

THRIVING
with RETT

WHAT I WISH I HAD KNOWN:

POIGNANT WORDS FROM PARENTS
ABOUT THE DAY THEIR DAUGHTERS
WERE DIAGNOSED

KRISTEN CONNOR | *Mother to Brynn Clair*

There's no "correct" way to feel about your daughter's Rett diagnosis. Take time to grieve and move at your own pace. It's okay to feel devastated, but you will come out on the other side stronger and more positive. Let it be at your pace. But remember, you can grieve forever or choose to be positive for your daughter. Once you grieve the daughter you thought you were going to have, celebrate the daughter you do have. She may have Rett syndrome but she's here and needs you to give her the best life possible. Don't let her diagnosis hold you back from pushing her to her potential.

JIM SMALL | *Father to Sophia*

I never had a hero growing up and today Sophia is my hero. My love and admiration for her has grown well beyond what I ever thought possible.

JENNIFER FACCHINELLI | *Mother to Ava*

Don't believe everything you read on the Internet. Everything I read at first seemed to be all about the things the girls CAN'T do. But I have a long list of things my 2-and-a-half-year-old daughter CAN do that I'd previously thought impossible, including learn, communicate, improve her physical abilities, and establish deep bonds with her sister and other family members. I also wish I had known that it gets better. I thought I'd never be truly happy again. There are still many days where I get very sad and even angry about the diagnosis, but there are many more happy ones. Slowly, and with lots of support from family, friends, and fellow parents of girls with Rett, I've managed to come out of the fog. Last but not least, nobody knows your daughter better than you. Listen to advice and to the experience from doctors, therapists, and other parents, but above all trust your instincts. You can and will do this.

JENNIFER CASTRO | *Mother to Katie*

I wish I had known that there are people who care and they have gone through the same things you are going through. I also wish I had known then of the great progress the research and science would be making!

LENA DeSANTIS | *Mother to Maren*

There are no nevers. My first days of Rett were full of never. I fixated on all the pleasures of life my daughter would never experience. Two-and-a-half years in and we are in awe of what Maren can do. She has an eye gaze computer and is learning to talk. We are introducing literacy concepts and know she will read. She took a step yesterday, albeit very supported, but she lifted her foot. We dance all the time. Most importantly, she is truly loved by so many. Other little girls say hi to her and look into her eyes when they speak to her, telling her little girl things like they just love her necklace. Our friends embrace and include her. She has an army of therapists and teachers who believe in her. We are buoyed by her tenacity, so much support and a real hope for treatments that will significantly change her life.

CARI DASEN | *Mother to Camille*

I wish I had known that we must take each day at a time. I also wish I had better understood Camille's role as our teacher: Not everything in life will make sense, nor does it have to. We can make some plans and try to understand the options available for our daughter, however, we are not always in control—it is helpful to accept that. I also know now that the research being facilitated by RSRT is a real source of optimism. Anything that we can do to further this work is rewarding and empowering; it provides us with a transcendent, larger-than-life feeling that we can help make a difference in our daughters' future. The gene has been identified, the possibility of reversal has been demonstrated, and we are moving in the right direction.

JEFF MATROS & KAREN FERENCZ | *Parents to Nikki*

We wish we had known what groundbreaking progress would be made in the research. We are convinced we will hear Nikki talk again. We wish we had known that Rett girls touch everyone in their path. We had no idea the impact Nikki would have on people's lives. There are so many examples — a classmate writing about her special friendship with Nikki for her entrance essay to college; a babysitter becoming an occupational therapist because of Nikki; a dance therapist writing a book about her; a filmmaker creating a moving documentary about her; two therapists who went on to get their PhDs using Nikki as their dissertation. You can't walk through our town without running into people who know Nikki. We wish we had known then that although our dreams for Nikki changed with her diagnosis, that her life would be inspirational; she would teach us to be better parents, more empathetic, generous and capable of unconditional love. This is Nikki's legacy, and it is very profound.

PIETER COENRAADS | *Father to Chelsea*

A diagnosis is a time of mourning, and it's important to take that time. But it's important to know that life does go on. One positive is that our two sons have become loving and adoring brothers, and I know it will shape them as they become adults. Chelsea is the heart and soul of our family.

