



# Special Times

Volume 25 No. 2

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NEWSLETTER OF THE DOWN SYNDROME ASSOCIATION OF MINNESOTA

## Down Syndrome Association of Minnesota receives \$25,000 as one of Allianz Life Insurance Company of North America's Charities of the Year

On February 19<sup>th</sup>, our Executive Director Kathleen Forney, joined representatives from the American Cancer Society, Animal Humane Society and Hope Kids as they were introduced at a company-wide meeting at Allianz to announce the four charities who were selected as Allianz' 2010 Charities of the Year. Each organization received a check for \$25,000.

Twenty-five nonprofit organizations were originally nominated. Employee voting took place during the month of January. Kathleen along with Kim Hei and her daughter Carina and staff member Catherine McDonnell-Forney and self advocate Nayef Albinali attended Charity Fairs held at Allianz early in the voting month. The charity fairs gave employees an opportunity to meet with the 25 non profit organizations who were nominated. DSAM members and Allianz employees Craig Parker, Matt Gray and Cathy Kaneski did a terrific job informing their colleagues about DSAM – handing out information sheets and bookmarks listing the programs and services of the organizations.

We are very proud and honored to have been selected by the employees of Allianz as one of its 2010 Charities of the Year! One of the commitments Allianz makes to the nonprofits selected for this honor is support at activities and/or events throughout the year. We look forward to giving Allianz employees a hands-on opportunity to learn more about the Down Syndrome Association of Minnesota and our families.



### 2010 Regional Conference Down Syndrome – The Movie Lights! Camera! Action!

The Down Syndrome Association will host its 9th Regional Conference on Saturday, April

10<sup>th</sup>. The conference will be held on the St. Paul campus of the University of Minnesota.

This year's conference promises to surpass the last eight! The lineup of speakers for this conference promises to make it one event you don't want to miss. We will be holding workshops on Nutrition, IEP's, Financial Planning, Educational Best Practices and Medical care among others.

If you haven't had a chance to register yet, please do as soon as possible. We don't want to have to turn any DSAM members away! Registration information can be found on the web at [www.dsamn.org/regconf](http://www.dsamn.org/regconf) or you can call the office for additional details, 651-603-0720 or 800-511-3696.

### 13th Annual Youth & Adult Conference

The Association's very popular Youth & Adult Conference will take place May 8<sup>th</sup>, 2010 at the Marriott West in Minneapolis. It is a one-day event with exciting workshops, opportunities to voice your ideas at the microphone, a delicious lunch and a dance to finish off the day.

On February 13<sup>th</sup>, 13 self advocates (David Forney, Peter Groff, Jake Walinski, Mallory Schwartz, Jeremy Collins, Chris Mason, Shaina Robb, Camilo Mejia, Hannah Rousar, Beau Karlen, Adam Hancock, Tom Sander and Tim Judge) joined board members Lori Turbenson and Tom Belka for a planning session at Camp Eden Wood in Eden Prairie. They have a great day planned for you! Back by popular demand are clay, creative writing and introduction to improv. New this year will be an outdoor skills training workshop as well as an independent living skills workshop.

The registration fee will remain at \$25 to make it affordable for our young people with limited incomes. Please remember that workshops fill on a first come, first served basis, so if there is a particular workshop you are interested in, get

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### Special Points of Interest

**9th Regional Conference**  
April 10, 2010  
U of MN  
St. Paul, MN

**13th Youth & Adult Conference**  
May 8, 2010  
Marriott West  
Minneapolis, MN

**Annual Picnic and Harley Raffle**  
June 13, 2010  
Columbia Park  
Minneapolis, MN

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of Minnesota**

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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*

Letter from the Executive Director  
By Kathleen Forney

Dear Members,

The year started off busy and it appears that the trend is going to continue. Your staff has been busy preparing for our 9<sup>th</sup> Regional Conference, 13<sup>th</sup> Youth & Adult Conference, 7<sup>th</sup> Grandparent Conference and our 3<sup>rd</sup> Educator Conference. In addition, we have added a conference which will be held September 11 focused on issues relevant to those of us with adult children with Down syndrome. Please watch your mail and our website for additional information on all the conferences.

I have been asked to make presentations about Down syndrome to staff at a few area schools lately and nowhere has the need been more apparent than in the recent news stories about our member family, Shawn and Lora Herman. You might recall that in January local radio station WCCO did a story on Kyle Herman. Kyle started kindergarten in 2006 and shortly after that the trouble began. Lora and Shawn began to see unexplainable, odd behaviors from Kyle. A little boy who enjoyed school, suddenly didn't want to go into the building anymore. As we all know, one of the greatest delays a child with Down syndrome often deals with is language delay, and most especially expressive delays. Kyle couldn't verbalize what was happening to him in his classroom and instead began acting out physically - having problems in school as well as at home with his siblings. Lora and Shawn spent months trying to determine the source of Kyle's behavior.

