PRISMS
Parents and Researchers Interested in Smith-Magenis Syndrome

Spectrum

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Smith-Magenis syndrome (SMS) is a chromosomal disorder characterized by a specific pattern of physical, behavioral and developmental features. It is caused by a missing piece of genetic material from chromosome 17, referred to as deletion 17p11.2. The first group of children with SMS was described in the 1980's by Ann CM Smith, MA, a genetic counselor, and Ellen Magenis, MD, a physician and cytogeneticist. Although the exact incidence is not known, it is estimated that SMS occurs in 1 out of 25,000 births. SMS is underdiagnosed, but as awareness of it increases, the number of people identified grows every year.

Inside this issue:

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Help Raise Money and Awareness for PRISMS with United Way and Entertainment Books!

As you may know, the United Way begins its annual fundraising drive each fall in nearly every community in the United States, Canada and many other countries. It provides a way for many charities to obtain funds by individuals contributing a portion of their paycheck through payroll deduction. Each United Way chapter lists a variety of organizations that may be chosen for payroll deductions, most of which are locally based. Many of the United Way's 1,400 chapters or member organizations also allow individuals to write in the charity of their choice. The 501(c)(3) non-profit status of PRISMS qualifies us for the write-in option. Here's all the information you'll probably need: PRISMS, Inc., PO Box 741914, Dallas, TX 75374-1914, Tax ID: 54-1652029.

To obtain a write-in campaign in your workplace, contact your company's United Way chairperson or your local United Way agency (http://www.unitedway.org/) to ask if there is a write-in or designation option. Most co-workers are eager to donate to a cause that is personally tied to a colleague. Posting a public letter or a poster asking your fellow employees to join you in our fight against SMS might be one way to reach all the employees and increase our funding. For more information contact our Fundraising Chair, Mike Singleton, mjsingleton@hdni.cc, (541) 473-2610 or the PRISMS office, info@prisms.org, (972) 231-0035.

PRISMS is once again raising funds by selling the 2004 Entertainment® books! Even though this is a 2004 book, the coupons are valid immediately and do not expire until 11/1/04. The Entertainment® book is available for 150 cities throughout the United States and Canada. The coupon books are packed with Buy-One-Get-One-Free and 50% off discounts on restaurants, theatres, video rentals, dry cleaners, sporting events, and more. The savings also continue nationwide with great offers like 50% off hotels and discounts on airlines and car rentals.

The easiest way to preview and purchase your own local book is to visit www.entertainment.com/support/ and enter the PRISMS Group Account Number (742332). PRISMS will automatically receive 20% profit of each book purchased. Please consider sending an email to your friends and family or purchasing 10+ books to sell in your neighborhood. For more information contact Michele Zdanowski, jzdanowski@comcast.net, or the PRISMS office.

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A Message from the NEW PRISMS President...

Randy Beall

After serving as PRISMS President for nearly 3 years, Connie Bessette has announced her resignation due to increased time constraints both professionally and personally. The good news is she has agreed to remain an active board member as Immediate Past President/Board Consultant. We want to express our heartfelt gratitude to Connie for her leadership, energy and dedication to PRISMS during the past 3 years. Behind many of our board members is a supportive and sometimes very involved spouse. Connie's situation is no different. Connie's husband, Marvin Armstrong, has also been very involved with PRISMS programs and activities over the years. Connie and Marvin – THANK YOU for your huge contribution!!

PRISMS now has a "new home" in Dallas, Texas. The transition plan from our NH office to the new TX office has been completed and PRISMS now has a new address, phone number and email which you will find throughout this newsletter.

In case you missed it, last year's SMS Conference was held in Westminster, CO (a Denver suburb). It was a wonderful time to visit with other SMS families and learn from the experts. Plus the views of the mountains were stunning. We are in the initial stages of planning our next PRISMS conference to be held during the spring of 2005 - exact dates and location to be determined at a later date. Please start saving now and plan to attend.

In the coming months, we plan to launch a new and improved PRISMS website at http://www.prisms.org. It's our hope that this new site address or URL will be easier to communicate to professionals, family and friends and easier to remember too! In addition to a new address, our new site will have additional features such as a site search function, easier site navigation, a frequently asked questions section (FAQ) and hopefully, instant language translation into several different languages.

