



# Rett GAZETTE

Accelerating Research.  
Empowering Families.

# GAINING MOMENTUM





Melissa Kennedy

At Rettsyndrome.org there is energy in the air. Great things are happening, and momentum is building around the country. This ongoing, increasing progress is ushering us into a new season with new partners and opportunities to make a difference for families affected by Rett syndrome.

I hope you feel this energy and momentum as you read this edition of the Rett Gazette. You will meet our new advisors, staff and volunteers who are passionate about serving our community as we work to find life-changing treatments and empower families. You will read about incredible new research, groundbreaking results and clinical trials that are moving us closer to a world without Rett syndrome.

We have made great strides, and the future is promising. As you explore these stories of love, strength, hope and momentum, I hope you will be inspired to join us. We need to make the world aware that we are here, we are strong, and we will not stop until we **OVERPOWER Rett**.

We cannot do this alone. You cannot do this alone. But together, we can and we will.

With Hope and Gratitude,

Melissa Kennedy  
Executive Director  
Rettsyndrome.org



Steve Kaminsky, PhD

I write this update with considerable excitement about everything Rettsyndrome.org is supporting, but with a special emphasis on clinical trials in search for treatments of Rett syndrome. Newron's investigation of the effect of sarizotan on breathing in Rett syndrome is coming to a close in their clinical trial; Anavex (by the time of this publication) has either started or will shortly begin their clinical trial with Anavex 2-73 looking at its safety and efficacy; AMO is gearing up for a clinical trial in Europe with their newly acquired compound AMO-04; and finally Neuren/ACADIA are finalizing their protocols and procedures with trofinetide for the largest Phase 3 clinical trial ever undertaken for Rett syndrome into the second half of 2019.

The Scout Program continues to test a battery of compounds in pre-clinical models. As we identify drugs that work in the mice, we will urge companies to take their drugs to the FDA for future trials with Rett syndrome. We continue to push new horizons on correcting the underlying genetic change in Rett syndrome by building on our gene therapy portfolio of grants, following new avenues to activate the silent X chromosome, and by identifying drugs that might work as read through compounds.

It is an exciting time as evident by the many questions from families about these trials. We are on the precipice of something big. At Rettsyndrome.org, we share your excitement and are pleased to have a hand in developing these trials that could change the standard of care and the course of Rett syndrome. We will keep up the momentum to ensure a better tomorrow.

Steve Kaminsky, Ph.D.  
Chief Science Officer  
Rettsyndrome.org

## Poised for Momentum

*Accelerating research and empowering families is Rettsyndrome.org's steadfast commitment. But we cannot do it alone. It takes strong allies to help raise awareness and fund research. We are pleased to announce six new Rettsyndrome.org partners in this fight to OVERPOWER Rett.*



**Tim Benke, MD, PhD,**  
Medical Advisor

As an investigator with the Natural History Study, Dr. Benke is well known in the Rett community. An accomplished clinician and researcher, he currently serves as the Ponzio Family Chair in Pediatric Neurology Research and Director of Research at the Neuroscience Institute at Children's Hospital Colorado where he is also Medical Director of the Rett Clinic. As a medical advisor for Rettsyndrome.org, Dr. Benke will support our continued development of a nation-wide, clinical infrastructure that provides best-in-class, family-centered clinical care.



**Tim Frank, Director,**  
Marketing & Communications

An award-winning art director and marketing strategist, Tim began his career in the music industry working with platinum and gold-selling artists. In 2012, his daughter Ella was diagnosed with Rett syndrome. As a Rett dad, Tim brings valuable insight to the messaging of Rettsyndrome.org for families and the community. His experience in nonprofit marketing and leadership is a valuable asset that will better position Rettsyndrome.org for growth.

## NEW BOARD MEMBERS

Recently, we appointed four new board members to advance the mission of Rettsyndrome.org. Each have been personally impacted by Rett syndrome and are committed to raising awareness and funds to accelerate research for life-changing treatment.

### William "Bill" Babiarz

Bill is a senior derivatives trader at IMC Financial Markets. Bill and his wife, Jackie, have two girls; Cameron (Rett syndrome) and Ryan. They created Cammy Can to raise awareness and money for Rett syndrome. Bill and Jackie are passionate about providing guidance to newly diagnosed families.

### Christian McMahan

Christian McMahan is President of Wachusett Brewing Company. Christian and his wife Ariane's daughter, Keilly was diagnosed at two years old. They helped to host the Boston Food and Wine Festival to raise funds for Rett syndrome research. Christian is a returning IRSF Board member.

### Steve Tomes

Steve has had many years as a successful senior leader in the Western Region of Delaware North, a global food service and hospitality company. Steve and his wife, Donna, have a daughter, Amanda, who has Rett syndrome. Steve has been instrumental in the development of the LA Feast and Fundraiser.

