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:**



## Tragedy of September 11, 2001

Our deepest sympathies to the families who have lost loved ones in the tragedies of September 11th. We mourn with you.

While becoming acutely aware of terrorism, there has been a coming together. Children and adults are reaching out to one another and countries are working together.

Yet there remain many who suffer alone, not knowing how to comfort or receive comfort.

Our SMS families are not strangers to hardship. And, we are well acquainted with feelings of isolation. Yet, we are also a community practiced at supporting one another.

Our words of understanding and encouragement have no language barriers and extend across oceans. We are a community with so much to share. Let us be the trail blazers for others.

## SMS Research Registry & Core Tissue Bank

**By Ann CM Smith, M.A., D.Sc. (hon)**

Since its establishment, the NIH SMS Research Registry & Core Tissue Bank has become indispensable in the collaborative research to study the many genes mapped to the SMS critical region as researchers seek to identify the gene(s) causing the syndrome.

The SMS Research Registry serves as a confidential database of individuals diagnosed with SMS to facilitate researchers initiative and promote the development of improved treatments for SMS.

The SMS Core Tissue Bank collects blood and/or tissue samples from persons diagnosed with SMS for ongoing research to understand the genetic basis of SMS. The SMS Core Tissue Bank coordinates the collection, storage and distribution of DNA and tissue samples for research to all researchers in a fair and equitable manner. A coding system is used for samples to protect the identity of participants to outside researchers.

Participation in SMS Research Registry and Core Tissue Bank is voluntary and does not require travel to NIH, thereby permitting SMS families from around the world to participate in ongoing research to understand SMS.

**For more information please contact:**

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# PRISMS Board Members Attend People's Genome Celebration

***By Connie Bessette, PRISMS President***

It was an exciting weekend in June as many gathered to celebrate the mapping of the human genome. It was a different kind of "melting pot" as all of the "stakeholders—individuals with genetic conditions, families, and representatives from government, healthcare, research, industry, media and the public" came together for the first time to discuss the critical issues in genetics.

PRISMS was one of 37 exhibitors at the Hyatt Regency Washington on Capitol Hill. It was great to learn about services and resources for our members and talk with other genetic group representatives.

The high point of the weekend was a "Gala" at the Smithsonian, National Museum of Natural History on Saturday evening. Our SMS children were the stars as their pictures were part of the art exhibit and slide show. During the month of April parents of : Grace Scully, Jessica Gomez, Neil Patrick Gonda and Deirdre Miller traveled to New York city for a professional photo shoot with Rick Guidotti. The exhibit entitled "Positive Exposure: The Spirit of Difference" is an international campaign to raise awareness of genetic conditions. Through his photographs and spirited attitude Mr. Guidotti punctuates the beauty in all those with genetic disorders and he erases the line that often divides those with disorders from those without.

Among the mix and celebration were presentations by world scientific leaders Sir John Sulston, the UK's Wellcome Trust and Francis Collins, MD, Ph.D. of NIH.

We were proud to represent PRISMS for a weekend of celebrating, sharing and education!

## Board Meeting Update

In between workshops, touring of exhibits, stimulating presentations, and dialogue with others of similar groups, PRISMS board members met to discuss the business and functioning of PRISMS. Conference planning was a major topic. There was also discussion of utilizing the PRISMS website to announce events, information, and happenings that are of interest to SMS families. Plans are underway to prepare a booklet of "educational strategies" for SMS children. There was also discussion of our continued strong need to raise awareness; hence making available additional brochures to hand out to professionals and others who provide care and service to an SMS person. And finally the board discussed the importance of research and PRISMS budgeting a small percentage to support SMS research.

# Attention



**SMS FAMILIES, FRIENDS & PROFESSIONALS:**

**The 3rd International Smith-Magenis Conference Update**

Put on your cowboy boots, pack up your wagon train and load up the horses, "cuz" we're headed to the wild, wild, west, pardners! The planning for the next SMS Conference has begun and a site and the dates have been chosen. We will share more information about the conference with our members, as the planning develops. So look for further details in future newsletters and also on the website, (www.smithmagenis.org).

- When: Thursday Morning, July 04, 2002 – Sunday, July 07, 2002 Midday
- Where: The Westin, Westminster, CO
- Theme: A Rip-roarin', rootin-tootin', family fun time mixed with science, sharing and solutions.

