

IRSF's Featured Angels

Note: The Featured Angel's intent is to give our Rett community an introduction to a few of the Rett angels for whom we are fighting to turn Research into Reality. Send Featured Angel submissions to lhayden@rettsyndrome.org

Featured Angel: Ava DePerry

Hello to all!

My name is Ava DePerry. I am called "The –Earth's –Angel." I am 5 years old and I was diagnosed with Rett syndrome at the age of two. I developed normally up until nine months old. At that time my parents noticed I wasn't doing the things my big sister was doing when she was nine months old. My Parents were concerned and took action. I had seen so many doctors and they all gave a different diagnosis - none of them were correct.

I was hospitalized with pneumonia for two weeks in Duluth, MN. They recommended Doctor Kanoff; he is one of the best neurologists at the hospital. He tested me, and told my parents that he was determined to find a diagnosis. He found one and came back and told my parents that I had a rare genetic deformity called Rett syndrome and that it happens in 1-50,000 women. My parents were shocked and cried and took a while to take it all in. My parents were in denial for about a year, until we got more information. My parents watched some videos of other children with some of the same features as me and realized that Rett syndrome is what I have and there are others like me.

My parents didn't care that I was different. They love me as much as they love my big sister and think I am amazing. I would describe myself as having a good sense of humor and am very intelligent. I am also very lovely. I am not able to do much on my own. I cannot walk, talk or sit-up with out support. I have a wheelchair and a stander to help me get around. I use the stander to help strengthen my core. I have a jeep stroller at home for now until my new and improved stroller arrives.

I do communicate using eye gaze or switches. The voice output system gives me an opportunity to communicate with others. I can't use my hands, but I have my big sister, parents, grandparents, great grandparents, uncles, aunties and cousins who lend me their hands when needed. I also have a feeding tube because I have a hard time eating and drinking. I have seizures sometimes, but currently they are under control. I haven't had one for a long time.

Some of the activities I like to do include laughing at my big sister and cousin when they are together. They are very goofy and funny. I love giving kisses to my baby brother, and I love going on walks with my family! I love the fresh air. My all-time favorite shows are Sponge Bob Square pants and Dora. When I am feeling sad my family always makes me

laugh by making daffy duck sounds or crazy faces. That always makes me smile and laugh. I also just love to cuddle.

I go to school and get lots of help from many therapists. Speech/language, Physical and Occupational therapists work with me as well as many representatives and coordinators. They are all tremendous helpers. I always get tired out after a days work with all of them, and have to take a long nap when they leave. I have a teacher's aide, Ms. Vicki. She is a big part of my life and is with me a lot. We have lots of fun together at school. Ms. Vicki likes to sing, dance and helps me learn and play. I love her.

Thank you for taking the time to get to know me. Miracles do happen and my family prays each day for a miracle to happen for me and for all the ladies out there with Rett syndrome. Please help us find a cure.

Featured Angel: Jenna Rose Mickelson

Hi world! My name is Jenna Rose Mickelson. I am the daughter of Tom and Lisa Mickelson. I am the middle child sandwiched between my two incredible sisters, Amanda and Hayley. Amanda is the best big sister a girl could ever have. She has always watched out for me. When I was little, Amanda would improvise playtime so I would be fully included. With her beautiful voice, she would sing her favorite little mermaid song to me "Part of your World." She did not know, but it was my favorite too! She really made me part of her world! My favorite little sister, Hayley, has been like a big sister too. When she was a baby she seemed younger, maybe even like a twin. Mom would lay us next to each other, and we would smile and look in each other's eyes. But as Hayley grew, so did her heart. When I was little, Hayley would come in my big bed and play with me. We would have hat parties! Amanda would join us too! As I grew up, Hayley has always been a kindhearted sister to me. I love my sisters so much! I am so fortunate to have such a loving family.

I also have two dogs. One is my Golden Retriever, Buddy. Buddy likes to lick my arm and put his paws on my lap. If I have a seizure buddy comes running and stays with me until he knows I have help. Casper, our little dog, likes to swim with me. My favorite sport is swimming. Since I was a little girl, my daddy would take me swimming all summer long. I am a West coast Arizona girl! On March 31st I will be 21 years old. So that's a lot of swimming. Just like a mermaid I could move around in water. Daddy and I always have had a special connection. I think it was because every time he walked through the door I lit up like the sun, and would say "Gaggy." I stole his heart...but I do share... Daddy's heart was always big enough for all his girls!