Inaugural SMS Experience

Camp Breakaway, Australia

February 2003

By Kate Tye & Karen Ollerenshaw

David Bates (father to Paige, age 4, with SMS) first approached Camp Breakaway located north of Sydney to organize a camp for SMS families. They said it would be possible if he could get at least 6 families together. With a lot of hard work by David and the Camp Breakaway staff/volunteers, over 20 families attended the first Camp Breakaway event. Although the camp was initially organized for respite and family networking, it seemed like a unique opportunity to also get some input from some SMS experienced professionals. In July, 2002, the Goswell, Ollerenshaw & Tye families attended the 3rd International SMS conference in Denver, and came back eager to share their experiences with other Australian families. Following the invaluable input from the professionals at the International Conference, Rob and Kim Goswell were instrumental in initiating the attendance of professionals from the National Institutes of Health in Bethesda, Maryland.

Ann Smith takes a saliva collection from Emma-Rae Tye to check her melatonin level. Several members of the National Institutes of Health (NIH) SMS Research Team traveled to Australia to take part in the first SMS conference and camp.

Australian professionals - Dr. David Dosseter, Dr. Meredith Wilson & Professor Trevor Parmenter (later labelled the SMART – Smith Magenis Australia Research Team) and their teams seized the opportunity to hold the 1st Australian SMS conference (which was attended by 70 professionals). So, in just a few short months and lots of hard work from a lot of people, the conference was arranged, the camp was organized and the American NIH Research team packed their bags (and boxes of equipment) to come downunder!

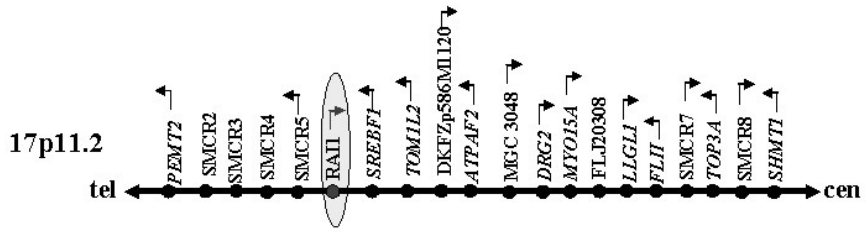
So at last February arrived and we were privileged to have Dr. Ann Smith, Dr. Wally Duncan (a sleep research specialist) and Beth Solomon (a speech and language therapist). Camp Breakaway was attended by 21 families from all around Australia who came together for the 1st time for respite and networking. 17 families agreed to participate in the SMS natural history study. Ann, Wally, Beth and lots of children and families had a really busy 3 days collecting spit, blood, data, information from actiwatches (from those children who would tolerate wearing them!), measurements and speech assessments.

The parents (between Dr appointments) attended social functions, massages, coffee, golf chipping camps, hair and beauty (& champagne) afternoons. The needs of the whole family were considered. The siblings were looked after with a fabulous programme of activities. They had an absolute ball doing crafts, playing tennis, on the slip and slide, possum spotting, Karaoke and even boomerang throwing! The care and attention given to our SMS children was second to none! They had full time 1:1 caretakers who provided not only medical care, loads of TLC and lots of fun activities 24 hours a day. They enjoyed visits from animal farms, and Captain Starlight and friends and many daytime activities but best of all during the wee small hours of the morning in the SMS sleeping quarters there were games of cards, videos and always someone to talk to/question/quiz all night long just what all SMS children and families should have all the time!! The parents also took the opportunity to form an Australian Support Group to replicate the warmth & support felt in Denver. Camp Breakaway is the most professional organization driven by love and has inspired us to push on as we network and grow together.

Sometimes You Have to Remove the Blinders to Clearly See

By Sarah H. Elsea, PhD, FACMG
Associate Professor, Michigan State University
East Lansing, MI

My interest in SMS began in 1994 when I decided to do a postdoctoral fellowship at Baylor College of Medicine with Dr. Pragna Patel. Dr. Patel had been working on SMS and mapping of genes on chromosome 17 for several years, and I found the disorder and the project very interesting and challenging. I received a fellowship from the National Institutes of Health (NIH) to work on gene mapping and 17p11.2 deletion analysis during my tenure at Baylor. I then took a faculty position at Michigan State University in 1998 and continued to work on SMS in my own laboratory. In 2001, I received another grant from NIH to continue this work on deletion analysis and gene characterization for SMS.