Since this conference occurs during a holiday and in the middle of summer vacations, we will be incorporating more family fellowship time into this conference. From the surveys gathered at our last conference, families expressed the desire to have more sharing time and "fun" time structured into the planning of our next conference. We hope this will be a conference where the entire family can attend and enjoy all the amenities that this area has to offer while making new friends with other SMS families. Research updates, medical information, workshops, educational strategies, and other vital SMS information will of course be presented as well. We hope to balance the science with the sack races!! We encourage all families and professionals to attend, even if you have attended the past conferences. The Rocky Mountains will provide a scenic and memorable backdrop for this particular conference.

The Westin is located in the town of Westminster, CO, which is thirteen miles from downtown Denver, and twenty-five miles from Denver International Airport. It is a new hotel, offering many in-house amenities, as well as local attractions. (http://www.westin.com) Some of the local attractions are:

- 45 miles of trails for hiking, biking, etc.
- Westminster Promenade (adjacent to the hotel) Restaurants, shopping, entertainment
- Butterfly Pavilion Insect Center (adjacent to the hotel)
- AMC 24 Movie Theatre (adjacent to the hotel)
- Sun Microsystems Ice Center (adjacent to the hotel)
- Legacy Ridge Golf Course (1 mile from the hotel)
- The Denver Zoo (25 minutes from the hotel)
- Sports Arenas (Colorado Rockies, MLB, 20 minutes from the hotel)
- White Water Rafting
- Hot Air Balloon Rides (30 minutes from the hotel)
- Horseback Riding (15 minutes from the hotel)

Besides all these wonderful attractions, PRISMS hopes to provide an educational format as well as a relaxing and supportive atmosphere where families can share, learn, and have fun! We can all look for our silver lining in the sunsets of the Colorado Rockies. So, brush off your boots and start practicing your "Howdy!"

*Reservations can be made by calling the Westin Hotel at 1-800-Westin-1. Advise them that your reservation is for PRISMS or the Smith-Magenis conference. The rate is $89.00 per night and has been secured for July 3rd through July 7th, 2002. We are hoping to have this rate available for early arrivals but this has yet to be confirmed. Please check with the PRISMS office or watch for upcoming conference mailings.*

# Meet One of Our Kids....Taryn Favaro

## Sugar and Spice and Everything?

By Tammy Favaro, Elk WA

Ever since Taryn was a baby, strangers have stopped us to say how beautiful she is. Her curly blonde hair and thick black eyelashes caught everyone's eye. Now at nine years old she not only still captures attention but hearts as well.

Taryn is a sweet and loving little girl who at times can shift from Dr. Jekyll to Ms. Hyde, which keeps us on our toes, and occasionally shaking in our shoes.

In Taryn's case those are short little shoes, somewhat squarish, just like the Fred Flintstone feet that occupy them. Taryn prefers bare feet to the confines of shoes, and at times also views clothing as optional!

Taryn is an outdoor kid. She loves to ride her bike, dig in the dirt, and because nothing scares her, has a fondness for bugs. Yes, bugs. Anything creepy and crawly that hides under rocks is a great find to her. Great to Taryn, unfortunate for the bugs.

Mainstreamed into third grade with the support of a developmental learning center, Taryn does very well in school. I love to sit and listen to her read. It is one of the few things that seems to come easy to Taryn, and she enjoys it very much.

Quick witted and always good for a funny one-liner, Taryn is quite the comedian. She has a great sense of humor and even when she was very, very young she could appreciate a joke. Once in a while she'll cross over to a hint of sarcasm…but knowing that she has my genes, I chalk it up to hereditary comic genius!

Although there are many bouts of sibling rivalry, Taryn gets along with her brother and sisters fairly well. Tyler, 10, Kristen, 7 and Kassidy 3 all love their "Sissy" too.

Life at our house is interesting to say the least. On a good day we can attempt a family outing…on a bad day we stay home and fight over the last two Excedrin at the bottom of the bottle.

Taryn teaches us something every day and I am proud to be her mom. That's not to say that there aren't those days when I tie a knot at the end of my rope and hang on for dear life…but when I stop and think about the last nine years the things that come to mind first are the good times. I cannot remember my life before Taryn and I am not sure it matters that I ever do. What we have now isn't always perfect, but what is? Imperfections can be assets and in that respect our entire household is doing great!