My mom and I have had hours and hours and hours together through joy and through sorrow. Mom loves to sing to me and sometimes I hum back. Mom whispers sweet things in my ear and gives me lots of hugs and kisses. Mom tells me how much everyone loves me; she tells me how much my Daddy, my sisters, my grandparents, my Aunts, my Uncles, my godparents, my cousins and all my special caregivers adore me. Wow there are a lot! Fortunately, mom was blessed with an abundance of energy to take care of me. She also talks a whole lot. Thankfully the extra words have been able to be a voice for ME (to speak, sing, be my advocate and say prayers) because I only have a few words.

I receive lots of friendship and love through my homebound school program, therapy, hospitals, Doctors, (My compassionate doctor... Dr. Ron Fischler has guided my care for 18 years) neighbors and friends.

I love taking walks and visiting with neighbors and working on my computer: creating art and playing the keyboard. I hear from mom that it is no secret that I have taught many people what unconditional love is all about. She sees and runs into people that have been in my circle, they sweetly speak of me. They go on saying...I am special; they speak boldly when they tell her that I have taught them so much about life.

Mom said not only have I taught people about life, but I also played a role in finding the Rett syndrome gene. I am grateful that I participated in a number of protocols. It was not easy, but it was worth it! Mom said that it gives hope for the future of babies that will be born with Rett syndrome, and possibly may even help some girls who live with it now. Mom told me that one day Rett syndrome will have a cure, but ALL who were affected by it...the babies, their families and all who cared about them, will all know that every single Rett Angel had a purpose on this earth. Mom beams when she says that these amazing girls have changed the world by being courageous, and continue to give hope for a bright future. I know Mom and dad love me just the way I am. I am a hero in their eyes. I am told that I radiate unconditional love. I am a Rett Angel.

Love, Jenna Rose xoxox

*Mom wrote a poem almost 7 years ago about me. I would like to share it with you.

For Sweet Jenna Rose Mickelson: Perfect Dancing angel: While she lays asleep on her feather pillow a perfect angel appears to be, not one flaw on this perfect angel who the lord sent to me,

Her jet black hair spun like silk, her ivory skin like porcelain. Her fine features that are just right, she lay there sleeping all through the night,

*Dreaming of dancing, dancing all night, waking up charmed with a smile insight. The dance was enchanting she danced all through the night

Her birth was a miraculous site, a baby born on Easter night, All ten fingers, all ten toes, a perfect baby, a button nose,

We did not know what lay ahead, our precious baby so pure and sweet began to bloom into our Rose,

One day our world began to crumble our sweet child began to change, one by one her skills diminished we were told to take her home and love her all you can, she will be passing soon,

We took her across the land, we would have taken her to the moon, to help our precious child, but answers were only gloom

Her daddy said "let me take her place lord, give this child life," But the lord had other plans in mind the purpose would soon be insight

Her second birthday came with a ring, a diagnosis on her birthday, bittersweet full of laughter, and tears for our child, She will live for now, we do not know how long , she will have special needs and it will seem so wrong

Society will see her shell, the one that cannot move very well, She will not talk, or run and play but her heart is full of love and will be expressed every day,

The lord's plan is apparent full of mirth, she brings about unconditional love to this earth

Through her eyes my child speaks to me, abundance in peace and happy as could be

*Dreaming of dancing, dancing all night, waking up charmed with a smile insight. The dance was enchanting she danced all through the night
A perfect dancing angel, she'll be dancing in her dreams.

written by Jenna's grateful mother, Lisa Mickelson August 2005

Featured Angel: Katie Nues

Hi, my name is Katherine Nues but everyone calls me Katie. I am 9 ½ years old! I live at home in California with my sisters Melissa (5), Abby (4), and mom and dad. I love being with them, reading stories, going places, swimming together, listening to my favorite songs. I especially love when my dad plays guitar just for me, and helps me pluck the strings. I am in the 4th grade this year and have a full-time helper and lots of friends, both in my Special Ed home room and my Regular Ed classes. Science is my favorite. I love seeing my friends every day. They have fun helping me get around school in my wheelchair because it has light-up sparkle wheels :o) I like my chair too because I couldn't go anywhere without it. They also think my new computer is really cool, more about that in a minute...

