



Special Times

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NEWSLETTER OF THE DOWN SYNDROME ASSOCIATION OF MINNESOTA



3rd Annual Joey Hebert Classic—What a Success!

By David Forney

I don't know about all of you folks, but I am pretty much weary of gloomy headlines foretelling the end of economic life as we know it. Somewhere along the line, I got this idea that optimism is way better than pessimism – that tomorrow can and will be better than today.

I want to stick with that.

Proof of this value was found at a lovely golf course located on the western edge of the Twin Cities metro area on Monday, August 3rd. That was the location for the Third Annual Joey Herbert Golf Classic benefiting the Down Syndrome Association of Minnesota.

Alvin and Colleen Herbert seem to share my positive outlook. For the third year in a row, they have amazed all of us by putting together a wonderful and wonderfully successful golf tournament.

Every foursome was sold out, sponsorships came in smoothly along with a rich trove of silent auction items and great live auction donations.

While I am pretty sure there were plenty of shanked drives, approach shots that came

up short and missed putts, the golfers came off the course smiling and happy. Following cocktails and banter, all were seated to a lovely alfresco dinner. Following dinner, self-advocate DSAM board member Lori Turben-son introduced all of us to what it means to be an adult with Down syndrome and, I suspect, turned many heads around.

Then the fun began with a rousing live auc-tion – this year featuring an-honest-to - goodness auctioneer. All of us apparently forgot for a while the stormy financial clouds that have seemed to have masked our sun for too long. People dug deep, bid large and, in the end, blew us away with their generos-ity.

To the delight and surprise of all, the combi-nation of entry fees, sponsorships plus silent and live auction proceeds surpassed what we raised in 2008. After all the bills were paid, the Joey Hebert Golf Classic raised over \$51,000 for the Association.

Maybe that is miraculous. Or, maybe, just maybe, that is a solid vote of confidence by a bunch of great people in the Herbert family, their friends and family who have gathered around them now for three years and the importance and quality of the work of our Association.

I am OK with the miracle thing, but want more to believe that, bottom line, it all hap-pened because we believe.

The Down Syndrome Association of Minne-sota, its officers, board of directors and staff and all of the members of the Down Syn-drome Association extend our deepest appre-ciation to Alvin, Colleen, their family and friends and all of the other volunteers, do-nors and sponsors who made this possible.

Special Points of Interest

12th Annual Muddy Open
September 13th
Eagan, MN

12th Annual Step Up for Down Syndrome Walk
September 20th
Como Park
St. Paul, MN

8th Annual Duluth Buddy Walk
September 27th
Duluth, MN

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It is the mission of the Down Syndrome Association of Minnesota to provide information, resources and support to individuals with Down syndrome, their families and their communities

A Black and Silver Night 25th Anniversary Celebration

Twenty five years ago this year a group of parents had a dream—to support one another on their journey of raising a child with Down syndrome. They dreamed big. And others who followed added to those dreams. We are now a strong regional organization supporting parents when they have or are expecting, a child with Down syndrome, grandparents, extended family, teachers, medical professionals and people with Down syndrome themselves.

We hope you will join us on **Saturday, November 7**, as we pay tribute to those whose dreams helped build the Down Syndrome Association of Minnesota into the organization it is today. We have a great evening planned! There is an appetizer dinner planned, which includes chicken and pork pot stickers, veggie crudités, chicken satay, meatballs and much more. There will be a live band and dancing and a silent auction. Tickets to attend are \$30 per person, which in addition to the appetizer dinner includes two free beverage tickets (beer, wine or soda). Formal invitations will be sent out mid-September. You may register to attend this event by ending back your RSVP or by going online to www.dsamn.org/gala. The Gala is being held at the Marriott West in Minneapolis. Discounted rooms are available to those wishing to stay over night. Please call for more information and rates.



If you or someone you know would like to donate an item to the silent auction, please contact Annie at annie@dsamn.org or by calling the DSAM office, (651) 603-0720



DSAM Welcomes New Parents to the Summer New Parent Breakfast

A New Parent Breakfast was held on Saturday July 25th at our office. The breakfast was hosted by board members Jessica Hancock, Bob Hei, and Jennifer Robinson. The 19 parents and children that attended enjoyed meeting each other and sharing information and stories. This experience is always so rewarding for new parents of children with Down syndrome. It is our hope that these new acquaintances that are made here will become long lasting friendships and help parents exchange ideas and experiences. The next New Parent Breakfast is tentatively planned for Saturday October 10th.