In the end, it was discovered that Kyle's teacher was physically and verbally abusing him. It is unbelievable enough that the teacher wasn't fired until near the end of the school year, but even more shocking was the fact that no one informed Laura and Shawn what was happening until months later....even though others in the school knew what was going on. It appears that current state law does not require parental notification in instances of child abuse in a school facility.

Every once in a while, we hear or read of something and say to ourselves "this just isn't right, something needs to be done". Such was the case when a group of Concordia University students heard Kyle's story. The students did their homework and drafted a piece of legislation "The Kyle Herman bill" which would require parental notification of a child being maltreated. According to the bill, parents must be notified within ten days after a mandatory report is made. Representatives Tim Mahoney (D - St. Paul) and Torrey Westrom (R - Elbow Lake) co-sponsored the bill. A house committee hearing was held on March 3<sup>rd</sup> and the committee approved the bill as written by the students at Concordia. It should be noted that while some districts routinely notify parents when abuse is suspected or confirmed, there is nothing in our laws as they currently stand that require parents be notified that an abuse investigation is underway.

Lastly, but the most important aspect of the Kyle Herman Bill is not just changing a word from may to shall but that this discussion is leading to more discussion about mandatory reporting and other issues that failed to work in Kyle's case. It was very apparent at the first hearing, law makers were totally unaware of how cases like Kyle's can be handled and not be in violation of state statutes. The Concordia students have the ball rolling and are doing their part to make a difference, now it is up to all of us to keep the momentum going and not let their hard work and perseverance go unnoticed or worse yet unsupported. WE HAVE THE LAWMAKERS EAR AT THIS TIME. WE NEED TO TAKE ADVANTAGE OF THIS OPPORTUNITY TO THE FULLEST.

You can show your support for the Kyle Herman Bill by contacting your representative and senators and by also becoming a friend/fan of the bill on the Facebook page that the Concordia students set up—The Kyle Herman Team.

**Welcome New Parents:**

Clinton & Christina Cole  
Laura & Brian Budziszewski  
Tamara & Jason Evers  
Christina & Tony Schaaf  
Kathy Kimani  
Jerry & Carla Greene  
Christine & Scott Peters  
Rosalia Aca & Reyes Diaz

**New Members:**

Judy Beaton  
Rocky & Ellie Zahrowski  
Carrie & Joseph Heisler  
Ramon, Barbara & Judy Thomes  
Melissa Koschak

**Patron (1000+)**

Carly May Foundation  
Allianz Life Insurance Company

**Benefactor (250+)**

Shelly & Bryce Boelter  
Aaron & Missy Smith  
Mark & Wendy Yungner  
Dave & Ellie Bilderback  
Kim McConnell  
Chris & Penny Kauffman  
Anonymous  
Ken & Kerri Ambrose  
James & Dorothy Arendt  
Debbie & Steven Plager  
Steve & Cindy Calvin  
Midway Bank, Wabun, MN employee bake sale

**Contributor (100+)**

Kowalski's Grand Market – Groceries for Good Causes  
Steve & Sue Turbenson  
Anonymous  
Gail Dorn & Steve Beddor  
Marilyn Kapter  
Clayton & Charis Jensen

**In Memory of**

Mabel Nelson  
From Braxton in memory of his Grandpa Jerry Herzog  
Carly Harris  
Mr. Gene Gibson  
Rebecca Hensel  
Sean Maher  
Marion Gilbertson

**In Honor of**

Mariarose Quelle's birthday  
Colton Blair Smith  
Wesley Dahle  
Julia Robinson

Megan Sturman  
Claire Ellen Larson's 10<sup>th</sup> birthday  
Rudy Slette

**Employee Giving and Matching through:**  
Wells Fargo Community Support Campaign  
Ameriprise Financial Employee Giving Campaign  
United Way of Olmsted County  
Liberty Diversified International

*(Continued from page 1)*

your registration in early! Scholarships are available and can be used for travel expenses for self advocates.

