



EVERY
CAST
GETS US
CLOSER





ELLA
FARNUM

LOOK INTO MY EYES
AND HEAR WHAT
I'M SAYING,
FOR MY EYES
SPEAK LOUDER
THAN MY VOICE
EVER WILL.

Casting 4 A Cure started with a need to help a little girl live a life up to her full potential. And an idea to connect that need with an industry filled with compassionate, caring, and generous people.

As Rett Syndrome is a very rare disorder, the majority of our funding for research has to come from private sources. Your generous donation will help us find a way for our girls to lead a life filled with tea parties, high school dances, soccer games, and being able to say "I love you Mommy and Daddy."

Casting 4 A Cure partners with research and family support organizations such as Rettsyndrome.org and The Rocky Mountain Rett Association to support critical research and family support programs. Since our inception in 2008, we have provided over \$1.2M in program support and is an IRS certified 501c3 non-profit organization.



THANK YOU

Casting 4 A Cure would like to thank all of our generous corporate sponsors and individual donors for their support. We could not do this without you, and we truly appreciate your partnership and investment in our quest for a cure.



FLY FISHING FILM TOUR

SILENT AUCTION



01 // WIN A TRIP TO AUSTIN TX!

Spend 3 days in the ATX with two nights hotel. We'll dial you in with some of the best from Austins locals, including a great package of the latest from Yeti Coolers, \$250 of gear from Howler Bros. Airfare, rental car not included.



02 // GEAR UP FOR YOUR NEXT SALTWATER TRIP!

Winner receives a Scott 10 Wt Meridian fly rod and Sage Spectrum 10 wt reel, a Fishpond Submersible duffel, and a \$300 Yeti apparel package. And keep time with your Seaholm Offshore diver watch!



03 // FIVE STAR MONTANA TRIP!

Winner gets a trip for two to the new luxury resort, Montage Big Sky! You'll spend two nights at the luxurious property, have a day of flyfishing private water with a new Scott flyrod, and enjoy the gateway to Yellowstone Park. We have also included a beautiful custom set of Agate earrings and necklace *generously donated by Matt Nelson.*



04 // BEST OF BEND!

Winners will enjoy a 2 night stay for 2 at Sunriver Resort and enjoy all the area has to offer, including golf, fly fishing, mtn biking. We'll get you set to golf with a Nike Golf package of Golf bag, apparel, gloves and more, and we'll also throw in a case of Pro V1 balls, an Odyssey Putter and gear from Guerilla Golf! Dates based on availability.



I CYCLE THROUGH THE STAGES OF GRIEF DUE TO MY DAUGHTER'S RETT SYNDROME



I used to think the **stages of grief** — denial, anger, bargaining, depression, and acceptance — only applied when someone died. That's not true.

I haven't lost my child — I lost the idea that my child would naturally develop to enjoy the life I dreamed for her. It's that loss that first launched my grief. It's the daily challenges of raising a child with a rare disorder that jumbles the grieving process into one that seemingly never ends.

When our daughter **Cammy** was 20 months old, we went to the **physiatrist's** office and first learned of **Rett syndrome**. I kept thinking my child couldn't have it. Not only did she not have all the symptoms, she was showing progress in therapy — painfully slow progress, but progress nonetheless.

This was denial. I returned to this stage when we added a wheelchair, a feeding tube, and most recently, an oxygen machine. There will be more setbacks in Cammy's physical health, and each time I will experience the same avoidance, confusion, and fear of denial.

It didn't take long to move into the next stage of anger. This one bothered me the most because I was aggravated with myself for feeling angry! Cammy wasn't progressing. I left a job I loved to begin my career as a stay-at-home mom, and already I was failing. Cammy wasn't reaching milestones, and I thought it was because of something I wasn't doing. I had no idea that children naturally moved from rolling to crawling to walking without coaching!

Watching other children bypass Cammy developmentally, being unable to communicate with my nonverbal child, a lack of communication between therapists, doctors, and other medical professionals, and a dozen years of sleepless nights can trigger the anger to resurface.

When anger gets you nowhere, you begin to bargain. You'd do anything for your child to be healthy and normal. I pleaded and begged for everything to be OK — for Cammy to feed herself, for her to pick up an object and hold it for 10 seconds, for her to say something. Nowadays, I negotiate with myself. If I can just get through this week, this month, this stage, I'll be OK. We'll be OK.

It has been 10 years since Cammy's diagnosis, and I still go in and out of the depression stage. The first few months after the diagnosis are a blur. I was in survival mode. I had a newborn and a child with profound special needs. I remember my husband coming home from work, and all I could report was that they are fed, changed, and alive, so I did my job today. Those were the only reasons I got up every day.

Our second child drew me out of the depression. Watching how a neurotypical child develops was so fascinating to me. The fortunate thing about the return of depression is that I have developed routines and strategies to manage it. It will return, and I've made peace with that.