I have some things on my wish list this year. Mom says shoot for the moon and maybe we'll catch a star! My first wish would be able to talk with my family and friends. I try to tell them what I mean with my eyes. Sometimes they get it, sometimes they don't. But they always try, and so do I. Last year my wish for a computer, a Tobii CEye, that works by tracking my eyes came true and we've been working to program it and get it mounted just right on my wheelchair. I practiced all summer and just started bringing it to school. We're working on conversations now, and I hope to move on to homework soon. Yes, really, I want to do homework! It's good that this computer reads my eyes because most of my body, and especially my hands, don't do what I want. They do their own thing....all the time...and people misunderstand me. One time, the teacher was going to put away my computer assuming I was too tired to do more, but I was able to find and say, "I need a break. I just want to stand a minute". She helped me do that, and then I worked on it again for another whole hour! People often underestimate me, but this year might just be the best year ever for me to show 'em what I've got!

I wish my seizures would go away too. They make me awfully tired, and I have to miss school. They happen all the time no matter what I do, or my parents and doctors try, but they seem to come less often these days and I am grateful for that. I am also glad that my mom and dad work so hard with the International Rett Syndrome Foundation, and Katie's Clinic (yep, I'm that Katie!) at Oakland Children's Hospital, to make my wishes come true. They say if they can make my wishes come true, then the wishes will come true for thousands of kids just like me, and that would be just incredible. These are just some of my wishes. Too many? No? Oh good, well then I'll add one more wish: that you have a wonderful holiday season and a happy new year, because you deserve to have fun too, just like me! Thank you for believing in me!
~ Katie Nues, CA

Featured Angel: Sejal Madeline Shah

Hi! My name is Sejal, and I am 5 years old. I was born in Williamsville, New York, and I was diagnosed with Rett

syndrome when I was 2. I have been through some tough times, but now I'm doing great. I have learned to walk short distances, I am learning to communicate with my eyes, I am starting to learn my letters and numbers, and I am happy, giggly, and healthy almost all the time. And in the fall, I'm going to start Kindergarten -- I can't wait!

I live with my mom, dad, and my favorite person in the world: my 7-year-old sister, Simran. I love to go over to Simran and interrupt whatever she's trying to do -- hey, that's what little sisters are for! I also have fun with all of my grandparents, aunts, uncles, and cousins. I really love being around people. I love making mischief, and I always have a gleam in my eyes. ;)

My favorite activity is horseback riding. I have been riding since I was 3, and I am getting pretty good at it. I love being around horses and bouncing up and down. I also love music classes, dance classes, swimming, and just getting out in the world with my family and friends. I like watching Disney Channel with Simran and dancing to the radio in the car. I have a feeding tube that runs all night, so I don't eat all that much during the day, but I do love soy milk, cheese, and fruit.

I am really happy the way I am, but it would be great if I could do more things for myself. I hope we will find a cure or a treatment for Rett syndrome. I know it would mean a lot to me and everyone who loves me.

Love, Sejal Madeline Shah

Featured Angel: Jillian Endres

Hi! My name is Jillian Endres but almost everyone calls me Jilly. I am 8 ½ years old and I was diagnosed with Rett syndrome at 17 months. I attend an amazing school where I am integrated into regular classes such as gym, art, music and library—and this year I will be in second grade! My main classroom is a therapy-based classroom so even when I am doing something fun, my teachers and therapists turn it into some form of therapy. I feel very blessed to “have it all” at school and I know my parents feel this way too!

Speaking of my parents, they could not be any prouder of me. I live at home, on Cape Cod in Massachusetts, with them and my two little brothers. My brothers, Griffin and Colin, are 3 and almost 2 years old. They have brought so much joy to my life—and excitement and craziness and loudness...but I love it all. They treat me so nicely by being gentle, caring and loving. They also bring me toys and books all the time. They help me move my hands to activate the toys or turn the pages of the book. They are always thinking about me and always want me to be involved in what they are doing.

One of my all-time favorite things is to listen to music. I love Raffi as well as all Jack Johnson. If I am feeling a bit sad, the magic trick is always my iPod! I also love the Wiggles, Barney and anything on the Disney Channel. When it is not too hot outside I love to go on my swing. I love the wind and even the rain! In fact, I have been referred to as “the element girl” in the past because I smile and giggle when I get to be outside on a windy, rainy or snowy day! I help my family and friends appreciate the little things in life!

