



APRIL/MAY NEWSLETTER

PRESIDENT'S MESSAGE

This has been an exciting month and a time for lots of learning. March 19-21 three DSAF board members, Dean Fuelberth, Jane Quiring, and myself plus 2 committee chairs, Caroline Fehlhafer and Liz Echterkamp attended the Affiliates in Action Convention in Kansas City. The AIA brings together Down syndrome groups from across the country to attend workshops and to share information among ourselves. Everyone is very willing to share not only information but actual programs they use so we aren't all "reinventing the wheel". We also want to see some continuity so that information you receive about Down syndrome is the same no matter if your baby is born in New York, Hawaii, or Nebraska. The different breakout sessions included information about marketing, the latest in prenatal testing information, medical outreach, Losing the Training Wheels, board training and effectiveness, research, dads groups, effective early intervention and so much more! One of the most helpful parts of this type of convention is the networking between groups. Many groups were impressed by how much the DSAF has done without having a paid staff person.

This transitions nicely to let you know we are presently interviewing for a half-time program director. As our group grows we have really been feeling the need to have a paid person who can give the time and effort to growing our group beyond what volunteers can do with their limited time. Of course we hope that we will be able to have a full-time executive director in the future with our own office. But this is our starting point.

Other information for you to particularly notice is our Summer Enrichment Activities Support (S.E.A.S.) program. This program allows a child to attend a summer program with para support. DSAF will reimburse the family for the para stipend. Applications and program guidelines can be obtained at upcoming DSAF events or on the website. Please consider using this program to include your child in an inclusive summer program. If you have any questions feel free to call me.

I want to thank Jane Quiring for offering to do the newsletter in the interim. It is important to keep in touch and this is one important way to do so. Don't forget about our upcoming events the Behavior Workshop, Super Stars Bowling and Mom's Night Out. Our website is a good way to check on upcoming events.

Deb Safarik, President DSAF of Nebraska

Newsletter Contributors

We're looking for individuals willing to contribute articles to the DSAF newsletter on a one-time, occasional or regular basis. Possible topics may include physical therapy, occupational therapy, medical issues, health, nutrition, other therapies, education, financial/estate planning, state/federal programs, and significant achievements to name a few. If you have an idea for an article and are willing to write it or know someone who will send information to Jane Quiring, Interim Newsletter Chair at www.nejq@hotmail.com.

DOWNSD ED CONFERENCE

By Angie Willey

On February 20, 2010 a handful of parents from Nebraska braved the weather to drive to Kansas City to attend the Down Syndrome Education Conference sponsored by the Down Syndrome Guild of Greater Kansas City.



Sue Buckley, Becky Baxter and Julie Hughes from Down Syndrome Education International presented on developing language and communications skills, developing early reading skills, supporting speech and verbal memory, developing play, number and cognitive skills and supporting social development and behavior in concurrent tracks broken down by age groups of 0-5 years, 5-11 and 11-16.

Here are highlights from the conference:

Visual Learning - It is probably not new information to most parents that children with Down syndrome learn better when visual teaching techniques are used. The DownsEd group did a really good job of breaking down

the learning process so that it was easy to understand why visual learning works so well. They offer a reading system called See and Learn that can be downloaded free or ordered from their website.

Errorless Learning - Start lessons out very easy so the child cannot fail. Then slowly start making each lesson a bit harder. By using errorless learning, you can prevent children from getting frustrated and giving up. Children do better when we work harder at teaching our kids instead of testing our kids.

Language versus Speech – Most children with Down syndrome understand way more than they can articulate. Speech and language are two separate items that are usually on very different levels that are often lumped into one communication goal. It is important to make sure that each area is address separately and at its current level .

Reading - Even very young children can be taught to read, first by word matching, then selecting and finally by word naming. It has been found that children with Down syndrome learn better when taught whole words first and then after they have a good understanding of sight words, go back and teach them phonics. One of the most impressive parts of this session was a video clip of a 4 year old boy with Down syndrome who was reading.