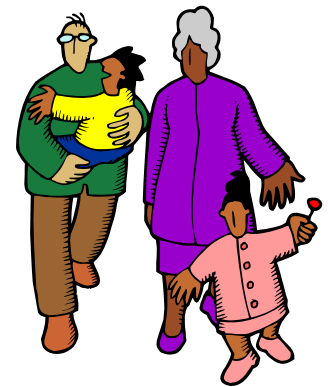
Volunteers are always needed for the Youth & Adult conference. If you are interested in joining us for the day, please contact Catherine, [catherine@dsamn.org](mailto:catherine@dsamn.org) or 651-603-0720

***Focus on***  
**Grandparents**

**Metro Grandparents Group**

Are you a grandparent in the Metro area? Join up with the new grandparents group! The group meets once a month for a sharing session and often has speakers!

Meets the 3rd Thursday of the month at 9 a.m. for breakfast and then discussion at 10:00 a.m. at the Edina Perkins at France Ave and I-494. Questions? Call Jerry Cooper at (952) 432-9769 or email [jerry-cooper@frontiernet.net](mailto:jerry-cooper@frontiernet.net)



**7th Annual Grandparents Conference**

Saturday, May 1st from 8:30 to 1:30. The conference will include a half day of workshops including breakfast and lunch. Please mark your calendar now and plan on joining us for this conference on May 1st.

Watch your mail for additional information. If your parent's are not members and you think they might be interested in attending the conference, just give us a call

## **Focus on Children's Health**

### **Joint Disease in Children with Down Syndrome**

*Melissa Teshler, MD and Karen Brandt Onel, MD*

*Division of Pediatric Rheumatology*

*The University of Chicago*

Doctors have known for many years that children with Down syndrome face an increased risk of autoimmune diseases. Autoimmune diseases are caused by a malfunction in the body's natural defense systems against infections. This category of diseases includes thyroid problems, diabetes, alopecia (hair loss), vitiligo (pigment loss), and celiac disease as well as arthritis. The American Academy of Pediatrics recommends that children with Down syndrome have screening tests for thyroid disease, diabetes, and celiac disease. However, many physicians and parents don't know that children with Down syndrome are at higher risk of arthritis or inflammation of the joints.

Juvenile arthritis is a rare disease but more common in children with Down syndrome. In the general population, between 1 and 2 children out of every 1000 have arthritis. According to one study, out of every 1000 children with Down syndrome, between 8 and 9 have arthritis. So, arthritis is about six times as frequent in children who have Down syndrome as those who do not. Researchers are not certain whether the arthritis which affects children with Down syndrome is the same disease as juvenile arthritis affecting other children. For this reason, arthritis in a child with Down syndrome is considered a separate disease, known as Down's arthropathy.

Arthritis can be hard to diagnose in any child. The symptoms of arthritis include joint pain, joint swelling, and morning stiffness. Other children may experience delays in learning motor skills like walking and running, or even lose the ability to do activities they had previously mastered. A doctor may notice that the child's joints have a decreased range of motion, meaning that they are less flexible than usual. Many children with Down syndrome have unusually flexible (hypermobile) joints, so a decrease in joint motion can be difficult to recognize. Sometimes, lab tests can help point to a diagnosis of Down's arthropathy, but in other children, lab testing is completely normal. The most important clues to diagnosis are the child's or parent's description of his/her symptoms, and the doctor's physical exam.

Can Down's arthropathy be treated? In most cases, the answer is yes! Usually, the earlier arthritis is diagnosed and treated, the better the chance of reducing or even eliminating the child's symptoms. Anti-inflammatory medications, such as ibuprofen or naproxen, can help relieve arthritis pain. Other medications, like methotrexate, are considered disease modifying agents and can stop or slow disease progression. If these treatments are not enough, a new class of medications known as biologics has shown excellent results for some children with juvenile arthritis. Physical therapy is

another key element of treatment.

Hopefully, parents and doctors of children with Down syndrome will increasingly recognize the need to watch for signs of arthritis in these children. With prompt recognition and early referral to a pediatric rheumatologist for treatment, the outlook is bright for most children with Down's arthropathy.

### *References:*

American Academy of Pediatrics Committee on Genetics. Health supervision for children with Down syndrome. *Pediatrics* 2001; 107: 441-449.

Juji H and Emery H. The arthropathy of Down syndrome: an underdiagnosed and under-recognized condition. *Journal of Pediatrics* 2009;154:234-8.

Olson JC et al. Arthropathy of Down syndrome. *Pediatrics* 1990; 86:931.

*Editor's Note: The inflammatory type of arthritis described in this article is different from osteoarthritis, which is usually associated with aging. Osteoarthritis is also more common in people with Down syndrome.*

*Reprinted with permission from NADSnews, newsletter of the National Association for Down Syndrome, January 2010*

## **Focus on Metabolism**

### **Metabolism**

*By, Joan Medlen, RD, LD*

In the first weeks after our son with Down syndrome was born, my thoughts strayed to his health throughout his life. My impression was that all adults with Down syndrome were very obese. As a dietitian, most of my work had been in the weight management area. I had seen firsthand the effects of long-term obesity on a person's life. I remember emphatically explaining to my husband that we needed to be an aerobically active family. I asked him to consider cross-country skiing, and to plan for activities like family biking trips.