COLLEEN REILLY | *Mother to Claire*

It's okay and normal to feel the stages of grief. Through time, the days you cry yourself to sleep at night will get less frequent. They may still come out of the blue at times, but, again, this is normal. Let yourself feel this and don't ever judge yourself for it or let others judge you. Also, if you have other children, make sure you give them plenty of attention. They are going through this as well in their own way, and ultimately they will provide amazing support for you and for your daughter.

BONNIE KECK | *Mother to Lyndie*

I wish I had known how bright and intelligent Lyndie was behind her sparkly eyes, locked in a body that just would not cooperate. She was diagnosed in 1989, shy of her third birthday, as severe to profoundly mentally retarded. I knew in my heart that the label just did not fit, but it took years of convincing professionals until the nature of apraxia was finally understood and accepted. Lyndie audited and passed Anatomy and Physiology and Algebra 2 in high school. The bottom line is not to let anyone put limits on your child. No one knows what the future will hold in any aspect of their functioning. I also wish I had known that there absolutely would come a day when I would see past Lyndie's disability. Lyndie is Lyndie — a lovely young woman with a fabulous personality with whom people love to share time. She is truly my hero and my teacher, as are all our girls! I no longer look at her as my child with so many obstacles. She is such a joy and has touched more lives than most folks and I could ever hope to do. Lastly, I wish I had known in the beginning that when people ask if they can help you, it's okay to say "yes!" And it's also okay to ask for help when you need it. There are many wonderful people out there. You will find out who your true friends are, and then you move on and cling to those who are there for you.

JESSE RANDOL | *Mother to Ruby*

We sent an email after Ru was diagnosed to all of the people in our life, explaining what happened, how we were feeling, what Rett was and how they could support us and the research. We all learned and "mourned" together. Ru has so much love, and I think we have had such tremendous support because we have been so open and all of these people have been on the journey with us. Also, don't freak about the future — take it one day at a time. We are all wired to plan plan plan ... but this can stress you out more than help you. Love your child, love your family, and take a deep breath.

JEN DALTON | *Mother to Emma*

When we finally got the diagnosis of Rett, it was, in a way, a relief. We knew what we were battling and we knew that Rett had been reversed in mice, so we had hope. Hope is a very powerful light in a world where your child is 1 in 10,000. Even on the rough days we know there are scientists working diligently all over the world because they believe Rett syndrome can be cured. This hope has gotten us through the last six-and-a-half years. Clinical trials and treatments await us!

Go with your gut. No one knows your child better than you. You will learn to understand her in a way that no else can. You will understand each look in her eyes, each smile, each cry. You will know when she is “just not right” and when you need to push to find answers. Always trust your gut; more often than not you will be right.

I remember being so nervous when Emma entered kindergarten. I remember crying the night before school started, worrying that the other children would be afraid of Emma because she was in a wheelchair and could not talk or play like them and that she would not have any friends. I could not have been more wrong. From Emma’s first day in kindergarten she has thrived! The other children want to sit next to her, to be her reading partner, to be the one who plays Connect Four with her. I teach in the same school that Emma attends and sometimes her classmates will say things to me like “Emma beat me at Connect Four three times! How did she get so good?” Or “I told the class a joke and Emma was the first one who laughed! She is SO smart!”

AIMEE FINI | *Mother to Eva*

I wish I knew what Eva was going to teach her siblings. She has taught them all how to be caring, empathetic, selfless, helpful, sad, and many other characteristics that make them all better children. I wish I knew that she would make me smile every day. When I see her first thing in the morning she makes me smile. She makes me smile when I walk into her room, feed her, put her on the bus, see her at school, get her off the bus, play with her, feed her again, bathe her, put her to bed. She makes me happy. I wish I knew when she was diagnosed that she would be the light of my life.

AMANDA & CHRIS COPE | *Parents to Gracie*

Although you just received bad news, please know you are not alone! You now have a bigger family of Rett families. Rett families are amazingly supportive and encouraging and you will feel so connected to them. Know that your daughter WILL live a happy life. Gracie is an amazingly strong and happy little girl. It amazes us how many people know her – people we don’t even know! She is a popular little girl! Which she loves, since she is a little diva. She puts a smile on our faces every day, and your daughter will do the same for you. We believe being very open about Gracie’s diagnosis has not only helped us, but helped others to understand about Rett syndrome. As a result, our family and friends and community have accepted her with open arms.

