



# Special Times

Volume 24 No. 2

March/April 2009

NEWSLETTER OF THE DOWN SYNDROME ASSOCIATION OF MINNESOTA

## 6th Annual Grandparents Conference

Saturday, May 2, 2009

The Down Syndrome Association of MN is pleased to present its 6th Grandparent Conference. It will be a great time to talk with other grandparents, listen to presentations and get answers to your questions. Conference topics this year will include a keynote presentation on "10 Hints to be a Successful Grandparent of a Child with Down Syndrome" and we will be bringing back, by popular demand, Wendy Selnes from Brih Design. Wendy will be speaking on the topic of behavior: how it is shaped, what considerations are needed to changing undesirable behavior. Extra time will be allotted for individual questions and answers. A lot of grandparents have asked that we have a speaker on sibling issues. We have decided to go to the experts—a panel of three adult siblings will share their stories of growing up with a brother with Down syndrome. We hope you can join us for this exciting conference!

Conference materials will be mailed out in March. If your child's grandparents are not DSAM members, just send us their contact information and we can send materials on the conference to them!

## 12th Annual Youth & Adult Conference

Saturday, May 30th, 2009

The Association will be hosting its 12th 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 30th of May 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 Creative Communication! New topics this year include "I Can Speak for Myself!" and Positive Relationships.

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!

This year self advocates will be electing a board representative at the conference. Nayef Albinali has filled his term of office and we will be looking for another self advocate to serve along with Tom Belka on the DSAM Board of Directors. If you are running for the self advocate position on the board, there are some forms you need to fill out—contact Catherine—either by phone 651-603-0720 or email: Catherine@dsamn.org.

## Get Your 2009 Harley Raffle Ticket!

A 2009 Black Heritage Softail Classic FLSTC will be the Grand Prize at our 16th Annual Harley Raffle to benefit the Down Syndrome Association of Minnesota. Tickets are now on sale at \$300 each and only 100 will be sold. Drawing will be held June 14, 2009 at the DSAM picnic.



## Special Points of Interest

16th Annual Picnic & Harley Raffle

Sunday June 14, 2009  
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.

## Inside This Issue

Letter from the Executive Director	2
Carly May Classic	3
Focus on Oral Hygiene	4
Upcoming Events in the Community	6
Stories to Share	7
Parent Groups	8
Summer Camping Opportunities	9

**Down Syndrome Association  
of Minnesota**

***Board of Directors***

Nayef Albinali  
Tom Belka  
Dana Cronin, Vice President  
Dan Galles, Treasurer  
Jessica Hancock  
Bob Hei, Secretary  
Chris Hesse-Withbroe  
Rochelle Hilson  
Kathy Nelson  
Craig Parker  
Laura Plys  
Mike Tvrdik  
Teresa Yira, President  
Steve Wevley  
Jane Krentz (advisor)

***Special Times***

Managing Editor, Kathleen Forney

Regional Correspondents:

Diane Brendemuhl, Northwestern Region,  
218-236-5501  
Jeanne Prittinen, Northeastern Region,  
218-741-1597  
Brenda Donahe, Southeastern Region,  
507-451-0367

***Staff***

Kathleen Forney, Executive Director  
Teisha Magee  
Catherine McDonnell-Forney  
Kate Pickford  
Marcy Rede  
Connie Gunderson Warner

Down Syndrome Association of Minnesota  
656 Transfer Road  
St. Paul, MN 55114  
Phone: 651-603-0720 or 800-511-3696  
Fax: 651-603-0726  
Website: [www.dsamn.org](http://www.dsamn.org)  
Email: [dsamn@dsamn.org](mailto:dsamn@dsamn.org)

