

SPECTRUM

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FALL/WINTER 2005

My Conference Experience

by Julia Hetherington

Our 4th International Conference "Building Bridges of Hope" was held on April 29 - May 1, 2005 in Cincinnati, OH. What a success our SMS conference was! A total of 260 parents, researchers, supporters, and children attended the conference, which was held in Cincinnati from April 28 through May 1, 2005.

Although there is no way to express all that was learned at the conference I thought I would pass along what I could. It truly is the nuances that are difficult to express. Like the emotions when Sarah stood and cheered every time Ann Smith's name was mentioned, or Tyler getting to the mike and saying "Mom, I need help", or Kayla standing at the end of the breakfast line asking a zillion questions of everyone. Priceless! There was a liberation by being around people who truly "got it". And not a beat was missed if a child had a melt down.

First, a huge thank you to all who worked so hard to pull this together. It was so professional and well run. Did you know that PRISMS raised \$7,000 with the silent auction? (Thanks Cooneys!). Our board just did an EXCELLENT job on everything.

The keynote speaker, Marcia Philipps, did a wonderful job with opening the conference. She spoke of the death of dreams, dreaming again, the power of vision, and turning points. She articulated hope--the inherent worth of every human being. This theme was continued by the awesome work of photographer Rick Guidotti (www.positiveexposure.org). This web site is well worth exploring...his photographs will make an impact on many people regarding genetic differences. Marilyn and Joe Henn (HennPen@aol.com) taught us that every child can be a productive member of society...you must start early in that transition from school to vocation...don't wait until the school district says it is time.

The Curbside Consultants and Parent Expo both provided information to attendees regarding professional help and "homegrown" ideas. These allowed for individual questions and data gathering.

Concurrent sessions were held on a multitude of topics led by both professionals and parents. Some of the topics included sibling nurturing, behavior management, respite care, wills, to name just a few.

Research continues. For a diagnosis which is rare we have a large amount of research going on. Better than the average rare diagnosis. There is ongoing research with the inverted melatonin rhythm our children have. There are efforts to develop a time released melatonin that can be taken at bedtime but does not actually release until the more needed time (2 am and on). Research continues to narrow in on the genes which cause SMS. Some places are running genetic tests which don't pick up in the RAI1 area. It is important that if a persons SMS screen comes back negative, and the clinical symptoms for SMS are there, that you make sure that the correct genetic probe was used. Peter Hammond is doing some amazing research with 3D facial morphometry. Many of our children have been photographed by Dr. Hammond...he needs younger children too. Australia has a relatively new research team developing under the leadership of Chris Blanchard (a researcher and a parent).

SAVE THE DATE: MAY 10 - MAY 13, 2007
HYATT REGENCY - RESTON, VA

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What Is Smith-Magenis Syndrome?

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.



Questions?

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A Message from PRI SMS President...



Randy Beall

Have you bought your PRISMS silicone band yet? These bands are a dark "hi-viz" pink and were very popular at the Cincinnati PRISMS conference. We have both adult and youth sizes. Please order your bands today from the PRISMS website.

I want to say a special "thank you" to the Van Nest family for hosting this year's OH golf tournament. This event raised \$15,000. Great job guys!! Not only do fundraising events like this raise money they also help to increase the awareness of SMS. Hosting an event is a very rewarding experience and a great way to make a difference! Please contact us if you're interested in hosting a fundraising event such as a walk-a-thon or golf tournament. It's easier than you think to host something...and it's fun!

Don't forget to visit www.prisms.org often. It's loaded with helpful information! We've made the site easier to navigate and added information on how to deal with SMS. We've also created sections for educators and medical professionals. Plus we've added language translation, photos and much more. A number of folks have worked hard to help us create our web site and make our new web site a reality. A special thanks goes out to our developers and content contributors -- Paul Severson, the crew at m3style.com (Duane Ronan, Peteris Bikis and Krisjanis Jukumsons-Jukumnieks), Ann C.M. Smith, D.Sc. (hon.), Wally Duncan, Ph.D., Lynn Campbell, Margaret Miller and others. A huge "thanks" to Brenda Finucane who was instrumental in creating our first site and much of its content. Also, Tony Rocha at CraFTEch Computer Solutions has provided web hosting pro bono for the past several years. They have provided a tremendous service to us all. Eventually the old site -- www.smithmagenis.org -- will be phased out. Please update your favorites. However, for a period of time you'll still be able to use both.

