TBRS
community

TBRS Community
2026 Summit

San Antonio, Texas | Morgan's Wonderland Camp
March 19 - 22, 2026

Meet. Support. Advance.

The TBRS Community aims to support all families affected by Tatton Brown Rahman Syndrome and advance research toward interventions. Learn more about TBRS, connect with families, and join our research network at [tbrsyndrome.org.](https://tbrsyndrome.org)

We are **STRONGER TOGETHER.**

Notes. (and things you don't want to forget!)

- ☐ Sign up for the TBRS and DNMT3A Patient Registry
- ☐ Get your questions answered about the Biorepository
- ☐ Talk to Kit and get an update on your research participation
- ☐
- ☐
- ☐

Welcome! We are so happy you are here.

To my TBRS Family,

Welcome to our TBRS Super Summit. This year feels especially meaningful. We are not only gathering as families, clinicians, and researchers. We are coming together to celebrate something even bigger, the unique strengths each of you brings to this community. Every person here has a role. Every role matters.

Our patients show courage and resilience every day. Parents and caregivers become fierce advocates. Siblings and grandparents bring love and steadiness. Friends show up with open hearts. Researchers and clinicians bring curiosity and dedication. And when all of those strengths come together, something powerful happens. We become unstoppable.

Over the last few years, this community has accomplished things I once only dreamed were possible. Our Patient Registry has become a vital tool for understanding TBRS. Families have contributed samples to our biorepository. We have identified life-saving cardiac surveillance recommendations, launched natural history studies, prepared for clinical trials, and begun planning Centers of Excellence so every person with TBRS can access expert care.

None of this happened by accident.

It happened because you answered the call. You shared your data. You donated your blood. You fundraised. You trusted us with your stories.

That is patient-powered research in action, and it is changing lives.

I truly believe we have the most extraordinary network of scientists and clinicians anywhere, not only because of their expertise, but because they care so deeply about our families. Still, progress only happens because families and researchers work side by side.

We are partners. We are teammates. We are building this future together.

This Super Summit is a celebration of that teamwork. The conversations, the hugs, the people who finally feel understood, and the ideas that grow into the next study or breakthrough.

Whether you are here as a person with TBRS, a family member, a friend, or a clinician or researcher, thank you. You are the reason this community exists. You are the reason we have hope. Each of you brings your own superpower to this mission.

I am so grateful to be on this journey with you, and I cannot wait to see what we accomplish together.

With heartfelt gratitude and immense optimism,

Jill Kiernan, Founder and Executive Director

We have already come so far!

Here are just a few of our accomplishments:

TBRS Research Toolkit: Provides researchers with the tools they need to accelerate treatment development and has led to important breakthroughs in understanding TBRS.

TBRS Community Research Grants: Created biomarkers, mouse models and cell lines, moving the needle forward on treatment development.

TBRS & DNMT3A Patient Registry: Unraveled the mystery concerning the medical and developmental symptoms that are associated with TBRS. In 2025, we opened our registry to include all DNMT3A mutations, like those associated with Heyn Sproul Jackson syndrome!

TBRS Summit 2023: Families got to meet other families for the first time, learn from TBRS scientists and clinicians, and share their priorities with the scientific community, creating a patient-focused research agenda.

Grew and Engaged our Collaborative Research Network in presentations, research roundtables, overgrowth webinars, and virtual discussions that sparked many collaborations for TBRS.

Need some directions? Morgan's Wonderland Camp Map

Morgan's WONDERLAND Camp

CAMP MAP

- A. Entrance Tower & Entrance Gate
- B. Bus Parking
- C. Main Parking
- D. Hartman Hall / Welcome Center
- E. Junction Station and Police Station
- F. The Depot
- G. Morgan's Mercantile
- H. Joy's Compass
- I. Frontier Amphitheater
- J. Bike Flatts
- K. The Four Seas
- L. Quarry Fieldhouse
- M. Maggie's Studio
- N. Vista Cavern Trails
- O. Bexar & Alamo Cabins
- P. The Stockyard
- Q. Spur Ranch
- R. Climbing Towers
- S. Fort Challenge
- T. Canyon Run
- U. Stone Swing
- V. Cavalry Range
- W. Water Learning Place
- ★ Restrooms

*The agenda will identify letters on map with corresponding activity

Things you need to know. Morgan's Wonderland Camp Policies

To best serve all our campers here at Morgan's Wonderland Camp, we kindly ask that all members of each family adhere to our MWC Policies outlined below. Please review/familiarize yourself and your family with our policies.