Some not-so-fun things come along with Rett syndrome but I am such a strong person that I deal with these things most

often with a good attitude and I never give up. I cannot walk, but I am wheeled around in a very sleek (and pink!) wheelchair. I cannot talk but I have several switches that I use every single day at home and at school—these voice output systems give me chance to communicate with others. I cannot use my hands but as I said, my brothers help me as well as all my family, friends and teachers. I have seizures but they are very under control and I have not had one since February! I cannot eat by mouth but I am ok with that because I am much happier and healthier now that I have my feeding tube. My whole family was really scared of it when I got it, but it has been the best thing that has ever happened to me.

I am so thankful for all that IRSF does for the families and all of the promising research they are funding. I know there are exciting times ahead for all of us who are affected by Rett syndrome. We just have to keep working hard and plugging away!

Ashley Fry

Hello. My Name is Ashley Fry. I am 31 years old and have Rett syndrome. My family thinks I am here to teach a different kind of love. To me, it's just love. After developing normally until 18 months, I started regressing. None of the doctors in Houston knew what was wrong with me. So, Mom and Dad took me to see Susie and Bears Kaufman at The Option Institute and integrated a program at home of one-on-one positive play which encouraged me, made me feel good about myself, and gave me lots of attention.

In November, 1983 my pediatrician, Dr. Merlene McAlevy saw a new article about Rett syndrome, and she and Mom diagnosed me. Dr. Alan Percy heard that my Mom and Dad thought I had Rett syndrome, and he had just returned from a conference on Rett syndrome and wanted to see me. He came to our home and diagnosed me with Rett. Everyone seemed very excited. We soon went to see Dr. Vincent Riccardi, our geneticist, where we met Dr. Huda Zoghbi, a young resident, who attended our visit. I think she fell in love with me that day, as she and Dr. Percy began researching Rett syndrome. The "Rett World" would not be what it is today without these Super Heroes. So, I am very proud that I was their first Rett patient.

I had breathing difficulties when I was younger, scoliosis surgery when I was 11, heel cord serial casting too many times to count, and have seizures, though they have now decreased in duration and intensity and last only 10-20 seconds long. I hate seizures. Walking is a part of my daily program, though everyone holds my hand as my balance is not great and no one wants me to fall.

I live in College Station, Texas with my Mom and Dad, Clifford and Judy Fry. My sister, Kristin, and her family live right behind our house. My nieces and nephews make me laugh a lot! My Granny, who is 97 years old, lives on our property in her own apartment. Every night I walk to her house and watch TV with her after dinner. That is our time alone. I also have two wonderful caretakers who help me. They are now part of our family. My favorite activities are going to the movies and restaurants and attending music day at my Dad's music gatherings, going to Jazz clubs or any other kind of music festival, and hanging out with my sister, Kristin, who tells me all of her secrets. I am involved in Project Sunshine, which is made up of Texas A&M University students. They have lots of parties for special needs kids and adults. I also have a college buddy who comes to my home every week, and we hang out and visit.

Having Rett syndrome has been difficult, but overall I have adjusted very well. Mom and Dad feel that we always have to make the best of everything, so that is what I have tried to do. I am happy most of the time, and everyone tells me that my smile is magic. At night my Dad tells me the Lord's Prayer. He tells everyone that the very first time he told me The Lord's Prayer I looked at him as if I already recognized that prayer.

I have heard there is the prospect of a cure for Rett syndrome because with replacement of the MECP2 protein the brain will work correctly. When I get my words back, after I have thanked everyone who has ever helped me, I will immediately ask for a Coke and tell everyone to never ever give me vegetable soup again! If you would like to help me be cured of Rett syndrome go to www.firstgiving.com/process/teamarea and join Ashley's Posse for 2011. Thank you, and blessings to all.

Cameron Babiarz

Hi, my name is Cameron, and I was born on March 10, 2009. My parents had concerns when I was six months old and did not show interest in transitioning or crawling. Doctors said "wait and see" for the next six months. When I was 12 months old, testing continued, and I began physical, occupational, developmental, and speech therapy. In the meanwhile, my MRI and blood work all came back normal. By 18 months, I was still unable to sit, transition, crawl, pull to stand, or walk. I lost my verbal communication and self-feeding and manipulations skills, and my left hand was constantly in my mouth. At 20 months, we visited a physiatrist who made a clinical diagnosis of Rett syndrome. On January 7, 2011 at 2:45 pm, my mommy, who was 35 weeks pregnant, received a call confirming that I had Rett.