*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,

I want to thank all of you who have been so diligent about sending in your membership and tell you just how delighted we have been to see so many members sending along an additional donation. Everyone agrees that this is going to be tough year. Fortunately, for many years, your board of directors have applied careful planning and extremely prudent financial management. As a result, our organization is strong and resilient. Your Executive Committee and I prepared and the full board approved a 2009 budget that, while it was streamlined, contained no program or resource cuts. We do however need the help of our entire Association—board members, committee members, volunteers and our families to ensure that this year's budget projections can be met. We are a very self sufficient organization—DSAM receives no government funds, and while we do receive United Way individual donations, we are not a United Way agency. All of our funding comes from donations, membership dues and fundraising efforts. How can you help? Please plan on financially supporting us at our Buddy Walks this year—our Buddy Walk raises almost 1/2 of our operating expenses; join us at the Joey Hebert or Muddy Open golf tournaments (all proceeds from these golf tournaments benefit the programs and services of the Association). Any help you can give promoting the Harley Raffle or our other fundraising events will also be appreciated. We run a pretty tight ship here at DSAM; with your help we can weather the current storm we find ourselves in!

At its January meeting, your Board of Directors put their final stamp of approval on the Association's Strategic Plan which will lead us for the next 5 years. Our areas of focus are: Families, Outreach to Greater Minnesota, Education, Fundraising, Public Relations, Medical Community Outreach and Adult Issues.

I'd like to give you a little more information about some of those focus areas in this issue of the newsletter.

**Fundraising:** Our goal is to increase our overall revenue and decrease reliance on one event. For years, our Buddy Walk has provided almost one half of our operating expenses and we hope to add at least one additional fundraising event. We also feel we need to expand our fundraising strategies to include foundation, corporate giving and planned giving.

Our strategies include seeking a major corporate sponsor for our Buddy Walk and developing additional fundraising events. (The Joey Hebert Classic for Down Syndrome golf tournament has been unbelievably successful and we hope to be able to replicate this success with other endeavors.) We also plan on strengthening our planned giving program, writing grants for some of our major programs and most importantly, continue working to reduce the expense ratio on all current and future fund raising events.

Our Development Committee has been meeting regularly to tackle some of these issues. Board members Bob Hei, Mike Tvrdick, Dan Galles and Carmella Sterling have joined DSAM members Arnie Gruetzmacher, David Forney, and Alvin Hebert under the leadership of Craig Parker as Chair to form the Development Committee. If you have a special interest in working on fundraising for the Down Syndrome Association, please give us a call.

**Education:** Our goal is to increase the level of support we are providing the educational community. Currently, we are hosting a teacher conference annu-

*(continued on page 6)*

**New Members**

Jon, Sara, Ella, Avae & Hans Burfeind  
Jerry & Kay Cooper  
Sheila Ekstrom  
Sunny & Tracy Pitt  
Liz & Richard Vlasak

**Patron (1000+)**

MJM Foundation

**Benefactor (250+)**

Dave & Ellie Bilderback  
James May & Julie Carson May  
Mary Jo Peterson  
Sunny & Tracy Pitt

**Contributor (100+)**

Stillwater Knights of Columbus

**In Memory of**

Shirley Clark  
Kyla Olvia Kostrzewski  
Bob Shafer

**In Honor of**

Elsy Mujulwa  
Andrew Nathe  
Olson Truck Stop  
McKenna Wohlers

**Employee Giving through:**

Honeywell Hometown Solutions  
Microsoft Matching Gifts Program  
UnitedHealth Group  
United Ways of New England  
Wells Fargo Community Support Campaign



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

The first annual Carly May Classic Memorial Golf Tournament last May was a huge success and a wonderful tribute to Carly Harris. Nearly \$15,000 was raised to support the Carly May Foundation.

Mark your calendars for the second annual Carly May Classic Memorial Golf Tournament. The tournament will be held Saturday May 30th, 2009 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 tournament will start with a boxed lunch, 18 holes of golf followed by a dinner and a silent auction. 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 & Jaime Harris via email at [mariaharris@earthlink.net](mailto:mariaharris@earthlink.net) or by phone at 952-432-2060. Register Early, Space is limited!!!!



**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 8th through May 11th, if you shop at any of the fiftyplus 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! For more information on Linder's locations near you, go to [www.linders.com](http://www.linders.com).

Please use the coupon in the left hand column. If you need more coupons, please contact the office.