PRISMS depends on volunteers. A few people have generously donated their time and energy to help us over the last few years.

I want to say a special thank you to Tracie Belcher for the tremendous job she has done producing our newsletters. I also want to thank Jen Comford for mailing out new parent packet and Kristen Hamilton for sending out thank you notes and acknowledgements to PRISMS donors.

Our new volunteers are Joe and Michele Zdanowski. Welcome!

SMS Awareness Bracelets Order Yours Today!

These “hi-viz” pink silicone bands are a great way to build awareness about SMS. Bands are available in adult and youth sizes on the prisms.org website.

12 bands	\$25.00
24 bands	\$45.00
36 bands	\$60.00
48 bands	\$75.00

*Please note that singles were only available at the conference.
All prices are US Dollar and do not include \$4 shipping fee.

Please contact Michele and Joe Zdanowski, jzdanowski@comcast.net , 248-437-7251 for bracelets.



Entertainment Books are Now Available

SMS is once again raising funds by selling Entertainment® books! In 2004, we raised over \$500 for our kids by selling these great books. Even though this is a 2006 book, the coupons are valid immediately and do not expire until 11/1/06.

We failed to mention in a past last communication that that if you would like to purchase 5 or more books (perhaps to sell at your office or school), you can contact Michele Zdanowski directly for free shipping and handling.

If you have questions please contact Michele Zdanowski, SMS Parent and PRISMS Fundraising Volunteer, jzdanowski@comcast.net, (248) 437-7251

P.S. Remember, Entertainment® books make great gift items! The price of the book varies by city ranging from \$20 - \$45 (average \$25). The coupon book can pay for itself after only 1 or 2 uses!! Please consider sending this email onto your family and friends. Again, the easiest way to preview and purchase your own local book is to go to www.entertainment.com/support/ and enter the PRISMS Group Account Number (742332).



GREAT LAKES REGION SMS TOURNAMENT

The 2005 PRISMS Great Lakes Golf Outing – Another Success Year!

by Julie Van Nest

The Van Nest family would like to extend a huge THANK YOU to each of you that participated in, donated and supported the 2005 PRISMS Great Lakes Region Smith-Magenis Syndrome Golf Outing!

This event was held June 25, 2005 in Swanton, OH (Toledo area). We had a great day with 100 golfers participating and 60 banquet guests. Not only did we raise money fund PRISMS we generated a tremendous amount of awareness about SMS. The best part about the day was sharing the excitement with all of the SMS families that attended!! We hope you will consider joining us again next year.....please mark your calendars for June 26, 2006.

A listing of the contributors appears in this edition of *Spectrum* and the list was also published in our local newspaper.

We send friends, families and extended SMS families blessings as we have been so greatly blessed also!



DONATIONS

APRIL—NOVEMBER 2005

GREAT LAKES REGION SMS GOLF TOURNAMENT SUPPORTERS

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Xcelity Service Inc.
Stephen and Barbara Yunker
Michele and Joe Zdanowski

PRISMS is a non-profit 501(c)(3) corporation. Some or all of your contributions may be tax deductible. Please consider PRISMS as a beneficiary in your will.

THANKING YOU FOR YOUR GENEROSITY!

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APRIL - NOVEMBER 2005

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SPECIAL THANKS!

**A special thank you to the
Xerox Reproduction Center at
Bank of America for their
generous donation of paper
and printing for this newsletter.**

If you are interested in making a donation in memory or honor of that special someone in your life, please consider making a donation to PRISMS.

REGIONAL FAMILY GATHERINGS

Northern CA SMS Family Picnic



The 2005 Northern California SMS Picnic took place on September 18 in the new Val Vista Community Park in Pleasanton, CA. More than 30 people (SMS families and extended families) attended the pot luck picnic where each family brought a dish that was a favorite family recipe or represented their heritage. Laura Clegg, the picnic organizer and Samantha's Mom, made lots of cupcakes for everyone to decorate and even prepared toys and games for SMS kids and their siblings. It was a great fun. Afterwards, families formed a round circle under the beautiful

shade of canopy trees and shared experience with their SMS kids, including school issues, behavior management, and medications.