Now, years later, Andy is a slender, tall boy, like his brother. He eats well but not perfectly. He appears "active," but it's not very aerobic. And, when I look at other children with Down syndrome at conferences and in my community, there seems to be a mix of body types: some are slight and petite, some are thick and stocky, and some are overweight. Where did that early image of obese adults come from? Had I fallen for a myth? Could it be that this younger generation of persons with Down syndrome will not have as many obese adults? Has the increase in community inclusion changed the incidence of obesity?

Probably not. Research suggests children with Down syndrome are as active as their peers, yet use fewer calories overall. They appear to have a lowered Basal Metabolic Rate, which is the rate a person burns calories for fuel when completely at rest or sleeping. Taking that information one step further, it means that they use fewer calories throughout the day to accomplish the same activities as their typical peers.

When Andy hangs out with his friend, and eats the same amount and kinds of foods, does the same activities with the same intensity for the same amount of time, he will burn up to 15% fewer calories than his buddy. Since he ate the same amount of food as his buddy, but needs less to do the job, he has calories leftover. These extra calories—even as few as 50 calories per day—can lead to an increase in weight.

For example, 50 calories is equal to a half of a large red delicious apple. The calories from half an apple leftover at the end of the day for one year will lead to about 5 pounds of increased weight. If that continues for 5 years, it becomes a troublesome 25 pounds. With this in mind, it is easy to see how slender children and adolescents with Down syndrome can change into overweight young adults.

There are three ways to adapt for this difference in metabolism: increase activity, limit calories or increase activity AND limit calories. Focusing on calories alone is one option. However, unless there are other medical reasons, it is risky to limit calories for children under 18 years of age without direct medical supervision. Children have great vitamin, mineral, protein, carbohydrate and energy needs while they are growing. Limiting calories may cause children to get too few of what they need to grow and develop well. For adults, a sole focus on calories becomes a battle of willpower and feels like a punishment.

As with everything else, focusing on positives and abilities has a far greater effect. Beginning with a focus on physical activity has many more positives. A person can choose from a variety of aerobic activities that are enjoyable. Additionally, regular aerobic activity has many health benefits; increased muscle tone, decreased resting heart rate, decreased blood pressure, a sense of well being, better sleep and an increase in metabolism.

Being physically active and focusing on aerobic activity doesn't mean you need to be an Olympic athlete. For the average person with or without Down syndrome, adding small amounts of aerobic activity on a regular basis makes a difference. Even small changes in daily activities can be beneficial.

Coming up with ideas to increase activity is the easy part. The hard part is choosing activities that are motivating. It is important that the person with Down syndrome make the choice of activity and be involved in setting goals.

Working together as a team in planning will help. Write your plans in a special place. Create a list of 2 small, but specific, activities to add in a week. Begin with things that are 99%

achievable. Talk about when activities will be and who will participate. Write them on the calendar. Then create a way to track visually as goals are met with a chart or checklist. Remember to leave room for doing more than the goals you write down a chance to over achieve!

For Andy, we hope to build habits that will last a lifetime and are fun habits that will increase his overall activity and hopefully reduce the risk he will have to fight the battles that extra weight can bring.

*From FEDS News Today, October 2009, Vol 20 #6, newsletter of Families Exploring Down Syndrome.*

#### **Ideas for Adding Aerobic Activity for Parents, Adults and Children:**

- Park at the far end of the parking lot
- Take the stairs instead of the elevator
- Walk or bike to activities in your area
- When you go to the park, play tag for 10 minutes with the kids. Don't catch them, chase them around!

#### **Ideas for Adding Aerobic Activity for Teenagers and Adults**

- Use a push mower to mow the lawn
- Go for a long walk, hike or bike ride with a friend weekly
- Join a local recreation facility
- Join a walking club
- One hour of television watched = a walk around the block.



#### **Carly May Classic Memorial Golf Tournament Supporting the Carly May Foundation Heritage Links Golf Course Lakeville, MN**

The second annual Carly May Classic Memorial Golf Tournament last May was another huge success and a wonderful tribute to Carly Harris. Nearly \$30,000 has been raised in two years to support the Carly May Foundation.