Behavior - Most children with Down syndrome are very social. However, because they are so darn cute, and they look at us with those beautiful eyes, they soon have many of the people in their lives jumping to help them. Our job as parents is to give them chronological age appropriate boundaries and behavior goals. They may need some support to meet these goals, but good behavior will only help our children later in their lives to be accepted by their peers.

For more information about DownsEd go to <http://www.downsed.org>. To view handouts from the conference go to <http://www.kcdsg.org/>.

FAMILY NEWS

DSAF wishes to extend a warm welcome to the following new families: Kathy and Scott Jenkins, Jenny and Mike Crank and Leigh Home-Pedersen and Tyler Pedersen.

Submit births, achievements, awards, etc... for future newsletters to Jane Quiring, Interim Newsletter Chair at nejq@hotmail.com.



What Do I Do If They Don't?

Helping Children with Discipline Expectations and Techniques

Mr. Matt McNiff, M.A., presenter

Mr. Matt McNiff, M.A. –
Matt McNiff is a behavior consultant with the Educational Service Unit No. 5 in Beatrice, Nebraska where he works with nine school districts to help teachers and administrators develop ways to help students with behavior problems. He spent nine years working as a teacher and counselor at Clarinda Academy in Iowa working with delinquent youth from around the nation and spent four years as a behavior disordered teacher at Beatrice High School in Nebraska. Matt has a Master's degree in special education from the University of Nebraska-Lincoln, specializing in behavior disorders. Matt specializes in helping teachers to develop programs that will reduce problematic behaviors and increase academic time. He also speaks to groups around the nation on how to reduce rude and defiant behavior in children.

Saturday, April 17, 2010

1:00p.m. - 4:00 p.m.

Hy-Vee conference room

84th & Holdrege

Lincoln, NE

Raising children is tough work. Raising children who have defiant behavior can be even tougher. What do you do if the children refuse? What if my child has a developmental disability? What are some strategies that I can use when they don't want to do what I ask of them? How do I stop my child from tantruming? By the end of this workshop, the audience will have a better understanding as to why children display defiant behaviors and provide strategies for when they refuse, how to use timeouts appropriately, what to do when your child tantrums, and how to help reduce many more behavior issues.

Preregistration is REQUIRED by April 14

Please register on-line at:

<http://dsafbehaviorworkshop.eventbrite.com>

or

Mail registration info to: DSAF of Nebraska,
PO Box 57362, Lincoln, NE 68505
Include your name, address, telephone number
number of people registering, and check

Cost to attend event:

\$7/person + on-line registration fee

\$10/couple + on-line registration fee

****There will be no child care provided.**

Questions about the seminar or specific behavior challenges you are experiencing and would like ideas from Mr. Matt McNiff can be sent to:

dsafconference@dsafnebraska.org

DOWN SYNDROME AND STUTTERING---HOW TO HELP

Article Submitted By Brenda Clark, Speech-Language Pathologist, Barkley Speech-Language and Hearing Clinic, University of Nebraska-Lincoln

The process of producing language is quite complex. First, an idea is formed. It is then converted into a language program that is further converted into a speech muscle movement program. Then the idea is spoken, and the message is heard and understood by someone else. Individuals with Down syndrome may find some or all of these steps particularly difficult. Ideas may not be clearly formed. The language plan and/or the speech movement plan may not be well established. The actual process of speech may be a problem, as well as a hearing loss, which is quite common in people with Down syndrome. Also, the individual may lack the social awareness needed to know when or where it is appropriate to say what is being thought.

For all of us, it is common to find that as the pressure to speak builds, a breakdown in fluency may occur. Imagine that you are trying to plan what to say in a foreign language—one where you know only a few words. You are likely to have long pauses when you are thinking of words; you might start a word, realize it's wrong, and then try another. If this is the case, you may appear very disfluent!