My parents allowed themselves one night to mourn. They woke up the next day and took action because our family is filled with fighters! The first thing we decided upon was my nickname Cammy Can. Then, within the next three months, my family and friends helped me raised over \$30,000. My mommy tells people all the time that I'm the hardest working two-year-old in town!

Each week I have physical therapy twice, occupational therapy twice, speech therapy twice, and developmental therapy once, in addition to various other appointments for my eyes, nutrition, and general health. I just starting spending time with a very cool lady named Susan Norwell who facilitates communication between silent angels like me and other people. She helps Rett families show the world what we already know—that girls with Rett are really smart!

My little sister, Ryan, is four months old and makes me laugh all of the time. Some of my favorite moments are spent playing with her. I shower her with kisses to let her know that her big sister loves her very much. I think it is funny to watch my parents interact with Ryan. Since living with Rett has always been a normal way of life in our house, they look at Ryan like she's an alien when she does things typical kids do!

I love being around people, especially my 19 cousins. And, I am so lucky that I get to see all four of my grandparents on a weekly basis. When I am not working hard in therapies, I love reading, swimming, listening to music, and swinging. My favorite time of day is family reading time with my mommy, daddy, and Ryan right before bed. I also love watching Sesame Street, especially the episode with Ryan Reynolds in The A Team. I wonder if he'll consider working with Cookie Monster on filming a segment called C is for Cammy!

Living in a world with Rett has been hardest on my parents, but I am as happy as can be because I do not know anything different. I am always surrounded by love and support, and I bring immense joy and inspiration to others. What could be more important than that?!?! My family and I constantly tell people that Rett is messing with the wrong kid. Cammy Can!

Please check out a couple of videos to learn more about me.

Victoria Francesca Calabrese

Hello, my name is Victoria Francesca Calabrese. I was born November 11, 2004. My friends call me Tori and my Mom calls me her angel.

When I was 7 months old, doctors were concerned with my low gross motor skills and referred me to the Infants and Toddlers program. Physical Therapy was started and by 9 months old I still was not making significant progress with my gross motor milestones, so I was referred for further treatment and testing.

Then, on October 23, 2005 I was diagnosed with Rett Syndrome. At first, my family was very sad and had a very difficult time understanding how my condition would affect all of our lives. Since that time, my family has grown accustomed to my differences and they have come to see me as a beautiful blessing from God.

I have many Doctors and Therapist who help me with the medical conditions related to my diagnosis. Because of my medical needs I have a nurse who comes to school with me each day and a nurse who watches me each night while I am sleeping. I love both of my nurses and they have become a very important part in our family's lives.

I have a wheelchair and I need a lot of help with all my daily activities. I receive physical therapy each day at school and my Mom takes me to a therapist who goes swimming with me. I love the pool and it helps my tight muscles loosen up. I also have a lot of help with communication. My teacher is trying to help me learn how to communicate with other people. My family understands what I need and want most of the time, but it is a lot harder with people who don't know as well. Mom is trying to get me a special computer to help me with my speech.

I have an older brother and sister and they help me a lot. I play with my brother who makes funny faces and likes to give me raspberries on my belly. My sister likes to play music and sing with me. I love my brother and sister very much. I am a happy girl most of the time and enjoy being around people. Mom calls me a social butterfly. Sometimes I just like to people watch.

Our family has lots of wonderful friends who like to spend time with us. We go to many activities and one of my favorites is church. I am very happy when I am there and I like to make sure Father knows I am there when he is saying the homily. He makes me laugh. We know lots of nice people at church and they all pray for me and my family.

Miracles can happen and my family prays each day for a miracle to happen for me and all my sisters with Rett Syndrome.

Gabriella Leone Peace

Hi! My name is Gabriella Leone Peace but everyone calls me Ella. I am 2 years old and live with my Mommy and Daddy in Carrollton/Dallas, TX. I am at my happiest when there is a big crowd around me. I smile and laugh all the time. I enjoy sitting in my stroller as we walk through malls or around the pond near my house. I also love to watch football and basketball with my Daddy, but my favorite shows are Yo Gabba Gabba and Dora the Explorer. They really make me laugh a lot.

I was diagnosed with Rett Syndrome last September. My family and wonderful daycare teachers had been getting worried for some time since I was getting sick a lot, I was always clapping my hands, I didn't want to play with my toys, never learnt to pull up or crawl and couldn't pick up my Cheerios by myself anymore. At first, my family was sad, but now everyone has gotten used to my differences. I get a lot of therapy – 3 times a week and my Doctors and Therapists really get me to work on stretching and exercising and communication. I am starting to get my point across with my real meaningful stares! I also hope to learn to walk soon.