New Members

Brandon & Tiffany Yerxa
Kristine & Christopher Voeltz
Charles & Sandra Kelley
Kyle & Somporn Simonson
Ryan & Karen Mueller

Welcome New Parents

Teresa & Chris Hedlund
Catherine & Evan Kaneski
Gayle & Micheal Misner-Elias
Julie & Dan O'Connell
Dena & William Rada
Andrew & Amanda Gislason

Patron (1000+)

Dan Wilson Benefit Concert
1st Annual Eli Matthew Lauer mann Motorcycle Run

Contributor (100+)

Kowalski's Market
Deon & Judy Stuthman
Joan Coverdale
Jill & Craig Carlson

In Memory of

Christine Chapdelaine
Sean Maher
Gert Sabins
Earl Nordstrom
Dave Magnuson
James J. Harrington
Jackie Heubsch's mother

In Honor of

Jeannie Saffert's birthday
John Lindeberg
Sally Sawyer's birthday and her grandson Erik
Shelley Harris' birthday
Marie Franzen's 90th birthday
Ben Duncan
Gail Davis' birthday
Signe Becker

Employee Giving and Matching through:

REI
Ameriprise Financial Employee Giving & Matching
Ecolab
Wells Fargo
Honeywell Hometown Solutions
Truist
ING
United Way
UnitedHealth Group



2009 Educator Conference

**October 20th—Metro Area
October 22nd—Grand Rapids**

The Down Syndrome Association is pleased to present the 2009 Educator Conference.

This year, we welcome DeAnna Horstmeier and Wendy Selnes.. DeAnna will be presenting "Teaching Math to Individuals with Down Syndrome." Wendy will be presenting "Creating Positive Behavior Change."

Registration materials will be going out mid-September and will also be available on the website, www.dsamn.org/educators.

Would you like your child's teacher to know about this conference? Send us their contact information and we can make sure they are on our mailing list!



In Memory of Eli Matthew

In memory of their son, Eli Matthew, Robyn and Jason Lauer mann decided to hold the 1st Annual Eli Matthew Lauer mann Motorcycle run to support DSAM. Their event raised more than \$1,300. This is what they sent us with the money: "My husband and I lost our second born son at 36 weeks gestation one year ago. Eli Matthew touched our lives so much. We wanted to take the time on his 1st birthday to honor who he was and give back to an organization that truly helped us out when we found out that our little Eli had Down syndrome. We had the 1st Annual Eli Matthew Lauer mann Motorcycle Run on July 26, 2009. We hope this will help continue to produce the Down Comforter packets and go to other areas with in the organization. From the bottom of our hearts, thank you for all you do in the state of Minnesota to help families like ours. ~ Robyn, Jason & Jacob Lauer mann"

Focus on Behavior

10 Things You Can Do to Support A Person With Difficult Behaviors

By David Pitonyak

Supporting a person with difficult behaviors begins when we make a commitment to *know* the person. Sadly, it is often the case that the people who develop an intervention to stop someone from engaging in difficult behaviors do not know the individual in any meaningful sense. Instead, they see the person as a someone (or *something*) that needs to be fixed, or modified. But attacking a person's behavior is usually ineffective and always disrespectful.

Think about someone you know who engages in difficult behaviors. Ask yourself, "What kind of life is this person living?" Consider how you would feel if you lived the person's life. How would you behave?

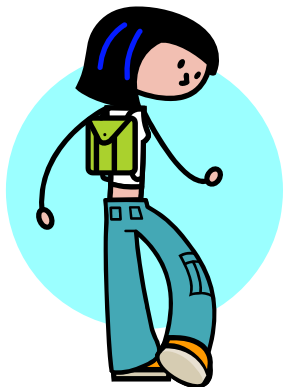
What follows are 10 things you can do to support a person whose behavior is troubling you. It is not a list of "quick fix" strategies for stopping unwanted behavior. It is a list of ideas for uncovering the real things that a person might need so that you can be more supportive.

1. Get to know the person.

The first step in supporting a person with difficult behaviors almost seems too obvious to state: *get to know the person!* It is too often the case that people who develop interventions to eliminate unwanted behavior do not know the person in any meaningful sense. They know the person as the sum total of his or her labels, but know little about the person as a "whole" human being.

Make a point of spending time with the person in places that he or she enjoys, during times of the day that he or she chooses. It should be a comfortable place where both of you can feel safe and relaxed (e.g., a quiet room, a nice restaurant, a walking trail in a nearby park).

At a time that feels right (you will have to trust your intuition on this one), tell the person about your concerns and ask for permission to help (it's rude not to). If the person has no formal means of communication, *ask anyway*. Sometimes people understand what is being said, but they have a difficult time letting others know that they understand. The important point, always, is to *ask* the person for *permission* to stick your nose into their business, even at the risk of seeming silly in front of people who think the person cannot understand up from down (they're usually wrong).



2. Remember that all behavior is meaningful.

Difficult behaviors are "messages" which can tell us important things about a person and the quality of her life. In the most basic terms: *difficult behaviors result from unmet needs*. The very presence of a difficult behavior can be a signal that something important that the person needs is missing. Here are some examples of the kinds of the kinds of messages a person may be conveying with his or her behavior:

"I'm lonely."

Michael's older brother was invited over to a friend's house for a sleep over. Michael is never invited to the homes of children because he goes to a "special" school 35 miles from his neighborhood. Michael has no friends to play with.

