca and I have shared and for everything she has taught me. I can't change every challenge she faces, but I can stand beside her, share her story, and advocate for a better future for everyone living with Ring 20.

Our friendship has no beginning and no end. Ring 20 does not have to be forever.

Looking to 2027

We are hoping to accomplish the following in 2027:

- Develop a strategic plan that communicates our future goals (this will be very important in trying to get additional funding for research)

- Write at least one additional paper to bring more attention to Ring 20 in the eyes of neurologists
- Fund a second research study to get us closer to finding the target for the formation of the ring on chromosome 20
- Increase our collaborations with Ring 20 UK, the Rare Epilepsy Network, and other organizations that focus on epilepsy
- Join an organization called Combined Brain with hope to develop a biobank which will stimulate future research
- Develop stronger ties to patients and families with Ring 20 in the United States and Canada
- Attend the American Epilepsy meeting, the Epilepsy Leadership Council and the meeting of the Rare Epilepsy Network
- Expand the number of experts working on Ring 20 to get new ideas for research and treatment
- Get additional major donors to provide a sustainable funding base for future research

Disclaimer

100% of the funds that are collected go to clinical or basic science research – all administrative and meeting costs are covered by the leadership team.

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