Identifier Wristbands & Security

While at Camp all family members (campers) must wear their Morgan's Wonderland Camp wristband given to them upon check-in. These wristbands will serve as a sign to all MWC Staff that you are a registered camper allowed to participate in activities and to be on-site. If your wristband becomes damaged or lost during Camp, please check-in with an MWC Staff member as soon as possible to avoid any interruption to your camp experience. We verify that all registrants over the age of 18 are not on the National Sex Offender Public Website.

Supervision & Behavior

While at Camp, it is the responsibility of the legal Parent/Guardian to supervise the child(ren) in their family and ensure the adherence to MWC policies. At no point should any child (person under the age of 18) be without at least one of the legal parents/guardians or designated family supervisor that were registered with them. This includes, but is not limited to attending activities, mealtimes, and public restroom trips.

We expect all guests to behave in a respectful manner. Anyone who uses excessive profanity and exhibits unruly behavior that is offensive to camp guests will be asked to leave without a refund. Clothing or tattoos with offensive language or graphics are prohibited.

Health & Wellness

Families will be responsible for providing their own medical care, including dispensing of prescribed and over-the-counter medications to their family members. Morgan's Wonderland Camp will have someone trained in basic first-aid available if needed.

Morgan's Wonderland Camp Staff

MWC staff are trained to provide you and your family with the best camp experience, so while attending, all registrants will be under the direction of Morgan's Wonderland Camp staff.

Schedule & Activities

Upon your family's arrival at Camp, you will be provided with an activity/conference schedule. Any scheduled activity that is missed is not guaranteed a chance to participate during another session. Only activity areas specified on the schedule will be available, and for all scheduled activities, they will only be available during the scheduled time. Please note that for challenge course and horse activities closed toe shoes are REQUIRED, Crocs are prohibited.

Prohibited Items

Prohibited Items: Weapons, fireworks, firearms, alcohol, vape pens, tobacco, and illegal drugs. We also ask that you leave all valuables at home. MWC is not responsible for the loss or theft of any personal items while at Camp.

No pets are allowed at Camp, only pre-approved registered service animals are allowed on-site. Morgan's Wonderland Camp is a smoke-free facility. No smoking is allowed anywhere on-site.

Lodging & Parking

Upon check-in, your family will be assigned a cabin for the weekend. You and your family members are only permitted access into your assigned cabin, with the exception of MWC staff for the purpose of maintenance/housekeeping. Entering an unassigned cabin may result in removal from Camp. Vehicles will only be permitted in cabin area for drop off/pick-up of luggage, outside of these times all vehicles must be parked in the main MWC lot in front of Hartman Hall.

Severe Weather/Emergencies

In any case of severe weather and/or emergency, listen to instructions provided by Morgan's Wonderland Camp Staff.

Any person(s) found in violation of these policies during Camp may be asked to leave without refund.

This is important! Things to pack and bring with you.

Suggested Items:

☐ Closed-toe shoes (ie: tennis shoes, sneakers) (required for all activities except at the pool) Crocs DO NOT count!

☐ Water Bottle - it is hot in Texas! The park has refillable stations to keep you hydrated

☐ Long Pants (if you want to be around the horses)

☐ Swimming attire / gear (pool towels will be provided)

☐ Clothing and footwear as appropriate (March in Texas ranges from 60-90 degrees in a day with light chances of rain. We suggest easily removable layers.)

☐ Toiletries (shampoo, soap, hairdryer, etc.)