Mark your calendars for the third annual Carly May Classic Memorial Golf Tournament. The tournament will be held Saturday May 22nd, 2010 again at Heritage Links Golf Course in Lakeville. All proceeds from this event will directly support the Carly May Foundation which helps families that have a child with Down Syndrome and/or a chronic illness. For more information and to register and/or donate please go to [www.carlymayfoundation.org](http://www.carlymayfoundation.org)

The event is promising to be a great time! Gather a team and join us for a wonderful day of golf, food, silent auction, prizes, raffle and FUN! The cost per person is \$150; \$30 if you just want to attend the dinner and silent auction. If you are interested in donating an item or service for the silent auction you can contact Maria Harris via email at [mariajharis@earthlink.net](mailto:mariajharis@earthlink.net) or by phone at 651-335-6201. Register Early. Space is limited!!!!

## From Segregation to Integration: Tracking a Revolution in Special Education

By Dr. John Rynders

At what point in time were individuals with Down syndrome set on a path toward education? A likely place for the starting point is 1866. In that year, John Langdon Down published a paper asserting that a group of people who were “feeble minded” and looked Asiatic to him were a degenerate branch of the Mongolian race. Interestingly, in his paper he emphasized that they (the “mongoloids”) responded very well – unusually well – to training. Shortly, from an education stand point, the word, training, would come to represent the fixed and universal ability level of students with Down syndrome. That is, they were believed to always be trainable, but never educable. Yes, they could be trained to dress themselves and sweep a floor. But, to learn to read, write and do arithmetic in the traditional sense was simply out of the question. This belief was wrong of course, but it would take years of evidence and advocacy effort to be corrected.

In 1912, the word, segregation, would gain prominence because of a phenomenon called the Eugenic Scare which would lead quickly to the Eugenics Movement. The movement based on fear that people with mental retardation, especially the cultural – familial type of retardation, would ruin the general population’s gene pool because, allegedly, they would breed indiscriminately and rampantly. This whole scare business was based on totally false information. Nevertheless, in short order the proponents of the movement proposed that segregation in residential institutions on a life-long basis was required.

While individuals with Down syndrome didn’t fit into the grouping dubbed cultural – familial mental retardation, they had been identified by Dr. Down as a genetic mutation. For the eugenics advocates, that was “close enough”.

In short order, acres of land in rural areas were set aside as institution campuses and a building boom in large dormitory construction occurred in order to accommodate institutionalized residents.

Racing to “protect” the general population’s gene pool, residential institutions were quickly established in remote geographical areas across the U.S. Persons with all kinds of cognitive limitations, including individuals with Down syndrome, soon began to fill them. Once filled, more institutions were established. By the middle of the 20<sup>th</sup> century, every state would have at least one institution. Many states, including Minnesota and Wisconsin, would have three major state residential institutions. Still demand grew, resulting eventually in severe overcrowding. The solution? Cram 10 beds into a space designed for five; then cram 15 into that space. Eventually, beds were barely separated from one another.

Individuals with Down syndrome were frequently institutionalized. Many were institutionalized in infancy, not so much because they “posed a threat to the gene pool,” but because

their parents received such a terribly pessimistic prognosis of their future. For instance, they were advised that “A mongoloid child will remain eternally immature.” “Your mongoloid child will ruin your life if you try to raise him at home.” “Institutionalize him now so that you don’t get attached to him.” “He will always be severely retarded.”

As institution dormitories became ever more crowded, over-worked employees developed ways to cope. These adaptations usually turned out to be maladaptations not only for the residents but for the employees. Nevertheless, “herding”, “hurrying” and “shortcutting” became common. (I will provide examples of these in the next installment of this article).

In 1957 I began my first teaching job as a special educator. I was employed at a state residential institution in Wisconsin, the Northern Wisconsin Colony and Training School (NWC & TS). I was assigned to teach two classes of children designated as “trainable.” A considerable number of my students had Down syndrome. Because of the expectation that “they were always trainable and never educable” my students with Down syndrome, along with my other trainable students learned self-care skills, such as dressing independently, and to master menial tasks such as floor scrubbing. Their academic instruction was limited to the most basic, functional 3-R’s such as name recognition, responding to verbal directions and recognizing signs for safety purposes around the institution grounds. Counting objects up to 10 was taught and practiced, as were numerous discrimination and matching tasks. Art, music and physical education activities were provided in my classroom as well as during set-aside periods outside of class. Overall, as a trainable program, under the direction of the State Department of Education, and staffed by fully licensed teachers and specialists, the school program was a fairly good one at NWC & TS. As a matter of fact, in an unusual way, it met a need not filled by public schools in the community. How come? Well, in 1958 an influential and nationally known special education expert published an article in which he argued that individuals classified as trainable should not be in public school classrooms at all. This opened the door for public school administrators to exclude any student identified as trainable. Of course, students with Down syndrome were “always trainable” so they were excluded very frequently. Hence, my students with Down syndrome attended the institution’s school, while those with Down syndrome living in the community often were not in public schools at all.