CO SMS Family Picnic



The annual Rocky Mountain SMS Picnic was held at E. B. Rains Jr Memorial Park in Northglenn, CO on Aug 21, 2005. There were around 21 people in attendance from Colorado and Wyoming. The weather was great. Some of the kids played on the playground equipment. There was a large handicap swing for Edwin to ride in. Andrew, Ellie's brother played his guitar and sang to us. There was plenty of Sloppy Joes, Fried Chicken, various salads, fruit trays, potato chips and soda. We visited with each other, discussed what was going on with our families,

shared experiences from the 4th International SMS conference in Cincinnati and discussed the next conference scheduled for May 2007 in Reston Virginia. We took lots of pictures to share and look forward to the next time we all get together.



York, PA SMS Family Picnic

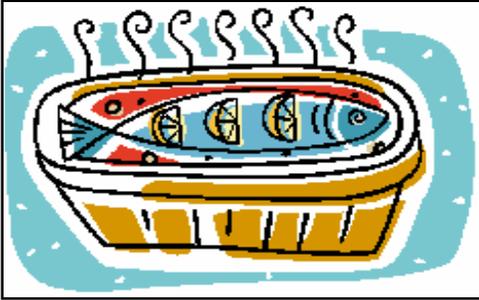
The 4th Annual SMS Tomestead Picnic, York, PA was held in late June this year. We had a wonderful event this year and 35 folks attend. The weather was nice and the kids enjoyed it tremendously. What scrumptious foods! Homemade baked barbecue beans and one with a touch of Mexico. The Joe Bury Hamburgers received a rave response. The Macaroni salad, potato salad, fruit salad, and Friendship cakes all went over well....Good healthy vegetables, Brownies, and Trail Mix. .We ate like there was no today. It was a highly organized picnic, and all the Tomestead staff was there to make it even less work for any of the parents. They went above and beyond to make the day a triumph. We are all very appreciative.

Besides gorging ourselves, we had lots of toys to play with, a beautiful wooded setting with very tall trees, and plenty of shade. In the open spots we had pools for the kids to play in, and Chuck helped all the kids to paint horseshoes. They also did bubbles, and had a peanut scramble. They enjoyed the hammock, and relaxing in the park-like setting. Ice cream was enjoyed by all. The date for next years SMS Picnic at The Tomestead will be Saturday, June 17th, 2006 in York,PA. Area families please plan ahead so you can all attend. Thank you for helping make this year's picnic a success!

Sandy, John , and Kimmer Tome

“IF I’M IN A CRISIS, THEN WHERE ARE MY CASSEROLES?”

by: Margaret Miller, PRISMS Board Member and parent, trellims@aol.com



Casserole: a stew or other moist food dish, cooked slowly at a low heat in a covered pot or dish.

Okay, now I know what one is (casserole)...let’s describe all the different categories of casseroles. There are “funeral” casseroles, “new baby” casseroles, “welcome to the neighborhood” casseroles, “post-surgery or hospitalization” casseroles, “get well” casseroles, “new home” casseroles and lastly “holiday green bean casseroles.” Why do

people give casseroles? Casseroles are comfort food; that which makes us feel warm and happy inside. People respond to the kindness of the one who makes the casserole because it cheers us up, makes us feel loved and thought about, and eases a daily burden that perhaps we are not up to; cooking dinner. Think about the last time someone rang your doorbell and presented you with a casserole. That ranks up there with the Publisher’s Clearing House Prize Patrol. WOW!

I just know for myself, that the last time I received that extraordinary gift of a pre-made dinner, I had just gone through many hours of labor and had to produce a baby to receive the casserole! That will not be happening again!

What’s the point of all this silly talk about casseroles? When a family goes through any of the above crises or joys, friends and family are mobilized to help and offer support, sometimes with the gift of ready-made dinners...(I.e., the casserole). Well, on behalf of all the Smith-Magenis families, “We are in a crisis and we need those casseroles!!” Let me say it louder, in case you didn’t hear me the first time, “WE ARE IN A CRISIS AND WE NEED THOSE CASSEROLES!!”

Smith-Magenis Syndrome presents some of the most difficult challenges that a family could face. The rarity of the syndrome isolates families. Connecting with other Smith-Magenis families in person is uncommon and infrequent due to our geographic boundaries. We are still few and far between, connecting mainly through email or phone. Our families would swim the ocean wide if they could, to meet with another family, who understands their frustration and extraordinary challenges. We may be living in a well-populated city or small town, but feel alone and remote.