"I'm bored."

Roberta's sister is a doctor at the local hospital. She has her own house and is her parent's pride and joy. Roberta works all day at a sheltered workshop where she packages plastic forks and knives. She lives at home and is tired of packaging. She wants to get a real job. Roberta's case manager says she day dreams too much.

"I have no power."

John likes to sit down on the sidewalk when the bus arrives to take him to school. His mother becomes very angry and tells him that there will be no dessert when he gets home. John laughs when the bus driver threatens him with time out.

"I don't feel safe."

Conrad uses a wheelchair and is not able to defend himself adequately from attacks by another man. Conrad worries that he will be hurt and often cries when left alone. Staff think he has a psychiatric illness.

"You don't value me."

Gloria has a "severe reputation." People from all over the state have heard stories about her terrible tantrums. No one knows that she is a very caring person who worries about environmental issues. The only part of Gloria people pay attention to is her problem behaviors.

"I don't know how to tell you what I need."

June does not know how to use words or sign to let other people know what she was thinking. She lives in an institution where she learned that the best way to get people's attention was to bite your arms. It hurts, but it is the only thing that "works."

"My ears hurt."

Walter hits his ears with his fists. His job coach wants to stop and wrote a behavior plan for "not hitting." Weeks later, at a scheduled doctor's appointment, it was learned that Walter had a low-grade ear infection. Antibiotics cleared up the infection and Walter has stopped hitting his ears.

"My body does not move like I want it to."

Aron wanted to order a hamburger at the restaurant, but

his mouth kept saying, "I want pizza." When the waiter brought him pizza, he became so upset he knocked it on the floor. Later, at home, he typed to his mom, "I wanted a hamburger but I couldn't stop saying, "I want pizza." Aron experiences differences from other people in the way his body



moves (see Anne Donnellan and Martha Leary's book, *Movement Differences and Diversity in Autism/Mental Retardation: Appreciating and Accommodating Persons with Communication and Behavior*

Challenges for additional information (ordering information on the last page).

Obviously there are many needs that a person may be conveying with her behaviors. A single behavior can "mean" many things. The important point is that difficult behaviors do not occur without reason. All behavior, even if it is self-destructive, is "meaning-full."

Ask the person (and/or the person's supporters) what he or she needs to be happy. Find out who he or she counts on in a pinch. How often does he or she see loved ones and friends? What are his or her favorite activities? Where does he or she like to go? Ask the person what leads to unhappiness. Who are the people who the person does not like? How often does he or she see them? What are the person's least favorite activities? Since many people are experiencing physical and/or psychiatric distress, it's also important to know something about the person's physical and emotional health. Does the person have a way to let others know what he or she needs and feels? Is the person experiencing physiological or psychological distress? What kinds of medications is he or she taking? Do they help?

Finally, if you're stumped, ask, "Are there times when the person exhibits this behavior frequently?" and "Are there times when person exhibits this behavior infrequently or not at all?" Answering these two questions can tell you a great deal about the meaning of the person's behavior. With time, you should be able to see a discernable pattern.

For example, you might find that the person engages in the difficult behavior in the morning hours, but rarely in the afternoon. Ask, "What happens in the morning that might cause the person to behave this way?" or, conversely, "What is happening in the afternoon that causes the person *not* to behave this way?" (Hint: it often has something to do with the things a person is being asked to do, and/or *who* is asking the person to do it).

3. Help the person to develop a support plan.

People who exhibit difficult behaviors are usually subjected to a behavior plan at some point in their lives. It is rare that they are asked if they want a plan, let alone invited to the meetings where one is developed. Instead, a plan is developed by strangers (e.g., the agency behaviorist who has spent less than two hours "observing" the person).

Think about how difficult it would be to stop a behavior that a stranger thinks you should stop. It can be difficult enough to stop behaviors we choose to stop (e.g, smoking, excessive eating)!

Instead of a behavior plan to "fix" the person, help the person and the person's supporters to develop a support plan that reflects a real and authentic life. John and Connie Lyle O'Brien suggest the following questions for building a support plan. Note how different these questions are from those we typically ask, such as "How can we reduce this person's problem behaviors?" or "How can we manage this behavior?"

1. How can we help the person to achieve health and wellbeing?
2. How can we help the person to maintain his or her relationships and make new ones?
3. How can we help the person to increase his or her presence and participation in everyday community life?
4. How can we help the person to have more choices in life?
5. How can we help the person to learn skills that enhance his or her participation in community life?
6. How can we help the person to make a contribution to others?

The team can ask, "Is our vision for the person similar to the vision we hold for ourselves and each other? When we think about what the person needs, do we focus on "fixing" deficits or do we think about supporting the person in achieving a *real* life?"

4. Develop a support plan for the person's supporters

Just as it is simplistic to treat a person's behavior without understanding something about the life the person lives, it is simplistic to develop a support plan without considering the needs of the person's supporters.