### Beth Farnum

Beth and her husband, Bill founded Casting 4 a Cure, to help their daughter, Ella, and the thousands of girls like her, live life to their full potential. Beth spent a decade at Nike in marketing and now stays home to care for Ella and guide her education process, medical and therapeutic needs.



# Small changes — Big impact

*As a parent waiting anxiously for a cure, it may feel like research for a new mouse model is of little help to your child. This story demonstrates how laboratory work leads to critical advances and discoveries that bring us closer to delivering treatments and a cure to you.*

This summer, two very significant breakthroughs in Rett syndrome research were made by Rettsyndrome.org researcher Jeannie T. Lee, MD, PhD and her team at Massachusetts General Hospital. The first breakthrough Dr. Lee made was to develop a female mouse model that can be used in Rett syndrome research. Until recently, male mouse models were primarily used in research for various reasons. However, male mice are not able to fully replicate a primarily female disease. This new female model will allow researchers to better study the effectiveness of *MECP2*-reactivating drugs. This model also exhibits many of the symptoms seen in children with Rett syndrome, such as repetitive and self-injurious behaviors, muscle weakness, tremors and gait disturbances.



*Rettsyndrome.org awarded Dr. Lee with a HeArt Award for this research. We would like to thank Dr. Lee and her team for their work and congratulate them on their success.*

The second breakthrough was unexpected — they found that *MECP2* expression does not have to be restored in **every** brain cell to have noticeable benefit. Expressing just 5-10% of the normal *MECP2* in the brain led to improved motor skills, reduced disease severity, and a 5-8-fold increase in lifespan in the mice. Dr. Lieselot Carrette (a member of Dr. Lee's team) says, "Even small amounts of *MECP2* expression appear to have big effects, which is very promising for the development of Rett syndrome treatments." Partial reactivation could improve symptoms while reducing potential side effects because a very low, safe dose could be effective. This could allow X reactivation to be a safer alternative to gene therapy which has many dosing challenges.

Dr. Lee's team will continue investigating methods of reactivating the silenced X chromosome to treat Rett syndrome. They have had previous success using a combination of 2 methods — blocking a molecule called Xist and using a process called DNA methylation. Testing this combination on the new female mouse model will be a significant advancement of their research.

## ROCKY MOUNTAIN RETT ASSOCIATION AND THE DENVER RETT CLINIC

*In 2011 the Rett Clinic at Denver Children's Hospital opened as a direct result of collaboration between the families of the Rocky Mountain Rett Association and clinical pioneers at Denver Children's.*

Born out of the RMRA families' desire to bring excellent clinical care to their children, the Rett Clinic, led by Dr. Tim Benke, has quickly grown and is now recognized as one of the preeminent multi-disciplinary clinics in the country.

RMRA was responsible for raising the awareness and funding required to open the clinic, but the work did not stop when the clinic opened its doors. They continue to raise money to support the changing needs of a growing clinic. They provide volunteers during clinic days to greet families, offer support and bring snacks to clinic guests.

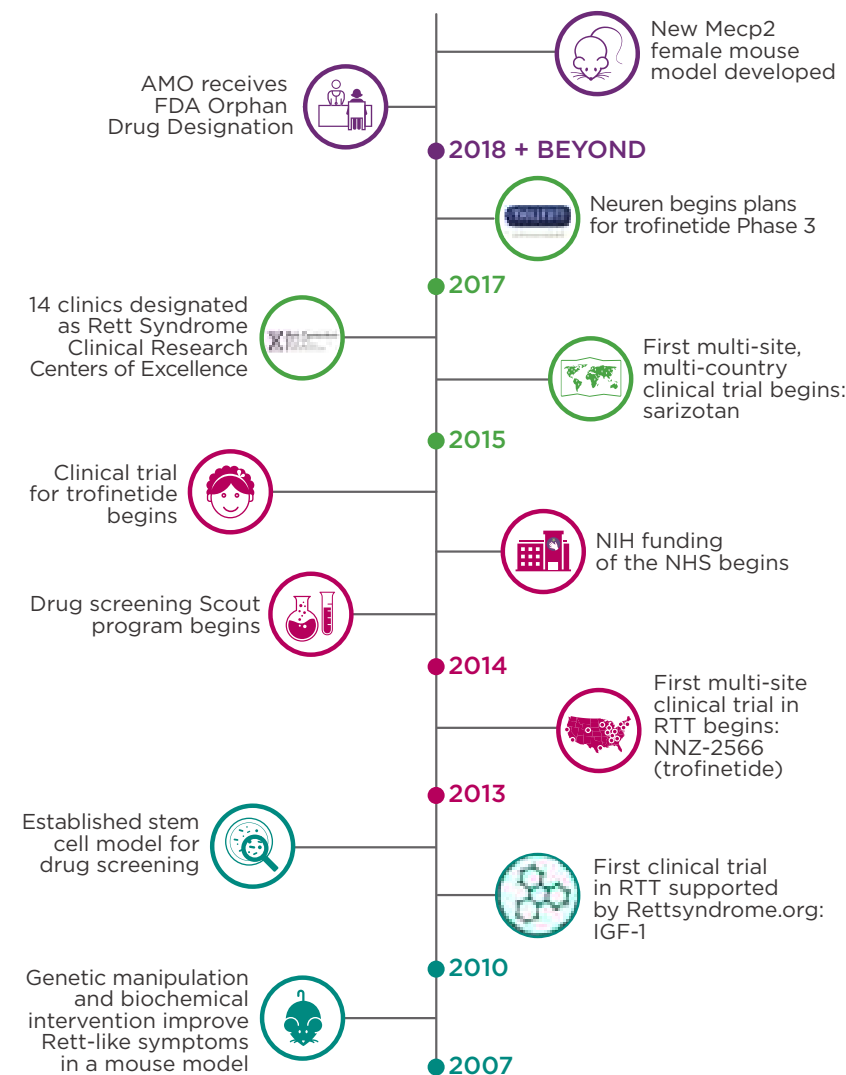
When asked what has made this collaboration successful, RMRA will tell you it is due to the leadership of Dr. Benke and his deep commitment to his patients and his work. The Denver Rett Clinic credits the success to the amazing RMRA family and their dedication to their kids and their community. We believe they are both correct.

