

## Welcome from Rett families

Let these letters serve as your first introduction to families in the world of Rett syndrome. These letters were written by Rett syndrome parents for the newly diagnosed Rett syndrome parent. They will welcome you into the community and wish you the best on your journey.

Welcome on behalf of the Board and Staff of the International Rett Syndrome Foundation. You have reached the right place for help and support on your journey caring for your loved one with Rett syndrome. IRSF is only as strong as the families and friends who support us. If you need anything please contact us at 1-800-818.RETT. We are here to help, and we understand.

Letters from our parents:

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Letter One:

Dear Families,

It's hard to know the right words to share with your family now that your precious child is diagnosed with Rett syndrome. There are so many difficult emotions to process. One of the most devastating feelings we experienced with the diagnosis of Rett syndrome for our daughter Angela was the loss of the "normal" life we expected. You may wonder, as we did, if your family can ever be normal with this new challenge?

The answer to that is "yes." Normal may not look exactly as it did in the dreams you held when you anticipated the birth of your child or during the time before regression when her skills developed naturally. It may take more work, more planning, and more faith, but life can go on as you adjust for the challenges Rett brings.

There are many factors that go into finding a new sense of "normal." One of these is time. You need to give yourself permission to grieve lost dreams, while still offering your child the security of familiar routine and happy distractions from the changes going on inside her body. You may find it helpful to reach out for help from clergy, counselors, or other Rett families, especially during this adjustment period.

It will help if you balance your expectations with the reality of your situation. If you can clarify the goals that are important to you, then how you reach them takes on less importance. Our family has learned to accept a slower pace of life that comes with impaired mobility and stamina. We give ourselves longer time to do fewer things. We probably over-prepare for the unexpected, but it saves us from crisis. We have learned not to over commit our plans and to be gentle with ourselves if we have to change them.

There are many styles of coping, and finding one that is positive and constructive will benefit your daughter and your whole family. For our family, creative problem solving has become a route for coping that feels healthy and energizing. We've become quite creative in adapting toys, clothing, recreational equipment, and leisure and computer activities. We look around with new eyes for inexpensive, creative solutions to the challenges of daily living. I gain energy from trying to work out the challenges of communication output and academic access for my daughter. So many issues that seem at first to be barriers can actually be opportunities to put our creative minds to work.

You may find that as you become comfortable living with Rett syndrome, you will be able to take on goals that seemed impossible early on. We had once thought a vacation in Hawaii would be outside our options for travel with Angela, but with planning, preparation, and adjusted expectations, our family enjoyed a truly delightful trip. It reminded us that life with Rett need not be full of "cants," but that life is a matter of asking "how might we...?"

Wishing you our very best,

Rose-Marie and Don Gallagher, Angela and Rebecca

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Letter Two:

Dear Families,

We knew early on that something was amiss with our little granddaughter. At first the signs were subtle. We chose to believe that she had low muscle tone. We chose to believe that she was developing a little slower than most babies. We chose to believe that it would all be all right. When my daughter called with the diagnosis we all cried. We wept with sadness and anger and disappointment and fright. We grieved for all the things that were not to be for our beautiful granddaughter. We would never hear her voice, see her play tag with other children, ride a bike, rollerblade, play sports

or walk down the aisle at her wedding. In addition, our pain was doubled as we watched our child and her husband try to deal with this monumental, life altering situation. As the days passed we all found our own ways to cope with and accept this curve ball that life had thrown us. We read and studied and talked with people who knew so much more than we did. Sharing our pain with those who understood somehow made things little easier. As we learned more and more about this devastating disorder the days passed. We watched little Jillian grow and our love for her grew as well.

Her little personality began to emerge and we could see that she has a wonderful sense of humor. Her ability to light up a room with her smile is amazing. She has so much personality and although she is unable to speak she says volumes with her beautiful blue eyes. She, along with the other "patient angels", relies totally on others to meet her every need. She brings joy to all who come in contact with her. She has brought together our family and our community. She has brought out her parents' strength and courage and sense of advocacy. Every day she teaches us about determination and courage.

At three years old Jillian might not be riding a Schwinn bicycle but she does sit proudly on her own adaptive bike. She might not sing to us but she entertains us with her love of music. She might not run on the playground but she enjoys school and her classroom of friends. To see Jilly and her friends with their wheelchairs in a circle is to behold a circle of love. Not all children have special needs teachers and physical and occupational therapists. Our Jilly does and now we, too, have new special friends in our lives. These are wonderful, caring, nurturing people who we would not know if it weren't for Jilly. We are richer for these friendships.

Yes, there are still moments of sadness but they are fewer and farther between. We celebrate milestones differently than parents and grandparents of healthy girls but we DO celebrate. Jillian is a blessing in our family. We revel in small milestones and we get so excited when we hear of new breakthroughs in Rett research. We are happy. We are hopeful. We are blessed. We hope that you and your family find strength and comfort and the ability to live with your patient angel knowing that she is a special gift.