The SMS critical region on chromosome 17p11.2. This illustration represents the SMS critical region and all of the known genes that lie within this interval. This is the common, overlapping region of the chromosome that is missing in all persons with SMS due to 17p11.2 deletions. *RAI1* is circled. New FISH probes have been developed to encompass *RAI1* for the most accurate diagnosis of deletions involving 17p11.2.

Research in my laboratory has focused on identifying the genes commonly deleted in persons with Smith-Magenis syndrome toward understanding the role these genes may play in the disorder. At the outset, we did not know whether SMS was caused primarily by a single gene or if several genes were necessary to develop SMS symptoms. We accomplished our genetic studies through a variety of processes, including evaluation of as many 17p11.2 deletions as possible. Our work narrowed the "critical region" to ~950 kilobases, (almost a million bits of genetic information called base pairs), encompassing ~25 genes. This means that all persons with SMS who have 17p11.2 deletions are missing at least these 25 genes on one of their two number 17 chromosomes.

While narrowing the region of the chromosome that is most important for the features of SMS, we were also interested in evaluating any potential role(s) these 25 candidate genes played toward the development of SMS symptoms. In our evaluation of 17p11.2 deletions, Elwyn genetic counselor, Brenda Finucane, told us about three individuals who had features of SMS, but in whom thorough FISH analysis was negative for any deletions involving 17p11.2 (see accompanying article). So, once we were convinced these patients did not have any FISH-detectable deletions on 17p11.2, we decided to screen

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their DNA samples for mutations (tiny changes in the base pair code) in single genes from within the SMS critical region. This was a long shot and not something many other researchers in genetics would actually do when studying a syndrome as complicated as SMS, but we thought perhaps these individuals carried very small deletions that FISH could not detect. Sequencing these genes was a tedious process, and we received some criticism for taking this approach. We thoroughly screened 3 different genes, known as *RASD1*, *DRG2*, and *RAI1,* in each of these three patients. No mutations were identified in either *DRG2* or *RASD1*. However, the third gene we screened, *RAI1* (*retinoic acid induced 1*), was found to be mutated in all three DNA samples. We discovered that each person carried a single mutation on one copy of *RAI1*. Thus, these individuals have one normal (not mutated) copy of the *RAI1* gene and one mutated copy. Each of the mutations identified was a very small deletion that was not detectable by FISH. In fact, rather than missing almost a million base pairs of genetic information as in other people with SMS, two of these individuals were only missing a single base pair within *RAI1*, while the third person was deleted for 29 base pairs; yet all three showed most of the physical and behavioral features of SMS!

In all three cases, the mutations ultimately stopped the *RAI1* gene on one of their two number 17 chromosomes from producing any normal protein. The other chromosome 17 did not apparently carry any mutations in *RAI1*. None of the mutations identified in the three Elwyn patients was found in their parents. Thus, the mutations identified in *RAI1* were new in the child and not inherited. While all three individuals evaluated had most of the key symptoms of SMS, none had heart, kidney, or urinary tract abnormalities, so we feel that another gene(s) in the critical region is likely responsible for these and possibly other variable features associated with SMS.

We feel confident that the reduced function of *RAI1* is the primary cause of Smith-Magenis syndrome. This is an exciting discovery which will help to focus our research efforts. Why does mutation of this gene (*RAI1*) cause the features of SMS? Unfortunately, we do not yet know the answer to this question. Studies in my lab over the next several years will focus on this gene in more detail in order to determine its function and to determine why two copies of this gene are needed for normal development and behavior. I hope we will have an answer within the next two to three years once we have evaluated the animal (mouse) models we are in the process of creating at this time. Ultimately, what we learn about the *RAI1* gene and its impact on development may translate into better ways of treating SMS symptoms.

We would never have found mutations in this gene if it weren't for the persistence and support of Brenda Finucane and the parents of these patients, as well as a belief in the clinical findings and their association with Smith-Magenis syndrome. Sometimes you have to remove the blinders from your eyes and look at things a little differently to really see what's there.

SMS Garden Tour Benefit

By Laura Paladini

Within the first twenty minutes of the last SMS Conference my father started his "mission".

It was one thing to see his granddaughter in all her "glory" and somehow not really understanding the totality of it all but when he saw all of the children at the conference and all of their families there was no more denial. It seemed as if there was validation that there truly was a Smith-Magenis Syndrome.

