

DSATnews

Down Syndrome Association of Tulsa

March, 2008

P.O. Box 54877 • Tulsa, Oklahoma 74155-0877 • www.dsat.org

President's Message

Well, we have had some wonderful people step up to the plate to volunteer for DSAT and we can't thank them enough. If you would like to become more involved in DSAT and help with a committee, please look at the numbers on the back of the newsletter and contact us. We can do so much more with your help!!

We say this all the time, but we feel it is very important. Please make sure we have your current e-mail for the e-mail list. Send this to Molly Ziriaux whose information is on the back. We send out a lot of information between the newsletters regarding current events! Please make sure we have your information!

Please make sure you consider signing up to help with the Changing Lives presentations. These packets will provide valuable information to the doctors about Down Syndrome, how to deliver the news, resources, growth charts, and much more.

Look for more info inside the newsletter.

Adam & Erin Paul

Scholarships

Congratulations to this year's scholarship winners who will be attending the National Down Syndrome Congress conference in Boston this July.

Family Scholarships: Troy & Susan Stephens and Kelli Bennett
Sibling Scholarship: Michelle DeBie (Benjamin Ahumada's big sis)
Self-Advocate Scholarship: Jesalyn Nelson
Educator Scholarship: Carolyn Cantwell (Jenks school district)

Calendar

It's calendar time again. Please fill out the attached profile sheet and have it in by April 1st. Please read the entire sheet before filling it out and sending it in. You can send it directly to me at April Wegener 1512 E. Tacoma St. Broken Arrow, OK 74012. I will also get this uploaded to the website in case you misplace this form. You can go there and print it off and send it to me. PLEASE remember to send a picture of your child along with your form.



Also, if you still have calendar money, please send it to the P.O. box or bring it to the next meeting. We are trying to collect all the money before we get going on next year's calendar.

Thanks so much!

April Wegener

Free Flight

Miracle Flights will provide airline transportation to and from medical appointments out of state. A few families have used this services and found it helpful. Check it out at: <http://www.miracleflights.org/>



Pictures

If anyone has pictures of the Buddy Walk or the Easter Egg Hunt please send your TWO favorite ones to Alana Kennon at (alanakennon@cox.net). She is updating the website.

D.A.D.S.

Tuesday, March 25th at 7:00 PM

Fox and Hound Pub

71st & Garnett

April Meeting

Thursday, April 17th at 7:00 PM

New Haven United Methodist Church

56th & New Haven

(between Yale and Harvard)

The Challenger League will be presenting.

Thank you TARC for making this newsletter possible!

STARS

The Statewide Training and Regional Supports (STARS) program is pleased to announce our 2008 calendar. All families involved in SoonerStart or in Public School are able to attend these workshops FREE of charge. Some limited childcare assistance and travel funds are also available. Visit the website for a calendar of trainings.



www.ah.ouhsc.edu/tolbert/courses_workshops

Should you have questions or require additional information about the 2008 STARS program, please feel free to call Judith Grove at 405-271-1836. We look forward to seeing you all in the coming year!

Down Syndrome Clinic

This is a great resource located in Kansas City. The appointment lasts about 5 hours. You see an OT, PT, Speech, Pediatrician and Behavior Therapist. They provide you with a wealth of information. Just wanted to make sure people knew this existed! Visit: www.childrens-mercy.org for more information. For appts call: 1-866-424-3771



Needs

There is a needs assessment online to assist in legislative influence. Please when you get a chance fill out this needs assessment and please forward to other families who have children with special needs, so we can have a priority on what families need.

For the 2008 Sooner SUCCESS Community Needs Assessment go to: <http://soonersuccess.oucpm.org/>

Mended Little Hearts



Look in this newsletter for a flyer on the Mended Little Hearts support group for parents who have children born with heart defects. This is a local resource and we wanted to share because half of the children born with Down syndrome are also born with a heart defect.