☐ All medical necessities/medications (reminder that families are responsible for their individual medical needs)

☐ Sunscreen

Optional Items:

☐ Camera / Phone / Charger

☐ Laundry Detergent (complimentary Washer/ Dryers available in each cabin)

☐ Hat / Sunglasses

☐ Fan (Every cabin has AC but do not have ceiling fans)

☐ Personal Bedding (a set of linens, blankets, and bath towels will be provided but bring any extra comforts you prefer)

☐ Additional/preferred snacks

☐ Bring your genetic testing report or email it to kit@tbrsyndrome.org

Things that the Camp will provide.

☐ Bed, pillow, and a set of bedding for each registered guest

☐ Towels (bath and pool)

☐ 3 meals, snacks, and drinks available daily

Travel Tips for International Summit Attendees

We're so glad you're joining us for the TBRS Summit. To help make travel, especially international travel, a little smoother, we recommend the following:

- Keep your passport with you while traveling and have digital copies of important documents.
- Have easy access to your flight itinerary, return ticket, and conference registration confirmation.
- If applicable, carry copies of your visa and arrival/departure record (Form I-94).
- Bring any documentation that supports the purpose of your trip, such as your Summit registration or invitation.
- Please make sure the emergency contact you listed during registration has all relevant information they may need in case of a medical or travel-related emergency.

If you run into any issues while traveling or during the Summit, **please call or text Jill at 1 845 264 3016.**
We're here to support you.

Meet our presenters. We are so excited to have them here!

Thank you to our fabulous researchers and clinicians who are presenting this week. If you would like to get in touch with a presenter following the conference please reach out to Kit: kit@tbrsyndrome.org.

Science Speakers:

Kate Tatton-Brown, MD

Professor Kate Tatton-Brown is a medical geneticist in London, UK, specializing in overgrowth and intellectual disability syndromes. In 2014, she helped identify DNMT3A mutations as the cause of Tatton Brown Rahman syndrome. She continues to define its clinical features and develop evidence-based management guidelines in collaboration with the TBRS family community.

Laura Lavery, PhD

Dr. Laura Lavery is an Assistant Professor of BioSciences at Rice University. Her research investigates how epigenetic regulators control gene expression during brain development and how mutations in these factors lead to neurodevelopmental disorders. Her lab aims to advance mechanistic understanding to support future therapeutic strategies and improved patient care.

Rachel Rau, MD

Dr. Rachel Rau is an Associate Professor of Pediatrics at the University of Washington and a pediatric hematologist-oncologist at Seattle Children's Hospital. Her research focuses on the molecular mechanisms of leukemia and treatment resistance, with special emphasis on DNMT3A mutations. She leads multiple clinical trials through the Children's Oncology Group to bring new therapies to children with cancer.

Serge McGraw, PhD

Dr. Serge McGraw is an Associate Professor at the Université de Montréal and leads the Developmental Epigenetics and Neurodevelopment Lab at Sainte-Justine Hospital Research Center. His research examines how errors in DNA methylation during early development contribute to neurodevelopmental disorders. Using patient-derived stem cells and advanced genomic tools, his lab studies disrupted epigenetic programs underlying childhood brain disorders.

Vicken Totten, MD

Dr. Vicken Totten is a physician with training in family and emergency medicine and a background in clinical research leadership. In 2019, her eldest son was diagnosed with Tatton Brown Rahman syndrome, prompting her to become deeply engaged in TBRS research and community support. She brings both professional and personal perspectives to help families better understand the long-term outlook for individuals with TBRS.

Irene Valenzuela, MD

Dr. Irene Valenzuela is a medical geneticist at Vall d'Hebron Hospital in Barcelona, Spain. Her research focuses on intellectual and learning disabilities, with a special emphasis on defining the clinical and molecular features of Tatton Brown Rahman syndrome. She works closely with the Spanish TBRS family community and serves on the Scientific Committee of the Spanish TBRS Association.

Meet our presenters is continued on page 8.