Many of our school and human service delivery systems are based on the idea that a few people with greater knowledge and power should bestow care and skills to a larger number of people with lesser knowledge and power. "Success" is based on compliance or obedience. A person who engages in difficult behaviors presents a real threat to a care-giver or teacher whose competence is being judged by this "compliance/ obedience" yardstick. The caregiver often expends great energy trying to suppress the person's behavior in order to maintain "competence" (in many of our workplaces it is acceptable to share knowledge but not to share power).

Punishment or the fear of punishment (coercion) may be the primary means of "motivating" staff. Many approach each day with a mixture of fear and dread. If they make a mistake, they could be "written up," demoted or fired. If they try something new, it may violate a policy or procedure. The unspoken message is "do as you are told" or suffer the consequences. Many of our human services environments are "toxic" with

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fear.

It is in this context that human services workers are “told” to be supportive. Workers are trained in positive approaches when the underlying organizational message is “maintain obedience.” Under the deadening weight of these systems, even the kindest and most respectful of caregivers may begin to exhibit their own difficult behaviors. They become excessively controlling and resistant to change. They begin to believe that individuals are worthy of their labels and “beyond hope.” They may even resort to forms of punishment procedures that the average citizen would find repulsive and unacceptable.

Take time with your colleagues to develop support plans for each other. For example, what can you do to increase each other's level of safety and comfort when someone is behaving dangerously? What can you do to have more fun at work? How can you have more control over your schedule and input into decisions? How can managers better support you?

A fundamental question is, “If you stopped responding to the person's difficult behavior the way you do now, who would you be?”

5. Don't assume anything.

It is easy to make the mistake of underestimating a person's potential because of her labels or because she has failed to acquire certain skills. This is a tragic mistake.

I have worked in the field for 15 years and am less confident in my ability to predict how much a person understands with every passing day. Recent developments make clear the folly of making predictions about a person's potential on the basis of diagnostic labels or past performance. Hundreds of thousands of people deemed “unfit” for society have left our institutions and now live in community. One hundred and twenty thousand people who were assessed “unemployable” because of the severity of their disability now work and pay taxes thanks to supported employment services.

The very definition of mental retardation itself has changed in recent years. The American Association for Mental Retardation (AAMR) has recently overhauled the definition. Gone are pessimistic predictions that saw little hope for the “severely retarded” and “profoundly retarded.” The new definition eliminates such terms altogether and emphasizes the importance of our supports. In short, an individual's potential depends largely upon the adequacy of his/her supports rather than some inherent flaw or “defect.”

Always remember that people are people first. Labels tell us nothing (in any real sense) about how we can be supportive. We need not forget the person's problem behaviors, but we must understand that people have gifts and capacities that eclipse our labels (or, as Herb Lovett has said, our “clinical accusations.”) Always remember to speak directly to the person and explain things as clearly as you can, even if the person's labels suggest that he cannot understand (at the very

least the person will understand the tone of your voice). Never speak about the person as if he were not in the room.

6. Relationships make all the difference.

Loneliness is the most significant disability of our time. Many people with disabilities, young and old, live lives of extraordinary isolation. Some depend entirely upon their families for support. A brother or sister or mom or dad are the only source of company. Friends are often absent altogether.

All too often, the only relationships people have are with paid staff. Although staff can offer a great deal, they change jobs frequently or take on new responsibilities. The resulting instability can be devastating to someone who is fundamentally alone.

Remember that there are many people in the community who will benefit from knowing the person. Chances are the person has already made someone's life fuller. Be confident that she or he will make someone's life richer again and again.

Learn more about personal futures planning and other person-centered approaches to planning.

7. Help the person to develop a positive identity.

John Bradshaw writes, “Our identity is the difference about us that makes a difference.”

Many people with disabilities develop identities as “problem people.” They are segregated into “special” programs where they are treated as people who have little to offer. Soon their “treatment” becomes a kind of cage to protect them from themselves and others. The real danger is that if enough people begin to think of the person as a “problem,” she will begin to believe it too.

We all need to be needed.

Help the person to find a way to make a contribution. Start when the person is young if you can. Giving is a lifelong endeavor. Things as simple as helping with household chores or helping out at church can teach the person that she can make a contribution.



Pour over the newspaper and find the “Volunteers Needed” section. Talk to the person about joining an organization with you or with a friend (e.g., Habitat for Humanity, a local food shelter, an environmental group).

Help the person to learn how to support friends (e.g., an invi-

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tation to a sleep over, birthday cards, learning to ask “How are you doing?” or “What's new?”).

Remember that it is important to overcome the belief that the person has nothing to share. It takes time and determination to help the person and others to see strength and the capacity to give when deficits were all that anyone ever saw before.

