



IRSF

*The International Rett
Syndrome Foundation's*
Family Advisory Board

A Message from Clifford L. Fry

Chairman, Family Advisory Board

WE ARE YOU

A group unified in purpose and effort can accomplish more than an individual typically can, and that understanding underlies the efforts of the Family Advisory Board (FAB).

We can all do something, and that “something” might make a big difference in someone’s life.

The members of the FAB are unified by our love for those with Rett syndrome, our love for their families, and by a desire to improve the well-being of those who cannot speak for themselves.

The FAB is an advisory group that provides strategic direction to the IRSF board of directors on issues important to families challenged by Rett syndrome.

We also work with IRSF staff to implement approved projects.

The FAB’s structure is defined by IRSF’s Board to address a range of issues.

Our current efforts include, among others, improving fund raising for research and family support, improving IRSF’s website as a critical source of information about Rett syndrome, periodically soliciting guidance through family surveys, and raising awareness of Rett syndrome through governor proclamations, media promotion, and family involvement.

All members of the FAB are directly affected by Rett syndrome, as parents, grandparents, and siblings.

We understand many of the challenges and the opportunities you face. FAB is here for you, and we welcome your ideas.

This gift booklet introduces you to the 2010 FAB members, many of whom you may see here at the IRSF Conference. We invite you to introduce yourself and share your concerns.

There are scheduled periodic rotations of the FAB members.

And when you return to your home, we invite you to learn more about the FAB from the IRSF website and consider applying to serve on the FAB in the future.

In the meantime, we hope that you find the IRSF conference experience to be an important time to learn and to make valuable contacts.

WE ARE YOU

WHAT THE FAB'S SUB-COMMITTEES PLAN TO DO IN 2010

All FAB members belong to at least one sub-committee in addition to the regular boards.

Support and Services Sub-committee

The Support and Services Sub-committee is reviewing the results of the survey from last year, along with all current programs and services offered by IRSF.

We also plan to develop some key questions regarding our programs and services and interview a few randomly chosen members. Based on the results, we'll make some recommendations to the Family Advisory Board and family support staff at IRSF.

Fund Development Sub-committee

Fund Development Sub-committee wants to increase each Strollathon's revenue by 15 per cent per event.

Working with the IRSF staff, we will assign one of our group to become the Strollathon Guru. Our guru will gather best practices from the most successful thons and help package those ideas so everyone can use them.

We also want to identify the five states most in need of an event and get an event going in each of those states.

And, as well, we want to draw up a list of families whose members are employees of public or large, private companies who could open doors for major gifts to the IRSF.

Advocacy and Awareness Sub-committee

The Advocacy and Awareness Sub-committee continues to pursue Governor Proclamations for all 50 states and create tools and establish procedures to assist long term continuation of this effort.

We also plan to identify and implement 12 major awareness opportunities with the goal producing one per month.

We'd also like to establish a process for Rett families to interact with the committee so we can ask families to support of advocacy and awareness efforts and families can provide advice and opinions to the committee.

Communication and information Sub-committee

The Communication and Information Sub-committee continues to be work on the IRSF website, looking at the Research and For families sections, noting possible areas for improvements and additions, such a technically feasible and practical way to solicit more photos/YouTube video material and drafting sections for financial planning, residential care and therapies.

We also plan to assist with the forums and the Family Matters outreach— and whatever else comes up.

HERE WE ARE: YOUR FAMILY ADVISORY BOARD

SHERRI BRADY

My name is Sherri Brady and I live in Whittier, California with my daughter Lauren Messer who is 13 years old.

Lauren was officially diagnosed with Rett syndrome at age three.

I noticed she was not meeting typical milestones around six months old and at 18 months old a doctor said he thought it might be Rett syndrome.

The following months were spent hoping, praying and trying to prove that it wasn't so but once the gene was discovered Lauren had the blood test and the results came back positive for the R168X mutation.

The diagnosis hit me like a ton of bricks. Like so many other parents of kids with special needs, I quickly realized that the dreams I had when Lauren was born of how life with her was going to be were quickly dashed.

The good news is I realized from the beginning that I was going to need help and support and I was fortunate enough to find it in many ways.

Family and friends have been great but the help, support, guidance and information I received from other parents in my same shoes has been just as vital.

Lauren is my strength and inspiration and she most definitely has made me a better person but knowing I'm not alone on this journey has been a tremendous comfort. The dreams I once had may have been dashed but I have new ones.

I am determined to stay focused on the possibilities, on what Lauren can do not on what she can't. She may not do all the same things she would if she didn't have Rett but she'll do a lot even if it's in a little different way.

Matter of fact we've had quite a few adventures and met so many wonderful people that we never would have had if not for Rett.

Of course, there are those hard days, if Lauren is having a hard time or when I hear of the loss of one of our precious Angels it can be tough to keep moving forward but then she flashes one of those amazing smiles and I know I have to.

I often tell people my volunteer work is a bit selfish because it helps me cope. Rett syndrome can make you feel so incredible helpless but being actively involved in the fight against Rett and helping other families is so rewarding.

My professional background is in sales and marketing. I graduated from San Diego State with a BA in Marketing in '91. I worked for several years in marketing, sales and public

relations with companies such as Pepsi Cola and Coors Brewing Co. until making the decision in '01 to stay home with Lauren.