In 1961, I became principal of the school at NWC & TS and figured that I was “set for life” as far as a career in special education was concerned. But then the Soviet Union launched Sputnik into space, an earth orbiting satellite, and the US entered into a “space race”. Over the next few years substantial amounts of federal funds were committed to higher education and research. I was fortunate to be invited to apply for a federal fellowship to pursue a doctoral degree at the University of Wisconsin. I did, and was accepted in 1964. In that same year, congress passed The Civil Rights

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Act. This legislation would not only assume a major role in moving people of color into the mainstream of society, it would help to move students with Down syndrome into the educational mainstream. This positive side of the special education revolution will be the subject of the final part of this article, coming up in May.

John Rynders, Professor Emeritus, Department of Education Psychology/Special Education Programs, The University of Minnesota.



### Linder's Fundraiser

The Down Syndrome Association has teamed up again with Linder's Garden Center and Flower Marts to give members an opportunity to help support the programs and services of DSAM.



From May 7th to May 10th, if you shop at any of the forty plus flower marts around the metro area and mention that you are with the Down Syndrome Association of MN, we will receive 15% of your pre-tax purchases as a donation. A great way to beautify your garden and help support the Down Syndrome Association!

### Pahl's Spring Flower Fundraiser

Pahl's Market  
6885 160th St W  
Apple Valley, MN 55124

Monday, May 10th—Tuesday, June 1st



Buy your plants and garden supplies at Pahl's Market to help raise money for the Down Syndrome Association. Pahl's Market will be donating 10% of all regularly priced merchandise purchases to the fundraiser. In order for us to receive the credit, please use the coupons below\* or mention the Down Syndrome Assoc. of MN to the cashier. The Spring Flower Fundraiser may not be used with any discount.

\*Additional coupons & links for both of these fundraisers can be found on the DSAM website.

**A SPECIAL INVITATION TO SHOW YOUR SUPPORT**  
**FOR: Down Syndrome Association of Minnesota**

In the 2010 fund-raising effort along with  
**LINDER'S GREENHOUSES, GARDEN CENTER AND FLOWER MARTS**

Your Name \_\_\_\_\_ Pre-tax amount \$ \_\_\_\_\_

Sign this invitation. Bring it to any of the 50+ Flower Mart locations or the main store **MAY 7 TO MAY 10**.  
 Our organization will receive 15% of your pre-tax purchase total that the cashier will record above.

Our sincere thanks to you for your patronage.

**Linder's** FM# \_\_\_\_\_ **GO TO WWW.LINDERS.COM FOR DETAILED STORE LOCATIONS.**

 **Fundraiser Coupon**  
**May 10th – June 1st 2010**  
 Down Syndrome Association of Minnesota

Total: \$ \_\_\_\_\_

Valid only on regularly priced merchandise.  
 Not valid with any discount or on services.

## Stories to Share

### A New Kind of Victory

By Susan McMullan



The girls only had six days to prepare, which really wasn't long enough. Cheerleading competitions bring in large crowds and a strong, aggressive spirit. Our team prided itself in working hard and performing to our greatest potential. But we were a new team and had never been in a competition.

So every day after school, the Centennial High School Adapted Cougarettes cheerleading squad practiced. We worked on clapping our hands in harmony. We worked on chanting the cheers in rhythm. We worked on facing straight ahead when we stood. Basic things the other cheerleaders in the competition probably never even touched on.

The big day arrived and our girls were confident. Walking into the nearby high school to a crowd of over 1300 cheerleader fans was scary. The stands were filled as if it were a State Basketball tournament. There were 32 squads and only two of them were for girls with special needs.

The other cheerleading squads put on shows reminiscent of Cirque du Soleil meets High School Musical. Hip hop dancing and high lifts were met with oohs and aahs. I gasped as the girls towered in the air, praying each one would get caught safely as they twisted downward. I quickly realized our cheerleaders were not in the same league as the rest of the teams.

Just like a typical sports competition, the crowd only applauded for their own team. This was serious business. After all, the parents paid lots of money for cheerleading, and

the girls contributed lots of time and energy to their routines. You don't clap for the competition; you clap only for your own team.

Then it was our turn to perform. I quickly placed name cards on the floor to guide each girl on where to stand. With their feet planted firmly on the ground at all times, the five girls began their first cheer. "Give me a 'C'," shouted the cheerleaders with their right fist pumping high in the air. This routine was simply something I had remembered from my high school days from over 30 years ago. I tempered my embarrassment by hearing the roaring crowd behind me echoing back with a thundering response.

