

President's Message

Communication is such an important concept but often so hard to be meaningful to everyone involved! We are trying to work on getting important information out to you as members or interested parties. We really want to hear from you. We want your suggestions how the DSAF can best serve families' & individual needs, ideas for new programs & outreach. We also need your help. This organization can not function without the help from our members to volunteer to help us put new ideas into action. I look at the DSAF as a lifetime commitment. It's what I "signed up" for when our son was born. It's never been just about Paul but about all individuals with Down syndrome.

How do we help our kids learn & have the most inclusive education possible for their needs? How do we work on helping all our families navigate the road we now start down after our children are born? How can we provide meaningful experiences with their peers who have Down syndrome & with their typical peers? How can we help families not be afraid to try new experiences? How do we educate ourselves & others on the marvelous potential there is for individuals with Down syndrome? How do we learn to set the bar high enough? All individuals with Down syndrome are individuals with different abilities and talents & we should be able to find things all of them can do well.

Does this mean I expect you all to chair committees? (Well, it would be nice...) No but you could help serve on a committee. Sometimes it just needs someone to say, "Ok, I'll be the "go to" person & you'll find others right behind you. What is your passion? Some of you really like the idea of visiting with doctors about how to deliver a diagnosis of Down syndrome or talk to new parents. Some of you might really enjoy being part of our Step Up Walk Committee. You may have

(cont. on page 2)

Program Director Update: Lori Tackett

We have had a busy couple of months. It was wonderful to see everyone at the Step Up Walk — What an amazing day! I was so impressed at how our group and the community came together to celebrate our members. I'm very glad I got to be a part of the day. If you haven't already done so, make sure to visit our website to see some great pictures of the walk.

We have also had great turn out at our Pumpkin Patch event and our Literacy Conference! And, our Husker Heroes

Event was a smashing success! I'm not sure who had more fun: the children, the adults or the athletes!

Now that 2010 is coming to an end we are looking forward to 2011. We hope to continue to offer wonderful events for our families and we'd love your input and help to make this happen. If you haven't already done so please take a moment to fill out the survey at: <http://www.surveymonkey.com/s/YSWC7TW>

With your feedback, not only do we hope to

get more of our current members involved, but we'll have the feedback to gain new members as well. We want to hear from you — what you would like to see happen in 2011 and how you would like to be involved. There are so many great opportunities we'd like to provide to our group and we need your help to make it happen! I look forward to a successful and exciting 2011.

— Lori

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From the Editor:

Assistive Technology. *This is a new term to a lot of parents, but it's an area that is required to be considered in every IEP meeting. This issue focuses on AT, and will hopefully you will find it informative.*

Medical Outreach Committee Needs Volunteers!

The Medical Outreach Committee was established in 2008 with Anna Calhoun as committee chair for the last 2 years. Thank you to Ame Creglow who will be the new chair! The committee is in need of more volunteers. There are various ways to help! Please contact Ame at Ame.Creglow@Kenexa.com if you wish to help on the committee as a presenter or with other committee tasks.

Mission Statement: The Down syndrome association for families (DSAF) Medical outreach committee is dedicated to ensuring that accurate and current scientific information is always available to OBgyn offices, hospital social workers and various members of the medical community who see mothers during pre or post-natal stages. The committee will also be dedicated to providing support to parents having babies with Down syndrome.

With their permission, we would like to add your child's educator(s) and specialist(s) to our mailing list. Send names and full mailing addresses to Dyann Rupp at dyrupp@inebraska.com

President's Message (cont.)

some new ideas how to reach out to the community. Maybe you're really good at planning parties; we have several "parties" throughout the year where our whole organization gets together. You may want to work with our Little Stars, Super Stars, or Teen group because that's where your kids are in age. We want to do something special in preparation for World Down Syndrome Day, 3-21-11. We're looking for a committee. Do you want to work with schools? Plan an event? Do you like to ask for donations of money, prizes, food? There's a place for you! We haven't had parent coffees for awhile; do you have that gift of hospitality? Want to organize more Dads' events, Grandparents get-togethers? The list is limited only by your imagination. We have openings for new DSAF Board members. We'll take suggestions of people to nominate from our group or the community at large.