*To learn more about multi-disciplinary care and how it can benefit your family, visit: [www.childrenscolorado.org/about/why-childrens/multidisciplinary-care/](http://www.childrenscolorado.org/about/why-childrens/multidisciplinary-care/)*



# Great Gains in Research

Over the last ten years we have made significant advancements in research, positioning us closer than ever to life-changing treatments and a cure.



## RETTSYNDROME.ORG IS PROUD TO HAVE SUPPORTED DEVELOPMENT OF 5 COMPOUNDS INTO CLINICAL TRIALS.

- Trofinetide** — Phase 3 to begin in 2019
- Sarizotan\*** — Phase 2 & 3 ongoing and actively recruiting
- Anavex 2-73\*** — Received Orphan Drug Designation to begin trial planning
- AMO-04\*** — Received Orphan Drug Designation to begin trial planning
- IGF-1** — Complete. Did not confirm positive effects.

\*Brought into trials through the Scout Program

# AMO-04 receives FDA's Orphan Drug Designation

Another pharmaceutical compound, AMO-04, has been given Orphan Drug Designation from the FDA after they found promising results while screening through Rettsyndrome.org's Scout Program. At this time, AMO Pharma is planning to begin clinical trials in Europe.

AMO-04 is intended primarily to improve breathing irregularities. In the early mouse studies, AMO-04 also improved motor coordination, gait, and visual function.

AMO-04 is a repurposed drug that has been approved as a treatment for other diseases. Because the FDA already approved it for other uses, AMO-04 may enter human clinical trials for Rett syndrome as Phase I or Phase II.

## UPCOMING EDUCATIONAL OPPORTUNITIES

*We have several online and in-person events to help you **OVERPOWER** Rett. Register online at [www.rettsyndrome.org/events](http://www.rettsyndrome.org/events)*

- 10/9** 1PM (ET) RettEd Webinar: Planning for a Protected Tomorrow with Mary Anne Ehler, CFP
- 10/27** Rett Syndrome Education Day — Vanderbilt University, Nashville, TN
- 11/13** 1PM (ET) RettEd Webinar: Gross Motor Skills and Environmental Enrichment with Jenny Downs, PhD
- 11/16** Rett Symposium — LAC+USC Medical Center, Los Angeles, CA
- 11/17** Family & Clinician Ed Day — San Gabriel/Pomona Regional Center, Pomona, CA
- 12/11** 1PM (ET) RettEd Webinar: Siblings

**Past webinars are available at [www.rettsyndrome.org/RettEd](http://www.rettsyndrome.org/RettEd)**





# Finding the Strength to OVERPOWER Rett Syndrome

*When your world has been shaken with a devastating diagnosis, how do you find the strength to fight? Read Jimmy and Kammy Chan's story to see how they are doing it.*

Our journey probably begins much like your own. A little over a year ago, we noticed that our 3-year-old daughter, Holly, was having some speech and physical delays. This spring, Holly was diagnosed with Rett syndrome.

The day we received the diagnosis, we were devastated, and our overwhelming desire was to go pick Holly up from daycare and just hug her. One of the most difficult things to face was the possibility that this child, who has always had so much to say, might lose her ability to do just that. We both agreed pretty quickly that we would turn this awful diagnosis into something positive. We would overpower it. We knew we would need a lot of strength and support to do that.



**Holly is an incredible child. She has a sweet disposition, enjoys traveling and seems to observe and embrace new experiences.**

One of the first and most beneficial things we did was simply to talk about it. Talking is a huge source of strength for us. Through those honest conversations, we have developed an amazing support system.



