



Special Times

Volume 23 No. 2

March/April 2008

NEWSLETTER OF THE DOWN SYNDROME ASSOCIATION OF MINNESOTA

Don't Miss This One! 8th Regional Conference Building for the Future April 5, 2008

By now, you have received the registration brochure for our Regional Conference. The lineup of speakers for this conference promises to make it one event you don't want to miss. 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 or you can call the office for additional details, 651-603-0720 or 800-511-3696.

5th Annual Grandparents Conference Saturday, May 3rd, 2008 Crystal Evangelical Church New Hope, MN

The Down Syndrome Association of MN is pleased to present it's 5th Grandparent Conference. It will be a great time to talk with other grandparents, listen to presentations and get answers to your questions. Topics this year: More Creating Positive Behaviors, Supportive Living, Introduction to Education Planning (IEP) and service options, Partnering after High School and Beyond, Communicating with Sign Language, and Handling those Challenging Behaviors from peers. Hear from young adults with Down syndrome, their parents, and professionals who provide support to people with Down syndrome and their families. Please watch your mail or www.dsamn.org for more information about this exciting conference!

11th Annual Youth & Adult Conference Saturday, April 26th, 2008

The Association will be hosting its 11th Annual Voices & Choices conference for young adults and adults with Down syndrome at the Continuing Education and Conference Center on the St. Paul campus of the U of MN. You must be fourteen by the 21st of April to attend the conference.

The committee members, Nayef Albinali, Tom Belka, David Forney, JT McElhatton, Lori Turbenson & Jake Walinski have been working with the Youth & Adult Conference coordinator to plan a fantastic day for you. Back by popular demand are Clay, Scrapbooking and Photography!

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 your registration in early!

Volunteers are always needed for the Youth & Adult conference. If you are interested in joining us for the day, please call Catherine at the office or email her at catherine@dsamn.org.

Don't miss out on a chance to win this 2008 Black Road King Classic FLHRC, Tickets still available, contact Marcy at (651) 603-0720



Special Points of Interest

15th Annual Picnic & Harley Raffle

Sunday June 8, 2008
Drawing @ 4:00 pm
Picnic 4-8 pm
Food @ 5:00 pm

Columbia Park
800 Columbia Blvd
Minneapolis, MN

Mark your calendar now and plan to join us for this fun filled afternoon in the park.

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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*

**From the Executive Director
Kathleen Forney**

Dear Members,

There has been, over the past year, considerable press coverage and not a small amount of anguish expended over actions taken by the American College of Obstetricians and Gynecologists (ACOG). For many in the Down syndrome community, nationwide, the ACOG has been the issue of the decade.

So what's it all about?

The ACOG sets practice standards for its members on patient care and treatment. It communicates those via "practice bulletins".

In late 2006, the ACOG released Practice Bulletin 77. Prior to Bulletin 77 the standard was to offer prenatal screening tests for Down syndrome to all expectant women age 35 and older. Bulletin 77 changed that to making the offer to all expectant mothers, regardless of age. In Practice Bulletin 88 which was issued in December 2007, the ACOG expands on its position regarding invasive prenatal diagnostic testing for Down syndrome. The main recommendation is "invasive diagnostic testing should be available to all women...Maternal age of 35 years alone should no longer be used as a threshold to determine who is offered screening versus who is offered invasive testing."

Practice Bulletin 88 does go on to suggest referral to the NDSC, NDSS or local Down syndrome organizations, when a diagnosis of Down syndrome is made. Although this is a step in the right direction, much work needs to be done to educate the medical community of the value of people with Down syndrome.

Data suggests that between 80 and 90 percent of pregnancies where Down syndrome is diagnosed, prenatally, are terminated and therein lies the primary reason for the great concern in the Down syndrome community.

The frightful termination rate, however, is but part of the story.

Research shows that often the patient's doctor is ill prepared to administer or analyze the screening tests and few have proper training on how best to deliver the news when the screening tests indicate the unborn child has Down syndrome. Too often, the research shows, the news is delivered in a highly negative manner and it is assumed the expectant parents will terminate the pregnancy, often solely on the grounds of the screening tests.