The severe sleep issue that is prominent in Smith-Magenis Syndrome, results from the flipped circadian rhythm that occurs in these individuals, and is unlike any other species on the planet. This unique and **exhausting** feature wreaks havoc on the mental and physical health of the SMS child and their parents and siblings. Night can become day and soon everyone’s “clock” is cockeyed and compromised. This is a life-long challenge. Sleep deprivation is a terrible consequence for the entire family. Who then takes care of who? One never recoups lost sleep, as there is no sleep bank, and it’s (sleep) a requirement for basic life! Sleep deprivation takes a tremendous toll on the child with Smith-Magenis Syndrome and their caretakers, namely, their parents. Parents who still need to go to work each day, take care of children, (sleep-deprived cranky children), drive cars, or operate machinery, coach baseball teams, grocery shop, balance bills and deal with everyday “normal” life. Despite the few hours of sleep parents may get, regular trials and tribulations await each

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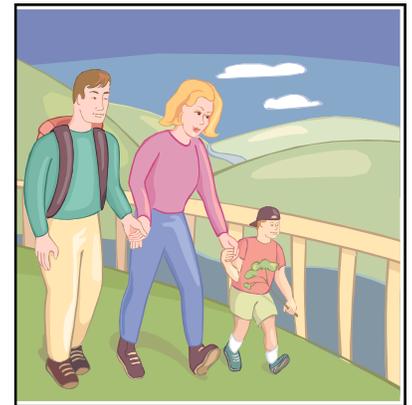


morning and the day offers no sympathetic reprieve.

The other most challenging feature of Smith-Magenis Syndrome is the behavior. All of our SMS children, from an early age, can exhibit severe behavior such as tantrums, and self-injurious behavior. These behaviors are characterized by head banging, skin picking, head slapping, hand biting screaming and throwing themselves on the floor. These “rages” can happen at home, school or in public places. The child is at risk for hurting his or herself and the parent is also at risk for injury. These behaviors can be cyclical and happen daily for weeks at a time. Bedrooms sometimes need to be stripped down to just a basic bed, for safety reasons.

Parents become masters at repairing drywall and learning to fix many household items. If it’s a bad day, parents cannot leave the home for fear that their child may have a rage in public or moreover, how will they even get that child in the car? Parents are called regularly from schools to pick up their child and take them home because of these behaviors. A mere trip to the grocery store can be a nightmare amid the stares and comments of ignorant passersby. These genetically driven behaviors can be further exacerbated by lack of sleep, onset of puberty and hormonal changes, seizures, side effects from medications, (“behavior meds”), and change in routine. These behaviors make the “terrible twos” or the “terrible teens” look like a walk in the park, literally! As the child grows, certain behaviors may diminish only to be replaced by new behaviors.

Smith-Magenis families must constantly “opt-out” of normal family activities and perfect the art of man-to man defense: One parent to one child for outings and activities. “Mom will watch your baseball game this week and Dad will come next week.” Siblings pay the price for this strategy, but soon recognize its need and accept the reality. How in the world do single parents ever do this alone? It is beyond my comprehension. What is not “normal” is quickly accepted as “normal” in our houses and we regulate our life so that we can go on everyday. We have to fit our situations into the standards of daily life. Family get-togethers can be the most difficult. There is great expectation on the behalf of the extended families, sometimes, and we are met with the challenge of convincing those closest to us of the worry and extreme stresses that we face each day. SMS parents are not always able to open up and feel accepted by those they are closest to. Sometimes it’s easier for family members to look the other way. Caring for someone with SMS is not for wimps. It takes lots of love, determination, patience, creativity, humor, nerve and pure Herculean strength!



We now have scientific studies that are identifying what chronic stress does to the body. Our telomeres, the end caps to our cells, are shrinking at a faster rate due to chronic stress. As a result, our cells are dying faster and speeding up the aging process. Lack of sleep can cause weight gain. We now also have a subset of SMS parents that have developed autoimmune diseases and stress-related illnesses due to the chronic stress. Can that be proven definitively? No. But it’s a very good guess. So, now that you have a pretty clear snapshot of what we face each day, what does any of this have to do with the “casserole?”