8. Instead of ultimatums, give choices.

Choice is a powerful alternative to punishment. If the person's behavior challenges you, help him to find more desirable ways to express the needs underlying the behaviors. Instead of ultimatums, give choices (e.g., “Bill, I know you're upset. What would help? Would you like to go for a walk? or take a ride? You need a chance to calm down.”)

Allow the person to make decisions throughout the day. If he has trouble making choices, find a way to help. Make sure there are at least three desirable outcomes to choose from. As Norman Kunc has said 1 option = tyranny; 2 options = a dilemma; 3 or more options = a real choice.

Don't assume that helping the person to have more choices means letting him do whatever he wishes. Limit-setting is an important and fair part of any relationship. The real question is who is setting the limits and why. If limits are imposed upon the person without their input, and if the limits are part and parcel of a life in which the person is powerless, even your best advice may even be interpreted as one more statement of “do it my way or else.” You can expect a general disregard for your advice if the person on the receiving end of the advice is “out of power.”

Make a sustained commitment to the person and to “fairness” in the relationship. If the person has been on the outside of power for too long, you may need to bend more often than not for awhile. The goal is to teach the person that giving is a two-way street.

9. Help the person to have more fun.

Fun is a powerful antidote to problem behaviors.

People with significant disabilities often live in ghettos of reward. Indeed, it is often this poverty of reward, not a lack of skills, that keeps people separate from other community members. Many must endure reward schedules for good behavior. The very few things that they enjoy are used contingently to reinforce compliance (talk about spoiling a good thing!).

Count the number of things the person enjoys, the number of places she likes to go. Compare this to the number of things other people enjoy, the number of places other people go. Ask yourself, “Is the person having fun? Is she experiencing enough joy? Is this an interesting life with things to look forward to?”

Help the person to add to her list of interesting (and really

fun) things to do. Spend time in regular community places where people hang out. If you feel compelled to take data on something, take data on the amount of fun you find. Make fun a goal.

10. Establish a good working relationship with the person's primary health care physician.

Mark Durand has said, “People tend to get immature when they don't feel well.” How often have you experienced a general decline in your mood or your ability to empathize with the needs of others when you don't feel well? When we are sick, we are not ourselves.

Many people who exhibit difficult behaviors do so because they don't feel well. The sudden appearance of behavior problems may be a signal that the person does not feel well. Illnesses as common as a cold or ear ache can result in behaviors as inconsequential as grumpiness or as serious as head banging.

It is important to establish a working relationship with a good primary health care physician. Although this is easier said than done, the person will, especially if he has difficulty communicating, need a doctor who can help him to stay healthy and well.

Remember that physicians, like many other people who grew up in our “separate” society do not always understand (and may even fear) a person with substantial disabilities.

Don't be afraid of telling the person's doctor that you don't understand a recommendation or finding. It is important to get a clear and straightforward answer to *all* of your questions.

Remember too that it is important to go beyond a concept of health as the absence of a disease or illness. “Feeling well” and “being healthy” involves everything from a balanced diet to a good night's sleep. Help the person to achieve a state of “wellness.”



Ordering Anne Donnellan and Martha Leary's book about movement differences. Anne and Martha's book *Movement Differences and Diversity in Autism/Mental Retardation: Appreciating and Accommodating Persons with Communication and Behavior Differences* can be ordered through the Autism National Committee Bookstore (AUTCOM). Telephone orders: 1-800-378-0386. Online: www.autcom.org

can be reached at Imagine, 3694 Mt. Tabor Road, Blacksburg, VA. 24060 (w: 540- 552-5629) or Dimagine@aol.com. You can also visit my web site: www.dimagine.com
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Announcing the new Southwest All Stars Adaptive Team!

The Southwest All-stars are pleased to announce their New Adaptive Cheer Team for the 2009-2010 Season.

This squad is open to all children with special needs ages 5 (by January 1st 2010) to 12 years of age. We will offer not only the chance to meet and make new friends, but the opportunity to learn important life skills such as teamwork, confidence and self esteem.

This team will practice for 2 hours the first Sunday of each month from September through March and have the opportunity to showcase their talent by performing an exhibition routine at competitions throughout the season.

Please join us for an informational meeting and registration on:

August 20th, 2009 @ 7:00p.m.
Classic Gymnastics
2885 Water Tower Place
Chanhassen, Minnesota 55318

If you have any questions before the meeting please contact:
Karna - Head Coach @ (320) 224-2697



2009 NDSC Convention

By Chris Brown

On July 29th Henry and I left on our much anticipated trip to Sacramento to attend the NDSC conference. It had been a dream of mine to take Henry when he was old enough. I would like to thank Kathleen and the DSAM for helping to make that dream possible.

Friday afternoon we checked into our hotel. After settling in Henry went off to the Youth and Adult kick off party while I went to a mom's sharing session. I sat with about 20 or so other moms of teenagers, age 13-16. As we shared our stories I was gratified to hear others voice the same concerns that I had. We brainstormed and shared vari-



ous strategies, helping each other problem solve. Meanwhile back at the kick off party, Henry was having a great time with his new friends.