Things get somewhat complicated at this juncture.

First issue is the nature of the non-invasive screening tests addressed in Bulletin 77. These are screening tools and include application of blood sampling and ultrasound technologies. Ob-gyns can choose from a wide range of procedures, but none are termed "diagnostic". Instead, they can be used only to establish a probability that the unborn child has Down syndrome. None can establish a faultless diagnosis and accuracy ranges from as low as 70 percent to a maximum of around 95 percent.

The ACOG Practice Bulletins make this clear and also establish referral to a genetic counselor as a standard when screening results indicate a high probability that a child has Down syndrome.

(Continued on page 7)

New Members

Tim & Gina Conklin
Functional Kids Clinic
Jimmy & Melissa Hansen
Christina & Jay Kilby
Jason & Jennifer Meyer
Alison Pickford
Matt Pickford
Mike & Jenny Sullivan

Patron (1000+)

MJM Foundation
Schwab Charitable Fund
Keith Scott
Smith Barney Charitable Trust, Inc
Thomas & Rita Welch

Benefactor (250+)

Kenneth & Kerri Ambrose
Nancy, Isabella, Joseph & Nicholas Bongiorno
Gail Davis
James Randall
Mark & Wendy Yungner
Our Blue Jean Wearing Friends at US Bank

Contributor (100+)

Anonymous
Eden Prairie Foundation
Dean & Sandra Johnson
Lance & Amy Lemieus
Kowalski's Market
Benjamin & Pamela Mason
Margaret & George Thorsel

In Memory of

Ken Bruhn
John Fieda
Dan Larson
Barbara Sterner
Max Stinnett
James Wallrich

In Honor of

Eric P. Hanson, Eagle Scout, Troop 695
Colton McArdell

Employee Giving through:

Alliant Techsystems
Ameriprise
Assurant
GE Foundation
ING
Microsoft
UnitedHealth Group
USBank
Wells Fargo Community Support Campaign

Presenting to High Schools

By Tracy Hafeman

Imagine...a classroom of 30 high school girls staring at me and my son, Will. I was definitely feeling the pressure!

I had been invited to speak at the local high school in a child development course as part of the unit on pregnancy and birth defects. My goal was to be as honest as I possibly could about both the joys and the struggles that I have encountered while raising a child who has Down syndrome. I was incredibly nervous.

But then, just as I was about to start speaking, Will began working his magic. True to form, he began winning over each and every one of those students with his bright eyes and charming smile. He blew a few kisses to the girls in the second row and the whole class erupted. It was just the beginning of a 45-minute class session that would prove to make quite an impression on these young women.

I started my presentation by showing a short video montage that I had put together celebrating Will's first year of life. I went on to give a brief description of the cause of Down syndrome, as well as some of the physical characteristics that come along with it. We talked about my normal pregnancy and we talked a lot about the day Will was born. I recalled the emotional roller coaster that comes along with having a child with special needs, and how the moments of pure happiness and intense pride far outnumber the moments of sadness or fear. I shared with them that Will is going to have friends, play baseball, go to school and get a job some day. And that he will make a difference in this world, whether he knows it or not.

It wasn't until I received thank-you cards a few weeks later that I realized the impact of our discussion that day. Here are a few quotes from the students:

"Thank you for showing me that having a baby with Down syndrome is nothing to be afraid of."

"You opened our eyes and helped us to learn so much more about Down syndrome. Thank you for that."

"What an inspiration your son is to all of us. Thank you for sharing him with us!"

Most of these young women will become mothers themselves some day. They will surely be confronted with the prenatal testing and some may even be faced with a Trisomy 21 diagnosis – and then with a decision. And maybe, for just one of those girls, she will remember that day in her high school classroom when my little man showed off his charming smile and bright eyes...and maybe, because of him, she will choose life.