For a person with Down syndrome, wanting to convey messages through a system that does not always work perfectly may lead to:

1. Repeating whole words or parts of words while trying to think of the next part of the sentences (it's...it's...it's big.)
2. Long pauses in the middle of the sentence when he or she cannot think of the next word to say (it's aball).
3. Pauses in unusual places in sentences, often followed by two or three words in a sudden rush that may be hard to understand (I'm going swim.....ming tomorrow).
4. Emphasis being placed on the wrong word in a sentence or on the wrong part of the word. This may occur because the language system is not precisely planned or the control of movements of the speech muscles is not sufficiently well organized. (I like to eat apples.)
5. Some struggling to find the right speech sounds to begin the word with (a...er...er...i...um...over there). Sometimes it may be difficult for the person to start the voice working, leading to sudden high pitched or loud sounds.
6. A possible problem with hearing others and/or with noticing that what has been heard has not been understood. This may lead to hesitant and unsure speech and to communication between the person with Down syndrome and the listener breaking down.

It is possible that fluency depends on an equal balance between demands made on the language system and the abilities of the individual to meet these demands. Stuttering may occur when demands exceed one's abilities.

HOW TO DECREASE DEMANDS AND INCREASE ABILITIES:

1. Give the person plenty of time to speak. Planning what to say and saying it may be slower than you might expect.
2. Take a slightly longer pause between what he or she has said and your reply---this slows the overall speed of the conversation down. Encourage the adult or child to also take longer pauses, this allows thinking time before speaking.
3. Try to avoid finishing sentences or saying what you think he or she might be trying to get across.
4. Speak a little slower yourself---this gives a model for the child or adult to follow.
5. Try not to use too many long and complicated sentences as you speak.
6. Give positive encouragement for the message rather than the style of delivery.
7. For children, helping the language to develop and the vocabulary to expand may reduce the amount of disfluency. Teaching rhymes and jingles that have a strong rhythm and that can be moved to or clapped out are particularly useful.
8. Encouraging the use of sign language and other visual aids reduces the pressure on children or adults who are disfluent and difficult to understand.
9. Encourage the development of good social and communication skills like knowing when to speak and when not to, using eye contact, listening carefully, smiling and nodding, taking turns to speak).

Continued on Page 5

Most children with Down syndrome will be particularly disfluent while their language is developing and their vocabulary is expanding. The disfluencies may pass or reduce as they become better at planning and organizing their language. However, for some, language and speech may always be difficult.

As adults, a number of people with Down syndrome will be quite difficult to understand at times, and they may have bouts of disfluency varying from mild hesitations to more severe struggling to get words out. The most important thing is that they should still feel that what they say has value and that others want to listen to them. Attempts to make people imitate sentences or practice speaking in different ways are unlikely to produce more fluent speech in the long run, and this might make them feel that the payoffs for speaking are not worth the effort.

(Taken from "Down's Syndrome and Stuttering," by The Stuttering Foundation, 3100 Walnut Grove Road, Suite 603, P.O. Box 11749, Memphis, TN 38111-0749, www.stutteringhelp.org)

SUPER STARS GO BOWLING

Sunday, April 25, 2010 2 p.m.
Parkway Lanes, 2555 S. 48 St, Lincoln
2 games & shoes for \$ 8

DSAF will pay for the Super Star. Must be accompanied by a chaperone. Super Stars may bring a friend or sibling. **RSVP** to Caroline cmfehlhafer@yahoo.com or Deb G. 421-7423.

MOM'S NIGHT OUT

Friday, May 7, 2010 7 p.m.
Hollywood Bowl, 920 N. 48 St, Lincoln

Join other moms for a night of bowling and conversation. Non-bowlers welcome!

LESSONS LEARNED – BALANCE AND PERSPECTIVE

By Deb Safarik

When you have a child with Down syndrome it's sometimes very hard to look past the disability. I know it bothers me to have people look at Paul and initially all they see is he has Down syndrome. But sometimes even we as parents have a hard time not focusing too much on the Down syndrome.

I think Paul was about 2 years old. I was talking to a co-worker and bemoaning some behavior he was going through. I think I ended my discussion "blaming" it on Down syndrome. This co-worker was from Texas and had just been home to visit so her accent was really fresh. She eyed me and said, "You don't have boys, do you." "Why no", I said, "Paul had 3 big sisters." She then gave kind of impatient sigh and said, "Well he's actin' like a boy!"