Since receiving the diagnosis in addition to caring and advocating for Lauren I have served in several volunteer positions that have given me the knowledge and ability to help Lauren and others. I have raised awareness and funds in many ways including organizing the Annual Rett syndrome Family Picnic and Fundraiser, doing presentations and trainings at elementary schools, colleges and conferences and working with other families to open the Rett Clinic at Children's Hospital Los Angeles.

Currently I am the IRSF regional representative for Southern California, chair of the family advisory committee for the Eastern Los Angeles Regional Center, and governor-appointed member and former chair of the board of directors for Area Board X on developmental disabilities.

I dream of the day when a cure is discovered but until then making sure that words of comfort, a helping hand and the information necessary to deal with the day to day challenges of Rett syndrome continue to be available to all that need it.

I feel serving on the Family Advisory Board is way for me to be a part of making that happen.

LARRY CALDERAZZI

My granddaughter is a beautiful little angel of almost six years.

She does not talk but has a beautiful smile and beautiful curly brown hair. Her favorite activity is watching her favorite movies; she loves Cars and Curious George. I can easily tell by her smile when she is happy and that is most of the time.

She lives a bit away, but we get to visit frequently and usually spend time together at the beach in the summer.

As a grandfather, my wife and I are continually concerned as what we can best do for her and her family, which, of course, are our own child and his wife.

I believe that personal involvement with IRSF and the Family Advisory Board is the best way to help our granddaughter.

Of course, at my age and as a grandparent, I am most interested in finding a cure.

My hope has been that this would happen within five years. My granddaughter would be about 11 and have the possibility of a life of a sort. This is the profound hope of me and my wife.

I am convinced that IRSF is the avenue to a cure. I would hope that a cure is near at hand as I would truly love to hear her voice.

My wife and I have been involved with various fund raising events for IRSF. Our family and our community have been and continue to be wonderfully supportive.

CLIFFORD FRY

There is an old country song, "I Love You So Much it Hurts."

I thought it extravagant, until Ashley (30, Rett syndrome) came into my life.

It is not that I love her more than I do others in my family. It is the type of love that I have for her that is different, and it stems from Rett syndrome.

There is a long lasting vulnerability and dependency in people with Rett syndrome that is not present with those without such difficulties.

My oldest daughter, Kristin, has a family and is capable of taking care of herself. Ashley is not.

Assisting Ashley for years is not the part of the love that "hurts."

In fact, some of my most joyful times have been spent with Ashley. I may not be here throughout Ashley's life to protect and care for her.

And, for me, that is the part of the love that hurts.

Ashley is a light of love in our house.

Her smiles and joy in the face of her severe disabilities inspire my family to be joyful and to be the best we can be.

Although there were sorrowful and rough times of adjustment at the outset, caring for Ashley has become a privilege.

Joining IRSF's Family Advisory Board is a way that I can care for Ashley and others who cannot speak for themselves.

I have been involved in a variety of capacities with Rett syndrome organizations, and it has been my privilege to help participate in what is now IRSF.

I decided to apply for the FAB after meeting Kathryn Kissam, President of IRSF, and Kenna Seiler, then on the FAB, at a Kevin Black/Clint Black fundraiser in the Woodlands, TX.

Kathryn knew of my past involvements as a board member, regional rep, and conference organizer and that I had an older daughter with Rett syndrome. She asked me to consider getting back involved.

I knew that I might have some insights to offer to those with younger girls. I felt confident that I could handle responsibilities of a FAB member. I decided I wanted to contribute - while I still could - to improving the lives of those with Rett syndrome.

I could sense the close relationship that exists between the FAB members and IRSF staff, and I valued that. My wife, Judy, and I have maintained a special relationship with some of the key physicians involved in Rett syndrome research, partly because Ashley was the first Rett girl some of them had seen, so we go back a long way, so to speak. I valued those relationships. With support from Judy, I knew I could assist the FAB.

If you are new to IRSF you can see that IRSF has a lot to offer to families. Each of these offerings is the result of effort by some individual or group of individuals, present or past.

We must be the voice and advocates for our precious children and grandchildren with Rett syndrome.

They cannot do it for themselves. They are counting on us. Be with them, love them, give them joy and allow them to give you joy, but also work for them in an advocacy manner.

The FAB provides that work avenue for me at this point in my life, and I am grateful to all those working on behalf of Rett syndrome.

JANE GEORGE

When my daughter Aniko died suddenly at 29 in August of 2005, I thought this would mark the end of my journey with Rett syndrome.

I only knew Aniko had Rett syndrome for the last 15 years of her life and during most of those years I was simply too busy caring for her and working full-time to be deeply involved with the organizations devoted to Rett.

My main contact with other parents came during my attendance at two or three conferences, one in the U.S. and two in Canada.

But generally I felt isolated from other parents.

And I felt very sad when the parents of another younger child who was diagnosed with Rett (and who actually went to my daughter's daycare centre) didn't want any to hear any of the information I had learned.

So I struggled and learned alone basically, dealing with the health and educational challenges Rett girls bring.

My isolation was only broken in 2003 when I became linked up to the RettNet and sought support from parents of older girls: they understood the roller-coaster of illnesses we were experiencing, my fears for the future and the lack of support that I often felt, even at home.

When my daughter died suddenly, RettNet became an unexpected link to her: every time I saw a posting I thought of her.

Sometimes I had information to share. I made new Rett friends and was able to even send some of my daughter's cherished books to another Rett girl to enjoy.

At that time, the Intl. Rett syndrome Assoc. and the IRSF were going through what seemed to be a stressful union, and often there was a war on RettNet.

As well, I felt the loss of the caring, personal touch of Kathy Hunter who had been the first point of contact for me when my daughter was diagnosed and when she died.