**Register soon!**

The 37th National Down Syndrome Congress  
National Convention  
July 31–August 2, 2009  
Sacramento, CA

DSAM scholarship dollars are available, please contact Kathleen Forney, (651) 603-0720 or [kathleen@dsamn.org](mailto:kathleen@dsamn.org) for more information.

**A SPECIAL INVITATION TO SHOW YOUR SUPPORT**

**FOR: Down Syndrome Association of Minnesota**

In the 2009 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 8 TO MAY 11**.

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.



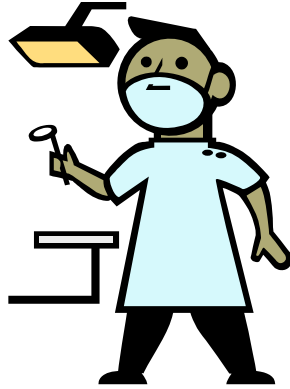
FM# \_\_\_\_\_ GO TO [WWW.LINDERS.COM](http://WWW.LINDERS.COM) FOR DETAILED STORE LOCATIONS.

## ***Focus on*** **Oral Hygiene**

### **Caring for the Teeth and Gums of Children with Down syndrome**

*By Dr. Jonathan Sierk, DDS*

Children with Down syndrome are at an increased risk for developing problems with their teeth and gums. Early preventive dental care and rigorous home hygiene will help reduce many of these problems and eliminate some of them entirely. This article will relate the problems children can develop, describe how Down syndrome can complicate the oral condition, and finally instruct children and families on how to care for the teeth at home.



#### **Dental diseases**

Most parents are familiar with gum disease and dental cavities as the main oral health problems that children develop. In addition to these concerns, children with Down syndrome develop an increased number of canker sores, oral yeast infections and destructive periodontal problems.

Dental decay is the result of bacteria in our mouths converting fermentable carbohydrates into acid, which over time creates the infected holes in our teeth that we know as cavities. Eliminating dental decay requires restoring or filling existing cavities and changing dietary and hygiene habits. Periodontal disease is the gradual loss of bone and supporting structures around our teeth due to inflammation. Gum disease can cause teeth to fall out over time if the bone and surrounding structures cannot hold the teeth in place. Many patients with Down syndrome develop significant periodontal problems by their teen years.

#### **Complicating factors of Down syndrome**

Natural cleansing of the mouth via saliva for patients with Down syndrome can be compromised due to a dry mouth from medications or from mouth breathing. Mouth breathing also creates more hard tartar deposits on the teeth, which can worsen gum disease.

The mouths of patients with Down syndrome tend to be smaller than average, therefore making it harder to brush the teeth. The tongue may seem larger, when in reality it is most likely only relatively larger due to a small mouth. Getting the toothbrush into all areas may be more challenging as a result. Poor muscle tone of the cheeks and tongue may also reduce the mouth's ability to cleanse itself. Food debris can stay on the surface of teeth longer and cause more de-

cay if not properly cleaned off.

This tendency to have a small mouth can be complicated by misshapen teeth or an imperfect biting relationship. Crowded teeth are more difficult to take care of and may worsen periodontal problems. Children with Down syndrome tend to have reduced immune responses and therefore more infections due to a lower number of T-cells. This makes them much more susceptible to developing destructive periodontal disease.

It seems to be a widely held belief that patients with Down syndrome develop fewer dental cavities than average. Many parents have heard this and it may be a myth based on outdated research. The thing to remember is that the negative outcomes of these cavities may be worse for children with Down syndrome. Clearly preventing dental problems before they start is the best strategy for all patients.

#### **Preventive strategies for home and at the dental office**

To prevent dental problems it is important to take a child to the dentist early. The American Academy of Pediatric Dentistry recommends the first dental visit within six months of the eruption of a child's first tooth. This is usually between ages one and two.

At home, a child's teeth should be brushed at least two times a day. Ideally, you should brush your child's teeth after breakfast and at bedtime. It is not necessary to use toothpaste with fluoride until a child has mastered the swallowing reflex and will not ingest the toothpaste, around age 3-5 years on average.