You should have received a survey by email; it's on Facebook or our website. Fill it out, let us hear from you. Don't be the kind who just tells us what to do; also offer to

help with some of the ideas you have. If you do volunteer you don't have to do the same thing forever. A "lifetime" commitment just means you're willing to help in a variety of ways. But once you've done one commitment think of another. It doesn't have to be at the same intensity or you may need to take a little time off, but come back. Someone once told me they were going to get more involved when their kids got older. As someone who has almost all their kids through the teens let me tell you life never gets simpler, it won't necessarily get harder but you will probably never be less busy than you are right now. Life with kids is always busy just in different ways as they grow!

That's my pep talk, really think about it. What can you do to help your child, Down syndrome, the DSAF? Help us let the world know our kids are, "More Alike than Different"!

-Deb

The Four Leaf Clover

Who knows why Down syndrome occurs? Why does the extra 21st chromosome stick to the cell when the fertilized egg begins its first cell division? It can be compared to what happens in nature to a field of clover. Usually, we see 3 leaves on each clover. Once in a while, however, we find a clover that has an extra leaf -- making it a four-leaf clover. We don't know why Mother Nature decided to add that extra leaf; she just did. There is no obvious explanation -- all of the clover plants grew in the same soil, were exposed to the same sun and rain, etc. Mother Nature just decided to add an extra leaf to one of the clover in the clover patch. This doesn't make it better or not as good as the other clover -- it just makes it different. Some people even believe it brings a person good luck when they find a four-leaf clover. It is much the same way with the extra chromosome. We don't know why Mother Nature didn't let the cell divide evenly, but she didn't. She decided to add another chromosome to that baby's cells. It doesn't make the baby better or not as good as the other babies -- it just makes him or her different. And if you find one of those babies, you are truly lucky for they are very special babies -- who grow into very special people. — Anonymous

MORE NEWS YOU CAN USE!

IPOD APPLICATIONS:

Caroline Fehlhafer submitted a website she thought might be of use to members. "Moms With Apps" isn't as dangerous as it sounds, but it can certainly use up lots of your time on the internet! Try this link:

www.momswithapps.com/apps-for-special-needs/ Once you spend a few moments on this website, allow yourself another adventure at <http://slpsharing.com/> Caroline was keen to point out the section (scroll down to the post dated July 20, 2010) "iPad apps I used

during extended school year." Both websites have multitudes of links to try out. But, be sure to carve out some time in your schedule, otherwise, you're going to be disappointed at your limited surfing time! Thanks, Caroline, for sharing these websites.

"Special Education: Learning for Everyone"

<http://www.apple.com/education/special-education/>

MORE APPLICATIONS:

Apple: Everyone in education knows Apple computers - now the company is taking a renewed interest in kids with special needs. Check out these applications:

If you've tried any of these applications and would like to share your experience, both positive and/or negative, please let us know! Email dyrupp@inebraska.com with "Apps" in the subject line.

Sibling Workshop

January 22, 2011 10-2pm

With the help of older siblings from our families and local paras and social workers, we will be offering a Sibling Workshop for the siblings of children with Down syndrome. We hope to provide an environment for siblings to feel comfortable to ask questions that they may otherwise be hesitant to ask about their brother or sister. We will provide education and support to help them recognize they are not alone in their experiences and feelings

and their feelings are okay. They will have the opportunity to meet other brothers and sisters and learn that there are others who experience the special joys and challenges they do. We will also give them an opportunity to learn how others handle situations commonly experienced by siblings of children with Down syndrome. Please mark your calendars for this event -more details to follow in future communications.

We hope to provide an environment for siblings to feel comfortable to ask questions and learn from each other.

Upcoming Event: Wrightslaw Conference

July 29-30, 2011

DSAF is thrilled to be able to bring Peter and Pam Wright to Lincoln to present their Two-day Special Education Law and Advocacy Boot Camp. The goal is to provide individuals with the knowledge and skills to advocate effectively for children with disabilities.

In a Wrightslaw Boot Camp, you learn how to use special education statutes and regulations to get answers to your questions; to use tests and measurements to measure educational progress; chart out test scores; write SMART IEPs goals and objectives; learn how to use NCLB as a tool to open doors to services; learn how

to create paper trails; write effective letters; and use advocacy strategies to negotiate for appropriate special education programs.

This will be a great learning opportunity for our families and all advocates; please mark your calendars for this event!