The new organization seemed young, and not yet as warm, cozy and confident.

And even though I still felt deep in grief I put my name in for the new IRSF Family Advisory Board, mainly to make sure that parents in need would continue to receive the information and support in a compassionate manner.

Since 2006, my communications and information committee has helped breathe some new positive life into RettNet— we've updated the website and been involved in projects like the IRSF survey.

Instead of a slightly nervous, fledgling organization, I see IRSF today as a group that stands on its own two feet and has open arms: a winning combination.

As for me? I still check every RettNet posting, although the loss of my daughter is easier to bear as I approach the fifth year anniversary of her death.

In my mind I see us as heading down a road together. In 2005, she stayed behind there on the road, and I had to keep on going. For a long time, it seemed like she was very close to me, now she's a bit further in the distance, but still visible. And I have to keep on going.

But I haven't forgotten about Rett syndrome. When I helping get my daughter through pneumonia, was juggling her oxygen levels and clapping her in the middle of the night to get her rid of secretions, I used to wish she and I were free of Rett syndrome somehow.

But for her, this freedom meant the end of life; for me, it turned out my life will always include Rett syndrome.

Now, if I have any dream, it's to make sure every family affected by Rett syndrome continues to fight for a cure and helps those still battling Rett syndrome to find the support they need.

SHARON HORNADAY

Sitting in a rocking chair in my family room at 3:30 am holding Marykate, one of my 15-month old twin girls, was how I spent most nights in the winter of 2006.

Marykate's sister Kayleigh was usually able to sleep through the night but Marykate always seemed to be agitated and would wake herself up from her constant movements.

Over the next two months the developmental abilities of Marykate and Kayleigh grew further apart.

Marykate didn't seem to be progressing at same pace as her sister.

Marykate and Kayleigh were born 56 minutes apart, 11 weeks premature on the night of October 20, 2004. Each weighing in at just over two and half pounds, they spent the first 49 days of their lives in the Neonatal Intensive Care Unit at Lenox Hill Hospital in New York City.

Early on, Kayleigh, who was born second, was the twin who walked the tightrope between life and death on a daily basis. After complete organ failure, extensive fluid retention and a significant bilateral brain bleed, Kayleigh had emergency surgery at 17 days old and we were told if she made it, she was at significant risk of having a disability.

At that point, I think my husband David and I knew we would have a child with special needs.

Interestingly, during her stay in the NICU, my first born, Marykate, who would later be diagnosed with Rett syndrome, had relatively few complications. The most significant issue was that the oxygen nasal canula wore away her septum and she would later require plastic surgery.

As Marykate's sleep patterns became more erratic from 15-19 months of age, we took her to four neurologists throughout the tri state area looking for answers to her lagging development.

At the end of every visit the physicians concluded that she was developmentally delayed due to being a preemie.

As her Mom, Marykate just didn't seem alright to me and I knew there was something more going on. After all, Kayleigh with all of her complications was consistently meeting many developmental milestones.

My father who is a physician and completed his residency at Columbia University Medical Center suggested that I make an appointment with one of their neurologists in New York City.

My appointment was scheduled for September 13, 2006. The neurologist passed Marykate in the waiting room and saw her hands claspings. He told us at the end of his visit that there was a chance Marykate had Rett syndrome.

After we arrived home, my father and I looked up Rett syndrome on the internet and Marykate met just about every diagnostic criteria.

That was the moment that changed our lives. I didn't need a blood test to confirm the diagnosis although we later received a positive result.

I went into a depression for two weeks and rarely left my bedroom. When I did venture out, everything around me, my house, my car, the roads that I drove everyday suddenly seemed unfamiliar to me. My family and nurses took care of the twins while I was unable to function.

One afternoon sitting in my kitchen I got the strength to call IRSF and speak to someone regarding Marykate's diagnosis. They told me about the traveling clinic and the great

strides and research that were being conducted every day for these little angels.

Several hours later I received a call back from Kathy Hunter who knew my emotional loss. I will never forget she told me there are far worse things in this world than Rett syndrome. At that moment I began to heal emotionally and physically.

Shortly after this phone call, Leslie Greenfield my state representative, got in touch with me and from that moment on I wanted to become involved in IRSF, the organization that gave me the support and strength to continue.

Last year was my first IRSF conference and I was in absolute awe of the caliber of speakers and the volume of extremely relevant information that was presented. IRSF is more than an organization; it is an extension of Rett families all over the world that are all connected by the unconditional love of their silent angel. I feel blessed and honored to be part of such a family.

I was fortunate enough to work with a group of very dedicated parents in New Jersey to incorporate the New Jersey Rett syndrome Association which opened a clinic at Robert Wood Johnson UMDNJ Medical School.

My passion is to help disabled families in NJ and I have worked diligently with elected officials to develop a childhood disability guide and promote Disability Awareness Day in Somerset County.

Marykate (with a little help) will be throwing out the first pitch at Disability Awareness Day in June at the Somerset Patriots Ballclub, a minor league team in NJ.

Today, I look at Marykate's precious eyes and say to her "You are going to make the world a better place because you are here" and she looks back at me through her eyes and says "Mom I wouldn't want it any other way."

This would not have been possible without the love and support of IRSF. Now as a member of the Family Advisory Board I have the ability to give back to the organization that helped me so much.

David and I currently live in Bernardsville, New Jersey with our twin girls Marykate and Kayleigh.