The conference officially began with the opening session Friday evening. The mayor of Sacramento, Kevin Johnson, welcomed us to the city. Next there were three very inspiring self advocates who spoke, telling us about their lives. They encouraged us to not give up on our dreams for our children. These young adults showed the rest of us what is possible. They are driving cars, going to college, getting good jobs, and even getting married.

On Saturday we woke up early, had breakfast at our hotel, and then went off to our respective conferences. I began my day by listening to a keynote presentation by Rosario Marin, former Treasurer of the United States. She has a 21 year old son, Eric, with Down syndrome. When Eric was 5 weeks old she attended her first NDSC conference. The keynote speaker was Eunice Kennedy Shriver. After the speech Rosario was so inspired that she told her husband she had to meet Mrs. Shriver. She got a hug from Mrs. Shriver and these words of advice, "We have set the table for you, now it is time for you to bring food to the table." She never forgot those words and later claimed to have had a revelation. Rosario told her husband that she was making it her mission to leave this world a better place for Eric. Her husband replied that his mission would be to see that she accomplished her mission. As she ended her speech there were very few dry eyes in the auditorium.

Saturday night there was a banquet and afterwards a dance. As the dishes were being cleared I turned just in time to see Henry heading for the dance floor.

On Sunday the Youth and Adult conference finished off with a talent show and I attended more workshops. It was quite a weekend.

Looking back over the summer I realized that my sixteen year old son has taken some important steps toward independence. Besides attending the national conference as a self advocate, this summer he held his first job. He has proven he can independently catch the bus in the morning and come home on his own if need be, when I can't be there. He recently got a cell phone and like his peers, he knows how to use it. He's growing up and it scares me but it also makes me very proud.



Dan Wilson Concert Raises \$8,300 for Down Comforters

What could be more wonderful than spending a warm, breezy July evening sitting on the shore of a Minnesota Lake and listening to live music fill the air? Raising \$8,300 for DSAM while enjoying it, of course!

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STORIES TO SHARE



Michael Grace is Ready for School

By Liz Hannan

Our son Michael is 8 years old and is so ready for school this fall. He will be in 3rd grade and is moving to the upper campus of his school. His parents are a little nervous but he isn't. He points out his new school whenever we drive by. His school supplies are by the door. He is excited.

He loves the schedule of school and following along with the class through the daily routine. He especially loves being with all the kids and being included, so we work with school staff to have him in the classroom as much as possible.

One of his favorite classes is music. He sings songs from school and enjoys performances so we ask to have the words and music sent home so we can practice at home, too. He is a very strong reader and is so proud of his accomplishments. His biggest challenge during the day is "remembering" to come in from recess when the whistle blows... That's when the notebook in his backpack is helpful so we can help address those types of issues at home with stars, stickers, ice cream, or whatever works!

Michael is very independent and adaptable. Summer school was at a different location than usual and when we pulled up to the parking lot he said, "Bye, Mom!" (I told him I thought I'd go inside with him.) By the end of the first day he was greeted by name by most of the adults and many of the students in the school. He often exceeds expectations of teachers and aides with his skills and abilities.

Michael is sociable, often pulling us out of our comfort zone.

Its impossible to go anywhere with Michael and not interact with someone—"quick errand" is an oxymoron with Michael. He introduces us to waitresses, people in line for movie tickets, people at the park. Recently, on a trip to the library he was talking to a woman and her baby and tickled the baby's toes. He asked the name of the baby and then called me over to introduce me.

His older sisters Margaret and Mary look out for him and belly laugh with him. He is learning things like asking for the car keys, arguing about taking turns with the music in the car, the importance of The Gilmore Girls and doctor shows, making plans on the phone, and having friends over. They learn tolerance, patience, and are acutely aware of how people treat their brother and others with special needs.

He teaches people about the positive attributes of people with Down Syndrome every day. Our friends visited from Seattle this summer with their teenagers. Michael was enamored with them and they were more than happy to play cars and golf with him. Later, after asking us about Down Syndrome, and seeing Michael's sunny personality and contagious smile, the 19 year old boy said, "Then I want to have one of them."

We are fortunate that we have a very supportive extended family with doting grandparents, aunts and uncles and cousins, and friends. With Michael, our lives are expanded and enriched and we wouldn't have it any other way.



(Continued from page 8)

Dan and Gretchen Thibault hosted a private performance by 2007 Grammy Award Winner, Dan Wilson, at their home on Turtle Lake in Shoreview. The singer/songwriter (formerly of Trip Shakespeare and Semisonic) is best known for the hit *Closing Time*. Dan



Wilson was kind enough to offer a private concert as a live auction item at the ARC Greater Twin Cities annual Gala last winter. The Thibaults bid on the concert because they loved Dan Wilson's music. It didn't take them long to realize that they could further benefit another organization with the concert, which led them to raise funds for DSAM. The Thibaults youngest child, Ricky, has Down syndrome. It is their great desire to educate the community and help parents replace the fear of a diagnosis with the well-deserved joy.