I was surprised and frankly relieved! For those of you who have both boys and girls and those of you who grew up with brothers and sisters you know boys and girls do indeed act differently! This was my first experience raising a boy and things were different from when I had experienced my girls as toddlers (plus there had been a few years between the last time I'd had a toddler!)

Was Paul acting up because he was a boy or he was in the "terrible twos" or because he had Down syndrome? The answer was a resounding, YES! Down syndrome is as much a part of our kids as breathing

Continued on Page 6

but it only colors the natural development our kids share with all other kids. We have to remember there is what is normal and typical in all of them.

A few years later I was talking to a mom whose first child had Down syndrome. She was expressing concerns about her behavior as a young teenager. Now remember I have 3 daughters and have experienced 3 teenage females and lived to tell about it! I looked squarely at my friend and said, "You've never has a teenage girl before, have you? Let me assure you she's acting like a teenage girl!"

New name, same great walk

DSAF decided it is time to rebrand the annual fundraising walk which includes a name change. The **Step Up For Down Syndrome Walk** will be held on Saturday, October 2, 2010 from 8 – 11 a.m. in Antelope Park. More information about the walk and changes will be included in future newsletters. We're looking for more volunteers to be on the Walk Committee that plans the walk and help on the day of the walk. Contact Deb Safarik at 421-1338 or deb@dsafnebraska.org for more information about volunteering opportunities.

MEMBER SPOTLOT – THE LUDWIG FAMILY

By Jane Quiring

The Ludwig family (Matt, Sally, Kathryn 14, Caroline 11 and Thomas 7) moved to Lincoln over seven years ago in October. In November of that year, DSAF had a full page of photos in the Lincoln Journal Star celebrating the Buddy Walk. Sally immediately called and the family has been involved with DSAF ever since that time.

Sally has served on the Capital City Buddy Walk Committee for several years in various roles. She has also been the DSAF Treasurer for the past three years. The entire family has served as set up and clean up crews for various events over the years. Sally will be stepping down in her roles as Walk Chair and Treasurer as the family will be returning to Iowa in the near future.

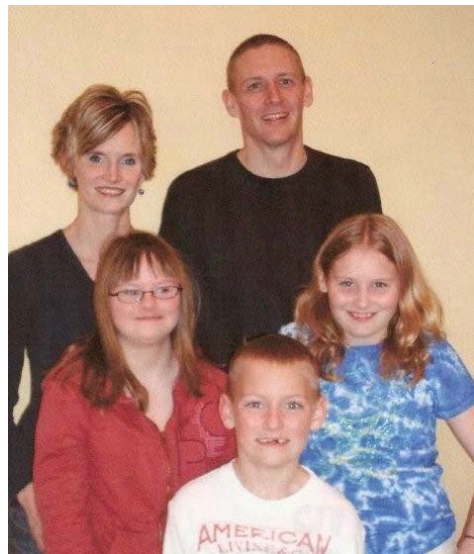
According to Sally, "Matt is a store director for Hy-Vee and was chosen from a long list of candidates to direct a store in eastern Iowa. It is truly bitter-sweet for us. It will be extremely hard to leave the people and community we have grown to love these past seven years. At the same time, we are excited to see what is in store for us in a new city!" Sally has "so enjoyed the people of DSAF! People I would have never come to know otherwise - people who have shared laughs, frustrations, tears, and celebrations with me. The Buddy Walk has truly been a joy and highlight of my involvement as well - but that's all because of the great PEOPLE that come to celebrate our kids."

Over the years the Ludwig family has learned many things from having a child with Ds: "family life doesn't have to revolve around Kathryn's disability"; a sense of priorities - "most worldly things just don't matter; celebrate the small stuff and take nothing for granted; having Kathryn has given Matt and me a sense of unity, taught us patience, endurance, and joy like we could never have imagine(d); and we see glimpses of character in Kathryn's siblings that we don't see in their peers - glimpses of compassion, acceptance, and advocacy that did not come from their parents."