JEFF HUISINGH

In the summer of 2002, my 13-month old daughter, Shelby, had not been eating normally for seven months.

Despite our best efforts to feed her, my wife and I could not get her to gain weight.

Shelby was admitted to a medical center in Virginia for observation where I videotaped her eating and vomiting patterns.

A pediatrician saw the video and diagnosed Shelby with voluntary rumination disorder. He told us the disorder was rare and he had only seen it in cases of extreme neglect in developing countries. He commented that there was a remote possibility that Shelby could have Rett syndrome.

However, his decision to order the test was subsequently overridden by his boss who then turned my wife, Laurie, and me into child protective services for suspected child neglect-citing we were to blame for Shelby's weight gain.

Shelby was diagnosed with Rett syndrome in February 2003 at 21 months.

While traumatic, the diagnosis was somewhat of a relief for our family.

We could take action. We could plan fundraisers (three Strollathons) and assist with others (five Strollathons and 6 golf tournaments). We could support other families as we were (and continue to be) supported. We could advocate for family support (appearance before the Washington State Legislature advocating respite care) and continue to live a full and rewarding life while including Shelby in wide variety of family activities.

Since inclusion is a family priority, we have taken Shelby skiing at Colorado's Keystone Resort, indoor skydiving, horseback riding, geocaching, camping, rollercoaster riding, hiking, biking, swimming, and golfing.

We are amazed how much we can do with her and how much she enjoys these activities alongside her older brother and sister. In all cases, these activities did require some level of accommodation from reserving specialized instructors to modifying a golf cart.

However, any additional coordination has been well worth the effort based on the incalculable benefit to Shelby and the rest of our family.

As a resident of Colorado Springs and a member of the Family Advisory Board, I welcome you to the Centennial State and encourage you to enjoy the majestic scenery and numerous activities specific to the region.

If you have any questions about the local area, please don't hesitate to ask.

SHIRLEY HURLBURT

My husband, Paul, and I live with our two children (Kaila and Kinley) in Syracuse, NY.

Our journey with Rett syndrome began when Kaila was 18 months old. Kaila was a typically developing child who met all of her milestones right on time. She rolled over, she sat up, she crawled, and she walked.

The only part that wasn't typical was her speech. Kaila's speech wasn't progressing past a couple of words. I consulted her pediatrician who thought it might be because of her constant ear infections. Kaila had tubes put in her ears and was then given some time and reevaluated. She was diagnosed with a mild hearing loss and fitted for a hearing aid.

A couple more months went on and Kaila still wasn't talking so I had her evaluated and she was diagnosed with Autism in the November of 2003. Over that winter Kaila continued to regress, so bad that she forgot how to walk up stairs.

I changed pediatricians to a developmental pediatrician. She believed as I did that these changes were more than Autism. A geneticist tested Kaila and in August of 2004 she received the Rett syndrome diagnosis (R106Q).

This was totally devastating. I thought my world had been rocked when we received the Autism diagnosis but this was by far worse than what I was prepared for.

I immediately got in touch with what was then International Rett syndrome Association. For the next couple of years I worked on doctors, therapies, and just coping as a single parent at the time.

I attended my first conference about nine months after Kaila's diagnosis. I felt happy to be there and miserable all at the same time. I was able to leave the conference feeling better about our future and with a better insight into Rett syndrome and what Kaila might be able to do in the future.

I now try to attend every conference because it is such a safe place. I am able to talk with other families, learn what is working with them, and know that everyone there understands what I'm going through.

I am excited to be serving my second year as a Family Advisory Board member and my first year as a Regional Rep. I love connecting with other families and helping them however I can.

SHAWN MANSFIELD

My wife, Shelley, and I live with our four daughters in Washington D.C.

I am currently working at the Lejeune Leadership Institute, Marine Corps University, Quantico, Virginia.

Our second to youngest daughter Lauren, age six, was diagnosed with Rett syndrome in July 2006.

Within a month of Lauren's diagnosis we attended a strollathon in Fairfax, VA. This emotionally powerful event convinced us to host our own strollathon in Wilmington, North Carolina.

With enormous help and support from family and friends, we are entering the fourth year of this event.

As a family, we believe God has given us Lauren to not only bless our lives but also inspire everyone around her. In the past four years we have seen more people receive blessings because of her than we could have ever imagined.

Through Lauren, our world has expanded to include wonderful people like her teachers, therapists, awesome volunteers and business partners that support the strollathon, and most importantly, other Rett families.

Our world has expanded, our friends have multiplied, and our purpose in life has become even clearer. As I'm sure all of you can relate; our girls have a spark in their smiles, their eyes, and their touch that moves people down to their souls.

I consider it an honor to serve the families of these special girls and women.

As a Family Advisory Board member, I will strive to help provide information and advocate for the resources that Rett families need to experience the unique joy and blessings that their daughters can bring to their family and the community.

MICKIE MCCOOL

I live in O'Fallon, Missouri (a St. Louis suburb) with my husband, Dave, and our two children, 12 year-old Ellie and eight-year-old Bryce. Ellie has Rett syndrome.

Ellie's loss of skills started at 11 months old without warning or a diagnosis.

She wasn't exhibiting the classic Rett syndrome behaviors and it wasn't until three years later that a blood screen ordered by our neurologist to rule-out a variety of unlikely disorders came back positive for Rett syndrome.

As devastating as the diagnosis was, it resolved some of my anxiety that the culprit for Ellie's disabilities were the activities I engaged in during my pregnancy – exercise during the third trimester, a bath that was too hot, a glass of wine before I realized I was pregnant!