People have come alongside us, helped us navigate special education, private services, and medical care and connected us with other Rett families. Our marriage has also been a huge source of strength and emotional support. We are truly a team, and we are facing this together.

Even with our support system, we still have challenges. All of the new things we have to tackle can, at times, feel overwhelming. We try not to focus on the difficulties and instead celebrate the progress that Holly makes.

Our advice to parents who have just received the diagnosis: **Reach out and talk to others.** We make sure people understand that although Holly has limited speech, she fully understands what we are saying. We also make sure they understand that there is no cure for Rett syndrome... yet.

We have decided to engage our business, Hawaiian Chip Company, in the fight for a cure for Rett syndrome. We donate one percent of all gross sales to fund Rett syndrome research. We have made it our goal to spread awareness about Rett and find ways to contribute to the Rett community.

Our biggest dream would be for Holly to be able to communicate with us, for her to be able to speak everything she is trying to say with her eyes. Of course, we also long for a cure within Holly's lifetime. Though gene therapy and editing may be our best hope for a cure, we believe that treatments which affect brain function have the most promise for improving her quality of life. Most importantly, we want her to experience as much as she can and enjoy life to the fullest. That is our purpose as her parents. That is why we are determined to OVERPOWER Rett syndrome.

Learn more about Hawaiian Chip Company at [www.hawaiianchipcompany.com](http://www.hawaiianchipcompany.com)

## Me and My Sister



**ABIGAIL, AGE 10 & ELLA, AGE 8**

The best thing about being Ella's sister is that Ella is the most perfect sister in the universe. She's cute, funny, smart, kind and loyal and I couldn't be more pleased to be her sister. We have special time called "Sissy Time," where we read together or laugh together. We use her Tobii. Ella plays jokes on her teachers with the Tobii, like if she says, "I'm hurting", and they ask, "You are?" she will say, "Just kidding".

The hardest thing about being her sister is when she has a seizure. When I talk to people about Ella and Rett syndrome I tell them that Ella has a sickness that causes her to not walk or talk and that she has these things called seizures.

Rett syndrome doesn't stop me from having big dreams for Ella and for me. My biggest dream for me is to be a missionary and my biggest dream for Ella is for her to be healed.

My favorite thing about being Finley's sister is when Finley wakes up in the night and comes in my bed and cuddles me. We like to play outside together. She likes to hold my hand way more than mommy's and daddy's hand. She makes the funniest faces ever!

The toughest part is when she doesn't do what I want and needs more attention. I tell people that she can't talk and has trouble doing the things I can do. I tell them that even though she can't talk, they should still talk to her and play with her because she is smart and wants to play too.

Finley only signed "I love you" one time and it was to me. I love her too. I have big dreams for Finley and me. I want to grow up to be a vet. I want Finley to have a cure so she can talk to me and tell me I'm the best sister ever.



**JOSLYN, AGE 7 & FINLEY, AGE 3**



**ALLY, AGE 21 & KAITLYN, AGE 19**

Kaitlyn is my best friend and the strongest person I know. She brings light to all who meet her and has the best sense of humor! One of the things I love most is being an advocate for Kaitlyn. Having the honor of being a Rett sister also means that I have a lifelong best friend who teaches me a million different life skills.

I love how my Dad described Rett syndrome to me when I was very young. He said, "Kaitlyn is an X-Men." (We grew up around comic books and super-hero movies, so he used this to describe her gene mutation.) So, I always thought my sister was a real superhero and still do!

My biggest dream for my future is to make my family, my close friends, and, most importantly, Kaitlyn proud! My biggest wish for Kaitlyn is just peace and happiness. Her whole life has been appointments and schedules. Seeing Kaitlyn happy, healthy, and relaxed is my biggest dream for her.



## BETA SIGMA PHI BATTLES RETT

***Can one woman mobilize an entire organization to OVERPOWER Rett syndrome? You bet she can! And Anita Poulton has done just that.***

Since she was a young woman, Anita Poulton has had a heart for philanthropy. In 1980 she joined Beta Sigma Phi, a sorority that focuses on women, their friendships and their philanthropic interests. She had no idea the impact that relationship would have in her life.

In 2002 Anita's granddaughter, Sonora, was diagnosed with Rett syndrome. The following year, Anita began the process of requesting funding for Rett syndrome research from an endowment held by Beta Sigma Phi. Anita began by raising awareness about Rett syndrome. Word about Rett syndrome spread and sorority sisters from all over the world began asking how they could help.

In 2004 Anita presented her first request to the Beta Sigma Phi board and membership. Every three years, Anita repeats the lengthy application process. Thanks to her efforts and the generosity of Beta Sigma Phi, Rettsyndrome.org is a 5-time Endowment Recipient. Anita's very good friend and current Beta Sigma Phi president, Laura Ross Wingfield has been an incredible help and support in this journey.