Meet our presenters. (continued from page 7)

Stephen Archer, MD

Dr. Stephen Archer is Director of the Translational Institute of Medicine at Queen's University and a practicing cardiologist specializing in pulmonary hypertension and mitochondrial biology. His research focuses on mitochondrial function, oxygen sensing, and experimental therapeutics for cardiovascular and pulmonary disease. He has published extensively and is actively studying cardiac phenotypes associated with Tatton Brown Rahman syndrome.

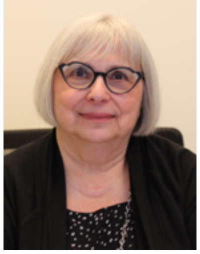
Kim Boua

Kim Boua is an MD/PhD student at Washington University in St. Louis in Dr. Harrison Gabel's lab. Her research focuses on Tatton Brown Rahman syndrome and the feasibility of gene therapy approaches for treatment. She holds a bachelor's degree in Neuroscience from Duke University and has experience studying transcriptional mechanisms in brain disease models.

Jacqueline Harris, MD, PhD

Dr. Jacqueline Harris is Director of the Epigenetics Clinic at Kennedy Krieger Institute and Associate Professor of Neurology, Pediatrics, and Genetics at Johns Hopkins University. Her work focuses on Mendelian disorders of the epigenetic machinery, including clinical trial readiness, biomarker development, and neurodevelopmental and behavioral phenotyping. She also conducts neuropsychiatric research with individuals with TBRS.

*Meet our presenters is continued on page 14.



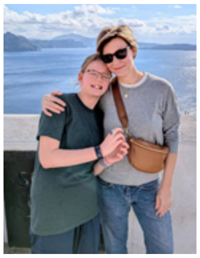
Rosanna Weksberg, MD, PhD

Dr. Rosanna Weksberg is a Professor of Pediatrics and Genetics at the University of Toronto and Associate Editor of the American Journal of Medical Genetics. Her research explores how genetic and environmental factors influence epigenetic marks in human disease. Her lab has made key contributions to identifying DNA methylation signatures used in the diagnosis of epigenetic disorders.

Family Speakers:

Jenny Beeson

Jenny Graham-Beeson is a mother of four, a Board Certified Behavior Analyst, and a nationally engaged rare disease advocate based in Frisco, Texas. Her family's experience with both Phelan-McDermid syndrome and Tatton Brown Rahman syndrome has shaped her work supporting families navigating rare genetic diagnoses. She co-leads the TBRS family support community and promotes early genetic testing and informed care for children with complex needs.



Jamie Class Cannon

Jamie Cannon and her husband Jeremy are members of the U.S. Foreign Service currently stationed in Dhaka, Bangladesh. Their youngest daughter, Mae, was diagnosed with Tatton Brown Rahman syndrome in 2021. The family has navigated TBRS care across multiple countries and healthcare systems, offering a unique perspective on rare disease in global settings.

Welcome Scientists. Wednesday, March 18, 2026

3:00 pm **Welcome and Registration:** Get settled, relax, and explore the Camp.

6:00 pm Dinner and **Welcome Reception with the TBRS Community Board**
In Contrada Vineyard 27490 Smithson Valley Rd, San Antonio, TX 78261

Research Exchange and Patient Priorities. (scientists only)

Thursday, March 19, 2026

Agenda for Researchers & Clinicians Attendees:

8:00 am	Breakfast *(D)*
9:00 am	**Welcome from TBRS Community**
9:15 am	**Biology and Mechanisms of TBRS:** Family perspective: Jenny Beeson and Family *Facilitated workshop linking scientific updates to patient priorities; working group formed for post-Summit follow-up. Facilitated by Dr. Harrison Gabel*
10:30 am	*Break*
10:45 am	**Biomarkers and Candidate Outcome Measures:** Family perspective: Jamie Class and Family *Workshop discussion tying outcome measures to meaningful daily life impacts; working group formed for post-Summit follow-up. Facilitated by Dr. Rosanna Weksberg*
12:00 pm	Lunch *(D)*
1:00 pm	**Comparative Clinical Effectiveness Research Questions and Treatment Development for TBRS:** Family perspective: Andrew Vitullo and Family *Facilitated discussion on planning to incorporate patient-centered CER-relevant questions into developing a moonshot for TBRS; working group formed for follow-up. Facilitated by Dr. Terry Jo Bichell*
2:15 pm	*Break*
2:30 pm	**Incorporating Patient Priorities and Comparative Clinical Effectiveness Questions into Research:** *Exploring patient-centered CER and why it matters for TBRS (Tailored to Researchers and Clinicians).*
2:45 pm	**Accelerating progress in 2026:** Open discussion facilitated by Kerry Grens, TBRS Board Vice President
3:15 pm	Networking and 1:1 Appointments
5:30 pm	See schedule below, to be included with families

Agenda for Families and Diagnosed Individuals:

3:00 pm	**Welcome and Registration:** Get settled, relax, and explore the Camp. Donate to our biorepository and/or participate in other research projects. Pool will be open for those who want to cool off! *(K)*
5:30 pm	**Welcome from TBRS Leadership**
6:00 pm	Dinner with families and researchers *(D)*
7:00 pm	**Evening activities:** Ice breaker games and campfire with s'mores and karaoke *(I)*

**Biorepository participation is available Thursday and Friday.*

**1:1 interviews and psychological evaluations are by appointment only and scheduled for Thursday, Friday, and Saturday.*

Building Capacity for Patient-Centered Research

Friday, March 20, 2026

Agenda for All Attendees:

This weekend is yours. There is no expectation to attend every session. Please feel free to enjoy activities, take breaks, or step away as needed. All sessions will be recorded, and you'll have access afterward.

7:00 am	**Early morning self care for parents and/or caregivers only:** Gentle morning yoga and sound healing (beginner-friendly yoga poses with a focus on down-regulating the nervous system, ending with shavasana and sound healing) *(K)*
8:00 am	Breakfast *(D)*
9:00 am	**TBRS Welcome: From Questions to Care:** How Patient Priorities Shape Patient-Centered Comparative Clinical Effectiveness Research (CER) *Plain-language introduction to patient-centered CER for all stakeholders*.
9:30 am	Genetics Presentation and Q&A Discussion, **Dr. Kate Tatton-Brown**
10:50 am	Break
11:00 am	**Support and Sharing Groups**
12:00 pm	Lunch *(D)*
1:00 pm	Neurology, cognitive, and behavioral concerns for TBRS patients presentation with questions & answers, **Dr. Jacquelyn Harris**
2:15 pm	Break
3:00 pm	**Science Session:** Research Roadmap Approaches to TBRS treatment development: gene science, drug development, repurposing, and other methods, **Dr. Kim Boua, Dr. Laura Lavery,** and **Dr. Serge McGraw** 20-minute Q&A, with facilitators highlighting patient-centered CER-relevant themes.
4:00 pm	**Family Activities/Support Groups:** pool is open, relax in your cabin, participate in research, or enjoy some yard games by Hartman Hall
5:30 pm	Gordon Hartman Welcome
6:00 pm	Dinner *(D)*
7:00 pm	**Evening activities:** Nighttime zip line and block party with silent disco, karaoke, and glow sticks *(T)*

Agenda for Diagnosed Individuals, Children, and Caregivers:

8:45 am	**Outdoor Activity Rotations:** Horses (Q), Nature *(P)*, RC Cars, Yard Games *(D)*
12:00 pm	Lunch *(D)*
1:00 pm	**Cabin Time:** Enjoy some downtime or visit the library/crafts *(M)* or courtyard games. We would also like to encourage all diagnosed individuals to **participate in research** at this time.
1:30 pm	Pool and Lazy River are open! *(K)*

**all outdoor activities are subject to weather (map corresponding letter) - see page 4 of program*

Patient Priorities and Stakeholder Engagement.