FAMILY NEWS AND MEMBER SUGGESTIONS!

Submit births, achievements, awards, etc. and ideas for future newsletters to Dyann Rupp, Newsletter Chair at dyrupp@inebraska.com

Using SETT in the Assistive Technology Process

Every parent wants what's best for their child and the area of assistive technology is no different. However, many times we let the glam of technology cloud our ability to identify what our child needs to be successful. Through the wisdom of Joy Zabala, I have learned that the best way to find a solution is to have a shared vision of the problem. In other words, if all members of a team are not on the same page with the problem that needs to be solved, then it will be hard to work together to identify a focused set of solutions.

For the area of assistive technology, one process for getting everyone on the same page is the SETT Framework. This framework states that when the interplay of the **S**tudent's strengths and weaknesses, the **E**nvironment and its supports, and the **T**asks that need to be accomplished are all considered in relation to one another, then a set of **T**ools may be identified that enable the Student to reach their goals (Zabala 2005).

When considering the student, the team should look at things such as the student's area of need. This is a general question that will identify the broad area of concern and allow the development of a conversation related to the student's strengths, weaknesses, interests, and motivation related to the identified area of concern. When the team moves to considering the environment, this is more than just the physical context. As Dr. Zabala says, this is "anything or anyone around the student in places where the technology is expected to be used" (Zabala, 2005). Things to be explored in this domain include all of the physical contexts, the people who will provide support to the student, and the attitudes and expectations of all of those providing supports. The final area to look out is the task. The team should analyze the larger area of concern and begin breaking it down into the smaller components, with consideration to the environments in which each component is being performed. This process of focusing on the interplay of the student, environment, and task, can then lead to a conversation about what tools are available to meet the identified needs.

As we begin to focus on the Tools, I believe it is important to recognize that the tools do not always have to be technology related. In fact, the SETT process could be used as a way to identify methods for meeting IEP goals in general, not just the ones where the team feels technology may be

indicated. As you might imagine, trying to figure out where to begin searching for technology tools can be daunting. One resource you might consider to organize your searches is <http://www.gpat.org/resources.aspx?PageReq=GPATConsider>, then scroll down the left side and click on Assistive Technology Resource Guide. This document categorically examines several areas of academics and functional skills, and assists with identifying specific tasks within those areas, as well as potential accommodations, modifications, and technology tools.

As you look through a document such as www.gpat.org, remember that assistive technology is a very broad category of tools. It is not simply things with batteries or computers or even just communication devices. It continues broadly from pencil grips to wheelchairs and special computer programs, to spoons with built up handles. Categorically, the document referenced above is organized into the following categories:

Writing, spelling, reading, math, studying/organization, listening, oral communication, activities of daily living, recreation/leisure, prevocational/vocational, and seating/positioning/mobility.

From this very general list, the team can begin to use the SETT process to narrow down the initial area of concern into its component tasks, bring in the considerations of the student and his/her environment and finally focus on the specific tools and strategies that are available.

In closing, I would like to point out that this article only begins to help you understand the process of finding potential tools to try. It doesn't address trialing those tools, to see if they are going to be successful for an individual student, nor does it address the process of trialing/acquiring/customizing devices, nor documenting the technology tools in the IEP. Each of these components is as important as the initial step of identifying a common problem and potential solutions. Some resources that might support you in these areas can be found at:

Device Trials -

<http://www.wati.org/content/supports/free/pdf/form/TrialUse-Form.pdf>

Documenting AT in the IEP -

<http://www.wati.org/content/supports/free/pdf/Ch15-DocumentingATinIEP.pdf>

Matthew Press, MHS, OTR/L, ATP is an Assistive Technology Coordinator for the Pendergast School District in Phoenix Arizona. He can be reached at mpress77@gmail.com.

For sale:

--Bumbo seat with tray...blue \$20
--Radio Flyer scooter...narrow seat and low to the ground so works better for kids w/ Down syndrome because of their short legs. Looks like a horse \$15
--Radio Flyer scooter...narrow seat & low to the ground...a little bigger than above, and the handle bars turn \$25

Items are 'like new'...scooters used inside. Can arrange to have items dropped off (to avoid postage).

If interested, contact Andrea at anderva@windstream.net

Missing Some News?