Anita has also done her own personal fundraising and continues to talk about Rett syndrome. This June, she spoke to over 150 women at Tennessee's Beta Sigma Phi state convention. Her personal efforts combined with the sorority's funding have contributed \$259,000 to Rettsyndrome.org. An astounding number!

The little girl who inspired all of this turned 20 in July. Sonora is her Gramma and Grandpa's delight. She loves spending time with them and is able to talk a bit with them. She loves SpongeBob cartoons, books, bowling, swimming and sleeping in.

Anita and Beta Sigma Phi, we are inspired by all that you have done to help OVERPOWER Rett and grateful for your generosity.



## 2ND ANNUAL OKLAHOMA CITY RIVER RUN



***Kendra is not your typical college student. She is a caregiver to Keira, who has Rett syndrome.***

I became Keira's caregiver because I believed I could give her the care she needed and help her even more by doing physical therapy exercises with her at home.

I have had many memorable moments with Keira. One of my favorite memories was taking her to the Milwaukee County Zoo. Keira is truly in her element outdoors. I love doing things with Keira that give her confidence and show her that she can do anything, like any other kid. This year Keira climbed to the top of the rock wall, which brought tears to my eyes.

I have a bond with Keira that makes working with her easy. She is my friend. I love the way she communicates with me.

She makes me laugh, and I want to make her smile every day.

When anyone asks me, "What is Rett syndrome?" I tell them the facts, and I tell them that the most important thing we can do for a Rett child is provide the best care to improve their quality of life. I tell them Keira is a regular girl trapped in a body she fights to control.

Keira has been my inspiration through college; motivating me to set a goal to pursue a doctorate in Physical Therapy after I graduate next May. My biggest dream for Keira is that she will always love who she is and will always find happiness. I hope that one day Keira can share her own story with others and spread her own message.

***Robyn and Clint Bishard will host the 2nd OKC River Run on October 6, 2018. Inspired by their daughter, Mercy Grace, learn how they started and organized this race to OVERPOWER Rett syndrome.***

We, like many families reading this article, have a child with Rett syndrome. Our daughter, Mercy Grace, has been instrumental in teaching us and her five siblings about mercy and grace! The challenges in caring for her have also shown us the critical need for continued research to find effective treatments and a possible cure for this disorder. Our family committed to designate 10% of the profits from our family owned business to benefit Rett syndrome research. Early last year we had the idea of seeing if we could raise even more by organizing a charity run for Rettsyndrome.org.

We decided to sponsor a race in the OKC area. The race included a 5k, 10k and half marathon. We advertised the run and let runners know that 100% of their registration fees would benefit Rettsyndrome.org. We found a USATF certified courses for the runs, hired experienced race timing, and made use of runsignup.com. We were grateful to find sponsors to help us pay for race expenses. Our family and many volunteers worked hard to serve the running event.

The first race was a success and this year's registrations are running ahead of last year's numbers. It has been a privilege for our family to be hands-on in the process of hosting, organizing, and volunteering for the OKC River Run. We are so glad we have been able to get more involved in our community, meet new people, raise Rett syndrome awareness, and especially to get to know other Oklahoma Rett families.

## WHEN THE STUDENT IS A TEACHER



***It was just another assignment given to students in Ms. Braswel's 10th grade Biology class. Meredith Wessel (age 16) was asked to do a project on any non-infectious disease she wanted to learn about. In her search for a topic, she read about Rett syndrome. She was intrigued because it affects mostly girls, is rare and she had never heard of it. It sounded like a great subject to teach her class.***

Meredith did a lot of research and interviewed Samantha Brant, Family & Community Engagement Manager at Rettsyndrome.org to learn to learn about her daughter Macy's life with Rett syndrome. She presented a research paper and powerpoint slide show to her class.

Thank you, Meredith, for teaching others about Rett syndrome and for joining us as we fight to OVERPOWER Rett!

***Who inspires you to OVERPOWER Rett? Share on social media using #OVERPOWERRETT or email tfrank@rettsyndrome.org.***





## Decide. Commit. Act. Succeed. Repeat!

*In our last newsletter, we introduced you to Kelly, Libby & Megan who set a goal of raising \$100,000 for Rett syndrome research at their next Strollathon. Find out how they did.*

### The 2018 Iowa Strollathon

Kelly, Libby, and Megan had two goals for their 2018 Strollathon: camaraderie and unification for Iowa families, and raising a “boatload” of money towards a cure. Accomplishing both of those things required a lot of planning. Kelly used social media to keep the teams and donors engaged and the competitive spirit among them alive. The Stroll committee reached out to new donors and sponsors for the event. They even decided to add in a live auction and auctioneer in addition to the silent auction.