Continued on Page 7

Sally offers this advice to parents about people with Ds:

1. Have expectations and set them high - in all areas. Don't expect a person with Ds to not do something simply because of a diagnosis.
2. Advocate, advocate, advocate (and always take treats!)
3. The best way to educate the public and break stereotypes is to engage in our communities. Find a way to share your passion about your child with those around you.



Sally asked to share this information with the DSAF community.

I have been afforded an incredible opportunity with the DSAF to use my gifts and passion for this short season - for that, I am extremely thankful. I am also thankful for God's many blessings and provisions for my family. While this one comes with some (okay, LOTS of) sadness, it comes with great anticipation and opportunity for "Team Ludwig" to bloom where we are planted in the next season. We pray that we bring honor and glory to God through it all! Thank you for allowing me to serve you through the DSAF.

Warmly,
Sally Ludwig

P.S. Thank goodness for Facebook... I'll be watching for your updates and pictures via that avenue!

We are thankful for the many benefits the Ludwig family has shared with the DSAF community. They will be greatly missed. We wish them well in the next chapter in their lives.

BALL NIGHT

Ball Night photos may be downloaded from the DSAF facebook page (not group). Look under events, see all, show past events, then click on Ball Night. Right click on each photo you would like to copy and paste into your own software for editing and printing.

Thank you to **Tracy Howell Photography** who donated her services and the beautiful photographs, our special guests Husker football players **DeJon Gomes** and **Prince Amukamara**, and volunteers from **St. Luke Methodist Church** and **UNL**.

CONTACTS

Deb Safarik, President of DSAF Board
Dean Fuelberth, Vice-President of DSAF Board
Sally Ludwig, Treasurer of DSAF Board
Dyann Rupp, Secretary of DSAF Board
Brenda Clark, Board Member
Jane Quiring, Board Member & Interim Newsletter Chair
Anna Calhoun, Medical Outreach Committee Chair
Liz Echternkamp, Lil' Stars Chair
Caroline Felhafer, Super Stars Co-Chair
Deb Gearhart, Super Stars Co-Chair

deb@dsafnebraska.org
dean@fuelberth.com
msludwig@windstream.ne
drupp@unlserve.unl.edu
bclark3@unl.edu
nejq@hotmail.com
acalhoun@neb.rr.com
eldrenliz@neb.rr.com
cmfehlhafer@yahoo.com
igear1959@aol.com

DSAF
P.O. Box 57362
Lincoln, NE 68505

NON-PROFIT
U.S. POSTAGE PAID
LINCOLN,
NEBRASKA
PERMIT 1024

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.

Calendar

Monday, April 12	DSAF Board Meeting 7 – 8:30 p.m. St. Mark's Workroom
Saturday, April 17	Behavior Workshop 1 – 4 p.m. Hy-Vee Conference Room, 84 th & Holdrege see page 3 for more information
Sunday, April 25	Super Stars Go Bowling 2 p.m. Parkway Lanes see page 5
Friday, May 7	Mom's Night Out 7 p.m. Hollywood Bowl see page 5
Monday, May 10	DSAF Board Meeting 7 – 8:30 p.m. St. Mark's Workroom
TBA	Dad's Night Out – watch for details in future communications
TBA	Picnic & Swimming – watch for details in future communications
Saturday, October 2	Step Up For Down Syndrome Walk 8 – 11 a.m. see page 6

SPECIAL OLYMPICS VOLUNTEERS

DSAF is now registered as a group on the Special Olympics US National Games website www.2010specialolympics.org to be held in Lincoln July 18 – 23. Go through the registration process on the website and choose DSAF in the group affiliation section (scroll up to get to the D's). **Registration deadline is May 1.** If you've already registered you can either 1) re-register or 2) contact Special Olympics at volunteer@2010specialolympics.org to add the DSAF group. We'd love to have 50 volunteers to participate from DSAF. It just takes one!

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.