Saturday, March 21, 2026

Agenda for All Attendees:

7:00 am	**Early morning self care for parents and/or caregivers only:** QiGong Practice (gentle movement and energetic awareness, ending with meditation and sound healing) *(K)*
8:00 am	Breakfast *(D)*
9:00 am	**TBRS Introduction to the Day:** Gathering Patient Priorities for Patient-Centered CER *Brief introduction to remind participants of patient-centered CER basics and explain how their input in focus groups and interviews will shape patient-centered CER questions for the PRISM Roadmap.*
9:15 am	Hematology and Oncology: Considerations for TBRS patients, **Dr. Rachel Rau**
10:00 am	Aortic dilation, the impact of participating in research, and an upcoming study into bone abnormalities, **Dr. Irene Valenzuela and Dr. Vicken Totten**
10:40 am	*Break*
10:45 am	Cardiology concerns for TBRS patients, **Dr. Stephen Archer**
12:00 pm	Boxed Lunch *(D)*
1:00 pm	**Research Participation and Cabin Time:** We will be holding **Patient Priorities Focus Groups** at this time. Participants who have been pre-consented and enrolled in the program will participate in the research project. Everyone else can enjoy some downtime or visit the library/crafts *(M)* or courtyard games.
2:15 pm	Break
3:00 pm	Support Groups
4:00 pm	**Group Activity:** Foam party at the pool!
5:30 pm	Awards Ceremony
6:00 pm	Dinner *(D)*
7:30 pm	**Evening activities:** TBRS Party! Watch a movie inside, or join us for dancing, campfire, s'mores or ice cream in the courtyard. *(D)*

Agenda for Diagnosed Individuals, Children, and Caregivers:

9:00 am	**Open Ropes Course:** Rock Wall (R), Zipline (T), Challenge Course (S), RC Cars, or yard games on the patio
12:00 pm	Lunch *(D)*
1:00 pm	**Cabin Time:** Enjoy some downtime or visit the library/crafts *(M)* or courtyard games. We would also like to encourage all diagnosed individuals to **participate in research** at this time.
1:30 pm	Pool and Lazy River are open! *(K)*

**all outdoor activities are subject to weather (map corresponding letter) - see page 4 of program*

Community and Reflection. Sunday, March 22, 2026

Agenda for All Attendees:

7:00 am	**Sunrise Walk:** Come one, come all, for a peaceful morning stroll. *(K)*
8:00 am	Breakfast *(D)*
9:00 am	**Closing Statements from the TBRS Community** *Reflections on the Summit, highlighting patient-centered CER questions and next steps for the PRISM Roadmap.*
10:00 am	Goodbyes.

Make the most of your visit!
Check out things to do while you are here.

- ☐ Sign your photo waiver and get your **picture taken**!
- ☐ Sign up for the TBRS & *DNMT3A* Patient Registry.
- ☐ Get more information about the **Biorepository** and participate in research.
- ☐ Introduce yourself to someone new - you might make a new friend!
- ☐ Pick a leaf from the **"Giving Tree"** - help make a difference in our Community.
- ☐ Introduce yourself to a Board member and tell us what the being a part of the Community means to you.
- ☐ **Explore the Camp** - there are so many fun things for all to do here!
- ☐ Stop by the TBRS research table to learn about **Citizen Health**.
- ☐ Sign up: **Count Me In For TBRS.**
- ☐ Take our **Patient Priority Survey**.
- ☐ **Create a CRID**: Ask at the TBRS research table to learn more.
- ☐ (For families) Ask a scientist or clinician a fun question.
- ☐ (For scientists) Ask a family member a question.
- ☐ (For scientists) Tell our kiddos a knock knock joke.
- ☐ Find out about the **Brain Gene Registry** at the TBRS research table.

Check off at least SEVEN items and we will add your name to be entered to win a prize!

Make a Difference in our Community!

Participate in TBRS Research or Join our Collaborative Research Network!