Newsletter Deadlines

Share with us your stories, news, interesting facts, company, product or book that has been helpful. Have your stories and information to Kendra Pennington me by April 26th for the May newsletter. Fax or phone 477-2999 or email kendra@soonerstart.com

DSAT Website

Checkout all of our current and previous newsletters on our DSAT website: www.dsat.org

Online Directory

Have you ever looked for a phone number or address for someone and couldn't find your directory? Well, this problem has been solved for you! **Introducing our new online DSAT Directory!**

You may now go to our DSAT website: www.dsat.org and click on the link for **DSAT Directory**. It will open to a login page. You will have to create a username and password in order to access the directory.

In order to do this you must click on "register" just below the login/password prompt. After you click register, you will be asked to register you name, email address and choose a username and password. Try to make your password as strong as possible for security reasons. (Hint: use special characters and caps to increase the strength). Once you have done this, click "submit".

An email will be sent to the Directory Administrator (Molly Ziriak) requesting access online. If you are currently listed in the directory you will receive an approval via email. Upon receiving this approval, you will be able to access the online directory through the username and password you created and view the directory.

Please check your information to make sure it is correct.

Any changes need to be made via email to Molly Ziriak and she will update the directory and our DSAT database.

If you filled out and submitted a directory information sheet, you were **automatically** added to the online directory. If you **DO NOT WISH TO BE LISTED ONLINE**, you must send an email to Molly Ziriak at ziriak@tulsacoxmail.com and make this request.

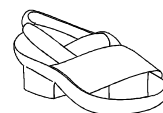
If you did not turn in a Directory Information sheet and/or are new to DSAT, and you would like to be listed online, you may contact Molly to be added to the directory, she will send you an information sheet.

We will also have a few printed directories available for anyone who can not access the internet, or would prefer a printed copy.

We hope this will be a great help to you! Thanks!

Shoes

Hatchbacks shoes for AFOs, DAFOs & Orthotics!



<http://www.hatchbacksfootwear.com/index.htm?session=CartID:4461B621054041B477UYsrD25B5A>

Check these out and let us know if they worked for you.

Changing Lives

Do you remember when you were told that your child had down syndrome?? Most all of us remember **who** said it, **when** it was said and **how** it was said to us. Some have good stories and some have bad stories... but we all have a story that we will remember for the rest of our lives.

You can help be a part of making “**good stories**” to remember!

As many of you know, the **DSAT Changing Lives Committee** was formed and has been working so hard the last year putting together a resource packet for all the pediatrician offices, hospitals and obgyn’s. This packet contains some wonderful information and we are going to be starting our presentations at the end of the month. We are going to provide lunch for the offices and do a short presentation about Down Syndrome and present them the packet of information to keep in their office. This is to help bring awareness and information to local medical facilities on how to inform parents that their baby has down syndrome. To aid in helping parents understand and to provide support.

If you are interested in being apart of a presenting team, we will be having a general meeting on **Monday, April 28th at 6:30 pm**. We will meet at “**Panera Bread**” at **91st and Memorial**. This will be an opportunity to come hear what the presentations will consist of

and how easy and stress free they will be to do. We can’t deliver the packets and information to everyone, so we need you to help us out.

Come be a part of “Changing People’s Lives”! It won’t take much of your time, if we all can get involved.

If you have any questions, please feel free to contact Erin Paul at erin-adam@prodigy.net or Molly Ziriak at ziriak@tulsacoxmail.com

We will look for you on April 28th! Thanks!



Governmental Affairs

Update on Kennedy-Brownback Legislation

The mark-up on the Pre-Natally and Post-Natally Diagnosed Conditions Awareness Act (S. 1810), known as the Kennedy-Brownback bill, has been rescheduled for Wednesday, February 27, 2008. Once the bill is reported out of the committee, our efforts will need to focus on moving it in the House of Representatives. As always, we will keep you posted about new developments.

To see the most recent version of the bill that has been introduced, go to: <http://thomas.loc.gov> and key in S. 1810 in the space for the bill number.