If you are not receiving our electronic communications than you may be missing out! Sometimes events happen between newsletters and the only way to get the word out is electronically. To ensure you get all the news, please send your current email address and contact information to dsafnebraska@gmail.com.

□ Please submit articles and items of interest to Dyann Rupp at dyrupp@inebraska.com We welcome information of interest to our membership! PLEASE — as you submit information, please include ALL details, such as event name, date, time, etc. If you make changes, please include all information again in the separate communication. (This saves the editor/desktop publisher from having to review multiple emails to gather the same information!)

DSAF 2011 Calendars

We are happy to offer 2011 Calendars featuring the sixteen children from our Facts Posters and the Facts (shown at the SUDS Walk). Each month will have an adorable picture of one or two of our members and, since each month features a fact about Down syndrome, the calendar will be a great awareness tool! DSAF plans to distribute these through our Medical Outreach group, to our new parents and to various community members. They are also available for purchase at our cost. You may order them by filling out and mailing in this form:

Name: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Calendars:

___ Number of Calendars x \$5.00 per calendar ___ **Total for calendars**

Donation (optional):

___ I would like to donate to help DSAF provide calendars for members of the community.

___ \$2.50 ___ \$5.00 ___ \$10.00 ___ Other ___ **Total Donation**

Shipping:

___ Number of Calendars x \$1.75 per calendar for shipping

(There is no shipping if you pick up your calendars at the Holiday Party; you may also contact Lori if you'd like to come pick up your calendars)

___ **Total for Shipping**
___ **Total Enclosed**

****Please mail form and checks to DSAF, PO BOX 57362, Lincoln, NE 68505****

The first 250 calendar orders will be filled immediately. All following orders will be filled with a re-order of calendars that will take up to 2 weeks.

Contact Lori with questions: lori@dsafnebraska.org or 314-1731

HUSKER HEROES EVENT



On November 14th DSAF helped host the first ever Husker Heroes event. The Hawks Center was nearly full to capacity with 220 individuals with special needs, their families, gracious volunteers and over 200 Husker student-athletes. Add in appearances from Lil' Red, Johnny Rodgers and Governor Heinemann and you have a full out celebration!

The NU Athletic Department partnered with DSAF and seven other local special needs organizations to make this event a success. Nearly every sport was represented and the individuals were able to participate in everything from tumbling with the gymnastics team to practicing their best tackle with the football players. The athletes played games with the children, signed autographs and posed for countless pictures with great big smiles all around.

The individuals with special needs were not the only ones who had a great experience at Husker Heroes, so did the student athletes!

In addition to providing a great night out for individuals with special needs, the event was also intended to give the athletes an opportunity to get a taste of community service and stir

their desire to serve. The athletes not only were happy to be able to give back to the community but seeing the smiles on their faces Sunday, it was obvious they were having fun too!

The night was a huge success that couldn't have been possible without the joint efforts of so many different agencies. We look forward to working with these groups on next year's Husker Heroes event and other events throughout the year.



LITERACY CONFERENCE

On Saturday morning, November 6, forty parents, educators and specialists gathered to hear Tiffany Hogan present about reading and children with special needs. Tiffany is Director of the Link N Literacy Lab, as well as an Assistant Professor at the University of Nebraska-Lincoln and holds an Adjunct Appointment as an Assistant Professor at the Center for Neurogenetic Communication Disorders with Munroe-Meyer Institute at the University of Nebraska Medical Center. In addition, she is the co-investigator of a number of grants totaling several million dollars — She is on the cutting edge of current research in literacy and children with special needs.

Because the conference was limited to four hours, much of the information given was broad in nature. Dr. Hogan did speak specifically about the Simple View of Reading, and discussed how, even though children with Down syndrome are visual learners, they still need to be taught systematic information specific to reading.

Feedback from the conference was very positive. Comments included:

"Dynamic. Helpful answers to audience questions. Clearly passionate about her research and sharing this information with others"

"She is an excellent, dynamic presenter. I like how she provides practical examples."

"She did a great job at making sure the information was understandable as well as interesting! I like that it was more personal rather than like a lecture."

Many thanks to those who attended and those who volunteered to make this a very worthwhile conference for not only our membership, but others in our personal, professional and learning communities.