The morning of the event, Kelly says she felt they would probably raise the same amount they had the previous year. Then the live auction began, and the first item sold for nearly \$5,000. Kelly knew in that moment that they would not only meet their goal of \$100,000 but exceed it. The crowd’s enthusiasm and excitement grew as the auctioneer worked his magic. By the end of the night, they had raised over \$15,000 in the live auction alone. The event was a success by every measure — raising over \$103,000. Kelly has a

favorite mantra she referred to often in planning this event: Decide. Commit. Act. Succeed. Repeat. And that is exactly what they did.

### Kelly, Libby & Megan share the keys to their success

- Ask for help** — Form a committee and engage with local Rett families
- Listen** — People who feel heard are more engaged. Listen with an open heart and mind, then use what makes sense.
- Act** — If you are thinking about doing it, just start, and you’ll figure it out along the way.

### What’s up their sleeve for 2019?

“More of the same, but better!” Kelly believes that if you give people a great experience, show your appreciation for their hard work, take their honest feedback to heart and vet out any and all ideas, that success is inevitable. And clearly, Iowa has proven that to be true.

We are grateful to Kelly, Libby and Megan for their hard work, dedication and commitment to OVERPOWER Rett.



**Rettsyndrome.org officially launched our new Family Advisory Council on August 8th.** The FAC will help us to develop new programs and advise our Board and leadership, acting as a conduit to better understand our families and shape how we communicate with them. The FAC includes Danny Warner, Co-chair, Jenny Mosca, Co-chair, Jack Kuwik, Katie Busch, Shanna Dunn-Vigare, Kate Ferdinandsen, Sherri Brady, Erin Smith and Leslie Mayorga. Rett syndrome has impacted each council member and we believe their passion will benefit our entire community. Our sincere thanks to each of them for their willingness to support our work.