Over 100 people were entertained by the outdoor performance. Jessica Hancock, a DSAM Board member, provided an overview of the history of DSAM and described the Down Comforter program. 100% of the \$8,300 raised was directed toward the purchase of the Down Comforter packages.

PARENT GROUPS

Attend a Parent Group meeting near you to meet other parents of children with Down syndrome, share information and experiences, discuss common issues or concerns, and find support. **Please call the facilitator for information, as times and locations are subject to change.** Information is also available at the Down Syndrome Association office: 651-603-0720 or 800-511-3696. **Special Note: Contact group facilitators for summer meeting schedules.**

Apple Valley

Shepherd of the Valley Lutheran Church
12650 Johnny Cake Ridge Road
3rd Monday 6:00-8:00pm
Jennifer Lee (651) 463-2226
Jennifer_lee@charter.net
Gretchen Martin-Miller (952) 403-6722
gretchen.martinmiller@gmail.com
Childcare \$3/child

Bemidji

ECFE Bemidji Community Service Bldg
3rd Wednesday, 10:15am
Randy Jurek (218) 759-0097
(800) 450-7338
jurek_randy@yahoo.com

Buffalo

Discovery School
301 NE 2nd Ave, Buffalo
3rd Monday, 6:30-8:00pm
Sheri Jorgensen (763) 682-0756
Sheri.jorgensen@co.wright.mn.us
Penny Kauffman (763) 498-7173
pckuffman@comcast.net

Chisago City

Call for meeting time & location.
Lorraine Skordahl (651) 257-8078
us4skordahls@fronier.net

Duluth

St. Paul Episcopal Church
1710 E Superior St, Duluth
3rd Monday, 6:30-8:00pm
Nick Faust (218) 786-9276
nick@downupnorth.org

Eau Claire, Wisconsin

Call for meeting times & location.
Janet Carlson (715) 836-9243
cjar5@msn.com

Faribault & Martin County Area

United Hospital District Classroom
515 South Moore St, Blue Earth
Use main entrance on south side of bldg.
4th Thursday, 6:00–8:00 pm
Andrea Miller (507) 848-0229
James Miller (507) 848-0224
dssgFmc@hotmail.com

Fargo – Moorhead

Call for meeting time & location
Diane Brendemuhl (218) 236-5501
wbrendemuhl@hotmail.com

Grand Rapids Area

Itasca Resource Center
1209 SE 2nd Ave, Grand Rapids
3rd Wednesday, 9:30-11:30am
Childcare provided
Suzanne Ducharme (218) 327-5570
sducharme@isd318.org

LaCrosse, WI & SE Minnesota Area

Children of the Heart Group
Call for meeting times & location
Rachael Pierce (608) 786-4277
www.dscoth.org

Lino Lakes

Galiilee Baptist Church
0 North Road, Circle Pines
3rd Monday 7:00-9:00pm
Susan McMullan (651) 407-6550
SusanMMcMullan@aol.com

Mankato/St. Peter

Bethel Baptist Church
1250 Monks, Mankato
1st Tuesday, 7:00pm
(during school year)
Laura Doherty (507) 934-2014
laura1252@msn.com

Maple Grove

Maple Grove Community Ctr.
12951 Weaver Lake Rd., Maple Grove
3rd Tuesday, 6:30-8:15pm
No summer meetings
Lisa Bartsch (763) 391-6634
ljbartsch@aol.com

Minneapolis

Wilder Complex
3328 Elliot Ave, So. Door #2
1st Monday, 5:30-7:30 p.m. (begin 10/6)
Jeneane Butrum (612) 668-5132
Jeneane.butrum@mpls.k12.mn.us

Minneapolis—Latino Parent Group

Wilder Complex
3328 Elliot Ave, So. Door #11
1st Saturday, 12:30–3:30 p.m.
Gladis Rosales (651) 487-5365
Tinas.Cleaning.Services@hotmail.com
Childcare provided

Minnetonka

Cross of Glory Baptist Church
4600 Shady Oak Rd, Minnetonka
2nd Monday, call for time.
George & Janet Linkert (952) 472-1641
georgemattthew@linkert.name

Owatonna

Call for information
Jane Mullenbach (507) 444-0323
jjmully@smig.net

River Falls, Wisconsin

Have a Heart Farm
W10356 Hwy 29, River Falls, WI
3rd Monday, 6:30 Social, 7:00 Meeting
Jenny Wazlawik (715) 262-8333
wazlawikj@centurytel.net
Terri Yira (715) 381-3015
terri_y@comcast.net
Susan Erickson (715) 381-9825
wsrm@baldwin-telecom.net

Rochester

Calvary Evangelical Free Church
5500 25th Ave. NW, Rochester
Meets quarterly
Call for meeting time & date
Debbie Monahan (507) 287-2032
dmonahan@arcse-mn.org