Depending on a child's age and development, they will need assistance brushing their teeth. It is important to introduce to a child how they should care for their teeth. Children with Down syndrome often benefit from using a mechanical toothbrush to better access difficult areas of the mouth. They may also find it more enjoyable to brush their teeth with a mechanical brush and will consequently spend more time at it. Some children have limited fine motor control and use of a floss holder should be considered.

It is important to establish a consistent schedule for brushing and caring for your child's teeth. You should try to use the same location and time so children will be comfortable and make it part of their daily routine.

Oral rinses should be used at home as well to reduce development of decay and gum disease. Fluoride rinse can be sprayed or brushed on the teeth if the child has not yet mastered the swallowing reflex. Brushing on a fluoride rinse at night can greatly reduce the number of cavities children develop. In addition, an antimicrobial rinse such as Listerine, or chlorhexidine by prescription, can be used to reduce the progression of gum disease. Antimicrobial rinses should be not be used at the same time of day as a supplemental fluoride rinse, so after the morning brushing would be ideal. Children with Down syndrome tend to develop cracks or fissures in

their tongue and lips that house bacteria. Daily brushing of the tongue, in conjunction with a rinse, can reduce the bacterial levels in a child's mouth. Diet modification is very important in reducing dental problems. Due to breathing primarily through the mouth and the use of some medications, children with Down syndrome can be dehydrated and often thirsty. You should use sugar-free medications and vitamins whenever possible. It is also important that your child drink plenty of water to remain hydrated, especially in arid climates.

Significant dental decay can develop if a child drinks sweetened beverages throughout the day to quench their thirst. Sports drinks and fruit juice can be as destructive as soda pop to the teeth, if a child's teeth and mouth are exposed to them over long periods of time on a daily basis. Foods high in sugar should not be used as rewards or motivational tools regularly. All children should avoid grazing and sipping patterns of food intake to reduce dental decay, and their caloric intake should match their level of activity. Preventive care at the dental office is important as well. Dentists treating patients with Down syndrome should be aware of gum disease developing. This may mean taking more frequent x-rays looking for bone loss around the teeth, or prescribing a mouth rinse or medication to reduce inflammation of the gums.

Crowded teeth and small mouths contribute to developing orthodontic problems. An orthodontic consultation and possible intervention may be helpful to prevent some gum problems, or to reduce biting forces if the teeth in one area of the mouth are being worn down unevenly due to bruxism or grinding. More frequent examinations and cleanings can help identify and prevent problems. Dental sealants can be placed in the grooves on the biting surfaces of teeth to prevent decay; unfortunately sealants do not prevent cavities on the tooth surfaces between teeth. A combination of fluoride treatments, sealants and diet modification can greatly reduce the amount of decay patients with Down syndrome develop.

## Conclusion

Children with Down syndrome have unique concerns that can make them more susceptible to developing problems with their teeth and supporting structures. Identifying and treating these concerns with aggressive preventive therapies can help maintain a healthy mouth throughout a lifetime.

*This article is the first in a series by Dr. Jonathan Sierk about oral health care for children with Down syndrome. Dr. Sierk is a pediatric dentist in Highlands Ranch, Colorado who treats many children with Down syndrome and focuses on the unique medical concerns of these patients. He is on staff at the Children's Hospital of Denver where he is an adjunct clinical professor. He can be reached at 303.865.4066 or by email at Jon@SierkPediatricDentistry.com for further questions or comments.*

## Step Ahead Pediatric Rehab Becomes a Non-Profit Corporation

By Janelle Jacobson

We are happy to announce that Step Ahead Pediatric Rehab, located at 5696 Blaine Ave, Inver Grover Heights, MN is transitioning to become a non-profit facility. This is very exciting as it will allow us to further expand upon the services we currently provide to the children and families who come to us for Occupational, Speech and Feeding therapy. It has always been the mission of Step Ahead to provide support and advocacy for our families in ways that go beyond the one on one therapy session, which has meant attending IEP meetings, whenever possible, accompanying families to swallow studies or other appointments when requested, and providing education information and materials. Our vision now includes expanding our clinic to include additional therapy rooms, an expanded sensory-motor area, and adding to our current space used for functional daily living skills training. Funding will also be utilized to increase our ability to provide parents education classes, sponsor family support meetings and group classes for the children we serve, such as therapy ball motor groups, yoga-based movement and balance groups, etc.