Assistive Technology Partnership/Education

1910 Meridian
Cozad, NE 69130
308-784-4525

Assistive Technology Partnership/Education (ATP/Education) provides statewide assistive technology services to children (birth to twenty-one) with special needs and their families, caregivers, teachers, service providers, etc. Some of the services offered by ATP/Education include:

Training (which may range from awareness of assistive technology to specific devices)

Consultations (child specific requests/identified needs)

Technical support (this may include phone support or on-site visitation)

Funding (assistance with working through the funding process and information on available sources of funding, but ATP/Education is not a funding source)

Equipment Loan Pool (short term loans of devices)

Because of the size of Nebraska, ATP/Education has divided the state into five regions, with an educational specialist assigned to each area. You are able to contact your educational specialist with specific questions you might have or requests for training, technical support, etc. There is not a charge for services provided by ATP/Education.

Please contact Patti Neill at 308-784-4525 or pneill@esu10.org for the name of the educational specialist in your area.

Under Nebraska Rule 51, all decisions for a child on an Individual Education Plan (IEP) must be made through a team process. Educational specialists must operate within this team process. They work in conjunction with appropriate school personnel (administrators, regular and special education teachers, paraprofessionals, occupational and physical therapists, speech language pathologists, etc.); parents; agency personnel; and most

importantly, the student to assist in determining what assistive technology will be most effective for the student.

Educational specialists provide guidance to the local educational team on gauging and selecting appropriate assistive technology. They do not make specific recommendations or do evaluations on assistive technology. All decisions related to assistive technology services and devices are made by the school educational team.

ATP/Education has a statewide loan pool which offers you an opportunity to "try before you buy." You are able to borrow assistive technology for a short period of time to try and see if it is appropriate. The loan pool equipment is listed on the AT4ALL website (www.at4all.com). This allows you to view the equipment available and request items via the site. The AT4ALL website includes descriptions and photos of the devices and links to the manufacturing companies. AT4ALL also has loan pools from other participating programs and items for sale or give away.

ATP/Education is a good resource for information on where to purchase specific assistive technology.

ATP/Education works in conjunction with the Assistive Technology Partnership (ATP). ATP has offices located throughout the state.

The education specialists for the Lincoln and Lancaster County areas are:

Dixie Trevarthen (Lincoln)
(based at ESU 3/Omaha)
6949 S. 110th Street
Omaha, NE 68128
dtrevarthen@esu3.org
402-677-2045/cell

Lenette Sprunk (Lancaster Co.)
(based at ESU 7/Columbus)
2657 44th Avenue
Columbus, NE 68601
lsprunk@esu7.org
402-910-1238/cell
402-564-0815 ext. 1049



Step Up Walk Statistics

Amount raised: \$ 52,000
 Number of participants: 1,200
 Number of teams: 66
 Number of volunteers: 135

Top Fundraising Teams: (as of September 17)

Austin's All Stars \$ 3,571
 Ben's Brigade 1,342
 Samuel's Posse 1,335
 Ethan's Entourage 1,309
 Grant's Gang 915

Largest Teams:

(online registrations as of October 1)

Anna's Angels 103 walkers
 Grant's Gang 44 walkers
 Gracyn's Guardians 35 walkers
 Ethan's Entourage 33 walkers
 Claire's Crew 32 walkers
 Jakey big boy 32 walkers

Largest School Teams:

Seward PS 55 walkers
 Elmwood-Murdock PS 28 walkers
 East HS 10 walkers
 Heartland Home Schoolers 8 walkers
 Irving MS 6 walkers
 Rousseau ES 6 walkers

These winners will be tough to top next year!

Is your team up to the challenge?

Capital City Step UP For Down Syndrome Walk Sets New Record!

The 9th Annual Walk was a tremendous success! We had over 1,200 walkers join us to celebrate individuals with Down syndrome and promote awareness, inclusion, and acceptance within the community of Lincoln. Over \$52,000 was raised to support individuals with Down syndrome, their families, friends, educators, and professionals who share in their lives! Thank you to our generous sponsors, donors, volunteers, team captains and team members who made this event a true success!

Thank you to our Step Up For Down Syndrome Walk committee who planned this event! They deserve a huge thank you for their outstanding work!