If I may digress to twenty minutes earlier, my father began the conference his typical charming self. After meeting the first family he maintained his charm. After the third and fourth family and the third and fourth SMS child he began his process of first compassion, then sadness then "what can I do to help these children and families." He sat quietly for the first fifteen minutes of the PRISMS President's words. Then I started hearing him clearing his throat then as discretely as he possibly could wiped his eyes. Moments later he turned to me and said, "I could put information on my sauce labels." A couple moments later he had completely organized a "Garden Tour " for the public and a "Cocktail Party" for the medical field to try and educate people on the syndrome and create funds for where they may be needed.

It was a monumental experience to go to the last conference with my father and the journey since we have returned has been the quintessential representation of what family and support truly means.

It didn't take long before he was redesigning the labels on his sauce jars and then putting the new labels on the jars going into production. One day quietly my father confessed that "the sauce line now has purpose".

The Paladini's Japanese Garden
"Smith-Magenis Syndrome's own little paradise"
in San Mateo, CA

Step two the "Garden Tour". A little insight on the "the garden". My parents have the largest, most authentic, privately owned, Japanese garden in the United States, a National Historical Site. Henry Pike Bowie built the garden in the 1890's with the help of John McLaren who employed the same designer that built the Japanese gardens in Golden Gate Park. To sum up the garden...it's spectacular. My father and mother were joined by Charlene Liao, who is a PRISMS board member and mother of Connie, a 9 year old SMS child. Charlene helped with all of the proper processes of fund-

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raising for PRISMS and helped coordinate her friends, family and church members to come and support the tour and some to volunteer.

My mom has been committed to this garden for sixteen years and knows every leaf on every plant and every fish has it's own name! She was absolutely ready to show it's magnificence to benefit her granddaughter and other people with SMS.

With dedicated focus on making this event successful, both monetarily and educationally, they worked relentlessly on organization, publicity and beautification of the garden for months. My sister, Diana, baked and baked and baked cookies, along with my mom and several other volunteers.

The first day of the Garden Tour was here...and so was the rain. Amazingly, it didn't stop the people from coming, my mom and sister from conducting the tours or slow down my father's "mission".

My sister Gina, who lives in New Zealand, called to get updates daily on the tour and posted the progress on the SMS listserv.

Randy Beall, Mike Singleton and Mikes' brother, Bob Singleton, who professionally works in the audio/visual field, created an extremely emotional and educational video for the fund-raiser. It ran non-stop all three days while people watched, asked questions and some...cried. As I was speaking to a gentleman, a physician who had never heard of the syndrome, his wife was watching the video. As she turned around she was crying and said, "this is Ryan".

To say the "Garden Tour" was a success to me, is an understatement. Proudly we made over $11,560 ($4,840 coming directly from my parents friends). Over 400 people came to this event, watched the video and learned about Smith-Magenis Syndrome. For me, watching family and friends come together tirelessly with dedication, support and love to do good for people they know and don't know is a successful "mission" started and guided by an extremely loving grandfather. The garden looked beautiful but more than anything the beauty truly came from all the love that made this a success.

Paladini Quality Seafood Sauces are distributed through-out most parts of the United States. For more information on their wonderful sauces, please see their website: http://www.apaladini.com

Our special thanks goes to Achille "Kiki" and Joan Paladini and their entire family for this monumental undertaking.

(Left to Right) Samantha Brown 10/SMS, her grandmother Joan Paladini, grandfather Achille "Kiki" Paladini and brother Maxwell.

The Long Road to Diagnosis, by Way of a Needle in a Haystack

By - Brenda Finucane, M.S., C.G.C.
Director, Genetic Services
Elwyn, Inc., Elwyn, PA

I've been a genetic counselor for a long time. Some days it boggles my mind that I've been sitting at this desk, day after day, working for the same organization, for almost two decades. One of the most satisfying aspects of having worked here for so long is that I've been able to establish long-term relationships with many families. I've watched young children blossom from early intervention to school programs to vocational training to adulthood. Sometimes, as in the recent discovery of *RAI1* gene mutations in three Elwyn students with Smith-Magenis syndrome, I also experience the satisfaction of watching laboratory technology catch up to real life.

Brenda Finucane with Scott, "who waited many years for a diagnosis".