If you have any questions about services at Step Ahead, or would like information about how to become a contributor, please contact Julie Skokan or Janelle Jacobson at (651) 554-9940, or visit our website: [www.steaheadpr.org](http://www.steaheadpr.org).



## GoodSearch & GoodShop

Would you like to help DSAM earn a penny every time you search the Internet? Or what if a percentage of every purchase you made online went to support DSAM? Well, now you can!

GoodSearch.com is a Yahoo powered search engine that donates half its advertising revenue, about a penny per search, to the charities its users designate. Use it just as you would use any search engine, get quality search results from Yahoo, and watch the donations add up!

GoodShop.com is an online shopping mall which donates up to 37 percent of each purchase to your favorite cause! Hundreds of great stores including Amazon, Target, Gap, Best Buy, eBay, Macy's and Barnes & Noble have teamed up with GoodShop and every time you place an order, you'll be supporting your favorite cause!

Just go to [www.Goodsearch.com](http://www.Goodsearch.com) and be sure to enter Down Syndrome Association of Minnesota as the charity you would like to support. And be sure to spread the word!

## Up Coming Events In the Community

### Medication Management and People with Disabilities

Friday, April 17<sup>th</sup>, 2009  
1:00-3:30 p.m.

Christ the King Church, Fellowship Hall  
8600 Freemont Ave S  
Bloomington, MN

How do medications affect people with disabilities as they age? Do you know how to recognize the side effects of medications? Can you tell when a person with disabilities is over-medicated or under-medicated? Do you want to know more about new medications on the market?

Learn more about medications, aging and disability from **Karen Finck, RN, MS, CNS, owner and president of Health Counseling Services**. Karen is a dynamic speaker who lectures throughout Minnesota on psychiatric and mental health issues. If you provide care for an adult with a developmental disability, you won't want to miss this informative and engaging presentation.

**Please RSVP by Wednesday, April 15<sup>th</sup>**, by calling Gina Carpenter at The Learning Exchange at (952) 681-6122. There will be a charge of \$15 per person for this event at the door. Please make checks payable to ISD #271.



*(Continued from page 2)*

ally. Along with continuing to host these conferences in the metro area and Greater Minnesota, our goal is to also approach individual school districts and schedule presentations on best practices for educating children with Down syndrome. Using our Down Comforter hospital contact program as a model, we are hoping to build stronger relationships with school districts throughout Minnesota.

We will be highlighting additional focus areas in future newsletters. If you are interesting in serving on any committees to work on the focus areas mentioned above, please don't hesitate to contact us. Our goal is to have a committee formed around each focus area; a committee composed of board members, staff and members from our general community.

If you would be interested in working on any of our committees, or just sharing your thoughts and ideas on growth areas for the Down Syndrome Association, please don't hesitate to give me a call. We welcome your feedback!

Kathleen Forney

## A Big Thank You

To all of our members who have continued to support the ongoing work of DSAM with their yearly membership dues we wish to thank you very much. We realize that in this economy paying dues can sometime be difficult. That is why we encourage any of our members who might need it to use our Alternative Category (\$0 - \$19 per year). At whatever level you renew your membership, it gives us the opportunity to know you want to remain members and we are also able to update your contact information.



Thank you to all of our members who replied to the "Greening of DSAM" postcards. We are making a concerted effort to save money and the environment by sending emails with links to our *Special Times* newsletter, so that you can read it online as soon as it is available. Please feel free to print it out and share! On your renewal notices there is a box to check to receive the newsletter electronically if you have not already notified us that this is the version you prefer.

Also, a paper Membership Directory has been mailed out to all members who requested it and those without email addresses in our records. It is available electronically; if you did not receive an email with the PDF attachment containing the directory and would like one please call the office at 651-603-0720 or email [dsamn@dsamn.org](mailto:dsamn@dsamn.org). The directory is now formatted so that it can be reproduced as needed within our office or on a regular printer.