My sense of isolation was replaced with a vague sense of membership in the community, the culture of Rett syndrome.

Two months after Ellie's diagnosis, we attended our first IRSA conference – “Possibilities” – in 2001. And what a life-changing week it was!

The conference was both informational and inspirational. We felt empowered by the staggering amount of knowledge we suddenly acquired, and inspired by how the organization had stirred so many different parties (researchers, physicians, therapists, educators, parents) into action with the momentum continuing to build.

We left the conference feeling an incredible sense of purpose and responsibility, as well as the moxie to take on the challenges of Rett syndromes as advocates for Ellie.

Becoming involved with IRSF (then IRSA) was the natural next step for me. I began as a Regional Representative and joined the FAB when it was formed shortly after the merger.

Rett syndrome is the paradox in my life – I'm constantly striving for ways to make it go away, yet surely life without it would seem impoverished by comparison because it has been the pipeline of our greatest blessings. We see Ellie as the embodiment of God's Spirit and the force that brings out His Spirit in others.

IRSF's Annual Conference is my annual check-up, my Flintstone's Vitamin, my glass of fine red wine.

It reconnects me to my extended Rett syndrome family, supplies new strategies for improving Ellie's quality of life and finding balance in my own, and let's me bask in the incomparable kinship that is reserved for those who have been touched by Rett syndrome.

DEBERAH PATTERSON

My husband, Patrick, and I live with our three children (Brandon, Ashley and Caitlyn) in Houston, Texas.

Our Rett Journey began when our youngest daughter, Caitlyn, was 15 months old. At that time we noticed she wasn't developing typically and was actually loosing some skills she had already developed.

During the following three months, as we carefully and prayerfully watched, Caitlyn showed no improvement. At 18 months, on her pediatrician's recommendation, we decided it was time to have her tested.

In September 2006, when she was 20 months old, we received the diagnosis of Rett syndrome (R168X). Naturally, we were devastated by the news, and we knew that it would change our family's lives completely.

Without a doubt, coping with Rett has been an emotional battle and a constant adjustment. However, through this hardship, we also have experienced many blessings.

We have met and developed friendships with other families going through the same struggles that we would not otherwise have met.

Just one week after Caitlyn's diagnosis, we attended our first fundraiser for Rett -- Kevin Black's annual golf tournament -- and we came away with a desire to work with other families to raise awareness and funds for Rett.

Since then, we have volunteered each year at Kevin's golf tournament, and this past year (2009), I served on the committee to help organize Houston's first Rett Strollathon.

I am not sure what all Rett holds for us in the future, but I do know that each and everyday is a special blessing for our family just to have Caitlyn with us.

I am excited to be a new member of the Family Advisory Board this year and look forward to working with other board members and IRSF to provide information on support and services to families on their Rett journey.

DIANE ROSS

I live in Illinois with her husband, Mick. They have four children: Kristi, 23, Lindsey, 21, Andy, 18 and Corey, 12.

Lindsey was diagnosed with Rett syndrome at the age of three.

Lindsey was fully included throughout her school experiences, and she enjoys skiing, horseback riding, swimming, movies, music and hanging out with her friends.

I am no stranger to the Rett syndrome community. I served on the International Rett syndrome Association's board of directors for nine years, six as chairman of the board.

I also chaired the personnel committee and served on the family support committee, transition committee and public relations committee for IRSA.

From the time of Lindsey's diagnosis, I have been actively involved in the Rett syndrome Association of Illinois, serving on the board of directors for 15 years, four years as president, four years as secretary and 10 years as the co-editor of the newsletter.

I also chaired the dinner, dance and auction, family day, family camp and annual conference committees for RSAI.

I contributed to the second edition of the Rett syndrome Handbook as well.

A licensed clinical professional counselor, my vision is to expand and grow family support services to the entire Rett syndrome community.

I want promote awareness and understanding of Rett syndrome throughout the world and expand IRSF's ability to encourage and fund medical, educational and therapeutic research.

On the Family Advisory Board, I chair the Support and Services sub-committee.

WILL RABKE

My family's Rett journey started long before we knew what Rett syndrome was.

My wife, Emilie (now the IRSF regional rep for Virginia), and I were blessed with our now almost nine-year old, Anna Cate in 2001.

In addition to Anna Cate, we live in Richmond with Betsie, six, and Eli, three.

Anna Cate did not receive her diagnosis until she was five years old, and she had been tested twice for Rett before a “positive” result came back.

Anna Cate’s speech development plateaued with about nine words from when she was about 18 months old until she was about four years old.

But until her diagnosis in 2006, we didn’t know what we were dealing with.

After the shock and grief that accompanied Anna Cate’s diagnosis, my wife and I decided that we wanted to fight for our little girl.

We got involved with the Rett syndrome community and have found a conduit for us to try our best to raise funds and awareness of this terrible disorder, while making new friends with other Rett families along the way.

We are so blessed that Anna Cate has a mild mutation, and we thank God that she continues to be mobile, is usually happy, and able to communicate with us.

Anna Cate’s 60-70 word vocabulary continues to expand very slowly (about one new word per month) and we pray for the day that she is going to be able to let us into her little world through meaningful speech.

Until that day comes, we intend to fight for Anna Cate and all of our Rett angels, so they can live the best, fullest lives possible.

As I mentioned, my wife is now a regional rep for Virginia and Washington DC, and I am serving for my third year on the FAB.

Together, with a few great friends and our ever-supportive families, we host a fundraiser in Richmond.