"C," the crowd yelled. I had expected our five parents to shout back the letters, but was surprised to hear the entire audience respond.

With bright eyes and an enthusiastic bounce, the adapted cheerleaders continued, "give me an 'O'."

"O," the crowd bellowed with equal volume and enthusiasm. Something was happening here, I thought. Wasn't this a competition? Why would the crowd respond so enthusiastically?

"Give me a 'U'," the girls continued triumphantly, surprised by the support of the crowd. Suddenly the moment was greater than the event. Shaking, I kept leading the girls in cheer as I crouched down on the floor, hoping this unimaginable response would continue.

"U," the crowd erupted once again, with all the vigor and gusto you would expect out of cheerleaders and their families. I kept thinking we must not be a threat. Our adapted team was a means to bring all the girls together. Perhaps having the audience rally around us was taking the edge off the competition.

Finishing the cheer, the girls savored the glory of the moment. The crowd was exploding with applause, howling and cheering like the Cougarettes were in the Olympics going for the gold. I popped up from the floor mat and ran over to the girls, jumping up and down as we embraced in a group hug. They did it! Not only had the Cougarettes performed their routine, they had won over the crowd. As we ran out of the gym, I glanced over to the audience who was delivering us a standing ovation.

Giggling and hugging in the hallway, the cheerleaders were overwhelmed with happiness. One by one, we started crying, knowing we all just experienced one of the best days of our lives. After several minutes, one mom asked if there was anything more the girls needed to do. I responded, "no, the judges are just going to hand out the trophies. And I'm sure, based on the competition; we will not be getting one."

That cheerleader left for home. But the rest of us, curious about the awards ceremony, wanted to watch. Like wet noodles, the girls sat on the floor mats, waiting to see the various victors glorified with their trophies. "The first trophy goes

to..." started the announcer. With anticipation on their faces, the cheerleading squads each hoped to hear their school name called first. "The first trophy goes to The Centennial Adapted Cougarettes!"

My jaw dropped and my eyes popped open wide. The adapted cheerleading squad got a trophy! Surprised, the girls had never imagined this portion of the event. Like the Griswold's running to Wally World in the movie Vacation, the four remaining cheerleaders triumphed forward with their arms extended high to get their prize.

I kept thinking that a new outlook had emerged from the audience that day. Our Cougarettes had attended the competition to simply be a part of what other cheerleaders do. Perhaps, I thought, there was a greater lesson here. Perhaps the Cougarettes, without realizing it, were teaching the audience the lesson of compassion and support for one another whether they are your competitor or not.

The adapted cheerleaders grabbed their trophy and smiled for the paparazzi. In the girl's minds, the team had earned something greater than ever imagined. Running back, the cheerleaders handed me their prize. I read the words inscribed on the plaque: Participation Award.

"Did we win coach McMullan? Did we take first place?" asked one of the cheerleaders with hope in her eyes.

"Yes girls, you did win," I responded as my heart brimmed over with pride. "You indeed did win."



## Camilo Mejia Presented With His Eagle Award By Patricia Schaber



On December 26, 2009 in front of family, friends, and fellow scouts from Boy Scout Troop 389 in Mahtomedi, MN, Camilo Mejia was presented with the ultimate honor in scouting, his Eagle Award. He stood proud and with a huge grin, accepted the honor from Scoutmaster, Mike Perron. His most prized letter of congratulations among many from Senators, Scout leaders, and Civic organizations, was the letter

of congratulations from President Obama. He has it framed alongside his Eagle Scout picture.

Scouting for Camilo began in his early elementary school years. He has been with his fellow scouts for 13 years. His parents believed he could benefit from belonging to a community organization that encouraged and promoted participation in a small group, provided positive peer interaction, and was fun. He learned leadership and now mentors the young Webelo scouts. He served as a patrol leader, librarian, chaplain, and even a bugler. He earned 32 merit badges, some which were adapted to his ability, with many he completed on his own. Adaptations included using a tandem bike for the biking merit badge, copying a letter to a civic leader instead of generating one for the citizenship merit badge, and pairing with a peer for orienteering and emergency preparedness badges. He conquered many of the challenging skills of scouting including setting up his own tent, CPR, and his favorite, whittling with a jack knife. Even though he struggles reciting the Boy Scout oath, he has no problems implementing it. He loves to help others, dress up impeccably in his uniform, and obediently stand at attention. He knows the rules and follows them.

His eagle project was building three trellises for O.H. Anderson Elementary school community garden. They were covered in vines this past summer.