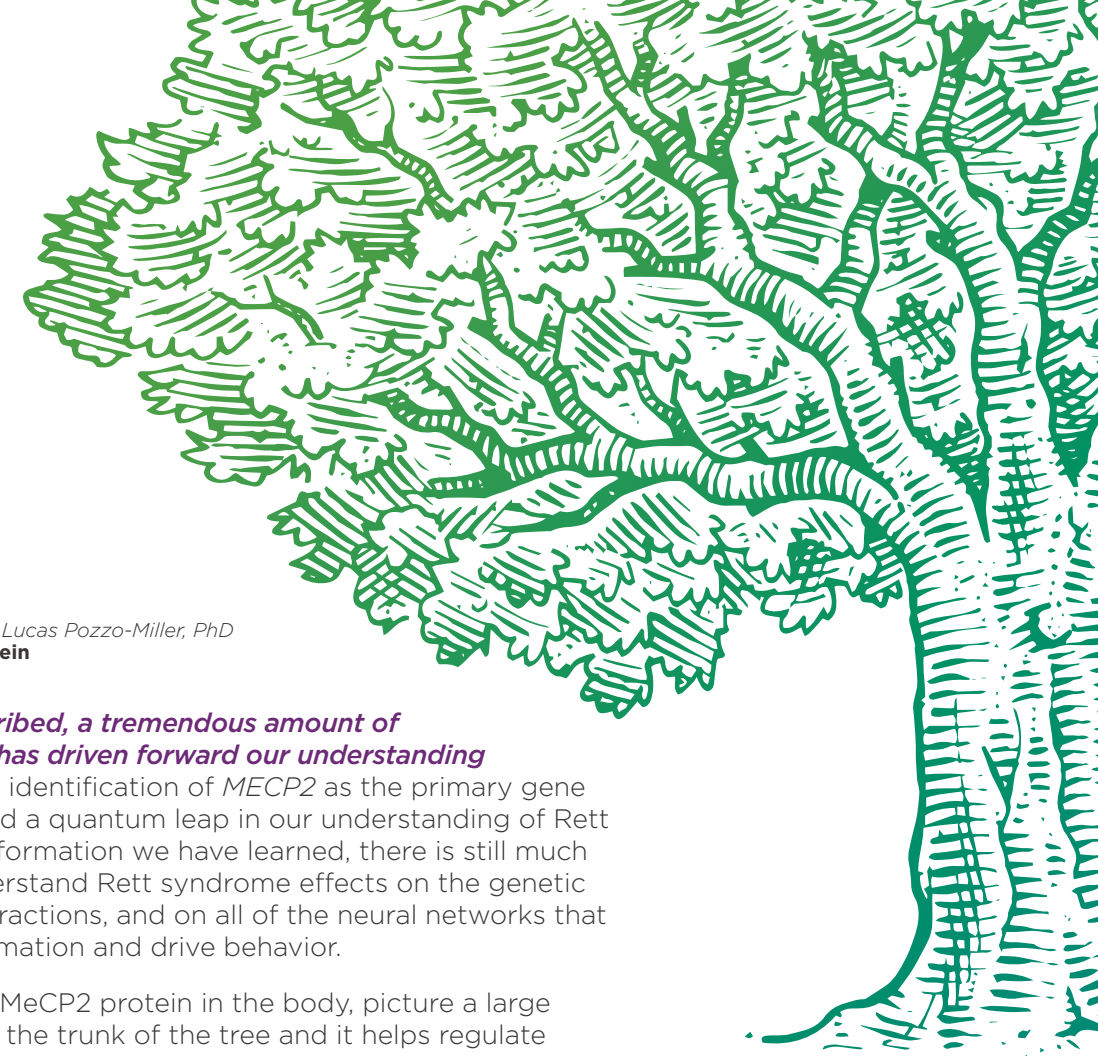
## What We Know in 2018

James Eubanks, PhD, Alysson Mutori, PhD, and Lucas Pozzo-Miller, PhD  
**Definitions: MECP2 — gene // MeCP2 — protein**

**Since Rett syndrome was first described, a tremendous amount of fundamental — “basic” — research has driven forward our understanding of this developmental disorder.** The identification of *MECP2* as the primary gene that causes Rett syndrome provided a quantum leap in our understanding of Rett syndrome. Despite the wealth of information we have learned, there is still much more to learn. We do not fully understand Rett syndrome effects on the genetic level, on molecular and cellular interactions, and on all of the neural networks that receive and integrate sensory information and drive behavior.

To help you understand the role of MeCP2 protein in the body, picture a large oak tree. MeCP2 would be found in the trunk of the tree and it helps regulate everything that moves from the roots out to the furthest branches. Each branch of the tree represents a site that one could potentially target for therapies. The closer to the trunk you target, the better the overall effect of the intervention could be. Getting closest to the trunk would mean finding an intervention that would restore MECP2 gene function. Gene therapy, protein replacement therapy, silent X chromosome re-activation, and nonsense mutation “read-through” drug therapies all have potential to achieve this goal. With respect to gene therapy, the initial outcomes have certainly been encouraging. However, these outcomes were in mice or cells in a dish. These studies are a long way from implementation in humans. More work must be done in animal models to increase the likelihood of success with the lowest risk of complications. We have to get it right because gene therapy is not reversible. Finding the correct dosing levels and methods is incredibly challenging. Introducing too little MECP2 and too much MECP2 are both problematic. Ten years ago, few felt these hurdles could be overcome. Now there is reason for optimism — but there is also more to learn.

**So where do we stand in 2018?** Today, we celebrate that research has moved five different drugs into clinical trials — each of those drugs targeting different branches of that oak tree. We also continue to identify new therapeutic targets that will effectively treat or even cure Rett syndrome. We will find out which branches of the oak tree are closest to the trunk. The consensus amongst scientists in this field is that there are more targets to be found, and that they will emerge only through hard work in fundamental or “basic” scientific research. We all know this is not a fast process, nor one that can be done without significant financial backing. Moving from “bench-to-bedside” has been frequently viewed as a pipeline. Rather, we prefer to view it as a staircase — even though it is hard to climb, it reveals new views at every step. A staircase that will lead to life altering change for those with Rett syndrome.



**...MeCP2 would be found in the trunk of the tree and it helps regulate everything that moves from the roots out to the furthest branches. Each branch of the tree represents a site that one could potentially target for therapies...**



# Rett syndrome awareness month:



## Let's **OVERPOWER** Rett!

*October is Rett Syndrome Awareness Month, and it's time to get the word out about Rett syndrome and the people we love affected by it.*

Rett syndrome has had the upper hand for too long. A child's diagnosis of Rett syndrome can feel like a death sentence — shattering a family's hopes and dreams. Rett syndrome robs a child of their voice, abilities, and strength.

Rett syndrome may try, but it cannot steal our hope.

Like never before, we are making great strides toward treatment and a cure. Momentum is building. The Rett community is stronger than ever. Our voice is louder than ever. Rett syndrome will NOT keep us down.

### **This month Rettsyndrome.org is launching its OVERPOWER Rett campaign.**

Since 1999, Rettsyndrome.org has been aggressively pursuing treatments to improve quality of life and discover a cure. We empower families to get back up after being knocked down by their child's diagnosis and stand firm to OVERPOWER Rett.

We need your help in this fight. Join us to accelerate research toward treatment and a cure and improve the lives of thousands of children and their families.

### **How will you OVERPOWER Rett?**

Everyone can do something to join the effort to OVERPOWER Rett. Use your passions and hobbies to make a difference. Flex your muscle. Use your voice. Make it loud. **Together, we can OVERPOWER Rett.**

## Ways you can **OVERPOWER** Rett



### **ADVOCATE**

- Write #OVERPOWERRETT on your arm, post a selfie, and tag Rettsyndrome.org
- Share your Rett syndrome story
- Follow Rettsyndrome.org on social and share our posts



### **DONATE TODAY**

- To accelerate treatments and a cure
- To help families OVERPOWER Rett
- To become a monthly partner



### **FUNDRAISE**

- Attend an Event
- Start a Fundraiser
- Start a Facebook Fundraiser

### **SHOW YOUR POWER!**

Apply these temporary tattoos, take a selfie and post to social media using #OVERPOWERRETT and help spread the word.