Focus on **Women's Health**

Women's Health Study: Hormonal Factors That Affect Women with Down Syndrome

Recently, a five-year study was completed that examined how menopause and its accompanying changes affect the health and cognitive processes of women with Down syndrome. Dr. Nicole Schupf, Head of the Laboratory of Epidemiology at the New York State Institute for Basic Research in Developmental Disabilities (IBR), was the principal investigator in this study, assisted by a team of scientists from IBR, as well as a team from Columbia University headed by Dr. Richard Mayeux. Funded by the Alzheimer's Association and the National Institute on Aging, and supported by funds from the NYS Office of Mental Retardation and Developmental Disabilities, this long-term study investigated the health of 260 women with Down syndrome between the ages of 45 and 59.

The primary purpose of this investigation was to gain insight into the correlation between the dramatic decline in estrogen associated with menopause and the increased risk for development of Alzheimer's disease, as well as other estrogen-related health conditions. This information is useful because women with DS, as compared to the general population, are already at a greater risk for developing Alzheimer's. Therefore, if factors can be identified that protect against the development of Alzheimer's in women with DS, better preventive health services can be implemented.

Information was collected from four areas: participant cognitive ability, interviews with caregivers, medical record review and blood samples. This data was collected several times, about 14-18 months apart, in order to have an ongoing and cumulative representation of the trajectory of the aging process.

Dr. Schupf and her team have been able to report the following significant findings:

- Women with DS have an earlier age at onset of menopause as compared with that of the general population. For women with DS, both the median and the average ages are 46 years, while 51 years of age is the average in the general population.
- Women who had "early" menopause were twice as likely to develop Alzheimer's as women who had "late" onset of menopause.
- Women with DS (as well as women in the general population) have a marked decline in production of estrogen as menopause progresses. Of specific interest to this study were the biologically active forms of estrogen, Estradiol and Estrone.
- Women with Alzheimer's had only half as much Estradiol in their blood system - the bioavailable form of estrogen that can go to the brain and interact with brain cells.

The outcome of Dr. Schupf's initial study is important because it demonstrates the link between early menopause and early onset of Alzheimer's. Thus, women with DS are more likely to develop Alzheimer's earlier, due to their earlier age at onset of menopause. Dr. Schupf and her colleagues are continuing their studies, in an effort to identify factors that could protect persons with DS from accelerated aging and from Alzheimer's disease.

*Reprinted from Down's Update, newsletter of the Mile High Down Syndrome Association, September 2007.
www.mhdsa.org*

Focus on **Children's Health**

Obesity-Related Hormone Higher in Children with Down Syndrome

Children with Down syndrome are more likely than their siblings to have higher levels of a hormone associated with obesity, according to pediatric researchers. The hormone, leptin, may contribute to the known higher risk of obesity among children and adults with Down syndrome.

A research team from The Children's Hospital of Philadelphia and the University of Pennsylvania School of Medicine published their study online in the Journal of Pediatrics. The researchers studied 35 children with Down syndrome and 33 of their siblings. All of the children were between the ages of four and ten and were from the Philadelphia area. The researchers intentionally did not include severely obese children in the study, in order to focus on risk factors for obesity before obesity occurred.

The children with Down syndrome had significantly higher body mass index, a higher percentage of body fat, and higher levels of leptin compared to their siblings. The higher leptin levels persisted even when the researchers adjusted for the effect of percentage of body fat, suggesting that differences in body composition did not account for the difference in leptin levels.

"The normal role of leptin is to suppress appetite and regulate body weight," said senior author Nicholas Stettler, M.D., MSCE, a pediatric nutrition specialist at The Children's Hospital of Philadelphia. "In general, obese people have higher levels of leptin, which suggests that they have some leptin resistance - their bodies do not respond to the hormone properly. Because Down syndrome is a chromosome disorder, children with Down syndrome may have a genetic predisposition to more severe leptin resistance."

Sheela N. Magge, M.D., MSCE, a pediatric endocrinologist at Children's Hospital, the first author of the study, stressed that more research remains to be done on this question, as the reasons are yet uncertain why patients with Down syndrome are at higher risk of obesity. "Although the study had

an advantage in including siblings as a control group, because this decreases the influence of different environments on children with or without Down syndrome, the sample size was limited, so larger studies are necessary. However, our findings may point to a useful approach to understanding why obesity often occurs in Down syndrome.