After this year, if you would like a hard copy of the directory it must be specifically requested at the above phone number or email address.

Thank you for helping us conserve the environment and our finances!

## Library Books

We encourage our members to come in, or visit the library link on our website to check out books. Books can be checked out two at a time for up to two weeks at a time. Unfortunately, many of our books that were checked out are long overdue, some of them seem to be permanently overdue. If you might have checked some of our library books out and forgot about them please look around you house and return them so others can also use these resources.



# STORIES TO SHARE

## Essay for College Application

By Elisa Folden

Drip. The tear slid from my chin to splash lightly on the once-bright keys as I stared down at the blinking call-ended indicator, trying to digest the news. What exactly did she have? Why did this happen to us, now? How could this occur? Bodies are supposed to function correctly. I had thought that was one of the miracles of birth. Questions raced through my mind in a swarm, a fully incoherent mess. The most important one: is this going to change my whole life?



My youngest sister Carina was born nearly five years ago with Down syndrome, and I at first wondered if that single extra chromosome, that nearly invisible variation could make any difference to me at all. But immediately that query was proved wrong. As I soon found out, the dangers of Down syndrome extend beyond the purely mental disabilities. Though I was not quite to the point of realization yet, I had begun to comprehend that nothing would ever be the same: "Wait, Mom, how does that even make sense? How is she even alive if she has four holes in her heart?" I gazed with unseeing eyes up at the ceiling, disbelief a shadow on my face while I sat, shocked, still not fully understanding the massive impact this myriad of problems would have on my future.

After my sister's surgery, the hospital visits, the worried days and sleepless nights, a certain sense of calm would befall me, only to disappear with every newfound problem and scare. I began to wonder if this was the only life I would ever know with her. But then one day, I had a revelation when she first looked at me with her bright blue eyes, calling me the name that still sticks to this day: Sissy. Carina's purpose in my life was not only that of a sister, just as my other siblings played other roles as well. Carina was meant to open my eyes and direct me along a more tolerant path.

One of the most interesting things I have learned is that not many people realize just how much they do not know. Before Carina, I had never stopped to think of the trials of the boy I saw in the wheelchair, or the girl with a speech impediment. However, as I watched Carina develop alongside average children her age, there was a deepening sense that I had previously been internally unaware, uncaring, and narrow

minded in my thoughts about the disabled. While it was difficult to watch my sister's hardships and struggles, the most challenging part of the ordeal for me personally was in forgiving myself for my past indiscretions, when I had allowed others to make fun of the mentally retarded or physically handicapped. The hardest battles I ever have had to fight dealt with the internal comprehension that I once tolerated string after string of taunts to be thrown at individuals who could not alter their situations.

She is only four, so cannot realize it yet, but Carina has done more for me than any other individual, even those who have influenced me for many more years. Her cheery face and infectious smile not only brighten my day, they also educate. I have learned that I, as well as others, should not go through life unaffected by the problems of others. To do so would be to accept into our lives ignorance and prejudice, cruel plagues infecting societies today. I need to take a stand, and though this is hard, the advantages of furthered understanding far outweigh any personal discomfort. That extra 21<sup>st</sup> chromosome has become a powerful tool for learning because, in spite of its effects, it is invisible, but has helped to open my eyes.



## Dearest Abby Grace

By Rebecca L. Davis

"Mama, what means 'dearest'?" my three-year-old Hannah Rose asked. She'd heard me use the word in a song I was singing. I thought a moment. "Well, it's the one you love the most," I replied. Hannah's blue eyes studied the thought seriously, then with a little smile asked, "Mama, do you know who I love the most?" I smiled back, "Who, honey?" ... "Abby!"