Elwyn is a large, nonprofit agency which provides a variety of day and residential services for children and adults with developmental disabilities. We serve thousands of people who present challenging behaviors and learning styles, most of whom do not have SMS. Our teachers, therapists, and counselors have "seen it all", from attention-seeking behavior to self-injury to sleep disturbance, not only in people with SMS but in those with other conditions as well. Since the early 1990s, we have identified 30 individuals with SMS within our various programs, and our staff is particularly familiar with the behavioral and physical features of this condition. In addition to a characteristic "look", there are three unusual behaviors which, in our experience, distinguish SMS from other types of developmental disabilities. These include onychotillomania (pulling out finger- and toenails), polyembolokoilamania (inserting foreign objects into body orifices), and the "self-hugging" or hand-squeezing behavior that most people with SMS show when they are excited. While many people with SMS exhibit one or more of these three key symptoms at some point during their lives, these behaviors only rarely occur among people without SMS.

Although we've become very skilled at accurately recognizing SMS in our Elwyn population, we've encountered a few people over the years who seemed to defy diagnosis. These individuals showed the three key behaviors and many other signs of SMS, but to our surprise, they consistently tested negative for the deletion. Each time a new breakthrough was made in diagnosis (e.g. narrowing of the critical region, improvements in the accuracy of FISH testing, etc.), I would contact their families to see whether they wanted to pursue additional studies on a research basis. Three people in particular had been studied extensively over many years, and as one result after another turned out negative, even I (stubborn though I am) began to question whether or not they really had SMS. In the end, though, persistence paid off! It was with great satisfaction that I was able to contact these families recently to let them know that we finally had an answer: all three were found by Dr. Sarah Elsea's group at Michigan State University to have mutations within the *RAI1* gene. (See Dr. Elsea's article on page 4.) The SMS diagnosis was finally confirmed, thanks to the dedicated efforts of the MSU lab, as they narrowed their search from among a million possible "base pairs" (pieces of genetic code) to find an abnormality. They literally found a needle in the SMS haystack!

For these three individuals and their families, the finding of *RAI1* gene mutations simply confirmed what we had suspected all along, that they do have SMS. In that sense, the news was anti-climactic. However, the finding did bring a sense of closure, giving families solid reassurance about the low genetic risk to future generations, as well as the comfort of knowing that these mutations were not caused by anything the parents did or failed to do. The SMS diagnosis now allows their doctors and therapists to access specific healthcare guidelines and information about the condition. These families can also be rightfully proud of their major contribution to SMS knowledge through their willingness to participate in research. Most importantly, as future breakthroughs are made in our understanding and treatment of SMS symptoms, all three of these newly-diagnosed individuals will be right in line to benefit.

3D Photography
Technology Helping Science

3D photograph of Kelsey Osborn.
Kelsey was diagnosed with SMS in 1998.
Photo taken at the 2002 SMS Conference.

Professor Peter Hammond attended the PRISMS meeting in Denver in July 2002 and brought with him a 3D photographic face scanner developed by 3dMD Ltd, a company based in Middlesex, England. Professor Hammond is the head of the Biomedical Infomatics Unit at Eastman Dental Institute (University College London) and has a special interest in the development and growth of the face. Over the past two years, his group has collected over a thousand 3D face images including children as young as 2 weeks and adults over 80 years old.

While at Denver he took 3D photographs of children and adults with SMS and about the same number of family members. The 3D images of the face surface contain as many as 10,000 points, as can be seen in the large picture of one of the children. Tim Hutton, a member of the Eastman team, has developed computer software that calculates the average of a collection of faces as well as the major ways in which each face differs from the average.

Peter and Tim have been working closely with Ann Smith and Dr. Judith Allanson in analyzing the images. The questions they are addressing include the following: when and how do faces of children with and without SMS differ; can computer models of 3D facial growth assist in the training and practice of clinical geneticists; are there significant differences in facial growth between girls and boys with SMS; can detailed analysis of 3D face shape contribute to research into how clinical features of SMS are influenced by individual genes? Their findings will be reported in a future edition of the newsletter. In the meantime, Professor Hammond wishes to thank everyone who volunteered to have their face captured in 3D. All volunteers should have received CDs with their 3D images by now. He is currently trying to raise funds to buy a mobile scanner outright so that the data collection in SMS and other syndromes can continue.