Contact Community and Research Engagement Manager, Kit Church @ kit@tbrsyndrome.org

Our Superheroes in Action

Everything we know about Tatton Brown Rahman Syndrome exists because **TBRS patients and families chose to participate in research.**

TBRS is a fairly **newly identified genetic syndrome**. When families first began receiving this diagnosis, there were few answers, limited guidance, and no clear roadmap for care. What we know today has been built in real time, alongside the individuals and families living with TBRS.

They are our trailblazers.

They are our superheroes.

Because of patient participation, we now have:

- A growing understanding of the **natural history of TBRS**
- Identification of **important health risks**, including cardiac findings
- Data that informs **clinical care and surveillance**
- The foundation needed to pursue **treatments and future clinical trials**
- A global network of researchers, clinicians, and families working together

Research does not move forward without courage, trust, and commitment. Every data point represents a person. Every discovery reflects lived experience.

The TBRS Community believes research should be done **with patients, not just about them**. Our progress is powered by partnership and guided by the voices of those most impacted.

To every TBRS patient who has participated in research: **This Summit exists because of you.**

Your courage is shaping the future of TBRS.

be a superhero!

Interested in becoming part of this journey? Learn more about participating in TBRS research:

Meet our presenters. (continued from page 8)

Andrew Vitullo

Andrew Vitullo is a healthcare executive living near Philadelphia with his wife Sara and their two daughters. His youngest daughter, Eleanor, was recently diagnosed with Tatton Brown Rahman syndrome. Drawing on both personal experience and professional expertise, Andrew is committed to strengthening connections between families, clinicians, and researchers to advance understanding of DNMT3A-related conditions.

Discussion Leads:

Harrison Gabel, PhD

Dr. Harrison Gabel is an Associate Professor of Neuroscience at Washington University in St. Louis. His lab studies gene regulation in brain development and plasticity using genetic and genomic approaches in mouse and human models. His group has developed multiple preclinical models of Tatton Brown Rahman syndrome and is investigating potential therapeutic strategies.

Terry Jo Bichell, PhD

Dr. Terry Jo Bichell is a neuroscientist and founder of COMBINEDBrain, a consortium focused on developing outcome measures and biomarkers for rare neurodevelopmental disorders. Her work bridges patient advocacy and translational research, including close collaboration with the TBRS Community through shared research projects and a biorepository. She also teaches translational neuroscience at Vanderbilt University and serves on the Tennessee Rare Disease Advisory Council.

2023 Summit Scientist Panel.
We are excited to hear what this year's discussions bring!

Virtual Meeting Information.

Join us from anywhere in the world!

https://tbrssummit.org

Login info will be emailed to registrants and presentations will be recorded for access to all attendees after the conference. To use live translation, click on the QR code and choose your preferred language.

Thank you to our sponsors!

Gordon Hartman
FAMILY FOUNDATION

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Want to contribute to our Community, just like these super stars?!

Volunteer: contact Board President, Kacee Richter info@tbrsyndrome.org

Donate: https://givebutter.com/togetherfortbrs

Connect with us!

Social Media:

We also have a private Facebook group (for families and individuals with TBRS).
https://www.facebook.com/groups/705487016188994

Newsletter: tbrsyndrome.org/news-updates

Website: tbrsyndrome.org

Email: info@tbrsyndrome.org

TBRS Family Connect: https://tbrs.circle.so/c/families-caregivers-community/

Our Vision

We envision a world where people affected by rare diseases, like TBRS, have a place to go for answers, support, treatments, and cures. It's as simple as that. Nobody should be left out when it comes to access to health and happiness.

The TBRS Community is turning this vision into reality for our families, while blazing a trail for all those impacted by rare diseases.

Thank you to our Board of Directors!

They all volunteer their time to help make our Community a success!

Kacee Richter, President

Kerry Grens, Vice President

Zoe Wisnoski, Secretary

Tim Bernier, Treasurer

Erin Rooker, Marketing Director

Monica Bejano, Board Member

Robert Thibodeau, Board Member

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