*If you are interested in writing a brief story highlighting your SMS family member, please send your story along with a photo to: Tracie L. Belcher, Spectrum Editor – PO Box 84, Griffithsville, WV 25521*

# Recommendations for Medical Testing

By Lorraine Potocki, M.D. and James R. Lupski, M.D., Ph.D

*Due to many inquiries by our members regarding additional medical tests which may be needed for their child after receiving the diagnosis of Smith-Magenis syndrome, we have reprinted this excerpt from the material presented by at the 2nd International Smith-Magenis Conference. As with any medical issue regarding your child, you should consult your child's doctor to discuss their individual medical needs.*

Just as there are common physical features and behavioral features in individuals with SMS, so there are medical concerns that are more common in this patient population.

1. All patients with SMS have developmental delay and cognitive impairment. Thus, even the newborn child should be referred for Early Childhood Intervention. Specialized education should probably continue into adulthood and definitely should continue throughout school age.

2. The majority of persons with SMS have abnormalities on eye examination such as strabismus (crossed eyes), and the need for corrective lenses. Other findings common to SMS such as small corneas do not impact on vision. Persons with SMS should be followed by an ophthalmologist (M.D.) for assessment and possible intervention.

3. Recurrent ear infections and hearing impairment are very common in SMS and therefore should be expected and assessed on a regular basis. Most SMS patients have seen an otolaryngologist (ENT physician) for "tubes" and related treatments. If hearing impairment is significant, hearing aids could be considered.

4. Speech delay is usually present (with or without hearing impairment) and complicated by oral-motor difficulties such as poor tongue movement, poor chewing and difficulty swallowing. Oro-motor therapy and speech therapy are essential for the infant and young child with SMS and often needs to be continued throughout the school years. Sign language and other methods of non-verbal communication should be offered to augment communication skills and thus decrease frustration in this expressive population!

5. While less than 50% of persons with SMS have heart defects or abnormalities of other organs (such as the kidney or urinary tract) clinical evaluations (by a cardiologist) and/or diagnostic imaging (echocardiogram, renal ultrasound) are recommended for SMS patients to properly evaluate these areas.

6. Children and adults with SMS can develop curvature of the spine. An X-ray of the spine (scoliosis survey) can detect this finding.

7. Persons with SMS can have a low-active thyroid gland, and therefore a yearly thyroid profile (blood test) is recommended.

8. A recently described medical concern is high cholesterol levels, which can be present even in children. Since this finding can go undetected, a yearly lipid profile is recommended. Referral for dietary or other treatment would depend on the level of cholesterol and triglycerides in the blood.

It is important that parents and health care providers also remember that the diagnosis of SMS does not protect against other illnesses and therefore common sense and clinical acumen should prevail in the medical management of a person who has SMS.

# 2nd Annual SMS Golf Tournament

Once again generous and energetic adults appeared on July 31st for the second annual SMS golf tournament at Tory Pines resort in a corner of the village of Francestown, N.H. where the population is about 1000.

Some came for the golf; some came for social reasons. Yet everyone came together for our children with Smith-Magenis Syndrome.

The 2001 tournament was different in many ways. Unlike last year there was no rain; in fact there was not a cloud in the sky and the temperature hovered in the high 70s --what players refer to as "perfect golfing weather."

The day began with registration, viewing of silent auction items, and snacking on delicious passtries that were baked by Maria Sklavounas who is the mother of 20 year old Demitra who has SMS.

With full bellies golfers headed out for 18 holes of golf and volunteers went to their stations. Upon arriving at the 16th tee/casino hole, golfers were warmly greeted by four volunteers: Joe and Michelle Zdanowski, parents of Krista; and Bill and Jeri Gawlowski, uncle and aunt of Krista. They had traveled from Michigan to give a hand; bringing with them their high energy and enthusiasm.

As golfers rolled their carts up to tees and greens they were treated to a SMS factoid, all single line informational statements that accompanied hole sponsor signs. Thanks to Ann Smith, Maggie Miller and Patrick McDonald for their last minute creative thinking and labor!

No one had a hole in one again this year; however everyone got to visit with the 2002 Saab donated by Saab Nashua North –NH. A special thanks to Janice Lamatina who is quite fond of one SMS person.