A better understanding of the causes of obesity opens up new possibilities for treatment. In the meantime, like others who struggle with weight issues, careful nutritional planning and exercise can help individuals with Down syndrome lead healthier lives.

For more information on this research, go to: <http://stokes.chop.edu/publicationspress/?ID=371> Reprinted from NADS News, www.NADS.org



MJM Foundation 6th Annual Fundraiser

Sunday, April 27th, 2008

12:00-3:00

Valley Middle School

(South on County Rd 42 on Gardenview Drive)

Apple Valley, MN

MJM Foundation is a living memorial to Mimi Roberts and her children, Jake and MaKenzie who died in a car accident. The Foundation supports Down Syndrome research and programs.

For additional information please contact:

Patrick Sullivan Jr. (952) 686-7920

Mary Sullivan (651) 452-2812

Fundraiser activities include: Live/silent auction, bake sale, raffle, entertainment, food, children's games and activities and family fun! If you are looking for a fun-filled afternoon, please be sure to join DSAM members, Mary and Pat Sullivan and their family and friends, on Sunday, April 27th!



Webwatch

By Catherine McDonnell-Forney



Do you ever wonder where we get the articles we run in *Special Times*? Here are two of our resources!

The article "Self Determination for All" by Kathie Snow is from Kathie Snow's website: www.disabilityisnatural.com The mission: "The mission of this site is to encourage new ways of thinking about disability and to help create a society in which all people are valued and included." Kathie has a lot of great articles about education, self determination, behaviors, safety, respect, people first language and common sense!

Another thought provoking site is www.dimage.com, by David Pitnoyak, who counsils people with disabilities. You can find a lot of great articles about "difficult" behaviors on this site, positive support for difficult behaviors, inclusion and integration.

STORIES TO SHARE



The First Day of Preschool

By Kim & John Weidert

Our baby girl started preschool at our elementary school the end of January. Okay, maybe she is not really a baby since she is going to be 3 years old in March but for mom it was hard to let go. The dreaded January day came and the only one with tears was mom. We put on her new My Little Pony backpack which was about as big as her. Of course we could not leave without a few pictures of her and her big brothers to make sure we would remember her big day. Then it was off to Ariana's first day of preschool. We walked into the preschool room and one little boy shouted, "Yeah, Ariana is here!" Since Ariana is shy she lowered her head. Ariana and I went to the table to color. One little girl handed Ariana a snowflake she had made for her. After a couple of minutes of coloring, Ariana decided to try out the slide. She had three kids following her to play on the slide with her. With tears in my eyes, I took that as my cue to leave. Ariana's daddy called from the farm to see who had more tears mom or his little princess.

The second day of preschool I helped Ariana get her coat off and hung it up. When I turned around she had already taken off to go play. Everyday I pick her up from preschool she runs to me with her big backpack bouncing and a huge smile. She loves preschool! It is great to see her so accepted!

Every issue of the newsletter has "Stories to Share." 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, if you are interested in submitting a story.

Self-Determination for All

Revolutionary Common Sense by Kathie Snow
www.disabilityvisnatural.com

Self-determination is a hot buzzword in the disability arena. But it's a concept that's actually been with us forever! What is self-determination and who needs it?

Self-determination simply means a person is in control of her life—she determines what happens to her, by making her own decisions, living with the consequences, and more.

For men, women, and children who *don't* have disabilities, self-determination is a natural by-product of living an ordinary life. Making decisions about when to go to bed, when to get up, what and when to eat, where to work, who to be friends with, and other daily issues—both small and large—are simply part of life in a free society. Children who *do not* have disabilities acquire self-determination naturally, as their parents allow them to make more decisions as they grow and mature.

For generations, self-determination was missing from the lives of many people with disabilities. Parents, service providers, educators, and/or others were in control: children and adults with disabilities were presumed to be incompetent, and because they were not *allowed* to make their own decisions, they never *learned* how to be self-determined. In the process, many acquired “learned helplessness.” There's no better example of the self-fulfilling prophecy!