I have a lot of family and friends who really love me and show me all the time. Soon I am going to have a new little sibling to play with. So even more people to love me! I have been going to the Children's Beginning daycare since I was 2 months old so my teachers really know me and love me a lot. I love all of the teachers, but Ms. Engracia and Ms. Maria are very special. They really understand me well. My Nanna comes to take care of me often during the week. She sings to me and reads me lots of good books. My Nanny recently came from Alaska to keep me for a few days while Mommy and Daddy went on a little vacation. Nanny joked that the hardest thing about caring for me is putting my false eyelashes on every morning. She is funny. They are not false! They are really mine and everyone tells me how pretty my eyes are. I love getting all dressed up and taking pictures- a good thing too, because my mommy takes pictures of me all the time.

My mommy is telling everyone about Rett Syndrome now. She says that they are going to find a cure soon and I believe her, although I am very happy just the way I am.

Kaitlyn Kelly

My name is Kaitlyn Kelly and I am from Bladenboro, NC. I am 4 years old and I am a Pre-K student in Mrs. Debbie Simmons class at Whiteville Primary School. Mrs. Debbie is such a wonderful teacher; she actually is the one who told my mommy to have me checked out for Rett syndrome! (Thank you, Mrs. Debbie. More than you'll ever know). I get Occupational Therapy, Speech Therapy & Physical Therapy every week. I cannot talk anymore but Mommy knows what I want and need without me telling her. Mommy says my big blue eyes and my pretty smile tell it all. I am an only child so far and I think I like it that way! I love to cuddle with Mommy & Daddy while watching my Disney movies. I was just fitted last week for my braces to help support My ankles so I can walk better. I can walk really well in my big girl walker and hopefully the braces will let me walk by myself. My favorite foods are Chicken Nuggets, French Fries & Cheez-Its! I love to go to McDonalds. I even clap when I see the golden arches!

I have so many people that love me. I am such a lucky little girl to not have to go through this alone. My mommy cries sometimes but I rub her face and smile and that dries her tears. She sings "You Are My Sunshine" to me every day. Ever since the day I was born! I am a special little girl in so many ways and prayer heals all. Even Me! My mommy and I didn't know what Rett syndrome was until just a few months ago when I started the process of being diagnosed. Now it all falls together. I started having seizures when I was 6 months old and by 3 I couldn't say any words anymore. I am trying real hard now to talk and soon I will! Mommy, Daddy and I are going to let everyone in our community know what Rett syndrome is and how they can help Me and all my other brothers & sisters around the world with Rett syndrome!

Leev Novel

Dear all, my name is Leev which means "life" and "protection." I am three years old. It is true that I am full of life, often happy, other times more observant and sometimes angry. But every day I prove to fight Rett syndrome.

I attend the local nursery where I made friends and even have a boyfriend who is sweet, but sometimes surprises me by giving me a big cuddle.

I love babies and I ask about them, so sometimes my caregiver brings me to the babies' room so that I can look after them. At the nursery I use a walking device that enables me to move around independently.

I look forward to the week-end and ask for "Papa, Maman" so that we can spend time together. We always enjoy lots of activities, meeting family and friends. We go to the theater, the circus and the zoo (I love animals). We also go to the swimming pool or to the sleigh in the winter. I love listening to music especially rock and roll (my Dad is very proud of that) and electro music which makes me dance.

I live in Geneva, Switzerland, and my parents have registered me for the IGF-1 clinical trial that will take place in Boston. If I am accepted in the program I will have the chance to visit USA, maybe meet some of you and also hopefully have the chance to see "Barney!" I just can't get enough Barney watching! My parents need to order the dvd on the internet because very few people know about Barney in Switzerland.

Thank you for meeting me! I hope to meet many of you in person soon if I am able to come for the IGF-1 trials! – Keep your fingers crossed for me.

Haylee Bautista

Aloha! My Name is Haylee Bautista! I am 5 years old. I cannot walk or talk but my mom says "I say it all with my eyes." I have tons of friends and my teachers and family just love me. They say I have an incredibly contagious laugh and beautiful smile! I love to eat ALL of my school lunch. I love Elmo's world and Barney! I have 2 sisters and 3 brothers but my parents say that I am the only princess! My family loves me and prays that I will continue to be HAPPY and HEALTHY!