The casserole is a metaphor for what we (the families) need most. We need support and help and RESPITE on an ongoing basis. We need to know that we can count on a commitment from family and friends to regularly lend a hand. Now, there are many ways to lend that hand, and I will get to that later. We parents are not very good at asking for help from others. We, first hand, know of the effort it may take to take care of our SMS child and we hesitate to share that burden with someone else. But perhaps a friend or family member is just waiting to be asked? So I’m asking. These families need you. They need you today, next week and next month. The challenges are constant and sometimes critical. They reach out to other SMS families for emotional sup-

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port, but the hands-on support needs to come from elsewhere. We need to have an active support base for our SMS families that initiates from extended family and friends.

So, what do we need and how can you help? I've come up with a variety of options and creative ways that you can help to support our families. These ideas are not all of my own thinking, but rather a collective reference gathered from many of our SMS families who have shared their thoughts and wishes.

RESPITE: We need respite!

Respite care allows the entire family to catch their breath, relax, catch up on household chores, maybe go grocery shopping, attend a sibling's ballgame, or just sit without interruption and read a book. If you can take the SMS child for a couple of hours or a couple of days, on a somewhat regular basis, this is single-handedly, the best support you can give this family. Their SMS child also needs the break! Parents can get very cranky and impatient and all the children in the family could use a change of scenery. Most often, the SMS child does extremely well with new and fresh caretakers. They need a variety of people in their lives to care for them and to spend time with them. Take them out of the house and spend time with our SMS kids. They are so much fun and have so much love to give in return. It's a win-win situation. They will remember that time that you have spent with them forever! Don't be afraid to watch our kids. Get to know them and see what they like to do. (They are often perfect "angels" with folks other than their parents.) Could you commit to this time once a month, three times a year, once a year? Many of us must pay for respite care. The cost is very expensive, usually between \$15.00-\$25.00 per hour. This becomes another expense that is not covered by insurance or agencies. Also, finding the best match for a respite person can be difficult. It may take several attempts with different people to find just the right person with just the right demeanor. But, we find a way to pay for respite, because it is a critical need. And, you won't find our parents jetting off to Aruba, while you are watching their child. They are content with maybe just re-organizing their closets without chaos or cleaning the house. We have great appreciation for just quiet time in our own homes.



RESPITE for the siblings



Our SMS siblings are the very best brothers and sisters on the planet! These kids are awesome in spite of all the sacrifices and turmoil that they have dealt with in their lives. They understand, at any early age, how far a sister or brother's love can reach. Sometimes, when Mom and Dad are just too tired or can't console their SMS child, in walks the Superstar Sib! They are the great equalizers who bring calm to the chaos and try so hard to make up for all the difficulties that our families endure. They are champion students and dedicated friends and have enough empathy to probably heal the entire world from all its ills. They are courageous and fierce protectors of their SMS siblings and their parents. I don't have enough descriptive words to perfectly describe these siblings. But, all of this comes at a cost. These sibs grow up very fast and forfeit otherwise family normalcy and learn quickly to adjust, readjust and then go to plan "B." Much is put on their shoulders and they carry the load with superior wisdom and strength, well beyond their years. These kids are tremendous and deserve a break every now and then. How about taking your "favorite" sib out for dinner and a movie? Let them have a carefree day, where it's "all about them" and they are the center of attention. Let them know they have a trusted confidant to talk with and share private thoughts and worries. Make them feel important and valued by spending time with them. (Dinner, movies, a ball game, bowling, whatever). Give them a change of pace and a little vacation. Your time will be well spent while spending time with any of these sibs. Many of our "grown-up" sibs have chosen careers in special education or working with the disabled in many different fields. Their life experiences put them on a path to serve this

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community and they bring with them a mind and heart full of compassion and deep understanding. Spend some time getting to know these sibs.

Casseroles

Dinnertime for most families can be very stressful. Parents rushing home from work, driving kids to practice, school events, checking homework, starting dinner! We all know the drill. Now factor in an SMS child whose body clock is now telling them it's time to go to bed. Perhaps they have been up since 3:00am, and had to go to school, while trying to sit still and learn and not fall asleep. They have now processed an entire day of sensory overkill and by dinnertime they do not have the capability to keep it together! A "sleep-attack" is on its way, (when a child falls asleep eating their food at the table), and who would dare to wake them! Keep in mind that the parents have also been up since 3:00am. This is a very unpredictable and "thin-ice" time of day. One wrong move and a meltdown or SMS rage will absolutely happen and it is bedlam! So, "What's for dinner?"