With the births of the Independent Living and Self-Advocacy Movements in the late 1960s and 1970s, respectively, people with disabilities asserted their power to speak for themselves and be self-determined. It's been a long, slow process, and some individuals have successfully taken charge of their own lives. Sadly, however, many have not—the myth that the presence of a disability makes a person incapable of being in charge of his own life lives on.

Most adults *without* disabilities would resist the efforts of anyone who tried to prevent them from making their own decisions, and children *without* disabilities do so on a regular basis. Any parent can testify to the daily struggles with a child over what the child will/will not be allowed to do. And even though this creates tension, parents welcome this emerging independence—it's what enables children to become responsible adults.

People with disabilities—like everyone else—need to be self-determined. Self-determination is not a privilege to be earned or a benefit one bestows on another; it's an inalienable right of being fully human. To prevent a person achieving self-determination is not only cruel and inhumane, it may also be self-serving: making a person dependent on you increases your value, importance, and power, while simultaneously diminishing the value, importance, and power of the “dependent one.”

However, self-determination may be difficult to achieve for

individuals who are in congregate settings of any kind—special ed classrooms, group homes, sheltered workshops, and similar settings. These placements, by their nature, reflect a belief that the “inmates” are incompetent, so they will not be *permitted* to be in charge of their lives. (And if they *were* permitted to make their own choices, the first one would most likely be a fast exit from the segregated setting!)

Therefore, our efforts must begin with ensuring children and adults with disabilities are included in the ordinary settings of general education classrooms, real jobs in the community, and other “regular” environments. This effort, however, is still no guarantee that children and adults will enjoy the precious opportunity to live the life of their dreams. For even in natural, ordinary, inclusive settings, we may still unintentionally prevent their self-determination. And this process often starts at home.

Because children with disabilities may not be able to do the same things other children do, parents often exempt them from the ordinary activities that teach responsibility, self-reliance, and independence—all crucial components of being self-determined. For example, most children who *don't* have disabilities are expected to do chores around the house. But parents may not expect their child with a disability to help. They may believe the child is not able to “do anything” around the house, they may not want to take the time to help the child learn new things, or they may feel the child has enough to cope with and they don't want to “burden” him with chores and/or other ordinary responsibilities.

Exempting children with disabilities from responsibility can erode their feelings of importance and competence, and may set them up for a lifetime of low self-esteem, learned helplessness, and dependence. How can we expect an adult with a disability to be in charge of his life if he didn't have opportunities to be responsible as a child?

Is a child with a disability expected to help around the house and contribute to the family's well-being? Does she receive an allowance? In other words, is she engaged in ordinary, age-appropriate activities at home and in the community? To achieve this goal, the child might need assistive technology devices or other modifications and support. Parents need to *presume competence* in their children and expect success!

Children with disabilities must also be allowed to exert control over their lives, making decisions and living with the consequences, just as their brothers and sisters do. While this may be hard on parents, children with disabilities must be allowed to experience the dignity of risk!

At school, are children active participants in their IEP meetings? (It's *their* education, not ours!) Regarding therapies and interventions, are children—even very young children—encouraged to participate in decision-making? And are their wishes and opinions respected by parents, therapists, and others?

Adults with disabilities can move toward self-determination

in the same ways as children: being engaged in age-appropriate experiences, being responsible for themselves, and more. Are they expected to make decisions for themselves—from the simplest, like when and what to eat, to the more complex, like a job—and are we listening and respecting their wishes? Do they have the assistive technology, supports, and/or accommodations to do what's important to them?

All of us need assistive technology, supports, and accommodations in order to live self-determined lives. I needed a computer to write this article, as well as support from my husband to get my work done and a variety of accommodations in my environment. Look at your own life to see all that you need in order to succeed. Thus, just because a person with a disability has a variety of needs should not be construed as an indicator that she cannot be self-determined!

When we make sure people with disabilities have what they need, when they have the opportunities to experience the ordinary activities most of us take for granted, when we value them as our fellow citizens who are our equals, and when we presume competence, self-determination will become a reality for all. Isn't it time? Can we afford to do anything less?