GREAT LAKES REGION SMS GOLF OUTING

By Kellie Cooney

At the 2002 SMS conference in Colorado, a few parents got together to discuss the possibility of doing a golf outing. We wanted to 1) Raise awareness for SMS, 2) Have fun with other SMS supporters and 3) Raise money to help PRISMS.

On June 21st, 2003, Julie and Linn Van Nest and John and Kellie Cooney, SMS parents, co-hosted this golf outing. It was a sunny day, about 82 degrees without a cloud in the blue sky. There were 151 guests for golfing, dining and auctioning fun.

Enjoying a day of golf (l to r): Cathy Hunt, Ann Smith, Lisa Maiher, Jean Pleszko, John Maiher, Joe Maiher, Jim Krainz and Robert Hunt.

Jeremy Maiher (with microphone) helps to make some of the day's announcements. Helping Jeremey are Joe and Jay Maiher, Carlie Marshall and Jennifer Cooney.

Ann Smith and Dr. Sarah Elsea honored us with their presence, making our day even more special. We even had several SMS families from Pennsylvania, Ohio and Michigan join us. Jeremy Maiher, Julia Cooney, Amber Van Nest and Isabelle Hamilton (all SMS children) and Joe, Jennifer, Blythe, Justin and Madison (all their siblings) joined us for the day to help with the festivities. (Boy do our SMS kids like the microphone!)

The day began at 11:00 am for tournament registration and viewing of both live and silent auction items. We had so many auction items; we used some of them to put into our golfers goodie bags!!! The guests could bid on the silent auction items and purchase 50/50 raffle tickets. Outside the clubhouse, was a putting contest.

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At 12:15 the course rules and announcements of our special guests were given. At 12:30 pm there was a shotgun scramble start. To see all those golf carts leave at once brought tears to several of the non-golfers eyes. It is one of the most rewarding feelings seeing people there supporting our children's syndrome. Julie and Kellie said it was one of the best days of their lives.

Immediately following play, at 5:30 everyone came in for the 50/50 drawing, a short welcome from Ann and Sarah and finally a steak dinner. The silent auction closed at 6:30 pm with everyone walking away with some terrifically wonderful deals! The live auction began and we had a lot of fun with our live auctioneer.

The 50/50 raffle resulted in $381, the putting contest resulted in $423 and the silent and live auctions resulted in $4,567 for PRISMS.

We had 3 Tournament Sponsors at $1,000 each. D.R. Ebel Police and Fire Equipment, T.H.E.M. of Ohio and Uncle Steve and Aunt Connie Van Nest.

Golfers take to their carts in anticipation of winning their first Great Lakes Region SMS Golf tournament championship.

We give a heartfelt thank you to Ann Smith and Dr. Ellen Magenis for their discovery and continued research, all the businesses, friends and families who have supported and continue to support the families faced with SMS challenges, Valleywood for being so accommodating with us! (They allowed us to have our SMS children present---meltdowns from Julia and all!!!) Above all else, a special thank you to Jeremy, Zachary, Isabelle, Amber, Julia and all our SMS friends for giving us the drive and the passion to help better your worlds. Thru your eyes we have seen, it is the small things in life that truly matter.

Over all Julie, Kellie, Linn and John accomplished what they set out to do. They raised awareness for SMS with several people who had never heard of the syndrome, they had fun (and challenges) preparing for the outing, running the outing and celebrating afterwards AND they raised money for PRISMS. The Great Lakes Region SMS Golf Outing netted a grand total of $16,519 for PRISMS!

Please look for another golf outing next year in Ohio. We would love anyone to come who can. We had a blast and formed new friendships. We did this for our children and for the success of their lives.

THANKS!

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PARENT TO PARENT

Did you know that PRISMS sponsors a parent to parent program? If you need someone to talk to who REALLY UNDERSTANDS what your life is like, try another parent. You may want to find another parent in your area, or perhaps one who has a child the same age as yours. Tell us what you need. PRISMS keeps a list of parents willing to be contacted. We'll send you addresses and phone numbers and then you can talk all that you want. Here's how, contact:

Mary Beall
414 Birch Lane
Richardson, Texas
Phone: 972-231-0035
mary.beall@comcast.net

Important note:
PRISMS parent to parent program will only give out information on parents who have agreed to be contacted.

PO Box 741914
Dallas, TX 75374-1914

ADDRESS SERVICE REQUESTED