Deb Safarik - Chair & Food/Beverages

Dean Fuelberth - Publicity

Lori Tackett - Program Director

Caroline Fehlhafer - Prizes

Liz Echternkamp - Prizes

Lori Kennedy - Entertainment

Jody Bartels - T-shirts

Dennis Kriz - Logistics

Jane Quiring - Treasurer

Angie Willey

Tina Barrett

Natasha Dobbins

Renae Rief

Thank you to our sponsors that believe in the work of the DSAF by supporting the 9th Annual Walk!

Our Media Partners - Froggy 98, Jacob North Companies, and Lincoln Journal Star

Our Sponsors -

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Mike Dunlap

Donald Everitt

Fidelity Charitable Fund

Harding & Schultz

Amy Harris

IntoMetal

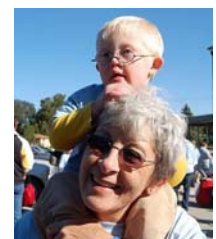
Kinder Porter Scott Family Foundation

Labenz & Associates

Roughriders Charities

Schaefer's

Wells Fargo



Thank you to our very important volunteers. We could not have had the Step UP for Down Syndrome walk without them!

Thanks to:

Southeast Cheerleaders
Concordia College Students
National Student Speech Language Hearing Association
Social Service Cub at York College
Council on Exceptional Children
Kohl's Employees
Boy Scouts Troup 7
AGA
Pius High School
Bill & Marvella Leitgeb
Arnette Garris
Alisha Clubb
DSAF Members, Families and Friends

SUPER STARS!

Super Stars Swim Party
Saturday, January 29, 1-3 pm
Fallbrook YMCA
700 Penrose Drive
<http://ymcalincoln.org/locations/fallbrook/media/fallbrookdirections.pdf>

We'll have a meeting room where you can leave your valuables & belongings. There's also a ping pong table, tables & chairs. We'll have light refreshments afterwards. Friends & family of the school age individual with Down syndrome are welcome. Funds from the Step Up for Down Syndrome Walk cover the cost of this event. We'd like a headcount for refreshments, please RSVP to Caroline Fehlhafer if possible... **We are looking for a person to co-chair this group w/Caroline.** It involves planning & scheduling events approximately 4 times per year. Please contact Lori Tackett or Caroline Fehlhafer of your interest.

PARENTS AND TEENS

Support group for parents of teens with Down syndrome. No current meetings slated. Questions? Call Amy at 742-4521 or amysvo@gmail.com.

MOM'S NIGHT OUT

Mom's Night Out at Grisanti's on Jan.14, 6:30 pm!

This newsletter reports items of interest relating to Down syndrome. DSAF does not promote or recommend any therapy, treatment, program, etc. Any medical articles included in this newsletter are solely for information. Any medical questions should always be referred to your family physician. DSAF does not support any particular political or religious view. Individuals or organizations are not necessarily endorsed by this publication or its editor. We wish to bring together those interested in Down syndrome and attempt to create a positive, optimistic outlook and attitude. We want to help our kids reach their fullest potential and be included in their schools and communities.

CONTACTS

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Jane Quiring, Treasurer of DSAF Board
Dyann Rupp, Secretary of DSAF Board,
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Ame Creglow, Medical Outreach Committee Chair
Liz Echternkamp, Lil' Stars Chair
Caroline Fehlhafer, Super Stars Chair
Amy Svoboda, Parents and Teens Chair
Lori Tackett, DSAF Program Director
Angie Willey, Email Blast Coordinator

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Return Service Requested

Down Syndrome Association for Families

Mission Statement: The Down Syndrome Association for Families is a Lincoln based non-profit organization that provides support for individuals with Down syndrome, their families, friends, educators and professionals who share in their lives.

Every person with Down syndrome is an individual who has a unique purpose and abilities. DSAF provides networking and a positive vision for the future.

www.dsafnebraska.org

Telephone 421-1388

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Calendar of Events Not to Be Missed!

- | | |
|------------------|--|
| Dec. 4 | 10:30 a.m. DSAF Christmas Brunch at St. Luke Church, 1621 Superior. Santa, balloon artist, book bundles! |
| Jan. 14 | Mom's Night Out. Grisanti's at 6:30 p.m. |
| Jan. 22 | Sibling Workshop at Gere Library 10 am-2 pm. See details on page 3 |
| Jan. 29 | Super Stars Swim Party, 1-3 p.m. |
| March 21 | World Down Syndrome Day |
| July 29-30, 2011 | Wrightslaw Conference, details to follow |