(Continued from page 2)

As most of our readers will know, a prenatal *diagnosis* of Down syndrome can, under current technologies, only be confirmed via an amniocentesis or a Chorionic Villus Sampling (CVS) test. For many, this is an issue because the tests are invasive, involving drawing a sample of amniotic fluid. As that requires physical invasion, there is a chance of miscarriage occurring.

So the two advisories from the ACOG are fraught with problems: high false readings on screenings, poorly prepared medical professionals and risk of termination via invasive testing.

So, what's happening around the country as a result of these Bulletins?

The Down syndrome community has responded with aggressive opposition to the two Practice Bulletins and their implications. Both regional organizations such as DSAM and the nationals have issued statements opposing the new standards and calling for improvement of medical training relative to both Down syndrome and the manner in which ob-gyns deliver a diagnosis of Down syndrome. Both our national organizations (NDSC and NDSS) exhibited at ACOG's 2007 Conference handing out copies of the book "Gifts".

Early in March the Kennedy-Brownback bill passed out of committee; that bill would provide for *accurate medical information to be offered to parents who receive a diagnosis of a*

disability either before birth or up to a year after the birth of a child. The Prenatally and Postnatally Diagnosed Conditions Awareness Act (S.1810) would make sure that families who receive a diagnosis of Down syndrome or any other condition will be offered up-to-date and accurate information about the condition and connections with support services and networks that could offer assistance. The measure is co-sponsored by Sens. Edward Kennedy (D-Mass.) and Sam Brownback (R-Kan.) It now moves to full Senate consideration.

The Down Syndrome Association has also responded to the ACOG challenge in a number of ways.

First, our Down Comforter program includes a packet specifically developed for expectant parents. That is made available across our region through ob-gyns and genetic counselors.

Second, we continue to offer expectant parents the opportunity to meet with other parents who have received a prenatal diagnosis of Down syndrome. Those people are all carefully trained and are on call. Finally, we are increasing all of our efforts to replace the negative myths and misinformation about Down syndrome so that it is up to date and accurate. We have engaged the news media, created a "sharing the news" brochure aimed at ob-gyns and other medical professionals and support the "More Alike" advertising campaign developed by the National Down Syndrome Congress – the first wave of advertising is targeted to publications serving ob-gyns.

I'm often asked what individual parents can do. Here are but a few suggestions. Keep your doctor up to date on your child's milestones. Send them a birthday or holiday card each year with an update on how your child is doing – enclose a photo! Also, consider dropping off DSAM materials - the calendar, a Down syndrome brochure, photos of the Buddy Walk and so on.

Another great idea brought to my attention by one of our members is highlighted in the article on page 3. Tracy Hafeman, mom to two year old Will, has been invited for the past few years to make a presentation on Down syndrome to a local high school class during their child development course. What a great way to help dispel myths about Down syndrome to a group of young people who might one day be faced with a prenatal diagnosis of Down syndrome! As Tracy describes it, not only is this a perfect way to share a balanced story about Will's life—but Will now appears to be the star of the presentation!

If you would like to participate in the Association's medical initiative or if you have some ideas you would like to share with our members, please give me a call.

Recall, the DSAM logo is composed of a butterfly in a heart. The heart is defined by the phrase "opening hearts, changing minds". We need to affirm the value of our children with Down syndrome by doing both.

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 6:30-8:30pm
Carrie Blom (651) 686-4453
ccblom@msn.com
Krista Specht
Childcare \$3/child

Bemidji

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

Buffalo

Buffalo ECFE Building
1235 First Avenue, Buffalo
3rd Monday, 6:30-8:00pm
Sheri Jorgensen (763) 682-0756
Sheri.jorgensen@co.wright.mn.us

Chisago City

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

Duluth

Hampton Inn Conference Room
310 Canal Park Drive, Duluth
2nd Monday, 6:30-8:00pm
Laura Plys (218) 728-3400
laurasplys@aol.com

Eau Claire, Wisconsin

Call for meeting times & location.
Janet Carlson (715) 836-9243
cjcar5@msn.com

Fargo - Moorhead

Hope Lutheran Church
2900 Broadway Fargo, ND
Call for meeting information
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
Dawn Magnusen (218) 327-5570
dmagnusen@isd318.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, MN
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
4th Tuesday 6:30-8:15pm
Lisa Bartsch (763) 391-6634
ljbartsch@aol.com