*Check out ALL of our OVERPOWER Rett resources and ideas at [www.rettsyndrome.org/overpower](http://www.rettsyndrome.org/overpower)*

# Rett Ride Across America

***One man's journey to OVERPOWER Rett syndrome leads him across the country.***

It's not every day that someone decides to ride across the country. And when they do you have to ask why. For KC Byers, it's because Rett syndrome hits close to home. His step-daughter Katelyn, who recently turned 24 in August, has Rett syndrome.

KC is a cyclist. He decided to engage his passion for cycling to help OVERPOWER Rett syndrome. In 2010, he rode his bike from Jacksonville, FL to Santa Monica, CA — against the wind — to raise money for research.

This year, he is taking on Rett syndrome for a second time in his Rett Ride Across America. KC explains, "When you love someone that doesn't have the ability to complain or speak for themselves you have to do something. This ride is for the girls, for the fight, and the plight that they are experiencing every day."

On September 30, KC began his month-long journey across America to raise awareness of funds for Rettsyndrome.org research. His mission is to create a buzz around Rett syndrome because so few know about it.

The trip will be grueling, averaging 100 miles a day with only a couple of days of rest. But Katelyn is his constant motivation. "It's hard," KC shared, "but so is what these girls go through. She motivates this old man." KC's travels will take him through California, Arizona, New Mexico, Texas, Louisiana, Mississippi, Alabama (KC's home state) and Florida by October 27. Houston is the halfway point, and KC will visit the Rett Clinic at Texas Children's Hospital, on October 15.

KC has invited many friends, Rett families, and the cycling community to join him on the ride or come out and cheer him on.

KC's 2,600-mile journey will conclude in Jacksonville, FL on Saturday, October 27 where we will be hosting a grand finale party at Sneaker's Sports Grill on the beach. Everyone is invited to join us in congratulating KC on this monumental achievement for Rett syndrome.

***We are so thankful for parents and advocates like KC working to OVERPOWER Rett. Way to go KC!***



## WHAT CAN YOU DO?

**Raise Awareness:** Share KC's story with your local media and share on your social media.

**Give:** help KC raise money for Rett research. Visit [www.rettideacrossamerica.com](http://www.rettideacrossamerica.com) to make a donation.

**Cheer:** Come out to cheer KC on. View his complete itinerary at [www.rettideacrossamerica.com](http://www.rettideacrossamerica.com)



## 3rd Annual LA Feast and Fundraiser

-Shawn Huff, Steve Tomes, Co-Chairs: LAFF

We are so pleased to be chairing the 3rd annual LA Feast and Fundraiser Benefiting Rettsyndrome.org on November 3, 2018. This very special event is an unforgettable evening devoted to these amazing children and the families and friends who love them. We are inspired by the devotion of the Rett community and the generosity of our donors and sponsors. It is an honor to help in the quest for treatments and a cure.

## Purple Pumpkin Gala returns!

Key West will once again have purple pumpkins all over town for the 2nd Annual Purple Pumpkin Gala on October 6, 2018. Hosted by parents, Michelle & Travis Bennett, Juliann & Andrew Edwards and long-time supporters, Kathryn & Luke Kissam, their goal is to continue to spread awareness in the Florida Keys while raising funds through an impressive event. In 2016, the event brought in an astounding \$170,000 and the committee hopes to top that this year. Michelle & Travis, parents to Stella, started this momentous event with the hopes that others will follow suit and host their own "Purple Pumpkin" galas in their cities. We wish them much luck this fall!



## 2018 FALL/WINTER EVENTS

Here are some of our events coming up in the next few months. To see a complete list of all of our events, please visit <https://www.rettsyndrome.org/events>.

### OTHER FALL/WINTER EVENTS

- San Antonio Strollathon, Texas – 10/13/18
- Raise a Glass Against Rett, Kansas – 10/13/18
- Rett Gets Rocked, Missouri – 10/13/18
- SoCal Family Fundraiser & Picnic, California – 10/20/18
- 9th Annual Florida Strollathon, Florida – 11/3/18
- City of Champions, Massachusetts – 11/10/18

### WHAT WILL YOU DO TO OVERPOWER Rett?

To plan or host a fundraiser, email [jventura@rettsyndrome.org](mailto:jventura@rettsyndrome.org)





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# Thank YOU!

The momentum needed to OVERPOWER Rett syndrome is created by the combined efforts of every person affected by the disease. Your effort and contribution are critical to our success. We are profoundly grateful to everyone who gives or fundraises on our behalf. Your support allows us to invest in critical research and provide life-changing support for families living with Rett syndrome. Together we are moving closer to our common goal of a cure for Rett syndrome. Thank you for your generosity and support.