How about a dinner prepared by a good friend or family member? How about that casserole? How about sending a gift card or gift certificate for take-out food or dinner at a local restaurant, if that's possible? How about someone committing to help out with a meal once a month or every other month? This small gesture would



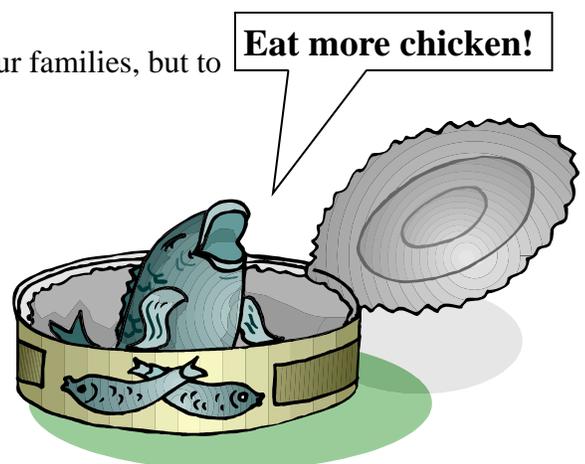
mean so very much to any SMS family. When you are trying to keep it all together and behave like a "normal" family, it is really hard work that is often times futile. Sometimes it's just going to be a grueling day and you can only hope for bedtime and what little rest may lay ahead.

Many of our parents have claimed that their front doors are possessed! The minute our SMS kids come off that school bus and step inside, it's mayhem. Our kids have put forth so much effort at school, keeping impulsive and "angry" behaviors at bay, trying to learn and please and cope,

that there needs to be a release from the "pressure cooker" somewhere. Home is a safe haven where that happens. It is a necessary release, and expected, but not easy to manage for the family, and not always safe for all persons involved. Managing a Smith-Magenis meltdown is not for the faint of heart or physically weak. It requires emotional, mental and physical stamina. It can last a few minutes or a few hours. It can put a stop to all activities in the household. It can define the day for everyone. Then, normalcy is required to take care of the household issues for the day. Clothes still need to be washed, kids still need to be fed and lives still need to be joyful, despite all the disarray. A single act of kindness on the part of friends or family can help to alleviate some stress and further impart a few moments of normalcy and joy. We need your support and encouragement and it needs to be ongoing. Connect with our families and see what joy they will give back to you!

This article is not meant to just present a compassionate view of our families, but to present a very clear and accurate picture of what they deal with each day. Perhaps it will also give you a creative idea of how you can support this family. Whatever you can do to provide this active and ongoing help will be met with great appreciation and with open arms! I challenge you to receive that appreciation!

So, keep those casseroles coming!! (I prefer chicken to tuna!)



What to Look For in Respite Care

An adaptation from the PRISMS 2005 Parent Break-out Session

By Rebecca S. Morse

In the chaotic and trial-ridden life of many SMS families, respite is often neglected for a variety of reasons. In an effort to pare down what battles must be fought while attempting to locate services, and the subsequent funding for those services, respite is often relegated to the backseat behind education, developmental therapies (speech, physical, occupational), and regular doctor visits. However there *are* creative alternatives to finding and utilizing respite services. The questions may seem overwhelming...what should I ask? Who is capable? What is the difference between respite providers? How much should I pay? How will I know if I can trust this person with my child (or protect everyone else!)? How can I make the most of the services for my child, my family, and my sanity?



Here we will try to answer some of these very real and potentially intimidating questions. The information presented here is intended strictly as recommendation, not prescription. These are ideas, strategies, and implementation techniques acquired through many years “in-the-trenches” working with children and adults with developmental disabilities.