Minneapolis

Sullivan School ECFE
3100 E 28th St, Minneapolis
1st Monday, 5:30-7:30 p.m.
Bldg. is locked - call for information
Jeneane Butrum (612) 668-5132
Jeneane.butrum@mpls.k12.mn.us
No January meeting

Minneapolis—Latino Parent Group

Centro Cultural Chicano
1915 Chicago Ave. S, Minneapolis
4th Friday 4:00-6:00pm
Gladis Rosales (651) 487-5365
Childcare & dinner provided

Minnetonka

Cross of Glory Baptist Church
4600 Shady Oak Rd, Minnetonka
4th Monday, call for time.
Tim & Ann Bremer (952) 939-0350
tim.bremer@goodrich.com
bremerann@hotmail.com

Owatonna

2nd Thursday 6:30pm
Call for location
Brenda Donahe
(507) 451-0367
bdonahe@mrsngerrys.com

River Falls, Wisconsin

Have a Heart Farm
W10356 Hwy 29, River Falls, WI
3rd Monday, call for time.
Jenny Wazlawik (715) 426-1613
Terri Yira (715) 381-3015
terri_y@comcast.net
Susan Erickson (715) 381-9825
wsrerrickson@sbcglobal.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) 780-9086
Haftr_803@msn.com

Spring Lake Park

Spring Lake Park ECFE
Woodcrest Elementary
800 Osborne Rd, Room A, Fridley
3rd Tuesdays, Jan—May, 6:30-8pm
Jen Meinert (763) 783-5615
jmeine@district16.org
Stacy Lilja
Michael.stacy@earthlink.net

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
johnjenmck@comcast.net
(651) 647-5771

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

YMCA
1000 Lakeland Dr SE, Willmar
2nd Tues, 5:30-7:30pm, every other
month starting March.
Childcare provided
Sara Bakker (320) 978-9115
bakkersara@yahoo.com

2/5/08



**Carly May Classic
Golf Tournament
Heritage Links Golf Course
Lakeville, MN**

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 16th through May 19th, 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!

Jaime & Maria Harris are hosting the First Annual Carly May Classic, a golf tournament to benefit the Carly May Foundation. The tournament will be held Saturday May 31st, 2008 at the Heritage Links Golf Course in Lakeville and all proceeds from the tournament will help families who have a child with Down Syndrome and/or chronic illness.

Jaime & Maria are parents to Carter (10 months) and Carly, who passed away May 18, 2007. The tournament will start with a lunch, 18 holes of golf followed by a buffet dinner and a silent auction. The cost per person is \$150; \$40 if you just want to attend the dinner and silent auction. If you'd like to receive more information about the golf tournament or if you have an item or service you would like to donate to the silent auction or want to consider being a hole sponsor, you can contact Maria & Jaime Harris via email at mariajharis@earthlink.net or by phone at 952-432-2060. A website is currently being constructed. Please join us rain or shine for a wonderful day to remember a special little girl and help support our families.

Register soon!

The 36th National Down Syndrome Congress
National Convention

July 11-13, 2008

Seaport Hotel
Boston, MA



**2nd Annual Joey Hebert
Golf Classic**

Monday, August 4th, 2008
Watch your May/June newsletter for details!

**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
Limited income	\$_____
Additional Donation Enclosed	\$_____

Calendar

March	
March 11	Board of Directors Meeting
April	
April 5	2008 Regional Conference
April 26	11th Annual Youth & Adult Conference
May	
May 3	5th Annual Grandparent Conference
June	
June 8	Annual Picnic & Harley Raffle
June 10	Executive Committee Meeting
July	
July 8	Board of Directors Meeting
August	
August 12	Executive Committee Meeting

Library & Resources

If you have over due books out, please return them. Remember that the Lending Library is for all members to use.

We will have books published from Woodbine House available at our Regional Conference at substantial savings! This is a great time to pick up a book for your home library or to donate a book to your child's school.

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

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dsamn@dsamn.org
www.dsamn.org

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