Sitting on the deck prepared to witness the hole in one were Maria Sklavounos, Mary Ann and Paul Duzan, parents of Sara, Jonathan Kelly with companion Donna Flannagan Sousa, and Janet Richards with daughter Molly.

A pretty competitive putting competition was supervised by David Duzan who is Sara's brother.

After the golfing everyone gathered under the tent for silent auction, raffle and a barbecue. There were over 100 prizes and once again PRISMS realized a substantial profit. Connie Bessette and Jonathan Kelly welcomed the group. Ann Smith shared a bit of science with the group as she explained the link and excitement between the Mapping of the Human Genome and deletion 17p.11.2, our SMS diagnosis. Competition winners, raffle and silent auction winners were announced by Marvin Armstrong, who was assisted by Jonathan Kelly.

A different twist this year was a plea to assist PRISMS in raising awareness of our "vastly under-diagnosed" syndrome. Everyone was handed a SMS brochure with a request that they pass it on to a professional, perhaps a teacher, doctor or therapist. This idea was well received as many asked for additional brochures with a plan of distribution to more than one person.

And finally, another reason for celebrating. This tournament exceeded last years profits by $3,000.00, netting PRISMS $13,000. 00.

In closing I want to thank everyone who attended, volunteered and those who provided the always needed "moral support." Again this year I was overwhelmed with the generosity of everyone, the tireless helping, and the camaraderie that made this event the success that it was.

I know I have not recognized every generous person because I would run out of space. So, I invite you all to visit our website, www.smithmagenis.org for a complete list of participants, donors, volunteers and others who assisted.

A heartfelt THANK YOU to all who participated in the Second Annual SMS Golf Tournament.

## Volunteers Needed!

Volunteers are needed for all types of tasks. As we gear up for our 3rd International Smith-Magenis conference, we will need some of our many members to help us get ready. No major time or commitment is required. If you have a little time to spare, contact PRISMS to discuss your interests.

**Check Us Out on the Web**
**Visit our website at www.smithmagenis.org**

# Miracles In Education

By Leanne VanDover and Christina Miller

***PRISMS is pleased to have an opportunity to publish an article regarding an educational approach to teaching children diagnosed with Smith-Magenis Syndrome. In a continuing series of articles, Christina Miller and Leanne VanDover will provide us with insights and applications into the educational approach of Leanne's daughter Evin. In this issue of Spectrum we would like to introduce you to our authors and a very wonderful young lady named Evin VanDover. Please see our next issue of Spectrum for part 2 in this series.***

**Meet Leanne and Evin VanDover**

My name is Leanne VanDover and I have a degree in special education, but more importantly I have a daughter who has Smith-Magenis Syndrome.

I received my degree before my daughter was born, so that I could help kids who had learning disabilities to become successful in school. I had a passion to do this because I myself struggled through school with a learning disability and received a great amount of mistreatment from teachers and students. Therefore I write to you with a three-fold experience that has served to greatly help my daughter, Evin age 11, in the education process. It is my hope that what I have learned from being a student, teacher and now parent will also benefit you and your child.

I titled this article "Miracles in Education" because that is exactly what we are experiencing in school with Evin, MIRACLES. Although Evin does have fits at home and in public, she does not have fits at school. This is a direct result of the type of program at Evin's school and the wonderful teacher who implemented it. Evin's learning rate has also increased with this program.

In the future I will share with you the things that I have learned on this journey that greatly benefit Evin and her success. Right now I would like to introduce to you, Christina Miller, the teacher who has brought these miracles about and let her share with you her success with Evin and Smith-Magenis Syndrome.

**Meet Christina Miller**

My name is Christina Miller. I have a BA in Elementary and Special Education from the University of Wyoming, and a M.Ed. in Literacy from Lesley University. I came to Katy, TX with seven years of experience teaching children with emotional and developmental disabilities.

The program I implemented at Evin's school was based on my modification of a structured teaching model where every student has his/her own schedule for the day be it object, picture, or written, as well as a work-job schedule on each desk. The schedules allowed Evin to become very independent in following her daily routine.

Implementing this program allowed me to teach every student in a one-on-one situation every day. In working one-on-one with Evin I was able to explore a variety of techniques to improve her performance. Once I found the correct one for her I implemented it as part of her program, e.g., color coding worksheets, using adapted writing paper, etc.