Efforts Continue on Education Legislation

NDSC and nearly 30 other organizations signed onto a letter from the Consortium for Citizens with Disabilities (CCD) to Senator Edward Kennedy (D. MA) chair and Senator Michael Enzi (R.WY) ranking member of the Senate Health Education and Labor Committee (HELP) voicing a strong objection to any attempt to use the Individualized Education Program (IEP) as the primary accountability tool under No Child Left Behind (NCLB). Some national education organizations are promoting this policy.

According to the letter,

“IEPs are not designed or used as tools for holding schools accountable for whether students with disabilities are taught to the academic content and achievement standards established by the state for all students.

IEP teams do not make curriculum decisions. Rather, the IEP is a legal document used by schools and parents to determine what services and supports are necessary for an individual child with a disability to have access to the classroom, to the curriculum, and to reach his or her potential.”

We do not know whether a bill will be introduced this year to reauthorize NCLB. We are closely monitoring activity on NCLB and will inform readers if and when legislation is introduced.

Thanks and remember: YOU are your child’s advocate. Get involved! Get active! Contact your legislators!

By Chris Wegener
DSAT Governmental Affairs
edward.c.wegener@gsk.com

Hello DSAT friends! We are the Urbans.

When we started thinking about opening our hearts and our home to an orphaned child, we decided we wanted to adopt a child that might otherwise be overlooked by most potential adoptive parents, a child with special needs. We were open to a boy or girl with a “minor” handicap. We still had our list of “requirements”, however. While researching special needs adoption we stumbled across a website, Reece’s Rainbow, (www.reecesrainbow.com) a ministry working to promote the adoption of children with Down Syndrome. Shortly afterward, we got an email from a missionary to Ukraine who had met the sweetest little 3 1/2 yr. old girl with Down Syndrome who lays in her crib day after day in the orphanage and had never learned to walk, crawl or even sit up. She can’t talk, but she has a smile that lights up the room.... she would be moved off the adoption list in a few months and transferred to the mental institutions where the funding is low, the conditions are horrible and most children die within the first year.



While she didn’t meet any of our original “requirements”, we knew she was just the little girl we were looking for. We started the paperwork last June, and seven months later, she is home with us, and already we can’t imagine life without her. While we know there will be challenges, we are confident that she will be a joy and a blessing to our family. We are looking forward to helping her meet her full potential, and also seeing what fun surprises she brings to us in return!

Home Alone

By Kathy Meeks

*Reprinted from The DSANI Star,
Down Syndrome Association of Northeast Indiana*

Many of us have watched at least some of the Home Alone movies. We’ve laughed at the antics of McCaulay Culkin’s character as he protects himself and his home from bungling burglars.

But for parents of children with special needs, the decision to leave a child home alone is often confusing and frightening.

The legal aspects of this decision can be confusing. When asked the question, “How old does my child have to be to be left alone in Indiana,” the following reply was posted on www.wiki.answers.com.

For children with normal mental capabilities:

Ages 7 and under cannot be left alone for any period of time.

Ages 8 through 9 can be left in their home alone for up to 2 hours.

Ages 10 through 13 can be left alone for up to 12 hours.

Ages 14 to 17 can be left at home up to 24 hours with adequate adult back-up supervision (an adult willing to take legal responsibility preferable within 5 miles.)

For children who are mentally disabled, you have to go by their maturity age and not their chronological age.

A website about fire prevention contains the following information form a checklist. Before leaving any child home alone, first ask the following questions:

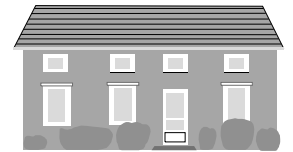
Physical Readiness *Can your child?* Lock and unlock the doors and windows of your home and perform everyday tasks such as fixing a sandwich or using the phone.

Mental Readiness *Can your child?* Tell time; Understand what stranger and emergency mean; Recognize danger and know how to stay safe; Solve small problems on his or her own but know when and how to get help; Consider how his or her actions affect others.