MIKE PRASK | *Father to Zoe*

We still get sad when we stop to think about all the things Zoe has had to sacrifice. She misses out on so many things a typical kid gets to do, but we’re strengthened by all the opportunities she does get, and even more strengthened by thoughts of all the research underway to alleviate the symptoms that have forced her to make sacrifices so far in her young life.

You will know your daughter and her personality in ways you can't imagine now. When we got Zoe's diagnosis, we pictured an isolated future for her, where even though she was part of our family, we never would relate to her in a meaningful way. But we've found that she can be a part of the community to which she belongs, and there are so many ways for her to express her true self and feelings to us. Zoe is the only person in my life that I talk more than, but the interactions I have with her are as valuable, if not more, than with anyone else.

AUDRA SMALL | *Mother to Sophia*

I wish I knew that I am a mama bear. I instinctively will do anything for my children. I felt weak and beaten on diagnosis day, but I got up. You will too. I wish I knew not to listen to everyone. Just because that person has a white coat doesn't mean they know my daughter. Our diagnosing doctor said our daughter wouldn't eat with a utensil. Well in your face, Dr. Negative. She does. They don't get to tell us what she will or won't do. Just because doctors are smart doesn't mean they know everything. Believe in what small triumphs you can accomplish rather than fear what anyone else says she won't do.

KEILA TORRES | *Mother to Serenity*

One thing that I wished I had known then is that I should just take a deep breath and take one day at a time. Enjoy your daughter and bond with her. This is so important. My husband and I adopted Serenity when she was 8 years old. We knew she had Rett syndrome, and we thought we would educate ourselves before she came home. We were far from knowing what we know today. There were times when we asked ourselves if we can do this. I believe we love her so much that we became more than adoptive parents; we became real parents by wondering, questioning, getting angry, and crying every moment something else struck, and as parents refusing to give up.

JOAN CHESS | *Mother to Zoe*

That I would be able to breathe again. That I would develop patience and strength and compassion. That although I've never heard Zoe's voice, she has spoken volumes. That I would learn about the character of others in how they responded to my daughter. That she would celebrate her 30th birthday with friends and family!

MIKE & SANDRA ANASTASI | *Parents to Jenna*

We wish we realized how many other families, daughters, siblings are affected by Rett — that we are not alone. We used to think asking for help was a sign of giving up, weakness, quitting, etc. Asking for help was the best thing we ever did. It allowed our family and friends a portal into our lives and, more importantly, a way to become more connected with Jenna, and our son Mikey, who is on the Autism spectrum, and what they live with every day.

MARCI VALNER | *Mother to Gaby*

I am convinced that there is a bright, smart child locked inside each and every little girl. Treat them as you would any child. Speak to them, read to them, teach them and assume they are learning, even if they can't respond. Watch their eyes. If you ask them a question or to identify something, watch where their eyes go. Their bodies can't do what their mind wants them to, but they understand. Keep up with physical activities like swimming, physical and occupational therapies, and all types of sensory exercises. If she can't speak, don't lose hope for communicating with your daughter. There are amazing means of communication now through eye gaze and other technologies. To be a good parent you have to be good to yourself. You need rest and free time, so don't feel guilty about taking it.

CHRISTINE SALERNO | *Mother to Lily*

I wish I had known that Rett syndrome is a spectrum disorder. The way that it manifests in every girl is different. Some girls walk, some girls talk, some have meaningful hand use. Unfortunately, many do not. But one thing is true of all girls with Rett syndrome: they are magical, beautiful, funny, and quirky. People are drawn to them. And most girls are highly intelligent. Bottom line: Never underestimate the potential for your daughter.

I wish I had known that even though my spirit may be broken at this moment, my daughter's most definitely is not. My kid is a fighter, a warrior, a princess. And she's still the same sweet angel she was the day before she was diagnosed. Falling into a pit of despair is not an option. And taking your cue from your daughter about having a positive attitude is the way to go. Bottom line: Though you will have your ups and downs, always go back to staying positive. And if you need inspiration, just look at your beautiful child and feel the love they radiate.