Searching for respite services through school systems or county/state governed programs can be daunting. Depending on your system, respite services may fall under a number of different terms or service “umbrellas.” Here are a few of the terms or names that may provide respite:

- Respite Service Provider
- Skills Educator/ Life-Skills Educator
- Life or Social Advocate
- Behavior Specialist (one-on-one)
- Vocational Rehabilitation
- Employment Specialist
- Coach

So where should one start? Again, depending on your state or county, different agencies may provide assistance. However there are a number of non-profit and private organizations that can provide direction. Some even provide instructional packets on how to organize your search:



<http://www.archrespite.org/ARcoalitions.htm>

State Respite Coalitions

<http://www.respitelocator.org/index.htm>

Search for programs by state

<http://ddamaryland.org/respiteservices.htm>

Developmental Disabilities Administration of Maryland (your state may have a similar program)

<http://www.cms.hhs.gov/medicaid/waivers>

Many states also have waivers programs in which Medicaid funds are used to pay for services

<http://www.specialinspirations.com>

Caring Communities Inc. (410-549-5705)

Information packet: Respite Workbook for Families and Care Providers

But ...where might you go if you don't have any “venues”? The following examples provide just a few ideas of creative advocacy for services that have previously worked for families.

#1 Ask your school

Schools often have untapped resources for “life skills education” and may even be able to provide recommendations for private-practice providers if they don't have, or have inadequate, resources for your needs. School administrators would also have a good idea who is an effective advocate. This is particularly important if your respite provider is to facilitate relations between your child and the community or school system.

#2 Contact local support organizations (i.e. Down syndrome, Autism communities, etc)

Many organizations have tools or strategies to help one another locate services and providers. They can also give you



insightful feedback with regard to individual providers and effective advocacy. Your local organization may also provide information for the “going” rate for respite in your area. Just remember, you are also paying for expertise, and children have varying degrees of challenging behavior. What is acceptable for one family to pay may be more/less than what your provider may require for comparable services. Your child’s age and level of impairment, or independence are primary factors in negotiating monetary compensation. There are also differences in pay schedules between providers who work directly for an organization or are private practice.

#3 Try your local college

Contact the special education or psychology program administrations – students may be allowed to use respite training as experiential learning for internship college credits if they are willing to write a paper or keep a journal based on their experiences.

Even if the college won’t provide student credit, students may find it is a worthwhile part-time job opportunity between classes. Bulletin Boards with job opportunities abound on local campuses –

with campus permission, try posting your own ad. Take care to be clear in your expectations and what you have to offer: approved college credit, monetary compensation, etc. This is a **GREAT WAY TO SAVE MONEY!!!** Students acquire on-the-job training and/or college internship/independent study credits, and you get free or low-cost respite care! Mature students can provide you with enthusiastic, energetic care and may be more flexible to your child’s individual needs and family lifestyle.

Selecting a respite provider who can integrate into your child’s developmental requirements and your family’s lifestyle *can* be accomplished! It helps to have some form of organized “checklist” of what areas are important, what questions to ask, and what might be a warning sign that a particular provider isn’t suited to *you* or *your child*. A parent/care provider should never feel that they cannot ask questions. Likewise, the potential provider should ask you questions. Remember that this is a two-way interview. While you know what you need, they know what they have to offer. The following “checklists” are those that have proven effective for other families and explanations why they may be relevant to your search.

What to look for in a Respite Provider:

- Experience or willingness to learn
- Age-appropriate for your child
 - An age appropriate respite provider is one who is old enough to be seen by your child as an authority figure, yet young enough to be able to physically “manage” your child should safety be compromised.
- Same Sex
 - Liability: hygiene help (using public restrooms can be problematic with mixed sex), and perceived sexual overtones or abuse in restraint, etc.
 - Decreased incidence of “infatuation:” While infatuation may be a useful tool in that your child will wish to please their provider, problems can arise on a number of levels. *E.g.* a teenager may become more aggressive toward others in the presence of the provider in a normal reaction to assert themselves in the relationship. Some individuals may “regress” in their independent behaviors in an attempt to gain the provider’s attention. It can also prove difficult for the developmentally delayed person to perceive reality as actual events and may perceive reciprocity of the sexual feelings that they experience. While there are instances where sexual abuse has occurred, and should *always* be investigated, parents can help protect their children by limiting unsupervised contact between opposite-sex dependents and their providers.
- Sense of their “adaptive coping mechanism”
 - Each person has their own technique for handling potentially volatile or compromising situations
- Ability to share prior experience without gossip
- Home Inspection –only if your child will be spending time at the provider’s home
- Driving Record
- Recommendations from other families
- Questions –forewarned is forearmed!