2010 marks our third event, and we will continue hosting this event until we find a cure for our little girl.

MARY ANN SABO

I live in Edgewater, Maryland with my husband, Steve, and our four children(Nicholas, Katie, Chris and Zachary). I have been very blessed with the family I have.

Nick has cerebral palsy and Katie was diagnosed with Rett syndrome at the age of 5, she is now 20.

We have lived with the Rett diagnosis now for 15 years. How our lives have changed.

Having two children with disabilities I have learned more than I ever thought I could. I continue to grow and learn each day.

When we first learned about Rett syndrome I just wanted to hide with Katie and wait until a cure was found, but I knew that was not reality. I knew right away I needed to make a difference for Katie and all those who have Rett syndrome.

I started my first fundraiser and learned more and more and grew so much. We have done bowling benefits, cruises, bingo, to name a few. It was the beginning of a new journey for us, one that continues.

I can say Rett syndrome has changed our lives. We have met so many wonderful people and we have been deeply touched by all these beautiful children. I want to continue to do whatever I can and will always be devoted to making a difference.

I am not only dedicated to Rett syndrome but to the disability community as well. I serve on our county commission for people with disabilities. I will do whatever I can to help my children and others have their voices heard.

Our children with Rett syndrome will touch the lives of more people than we can ever imagine and together we will make a difference.

That's a reason why I am proud to be a member of the Family Advisory Board.

DONNA WRIGHT

I raised five children in northern Michigan, my home state until I moved to Warren, Pennsylvania with her life partner Bob Dean, an oil and gas industry executive, in 1998, along with my two step-daughters.

I have 13 wonderful grandchildren, including Naomi, age six, who was diagnosed with Rett in 2007, and I travel back to Michigan often for extended visits with family there.

I admit that before Naomi's diagnosis I had never even heard of Rett syndrome, and this has motivated me to do all I can to spread Rett awareness, not only to individuals, but to entire communities, including politicians and medical professionals.

In 2009 I became the IRSF's Grandparent Representative for the Mid-Atlantic region. That year I helped obtain gubernatorial Rett syndrome Awareness Month proclamations from Pennsylvania, West Virginia, Alabama, Alaska and Delaware.

I believe that raising awareness is a crucial factor in improving Rett treatment and, soon, I'm confident, a cure.

I feel fortunate to have the opportunity and the energy to devote to that goal.

I want to spend time in contact with other Rett families across the country, providing information, support, and her message of hope- that's why I am a member of the Family Advisory Board.

LYNN PEEL

My beautiful sister, Jennifer Hughson, is 31 years old and has Rett syndrome. Jennifer lives at home in Townsend, Massachusetts with our parents Diane and Scott.

Jennifer loves spending time with the family especially weekend visits from her brother, David and sister in law, Nikki.

But if you want to see her eyes really light up watch her interact with her two-year old niece Addyson.

I live in Portland, Maine with my husband Quin, daughter Addyson and soon we will welcome another little addition to the family. In Portland I am currently president and senior care consultant of Beach Glass Transitions, llc, helping seniors and their families make the transition into senior care.

I have been involved with the Rett syndrome community for nearly my entire life. My involvement began as Jennifer's sister assisting in day-to- day care and being lucky enough to be her roommate.

Since then, I have become an advocate for Jennifer and for the entire Rett syndrome community through development of and participation in fundraisers like the Roll for Rett, and the Rip it for Rett Golf Tournament, as well as countless others that have taken place over the years.

I have been able to channel my experiences living with Rett syndrome into a passion for advocating on behalf of Jen and girls with Rett everywhere.

As a Family Advisory Board member I hope to help other friends and families do the same. I hope to lend my ear to those who need someone to listen and I hope to provide advice and solace to those who ask for it.

I also simply want to dig in and help people be successful in their own efforts to advocate for Rett, whether that is through fundraising, organizing or other means.

2010 FAMILY ADVISORY BOARD CONTACT INFORMATION

2010 FAB CHAIR:

Term Ends	Name	Address, City, State, Zip	Contact Number	Email
12/2011	Fry Clifford L. Ph.D.	c/o RRC, Inc. 3833 S. Texas Ave, Suite 285 Bryan, TX 77802	(979) 204-4489	cfry@rrc-inc.com

ADVOCACY & AWARENESS COMMITTEE:

Term Ends	Name	Address, City, State, Zip	Contact Number	Email
12/2011	Mansfield, Shawn (Chair)	8014 Garlot Drive, Annandale, VA 22003	(703) 507-4756	shawn.mansfield@usmc.mil
12/2011	Hurlburt, Shirley	7 Gardner Court, Liverpool, NY 13090	(315) 447-5200	cnyrettrep@twcnv.ny.gov
12/2012	McCool, Mickie	2671 Whitetail Lane, O'Fallon, MO 63368	(314) 610-5651	mickmccool@charter.net
12/2011	Sabo, Mary Ann	1245 E Central Avenue, Edgewater, MD 21087	(410) 798-6425	rettmom@verizon.net
12/2012	Wright, Donna	191 Jennie Lane, Warren, PA 16365	(814) 688-4317	donnaewright@yahoo.com

FUND DEVELOPMENT COMMITTEE:

Term Ends	Name	Address, City, State, Zip	Contact Number	Email
12/2010	Rabke, Will (Chair)	4905 Sadler Glen Place, Glen Allen, VA 23060	(804) 405-2420	wrabke@williamsmullen.com
12/2012	Calderazzi, Larry	484 Fort Mill Lane, Spring Hill, FL 34609	(352) 684-8266	lcalderazzi@tampabay.rr.com
12/2010	Hornaday, Sharon	82 Old Army Road, Bernardsville, NJ 07924	(908) 581-5465	sharshar10@aol.com
12/2012	Peel, Lynn	1673 Washington Ave, Portland, ME 04103	(207) 272-2797	lpeel@beachglasstransitions.com

INFORMATION COMMITTEE:

Term Ends	Name	Address, City, State, Zip	Contact Number	Email
12/2010	George, Jane (Chair)	185 Main Street, West Cookshire, Quebec Canada, JOB 1M0	(819) 446-5370	jgeorge@globetrotter.net
12/2011	Brady, Sherri	6252 Gretna Avenue, Whittier, CA 90601	(562) 619-0109	sbrady0457@charter.net
12/2012	Calderazzi, Larry	484 Fort Mill Lane, Spring Hill, FL 34609	(352) 684-8266	lcalderazzi@tampabay.rr.com
12/2012	Patterson, Deberah	9883 Sageroyal, Houston, TX 77089	(713) 231-4643	dpatterson@prideinternational.com
12/2012	Peel, Lynn	1673 Washington Ave, Portland, ME 04103	(207) 272-2797	lpeel@beachglasstransitions.com

2010 FAMILY ADVISORY BOARD CONTACT INFORMATION CONT.

SUPPORT PROGRAMS AND SERVICES COMMITTEE:

Term Ends	Name	Address, City, State, Zip	Contact Number	Email
12/2011	Ross, Diane (Chair)	737 South Point Drive, Schaumburg, IL 60193	(847) 567-0964	Diross62@aol.com
12/2011	Brady, Sherri	6252 Gretna Avenue, Whittier, CA 90601	(562) 619-0109	sbrady0457@charter.net
12/2010	Huisingh, Jeffrey L.	1065 Crystal Basin Drive, Colorado Springs, CO 80921	(719) 963-4048	jhuisingh@mac.com
12/2011	Hurlburt, Shirley	7 Gardner Court, Liverpool, NY 13090	(315) 447-5200	cnyrettrep@twyny.rr.com

NON FAB MEMBERS OF INTEREST:

Name	Address, City, State, Zip	Contact Number	Email
Bajardi, Steve	260 Madison Avenue, 8th Floor New York, NY 10016	(917) 267-4503	sbajardi@rettsyndrome.org
Endres, Jennifer	25 Augusta Way South, Yarmouth, MA 02664	(508) 362-2220	jendres@rettsyndrome.org
Grammer, Jenni	IRSF 4600 Devitt, Dr., Cincinnati, Ohio 45246	(513) 874-2657	jgrammer@rettsyndrome.org
Griffin, Mary Joyce	IRSF 4600 Devitt, Dr., Cincinnati, Ohio 45246	(513) 870-4378	meriffin@rettsyndrome.org
Hayden, Lisa FAB and Family Support Coordinator	IRSF 4600 Devitt, Dr., Cincinnati, Ohio 45246	(513) 870-4375	lhayden@rettsyndrome.org
Horton, Dr Tony	260 Madison Avenue, 8th Floor New York, NY 10016		thorton@rettsyndrome.org
Keller, Jim	260 Madison Avenue, 8th Floor New York, NY 10016	(917) 267-4504	jikeller@rettsyndrome.org
Kissam, Kathryn	2 Oak Alley, Baton Rouge, LA 70806	(225) 810-3687	kkissam@rettsyndrome.org
Lane, Jane RN and IRSF HealthMatters	UAB Rett Center 1530 3rd Avenue South CIRC 320 Birmingham, AL 35294	(205) 934-1130	jlane@uab.edu
Nues, Paige	316 Bolero Drive, Danville, CA 94526	(510) 499-3858	pnues@rettsyndrome.org

TOLL FREE PHONE TO IRSF (800) 818-7388



Family Advisory Board Description and Application - 2011

Applications must be submitted before November 22, 2010 for term appointments commencing January 1, 2011.

The IRSF Family Advisory Board is comprised of 15 active members who have both personal and professional skills to best represent and advise on behalf of all families affected by Rett syndrome. We seek family members (mothers, fathers, grandparents, aunts, uncles, adult siblings, etc) who especially have expertise, personal and professional, in more than one of the following areas:

- An individual with RTT: young child, school-age child, teen, young adult, older woman, an individual with RTT who has passed away
- Family make-up: Married, single, divorced, remarried, adopted child
- Therapies: especially OT, PT, Speech/Communication, Nutrition, Marital/Family
- Medical
- Residential Placement
- Special needs law
- Support services
- Advocacy
- Public relations, media reporting
- Fundraising
- Programs/services/materials development and copywriting

Providing well-organized, sincere, sound, timely support and offering connections to information and each other is the best service that the IRSF Family Support staff can provide for families. IRSF promises this from the day a family begins searching for a diagnosis, through coping with day-to-day care issues after the diagnosis and beyond. Some of the best wisdom is learned from other parents, so we work to connect families with each other. Advice on how best to handle many care issues, medical issues, and communication/ learning strategies are vague at best in the general medical, therapeutic, and education worlds so we strive to connect families with the professionals we know and trust to turn to. Local and regional groups are vital for connecting families with specific resources in their community given the diversity of support services available across the country. IRSF provides baseline support for these local and regional groups to foster and thrive. When families that have never held a fundraiser, educational seminar, awareness activity or social gathering - or contacted a legislator or policymaker - become motivated to make a difference for those with Rett syndrome, we are there to help them be as successful as they can, regardless of the size of event or activity. When a family member, friend, caregiver, doctor, therapist or educator wants to know more about Rett syndrome, we are there to answer their questions.