Yes, sweet baby Abby Grace. How could I ever have imagined what a blessing this baby would be? A year ago I was overwhelmed by a pregnancy surrounded, not by joy, but by questions, stress, and tears. My sixth pregnancy... an abnormal blood test, the level 2 ultrasound showing the AV Canal heart defect, the Down Comforter, the cloud of uncertainty always there when I opened my eyes to face a new day. We chose to forgo an amniocentesis, knowing we would welcome this baby whatever conditions it may have. Yet, I wondered what this baby would mean to our family. With 5 young children,

*(Continued on page 9)*

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](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.miller@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  
pckauffman@comcast.net

### **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  
3rd 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

### **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  
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  
3rd Tuesday, 6:30-8:15pm  
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.  
Tim & Ann Bremer (952) 939-0350  
tim.bremer@goodrich.com  
bremerann@hotmail.com

### **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  
Haftr\_803@msn.com  
JoAnna Harris  
joanna0909@mac.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 Lilya  
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**

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

02/2009

(Continued from page 7)

one with Juvenile Diabetes, I felt my load was pretty heavy already. And what would the children think of this new baby with all its needs? One night as Hannah lay sleeping beside me, and I sat pouring over one of my Down-Syndrome books, the weight of it all hit me like a downpour. How will I manage? How will baby Hannah handle not being the baby? I let my tears fall as I cried silently out to God.

That was the spring of 2007. Now, I look back at all the changes the tiny 4lb gift that arrived on June 30th, 2007 has brought to our lives, and I can't even express how GOOD those changes have been - not always easy- but good. The hospital time was the hardest, especially open-heart surgery. Abby still has moderate to severe mitral regurgitation requiring medication and on-going follow up. We continue to pray for her heart and to thank the Lord for giving Abby to us. She is now 14 months old and weighs 14lbs. Her smiles light up our home and hearts. The other children absolutely adore her. We were talking about some progress in her development the other day and nine-year-old Elizabeth said, "But she's so sweet, I don't want her to grow up too fast!" And yesterday, 6-year-old Joseph was covering her head with kisses (she didn't even complain!) and said, "You're just the right kind of baby for kissing." And I wonder why I ever worried about Hannah -she and Abby are BEST of friends. Abigail Grace-her name means "joy" and "grace" -she has certainly taught us and brought us both. Down syndrome was certainly not my plan, but I'm thankful for God's plan that sent this beautiful gift- dear Abby Grace- to us. And now, we look forward to welcoming another baby of His plan into our home this coming January. We are truly blessed!

## Summer Opportunities

### Wilderness Inquiry

Mark and Mary Maher would like to remind all of you campers out there to take advantage of the Sean Maher Endowment Fund at Wilderness Inquiry. Wilderness Inquiry's mission is to *integrate people of all ages, backgrounds and abilities through outdoor education and adventure experiences*. The nonprofit organization began in 1978 when a small group of people with and without disabilities took a pioneering trip into the Boundary Waters Wilderness Area in Northern Minnesota. It continues to serve as the national leader in providing socially integrated outdoor adventures. You can check out the current Wilderness Inquiry programs on line at [www.wildernessinquiry.org](http://www.wildernessinquiry.org) or call 800-728-0719 (612-676- 9400) to receive a current catalog. Remember these adventures are Sean endorsed!



### Friendship Ventures

Friendship ventures is gearing up for another fantastic summer of creating fun activities and camping experiences for children, teenagers and adults with developmental disabilities and they are looking for your participation! Friendship Ventures has three great camp locations, McGregor, Annandale and Eden Prairie. For more information about their summer camping program visit: [www.friendshipventures.org](http://www.friendshipventures.org).

#### 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

**Marcy**  
March 10 Board of Directors Meeting

**May**  
May 2 Grandparent Conference  
May 12 Executive Committee Meeting  
May 30 Youth & Adult Conference

**June**  
June 9 Board of Directors Meeting  
June 14 Annual Picnic & Harley Raffle

## Library & Resources

**Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters** By **Brian G Skotko & Susan P Levine** A complete guide to the joys and challenges of growing up with a brother or sister with Down syndrome.

### *Save the Date!*

**The 3rd Annual Joey Hebert Classic**  
August 3rd, 2009

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

**8th Annual Duluth Buddy Walk**  
September 27th, 2009

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

Non-Profit Org  
U.S. Postage  
PAID  
Minneapolis, MN  
Permit No. 31376

**Special Times**