Who/what *not* to look for:

- Opposite sex
- Same age cohort
- Your best friend’s teenager- even the most mature and responsible of teenagers do not yet have the appropriate skills to be a respite provider

They lack the life-experience to “look ahead” for potential behavior triggers or situations

They lack the *emotional* maturity to differentiate “acting” from “reacting” to your child’s behavior

When you allow your child to enter into public with a teen, you are entrusting *your* liability to someone who is still

legally a minor. This could be liability for property damage, harm to another person, or harm to your child and/or provider. While liability may be legally deferred to parents, regardless of provider status, the “ante” on the liability gamble increases when you entrust your child to a minor

If there is an emergency, a minor may not be allowed to seek treatment for your child until you are contacted, which can delay vital treatment

When the teenager is the child of a neighbor, relative or friend, there is the potential threat to that relationship between adults –even if NOTHING GOES WRONG!

- Perfect “grandparent” with physical limitations
- Provider with an inability to adapt to your child’s individual needs/coping strategies

What do I ask my prospective provider?

- What training have you had?
- What experience do you have?
- What ages/disorders have you worked with?
- What is your behavior modification style/strategy?
- What would you do if...
- How would you stop ...
- What clues might you look for ...
- How have you circumvented ...in the past?

What Your Respite Provider Should Ask You:

- *Information you should provide about your child*
- What is your strategy for behavior modification?
- What are your child’s known “triggers”?
- How do you adjust for them?
- How do you handle “melt-downs”?
- What is your child’s current regime?
(Medicine/ daily routine)
- Is your child bathroom independent?
- Pertinent Medical History

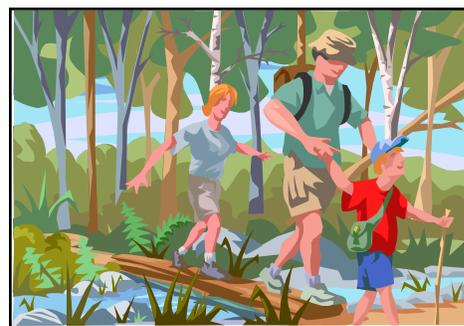
Provide your provider with an emergency “Rx card.” In an emergency it is imperative that your provider have this information to minimize risk during treatment. A small wallet sized note card with your child’s medications, doses/times, and your family doctor or pediatrician can be tucked neatly into your provider’s wallet for future reference.

- Emergency Contacts & Plans



Implementation Strategies –ways you can put your provider to good use:

- Liaison with peers
 - Camp
 - Social Activities (shopping, movies, theme parks, nature hikes)
- Life Skills
 - Cooking
 - Budgeting
 - Social Graces
 - Exercise!
- School-place Advocate
- Work-place Advocate



Warning Signs that all is not right in “paradise:”

- Lack of initiative reporting problems/concern behaviors
 - Providers may neglect to mention or deny issues or potential issues out of a desire to protect your child from consequence, or the fear that parents will hold them responsible. Regardless of intent, as the parent, you need to be fully informed of all issues in order to address them appropriately in caring for your child.
- Inconsistent care/behavior from the provider
- Irresponsible behavior –you are paying *them*
 - Forgetting your child’s medicine, driving recklessly, not providing adequate supervision, not informing you of changes

- Misreported time/expenses
- Inappropriate or unacceptable habits & behaviors
These are discretionary - things that you do not wish your child to imitate: cursing, drinking, smoking, lewdness
- Personalizing your child's behavior
Situations and behaviors will be exacerbated if a provider internalizes your child's behavior –negative or positive. The more professional your provider in not taking changes in behavior as a direct compliment or insult, the more able they are to provide consistent and appropriate behavioral intervention and care.

Remember: You and your respite provider are a team working for the common goal of improving the quality of your family life and fulfillment of your child's potential ... take the time to talk to your provider.



A good captain always debriefs his team!



2005 CONFERENCE

APRIL 28—MAY 1





Parents and Researchers
Interested in
Smith-Magenis Syndrome

NONPROFIT ORG.
U.S. POSTAGE
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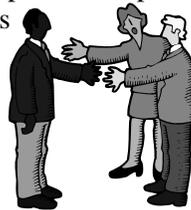
ADDRESS SERVICE REQUESTED

**PO Box 741914
Dallas, TX 75374-1914**

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 SMS 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. Contact:

Mary Beall
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. If you would like to be added to the list of contact parents, please email me at the above address.

THANKS!

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Editors

*Susan Voigt
Randy Beall*

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JANUARY 31, 2006