And if IRSF staff is the backbone of the foundation, it is the unselfish commitment of our volunteer network that is our heart and soul. Our network of expert families and friends who lend their talents, energy and resources to IRSF make our Family Support programs and services the best they can be. There are opportunities every day for any interested person to help IRSF in the critical areas of Advocacy, Awareness, Information, Support and Fundraising.

The driver for all of these programs is the Family Advisory Board (FAB). The success of the FAB is dependent on skilled, active, committed members. Our members desire to serve on the board because of a personal connection to Rett syndrome, but their rationale for serving on the board is much more inclusive. Our board of Family Advisors gives unselfishly of their time, experience, and skills to advance and better IRSF Family Support programs and services. They strive for unity, always supporting the board team even if they disagree with a majority decision. Members are motivated by a desire to see IRSF Family Support programs and services grow and develop for the good of all we serve.

We encourage you to apply. Please complete the application below and submit by NOVEMBER 22, 2010.



IRSF

INTERNATIONAL
RETT SYNDROME
FOUNDATION

FAMILY ADVISORY BOARD MEMBER DESCRIPTION

- TITLE:** Member, IRSF Family Advisory Board
- REPORTS TO:** Family Advisory Board Chairperson
- PURPOSE:** To recommend, advise and consult on IRSF Family Support programs and services; to monitor the programs and services for success
- TERM:** Three years
- EXPECTED MEETING ATTENDANCE:**
- Regularly attend FAB conference call meetings (approx 6/year)
 - Participate in standing committee meetings if a member
 - Actively participate on ad hoc working committees as needed
 - Attend and participate in special events as needed
- OBLIGATIONS:**
- Advise on policy and procedures
 - Advise, strategize, and recommend solutions for programs and services
 - Monitor and aim for short-term and long-range success
- SPECIFIC DUTIES:**
- Educate yourself about the needs of the people served
 - Attend meetings and show commitment to board activities
 - Be well-informed on issues and agenda items in advance of meetings
 - Contribute skills, knowledge and experience when appropriate
 - Listen respectfully to other points of view
 - Participate in organizational decision-making
 - Assume a leadership role in all board activities
 - Represent the organization positively to the public and in private
 - Contribute at least one article per term in your area of expertise to the Foundation newsletter
 - Attend and contribute to the annual IRSF Family Education and Awareness Conference if circumstances allow

Current terms of the FAB will commence January 1, 2010, with the option to reapply for a second consecutive 3-year term if all conditions of service were met in the first term. Members may only serve 2 consecutive terms of service. They are welcome to reapply for board service once they have rolled off for at least one term.

Questions? Email Paige Nues, Director, IRSF Family Support, at pnues@rettsyndrome.org or Clifford Fry, current FAB Chair, at cfry@rrc-inc.com

Applications can be:

Emailed to us at: admin@rettsyndrome.org

Faxed to: 513.874.2520

Mailed to: International Rett Syndrome Foundation
Attn: Paige Nues
4600 Devitt Dr
Cincinnati, OH 45246



IRSF

INTERNATIONAL
RETT SYNDROME
FOUNDATION

IRSF FAMILY ADVISORY BOARD (FAB) APPLICATION

Completed applications must be submitted by November 22, 2010 for term appointments commencing January 1, 2011. Applications can be:

Emailed: admin@rettsyndrome.org

Faxed to: 513.874.2520

Mailed to: International Rett Syndrome Foundation
Attn: Paige Nues
4600 Devitt Dr
Cincinnati, OH 45246

Questions: Contact Paige Nues, Director, IRSF Family Support, at pnues@rettsyndrome.org or Clifford Fry, current FAB Chair, at cfry@rrc-inc.com

NAME: _____
ADDRESS: _____
PHONE: _____
FAX: _____
EMAIL: _____

1. WHAT IS YOUR RELATIONSHIP TO RETT SYNDROME AND WHAT IS THE NAME AND AGE OF THE CHILD WITH RTT THAT YOU ARE RELATED TO?
 2. WHAT IS YOUR CURRENT OR MOST RECENT PROFESSION?
 3. HOW LONG HAVE YOU BEEN INVOLVED WITH THE RETT SYNDROME COMMUNITY?
 4. WHAT RETT SYNDROME ISSUES ARE YOU MOST INTERESTED IN?
 5. WHAT SPECIAL SKILLS, EXPERTISE, OR LEADERSHIP EXPERIENCE WOULD YOU BRING TO THE ADVISORY BOARD?
 6. DO YOU, OR HAVE YOU, SERVE(D) ON ANY OTHER BOARDS, RETT-RELATED OR OTHER?
 7. WHAT CAN YOU CONTRIBUTE TO THE ADVISORY BOARD (time, energy, resources, personal connections, contacts)?
 8. HOW HAVE YOU CONTRIBUTED TO THE ADVANCEMENT OF THE UNDERSTANDING OF RETT SYNDROME OR THE BETTERMENT OF THOSE LIVING WITH RETT SYNDROME (personally, in your community, with IRSF, or other RTT associations/organizations)?
 9. WHAT WOULD MAKE YOU A GOOD ADVISORY BOARD MEMBER?
 10. PLEASE PROVIDE AT LEAST TWO PERSONAL REFERENCES.
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