My family, especially my parents, does so much for me every day. They are always talking about me to others and using my story to spread awareness for Rett syndrome. I am a very lucky little girl to have so many people around me who love and care for me so much. I hope that one day I can say "thank you" for all they have done!

Sonora (Sonny) Bodine Poulton

Greetings! I am Sonora (Sonny) Bodine Poulton. I am 12 years old. I live with my mom in Ohio. I don't have siblings. So being an only child makes me extra special. I go to school and attend the 7th grade. I use devices to communicate and have a computer that works by eye gaze. I received a certificate for being able to pick my name out on the computer 100% when tested. I walk and am close to being potty trained. I have learned to make special sounds when I need to go to the toilet. My dad and his parents, grandma and grandpa Poulton, live in Tennessee. I go there and stay frequently.

Grandpa is very special to me. We can really communicate. He can read me very well and is so patient! I like to do fun things like go bowling, swimming, to the store for a cookie and McDonalds for a yogurt parfait. I love SpongeBob Squarepants cartoons. They make me smile and laugh. I get to watch him when I am really good at school and when I travel to Tennessee. My bedroom is decorated in SpongeBob. I enjoy hugging my pillow and rolling up in my comforter with him. I have several cousins that know I am special. They treat me very nicely. I like to tease. I sneak up behind grandpa and kiss him on the bald head. That makes us both smile. I love my family and they know by my smiles, hugs, and kisses. They all love me. I know through their affection and loving care.

Happy wishes, Sonny

Kayla Cox

Hello, my name is Kayla Marie Cox. I am 14 years old and I am in the 8th grade. Next year, I will graduate to High School, as a 9th grader. I live in Shepherdsville, Kentucky with my Mom and my little brother. We have 2 dogs, Rosco and Lily.

My mom, Stephanie Miller, is 34yrs old. Mommy has given me a baby brother, Nathan; he is 3. She is also going to be giving me a new brother or sister on April 29th, 2011.

My Daddy, Tony Cox, is 36yrs old, and he has also given me 2 younger brothers: Waylan and Colton.

I have so many people that care for me and love me; I never get lonely. Even though I can't tell them that I love them all, I can show them with my eyes, my beautiful smile and my body.

I love going to school. Getting to be with my friends and ride the bus is exciting for me. I have wonderful Teachers, Therapists and a lot of great friends.

My favorite animals are Horses. My favorite TV shows are Barney and Wiggles. I love going horseback riding, watching Barney and Wiggles and spending time with all of my family and friends. These are my favorite things in the whole world. These things keep me happy and entertained.

I have good days and bad. Even with my disability I wake up each morning with a smile!

I am grateful for my Mom and Teachers that help me every day. These are the everyday things that some people take for granite: like feeding, changing, clothing and bathing me. I have to wear braces on my legs to help me walk. Some days I can walk, some days I can't; but, I have a wheelchair to help me get around.

I live each day around everyone I love and being happy, not worrying about my disability. My mom and I will wait for that call that WILL come saying that "There is a cure" For me, and all of the others out there!! - Hopefully in my lifetime, but if not in mine, I know it will be soon!

Please help us find a cure and donate today!!!

Riley Steventon

Hi, my name is Riley Steventon and I am four years old and I have Rett syndrome. Some days Rett syndrome has me too, but I am determined to not let those days out weigh the days that I have it. My mommy and daddy help me with that a lot. Before they even knew my diagnosis, they had me in therapies to help. Since then I have learned how to walk, how to use my communication devices, and much more. I attend school and am even in an inclusion classroom. Mommy volunteers in the class at least once a month (I honestly think it helps her feel more comfortable with me gone all the time). Daddy does as much with me as possible too. Sometimes it's harder than others though because my daddy is in the army and has to go away for more than a year at a time (like when I got my diagnosis, he was gone then, and he is gone again right now). People always say to mommy and daddy that it must be hard to deal with the diagnosis and all that it encompasses, but they always tell everyone that this is just how I am and since I am an only child, that they don't know what it's like to raise a typical child. They think that seems harder! Besides, I am their little angel and they love me just the way that I am. They are always telling people about me, face to face, newspapers, and even magazines. I know that they are proud of me, and will always continue to educate people on Rett syndrome and me, because like I said, I am their little angel and they love me!