I am now the lead teacher for the district's Young Children's Autism Program at another building. However, the program I created for Evin remains the same. Evin continues to be very comfortable at school because she knows what to expect and when it is going to happen.

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FACSIMILE

# Growing Up Special

by Kitty Porterfield

It wasn't an accident that I became a communications and public relations chief in a large public school division. The skills I learned growing up as the older sister of a boy with cerebral palsy, and who is mentally retarded, are the skills that I use every day as I work with media and the community, interpreting the world of teaching and learning.

My brother, Johnny, and I were young together a long time ago–before much was known about siblings. My parents thought they had one "normal" kid (me) and one "special needs" kid (Johnny). To their credit, they had a hunch that being part of this particular family made some exceptional demands of me, but no one–I least of all–understood what those demands really were. What my parents knew, they figured out by themselves. There was no one to help them.

In the last 20 years, a good deal of research has been conducted on siblings of children with disabilities and severe illness. What we now know–that my parents did not know then–is that siblings are pretty terrific kids who have some unique opportunities and who face some unique challenges. Research has documented that siblings have some very special and important needs of their own.

Siblings of children with special needs often carry a lot of anger. They are angry because they do not get much attention, because they must wait while their parents take care of their brother or sister, and because they often have significant family responsibilities that their friends don't have.

Siblings live with a lot of grief. They grieve for their brother or sister's loss of ability. They grieve for their parents' loss. They grieve their own loss of a normal sibling relationship.

Siblings have a lot of fear. Could it happen to me? To my children? And a lot of guilt. Their childish imagination makes them think, "Maybe I caused all this trouble by being bad."

Siblings can feel isolated, embarrassed to go into public with their families, and guilty because they are embarrassed. They can feel shame, resentment, and pressure to be good kids and to succeed themselves to fill gaps they perceive in the family. Looking back as adults, siblings often feel that they grew up too fast, that they lost their own childhoods.

Don Meyer, who has studied families with special needs kids and heads up the national Sibling Support Project–and who is himself a sibling–contends that siblings don't need to be "fixed." "They are just fine, thank you!" he says emphatically.

Siblings do need support, however. They need to meet people who share their experiences, including other sibs their age and older sibs. Sibs need to learn that they are not unique or strange or alone. They need to know that there are lots of other people in the world who have lived similar lives. Siblings need to talk out loud about their experiences so that they will not bury their anxieties and carry them, unresolved, into their grown-up lives.

Don Meyer's model of *Sibshops*, workshops where kid siblings meet to play and talk, is now being replicated all over the country. I have participated in a number of *Sibshops*, playing sweaty games, eating messy pizza, and sharing stories about our brothers and sisters. Even for an adult, it is a wonderfully healing adventure.

The good news about siblings is that we have the chance to develop some pretty awesome skills–skills that often influence our whole lives. In our families, we quickly learn to take responsibility, to become leaders, to be part of an effective team, to act in crisis, to develop a bigger view, to teach. (Does all that sound like a communications career to you?) We learn empathy, patience, flexibility, resilience, compassion, tolerance, loyalty, and optimism. We are great problem-solvers. We are independent. And, on most days, we are pretty mature. Not a bad combination.

It is all in the balance. If families are not careful, young siblings learn the good stuff at a very high price. Parents can help make that price reasonable. Here are some suggestions:

1. Spend quality time *alone* with your sibling. That's tough, I know. There are many demands on parents' time. But face time is key. I can describe for you in great detail the happy day, when I was eight, when my parents took me to pick out wallpaper for my room. It was a rare moment for me to be alone with both my mom and dad together, and it is indelibly etched in my mind.

2. Talk to your kid a lot. Talk about feelings–*your* feelings. Let your child know that sometimes you feel sad or angry. Be clear that it is hard for you too to live in a "special" family. By talking about your feelings, you give your child permission to talk about his or her own feelings.

3. Help your sibling understand how terrific he or she is. Be specific about his or her strengths. Name the skills. At the same time, be clear that everyone isn't perfect, and that taking risks and falling on your nose is OK too. Hugs help a lot.

4. Talk about the future. Siblings are terrified about what will happen when they grow up and their parents grow old. Make plans together.