What Camilo gained from scouting is immense; what his fellow scouts gained from his membership in the troop is immeasurable. They have pledged to support the "R" word campaign but more importantly, have learned what a contribution people with Down syndrome can make to a community. Camilo was the top seller in fundraising for a number of years. He consistently rallied fellow scouts to try activities that were challenging and always encouraged others with smile or antic. He hopes to continue in scouting as an adult/support person for the troop and model possibilities for other scouts with special needs.

We strive to have at least one "Stories to Share" in every issue of the newsletter. We would like to invite you to share your own cause for celebration! The event doesn't have to be momentous for anyone other than your family, but other readers are likely to relate and share your joy. Submitting something doesn't guarantee it will be included, but we know that you want to celebrate – and we want to hear about it! Please contact Catherine, [catherine@dsamn.org](mailto:catherine@dsamn.org), if you are interested in submitting a story.

## 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) 682-7468  
sheri.jorgensen@co.wright.mn.us  
Penny Kauffman (763) 498-7173  
pckauffman@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  
cjcar5@msn.com

### **Elk River**

Handke Family Center Rm. 112  
1170 Main St. NW  
1st Wed, 7:00-9:00pm  
Julie Mielke (763) 856-1078  
mielkman@hotmail.com  
Heather Coudron (763) 274-1710  
woodland132@yahoo.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.dscotch.org

### **Lino Lakes**

Galilee 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

### **Minnnetonka**

Cross of Glory Baptist Church  
4600 Shady Oak Rd, Minnetonka  
2nd Monday, call for time.  
George & Janet Linkert (612) 245-1030  
georgemathew@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 p.m. Social, 7:00 Meet  
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  
Haftr\_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

### **Stillwater**

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

### **Virginia**

Our Savior's Lutheran Church  
1111 8th St. S  
3rd Tuesday, 6:00-8:0p.m.  
Jody Koschak (218) 741-8493  
jodyhaavisto@msn.com

### **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

3/2010

## Volunteer Corner

DSAM would not be the successful organization today if it weren't for the time and efforts of our volunteers! We always need volunteers to help at our events and in the office! Below is a list of upcoming events that where we need volunteer help!

### Regional Conference, April 10th

Volunteers needed to help at registration, book and merchandise sales, helping speakers, introducing speakers.

### Youth & Adult Conference, May 8th

Volunteers needed to help support teens & adults with Down syndrome enjoy the day!

### Step Up for Down Syndrome Walk—Duluth & St. Paul, September 26th

Volunteers needed to help at registration, t-shirt table, food table, supporting self advocate projects, first aid

Not interested in volunteering at events? There are lots of opportunities to help out in the office too! Volunteers are always needed to help with mailings: newsletter, event mailings, membership mailings. Volunteers are also a big help for putting together our Down Comforter Packets for new parents, expectant parents, Spanish speaking parents and grandparents.

Please contact the office by phone (651) 603-0720 or by email dsamn@dsamn.org if you are interested in helping out!

## Save the Date!

### 2010 NDSC Convention

July 16th—July 18th  
Walt Disney World, Florida

Scholarships available, contact Kathleen at kathleen@dsamn.org or by phone (651) 603-0720

### 4th Annual Joey Hebert Classic

August 2nd, 2010  
Deer Run Golf Course  
Victoria, MN

### Step Up for Down Syndrome Walk

St. Paul & Duluth  
September 26th, 2010

### Educator Conference

Twin Cities: October 13th, 2010  
Brainerd: October 14th, 2010

## 2010 Harley Raffle

### Black 2010 Road King FLHR with cruise control

Sunday June 13, 2010 - Drawing @ 4:00 p.m.

Picnic from 4-8 p.m., Food @ 5:00 p.m.



Columbia Park

800 Columbia Boulevard

Minneapolis, Minnesota

**\$300 per ticket - Only 100 Tickets to be Sold**

## 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

### February

February 9 Executive Committee Meeting

### March

March 9 Board of Directors Meeting  
March 21 Spring Dance at the Medina Ballroom  
World Down Syndrome Day

### April

April 10 Regional Conference  
April 13 Executive Committee Meeting

### May

May 8 Youth & Adult Conference  
May 11 Board of Directors Meeting

## Library & Resources

Do you have books checked out? Please return them to the member library so others can have the opportunity to read them.

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.

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Going Green

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656 Transfer Road  
St. Paul, MN 55114  
(651) 603-0720 or (800) 511-3696  
[dsamn@dsamn.org](mailto:dsamn@dsamn.org)  
[www.dsamn.org](http://www.dsamn.org)

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