I wish I had known that asking for help doesn't make you weak. I've learned that you need to take people with you on this journey. Get yourself a strong network of friends, supporters, advocates. If they're not comfortable with your kid's diagnosis, they're not worth having around. It's easy to insulate yourself from the rest of the world. But that does you, and your daughter, no good. I take Lily out to restaurants, grocery shopping, walks around the neighborhood. And I've built up relationships with the managers, wait-staff of our regular haunts, neighbors to let them know that even though my sweet kid has a hard time with her hands and words, that she understands everything and wants to participate. Bottom line: Ensure you and your daughter have a strong support network.

KARON PAULHAUS | *Mother to Emma*

I'm glad that I continued to involve my daughter in activities with her typical peers—Girl Scouts, birthday parties, dances, etc. She has made some wonderful lifelong friends, and she has taught so many people about Rett syndrome and the love that people with disabilities have to give. Most of all, I wish I had known that even though there would be heartache, that my daughter would make my heart happy every day.

MAGGIE WURM | *Mother to Madasyn*

When Madasyn was first diagnosed doctors told us that she would deteriorate fast, particularly her mobility. She is still walking on her own today. We hit the ground running with therapy at an early age and I believe that helped—horseback, swimming, making her walk everywhere! Every day our daughter amazes us and shows us she is a fighter; and the power of our belief in her pushes her.

AJ TESLER | *Father to Maggie*

I wish when we were diagnosed (and it's definitely a "we" not just a "her") that I had known that Rett syndrome wouldn't change how much I would enjoy her smile; that I would still be able to make her laugh. I wish I had known how much joy I'd find in every surprising breakthrough—every time she would do something she hadn't done before, find a way to communicate what's in her mind, or show off her mischievous side. But, in the end, I wish I had known then that even though Rett syndrome would change our family, it would never break us, because at the time, I certainly wasn't sure.

RUDY VALNER | *Father to Gaby*

Gaby surprises us every day with something new, where the seed was planted many moons ago. As parents, we need to remember that this process is not a 100-yard dash, but rather a marathon. A lot of all the speaking and therapies we did with Gaby did not have immediate results. But the results came later on, and sometimes when we least expected. Even when you don't see results, the child inside is processing and progressing along, and when it is in them to act or perform on it, it will come out.

ROX ANNE BATTERMAN | *Mother to Danielle*

What we have learned in the 20 years since that day is that our lives are still wonderful and very fulfilled. Our daughter is happy most of the time and has taught us to view life through a completely different lens. We have met wonderful people, learned the true meaning of unconditional love, and have become more compassionate and caring human beings. Our priorities are different, but life is good.

CAROL TOFT | *Mother to Nicole*

I wish I knew then that despite all the tears of grief for what should have been, there will be as many tears of overwhelming pride and joy for moments that you never imagined. The most profound moment of all was when we snuggled in her bed and she threw her arm over me and said "I love you". She was 30 years old! Never, ever give up. There is so much more to come.

DORIS LEE | *Mother to Edda*

Edda is my greatest teacher, I learn from her every day. I also learn from the people who Edda has brought into my life, her teachers, her therapists, her friends, her caregivers and other families who have children with Rett. I am a completely different person than I would be if Edda was a typical child. I'm a kinder and more forgiving person. But don't think I wouldn't trade all that for Edda to not have Rett syndrome.

CORY HENKEL | *Mother to Kyra*

Things will get better because one morning you wake up and say I didn't cry myself to sleep. My love is so deep. It's amazing what Kyra has done for us. She has made us be people we never thought we would be. It's what our daughters do for us that's so remarkable; they make us people that need to dig deep into ourselves.

RAQUEL PRIOLO | *Mother to Valentina*

The diagnosis will not make a difference to your love for her – you will love her the same if not more! Make her matter – don't be afraid to put her in dance, bring her to parties, take vacations, have playdates! Push for her – if they say No you respond, Why not!? Spend quality time with your other children and your spouse. Believe that treatments and a cure are on the way.

ANNAMARIE IZZO | *Mother to Cassandra*

Twenty-three years after Cassandra's diagnosis at age 2, she is doing great and so is everyone in the family. Rett syndrome does not stop us, it guides us in ways we never thought possible.