Roseville Area Parent Group

Brimhall Elementary School
1744 North County Road B, Roseville
4th Monday 6:00-7:45p.m.
Tracy Hafeman (763) 208-4495
Hafrtr_803@msn.com
JoAnna Harris
joanna0909@mac.com

St. Cloud Area

Hope Covenant Church
336-4th Ave. S, St. Cloud
3rd Thursday, 6:00pm
Cindy Owen
cowen@arcmidstate.org
(320) 251-7272 or (877) 251-7272

St. Paul

St Matthew's Episcopal Church
2136 Carter Ave, St. Paul
3rd Thursday, 7:00pm
Jennifer McKeown (651) 647-5771
johnjenmck@comcast.net

Stillwater

Rutherford School
115 Rutherford Rd, Stillwater
2nd Tuesday, 6:30 gather,
7:00-8:30pm meeting
Childcare provided
Jan Kramer (651) 439-7037
ozkramer@cpinternet.com
Megan Sundgaard (651) 430-2013

Willmar

Call for information
Jamin Johnson-Schneider
(320) 354-4888
jamin@wciservices.org

Winona

Goodview Elementary School
5100 W 9th St, Winona
Call for meeting times
Bruce Potter (507) 523-3311
Karen Bunkowski (507) 457-6264

06/2009

Fundraising Opportunities

Kowalski's—Grand Ave, St. Paul

If you live in St. Paul and shop at Kowalski's, drop off your receipts at the "Shop and Give" receipt drop at the Grand Ave Kowalski's and a portion of your spending will go to the Down Syndrome Association of Minnesota.

Dunn Bros.

We still have Community Giving cards available. If you frequent Dunn Bros and don't have a card yet, call the DSAM office and we can send you one. A portion of your purchases will come to DSAM.

United Way

Although DSAM is not a United Way-funded agency, you can designate DSAM to be a recipient of your gift made through payroll deductions or as an outright donation. In 2007 DSAM received over \$10,000 through United Way giving.

Donate your used car

Donate your car to benefit DSAM. Cars, Trucks, RV's - running or not! Free pick up anywhere. Visit www.dsamn.org/fundraising for more info and other ways to support DSAM!

Save the Date!

12th Annual St. Paul Walk
September 20th, 2009

8th Annual Duluth Walk
September
27th, 2009

25th Anniversary Gala
November 7th, 2009



Going Green

Help us save money and paper! Remember: You can request to receive *Special Times* by email! Just send your request to Kate@dsamn.org



Want to know when your membership is due?

Check out the mailing label on the back page! The month and year your membership is due will appear after your name:

John & Jane Smith 9/2009

Remember, there is an alternative category for membership, pay what you can, even if its \$0!

DOWN SYNDROME ASSOCIATION of MINNESOTA MEMBERSHIP APPLICATION

- NEW MEMBERSHIP RENEWAL GIFT MEMBERSHIP
 CHECK IF YOU DO NOT WANT TO BE INCLUDED IN THE MEMBERSHIP DIRECTORY

NAME _____

ADDRESS _____

CITY _____ STATE _____ ZIP _____ COUNTY _____

PHONE _____ Email _____

NAME & DATE OF BIRTH OF PERSON WITH DOWN SYNDROME _____

Relationship to person w/Down syndrome: _____

If this is a gift membership, list the recipient's information above and list your name here

MAIL THIS APPLICATION WITH YOUR CHECK

Down Syndrome Association of Minnesota, 656 Transfer Road, Saint Paul, MN 55114

MEMBERSHIP LEVELS

- Patron \$1000.00+
 Benefactor \$250.00+
 Contributor \$100.00+
 Regular \$20.00
 Alternative \$_____
Additional Donation Enclosed
\$ _____

Calendar

September

September 8 Board of Directors Meeting
September 20 Step Up for Down Syndrome Walk
September 27 Duluth Buddy Walk

October

October 13 Executive Committee Meeting
October 20 Educator Conference—Metro Area
October 22 Educator Conference—Grand Rapids

November

November 1 Pancake Breakfast
November 7 25th Anniversary Gala
November 10 Board of Directors Meeting

Library & Resources

Do you have over due books checked out? If you do, please return them to the DSAM office as soon as possible!

This newsletter reports items of interest relating to Down syndrome and will provide a forum for others. *Special Times* does not promote or recommend any therapy, treatment, educational setting, etc. We will not espouse any particular political or religious view. Individuals or organizations referred to do not necessarily endorse this publication or its editor. We wish to bring together those interested in Down syndrome and attempt to create an optimistic outlook attitude. The editor reserves the right to make corrections as appropriate and in accord with established editorial practice in material submitted for publication.

Address Service Requested

Down Syndrome Association
of Minnesota
656 Transfer Road
St. Paul, MN 55114
(651) 603-0720 or (800) 511-3696
dsamn@dsamn.org
www.dsamn.org

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