5. Don't be fooled by constant smiles. The tricky thing about siblings is that no matter what we are feeling, most of us become very skillful actors or actresses. We hide the real stuff. Either we become chronically angry, aggressive, or aloof, or we make everyone believe that we are chronically happy and content.

I have had parents tell me, "My kid doesn't have any problems. She just loves her sister and is always there to help. She is very happy."

Whoaaaa, I say. Wait a minute. I'm sure she does love her sister, and she does love to help, but I bet that this young lady is also trying very hard to protect her parents from additional pain by hiding her own sadness. It's part of our sibling constitution.

Also, don't think your sibling is too young to understand what is going on. We are *way* older than you think! We listen a lot and process on our own time. When we don't have good information, we sometimes make up answers that are a lot worse than the reality.

6. Get your sibling to a *Sibshop* or some other place where he or she can meet regularly with kids with sisters or brothers who have special needs. Help your child find some grownups in whom they can confide. Give them a place–away from you–where they can vent and learn and feel respected.

Today, there are lots of resources to help parents learn more about siblings. The Sibling Support Project, based at Children's Hospital in Seattle, Washington, has a web site that is a wonderful place to begin (http://www.seattlechildrens.org/sibsupp/). The site has an extensive bibliography of books, newsletters, videos, and movies; links to other sites and organizations; and a list of regional contacts all across the country. Check it out.

If this were a press conference, as the press officer I would finish up by asking the reporters if they had any questions. So I will ask you the same thing: Any questions? You can reach me on the job at kporterfield@fcps.edu. (I learned to be available for follow-up growing up with Johnny.)

***Kitty Porterfield is the director of communications for Fairfax County Public Schools. She is writing a book about her experience growing up in a family with special needs and occasionally conducts parent workshops on sibling issues. She and her husband live in Alexandria, Virginia. They have three have three grown children..***

## SMS Bulletin Board

**2001-2002 Annual Membership Drive Continues**

Recently, the PRISMS Executive Board voted to start having annual membership dues. If you haven't responded to the 2001-2002 annual membership drive letter, we need to hear from you today!! Your dues will help us continue to provide information and support to families of persons with Smith-Magenis Syndrome (SMS) and to foster partnerships with professionals to increase awareness and understanding of SMS.

Joining PRISMS will get you:

- Connected to other SMS families and professionals
- A subscription to SPECTRUM, the PRISMS newsletter
- A discount at SMS conferences
- Mailings of current SMS news: latest research, fundraising events, regional gatherings and more.
- Referrals for consultations to professionals who understand SMS
- Conference information and access to conference videos

PRISMS is a 501(c)(3), tax-exempt, member supported organization that is run by a volunteer staff. Every dollar helps! Since this will be PRISMS first year of annual membership, donations made this year will be effective through December of 2002. Use the form we recently mailed you, call or email Marsha Bach for another form (630) 416-7589; mmb817@earthlink.net) or signup on the web at http://www.smithmagenis.org/membership.html

**Help PRISMS by designating your United Way gifts**

As you 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, Inc. qualifies us for the write-in option. For more information contact our Treasurer, Randy Beall, rmbeall@home.com, (972) 690-1016 or the PRISMS office, info@smithmagenis.org, (603) 547-8384.

**2nd International Smith-Magenis Conference Videotapes**

Videotapes of the 2nd International Smith-Magenis Conference are still available for purchase from PRISMS. Many of our members have responded to let us know that these tapes have become a great tool in educating their children's teachers, friends and extended family on the many aspects and issues related to raising a child with Smith-Magenis syndrome. If you are interested in purchasing the conference videotapes or need additional information regarding the tapes, please contact Caroline Pope at cpopern@aol.com or by calling (856) 875-7040.

# THANKS!

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## Parent-to-Parent Program

PRISMS receives calls from parents of children newly diagnosed with SMS. Often they ask to talk to parents with SMS children of similar ages. As a link between parents, PRISMS has a Parent-to-Parent Program.

**If you are interested in serving or participating in this program, we require your permission to release your name, address, and telephone number as appropriate requests are received.**

*I am interested in being a resource/contact parent for* ***PRISMS*** *and give my permission to PRISMS to release my name, address and phone number as a contact parent.*

**Name (print):** _____

**Telephone:** _____

**Address:** _____

**Email Address:** _____

***Signature*** _____