Sincerely,

Caron Welch Grammy to Jillian Endres

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Letter Three:

A Parents Perspective

by Dan Brinkhaus

Our Gift

Our gift was new life. The sheer wonder and miracle of her was undeniable. We recall it vividly, the morning that she was born. At that very moment in time at which she whined herself into this world, it resembled the ring of a fantastically harmonious choir. And though not yet known to us, our gift was extra-special. For this little angel was earmarked, a precious gift, sent unto us by God Himself. And in that instant we were blessed, we were humbled and we were graced

with her presence.

## Our Sorrow

Our sorrow was profound. It arrived to us swiftly & unexpectedly on that tempestuous spring afternoon. No words can accurately describe the anguish of it. Our world was uprooted, as north became south, and the universe turned onto its head. Our minds rebelled, and our hearts despairingly protested. The dreadful diagnosis had firmly clutched our dream and wrenched it away.

## Our Journey

Our journey is Rett Syndrome. There is no sugar-coating its hardships. The fact is that the physical sufferings and the emotional tensions are both embodied expressions and ferocious forces of Rett Syndrome. Yet in the face of these great challenges, we find amazing ways to endure. It is indeed our shared destiny. Our journey's guide, our beloved angel with her infectious smile and her courageous spirit, contentedly leads our way. Our journey's path, once shadowed by the shock of that dreadful diagnosis, is now crystal-clear. It is to endure. It is to provide. It is to celebrate the amazing spirit that is her. Our journey is an extraordinary one.

## Our Hope

Our hope is alive. It vivaciously breathes within her. Inspired and ripe with optimism, we imagine that someday every family will live in a world without Rett syndrome. We must all help make it so. The brilliant minds and ambitions of our world's leading scientists are on our side. And they are leaving no stone unturned. For where there is understanding, there is hope. The certainty of a cure will soon be realized. Her prize is our promise. It is a cure to Rett syndrome.

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## Letter Four:

Dear Parents,

I am the mother of a twenty eight year old woman with Rett syndrome. My daughter Erika was one of the first children in the United States to be diagnosed with Rett syndrome. In many ways our journey in the Rett world differs from that of families receiving a diagnosis now and yet in many ways I am sure our experiences are very similar. The facts that my daughter is healthy, happy and enjoying her life should give young parents hope for their daughters' future. The facts that my husband and I love Erika deeply, take pleasure in her accomplishments and manage to find enjoyment in life in spite of Rett syndrome should give you hope for your future.

I first became aware of Rett syndrome in 1985 when Dr. Rett was visiting the Kennedy Institute in Baltimore. I read of his visit and the syndrome named after him and quickly recognized that I finally had a diagnosis for my six year old daughter. The following year we met Dr. Rett when he made his second visit to Baltimore and he confirmed the diagnosis. I will always remember his words as he told me Erika is a classic case and that above all else we should "keep her walking." At that time very little was known about Rett syndrome. There was little awareness of the disorder and very little research being carried out. The International Rett Syndrome Association was in its infancy. I am grateful for the

support and information offered by IRSA in those early years and for the conferences IRSA organized that allowed me to meet other parents and Dr. Rett.

We had spent years traveling to many medical facilities trying to find answers to our daughter's unusual development. Strangely, we were the ones who told our neurologist about Rett syndrome. I hope that twenty two years later parents find answers more easily. I know that there are more sources of support now. The International Rett Syndrome Foundation can provide support and hope. There are now local groups in some areas for families to turn to and Rett centers to provide medical expertise. Yet in spite of the positive changes in the medical and research world, the emotional experience of learning that your child will not have the life you envisioned is as devastating now as it was for us years ago. The pain of those first few years is awful, but things do get better! My husband and I really were able to smile and laugh again and to focus on things not Rett related. There were years when life went along smoothly for our family and then there were times that were hard. Milestones not met whether related to early development, high school graduation or so many other things that we expected to experience with Erika brought new disappointments. We would be happy never to have heard the medical terms that are now too familiar. Our lives have certainly been changed by Rett syndrome, but we are appreciative of all the wonderful people we have met along the way. I also know that in her own way Erika has touched the lives of many people through her happy nature and communicative smile.

Erika now attends a day program where she receives therapy services and takes part in community events. From the time she was ten years old, Erika has attended a session of sleep away camp each summer. She participates in an evening swimming program and a Sunday afternoon recreation program. Her life is busy and her smile and "look of love" tells us she enjoys her special activities. We have begun to explore residential housing for Erika. This move to a "home of her own" will be a big transition for all of us. As Erika grows older so do we and we need to plan for her future.

As parents we can support each other and support the efforts of IRSF to find answers to the puzzle of Rett syndrome. Awareness and understanding and hope have truly come a long way since we first heard about Rett syndrome, but until there is a cure, we have far to go.

Irene Gladstone