My family has appeared in the news quite often, and watching us on television or seeing us in the newspaper, I lose my perspective. A sense of sadness comes over me thinking about this "poor family." Then it hits me — this is my family!

For this reason, I don't know if I'll ever arrive at the last stage of grief, acceptance, because I don't know if I'll ever be able to accept Rett syndrome. What I have accepted is that grief is a natural part of raising a rare child.



05 // DELUXE FLY FISHING PACKAGE!

You will win a set of SIMMS G3 Waders and boots, \$250 of Simms Apparel, a pair of Smiths Guide Choice polarized glasses Scott 6 wt Rod, and a Sage Reel.



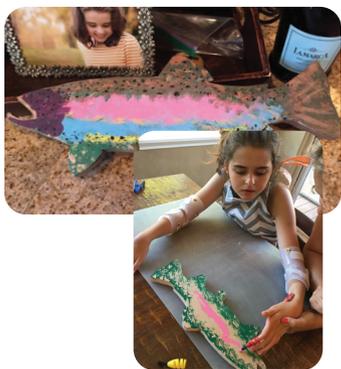
06 // TARPON TIME WITH, SEAHOLM, SCOTT AND NAUTILUS!

Winner receives a 3 day tarpon and snook trip with Capt Scott LeClair and Wabi Sabi Adventures out of Tampa, FL. Pick three days avail between June 1 and June 15th. Also included a custom Casting 4 A Cure Seaholm Offshore Diver watch, and a 10 wt. Scott Fly Rod and Nautilus Reel! Airfare, hotel and rental car not included. *Generously donated by Wabi Sabi Adventures, Seaholm, Scott and Nautilus. Dates based on availability.*



07 // GRILL AND CHILL!

Win a Weber Genesis Gas Grill, a set of your favorite spirits from Dry Fly Distilling, a City Boy custom Cigar box, two bottles of the best Pinot in Oregon from Lange, and a collection of BBQ rubs from Meatchurch!



08 // ELLA'S CATCH!

Winner gets a one of a kind custom hand painted trout from Ella Farnum.... One of only 15 ever created! Also includes custom Cody Richardson creation, a Casting 4 A Cure custom Scott Fly rod and Nautilus reel! *Generously donated by Ella Farnum, Cody Richardson Creations, Fishpond and Nautilus Reels.*



ALL IN. EVERY DAY IRSF IS ALL IN TO FIND A CURE FOR RETT SYNDROME AS WE EMPOWER FAMILIES.

Melissa Kennedy
Chief Executive Officer

OUR RETURN TO IRSF

Many of you know that our Foundation's roots were firmly planted by the International Rett Syndrome Association (IRSA) in 1983. Through a series of collaborative efforts and mergers, we became the International Rett Syndrome Foundation — known to many as Rettsyndrome.org. Recently, we reclaimed our organization's name: International Rett Syndrome Foundation (IRSF) to honor that history. Our two-pronged mission — to fund groundbreaking research and help empower families living with Rett syndrome — continues to be our North Star, and that is how we will create a world without Rett.

ALL IN FOR A CURE

Over the last year, our Foundation has funded promising gene replacement and gene therapy research as well as research that is looking for new ways of treating the course of Rett syndrome. Throughout the world, we are supporting labs and new trainees who are dedicating their careers to the study of Rett.

Recently, we launched our Centers of Excellence Network, giving our clinics a platform to work together to improve quality of care and advance clinical research. And with the support of clinical investigators throughout the country, we assumed stewardship of the legacy Natural History Study database. Building upon it with data collected during regular clinic visits at our Rett Syndrome Centers of Excellence, we formed the Rett Syndrome Registry™ — with involvement from the FDA and industry to ensure that it will enhance drug development and clinical trials.

ALL IN FOR FAMILIES

In addition to supporting families with resources and monthly educational webinars, we are THRILLED to be gearing up for ASCEND 2022 — the first national meeting hosted by our organization in almost six years. We will be in person with a great line-up of speakers and interactive sessions. You'll be able to connect with other families, grab a cup of coffee with a Rett syndrome researcher or the director of one of our Centers of Excellence, and mingle with industry partners and companies that are investing in Rett syndrome. We can't wait to see you there!

We are grateful to you for your involvement and engagement with our Foundation. Everything we do is made possible because of your support. It is truly our honor to serve you and your family.

With Hope and Gratitude,



Rett syndrome doesn't stop.

NEITHER DO WE.

Because of your faithful support, we continue to provide critical care and support to families affected by Rett syndrome, while accelerating research toward life-changing treatment and ultimately a cure.

We are fueled by the collective effort of researchers, clinicians, clinics, parents, regional associations, advocates, and supporters to help us reach our vision to create a world without Rett syndrome.

THANK YOU!



www.casting4acure.org