Social Readiness *Does your child?*

Talk easily to you about what happens at home or school and about his or her feelings; Feel confident enough to contact another adult if a problem arises

Emotional Readiness *Does your child?* Feel confident and secure when alone; Seem willing to stay alone; Know how to handle fear, loneliness and boredom



Several experienced parents offered these words of wisdom Boredom can become an issue if a child is left alone for too long. Two shared instances where teenagers who had never shown any interest in driving suddenly decided to move the car out of the driveway when their parents weren’t home. They recommend never leaving keys lying around to offer a temptation. Several parents described a process of first leaving their child alone inside while they would do outside activities such as gardening or yard work. Following success at this level, a parent might run a short errand, gradually building up the time that they were left alone. Having trustworthy neighbors often helps give parents a secure feeling.

One mother said she always checks to make sure a neighbor is available during specific times that her child stays home alone. Most parents agree that cell phones make it much easier to communicate with their children. Some popular models allow preprogramming important telephone numbers in speed dial, requiring the touch of just one button. It’s also possible to limit phone calls from a cell phone, avoiding nasty surprises when the cell phone bill arrives.

Leaving any child home alone is something every parent needs to evaluate on an individual basis. Hopefully, these guidelines may help with this important decision.

Dad's Corner

By Dion Inclan



The first time we saw Grail he was five months old. The birth family and adoption councilor were all ooohs and aaahs about how much he loved to snuggle in. Curious that they thought there was nothing wrong with the fact that a five month old could not lift his head. Most likely they blamed the Down Syndrome. Just like the glee they had in his lack of tongue control. "What do you expect, he has Down Syndrome" I made a vow to myself that I would expect more. No excuses, higher expectations. We saw right

away that he was a people person. Grail loved to make eye contact. Loved to make interactive noises (His way of talking) to those in the room. Therapists told us that Grail's awareness was a good sign. They hinted that his DS was on the "Milder" side. My resolve to have higher expectations for my son grew. I would have none of this sitting in the corner with his tongue hanging out. I envisioned my son with a job. I just knew he'd be able to have a job busing tables or emptying the trash cans at the food court. I just knew that once he was old enough to leave home he'd be able to live in a group home with other DS adults and become pseudo-self sufficient.

As Grail grew he became much more physically active, strong and capable. He could run and climb. People in the nursery would call him, "That Fast kid". I cultivated my expectant thoughts in the self-satisfied, if not sanctimonious recesses of my mind. Each milestone we celebrated as a little victory and every time pride welled within me as we saw how Grail grew into a strong, energy filled, and athletic little boy. Friends and family marveled at how obedient my son was. They remarked how amazing it was that a child of his age with DS could know what, "Get self control" meant. "Of course", I would think smugly, "I have high expectations for my boy"

Pride can be good, but pride when focused incorrectly, can be an ugly thing.

Welcome to Kansas City and the 2007 National Down Syndrome Congress Convention. Welcome to the slap in the face of my reality. Married DS couples? DS karate instructors? Oh my, DS associate degree holders who swim the English Channel!? My world was turned upside down. Cleaning tables? Taking out Trash? My "High expectations" that I held for my son seem pretty low if you ask me.

What I now realize is that it's OK for me to have High expectations for Grail. My son may not earn an associates degree or run a marathon, but I need to cultivate and encourage his interests. While doing so I must support every goal that Grail sets and relish in every victory that Grail celebrates. Most importantly throughout whatever path Grail sets to follow I need to just enjoy my son.



Special Olympics



SPECIAL OLYMPICS RUN
March 15th at 43rd and Peoria



There is a Fun Run at 8:30 am and then a Special Olympics Exhibition Run for all children and adults with disabilities to participate in at 9:00 pm. They get a FREE t-shirt and a medal. If you would like your child/adult to participate in the exhibition run, please call Steve Kime at 232-4372 or steve.kime@cox.net to give t-shirt size. There is NO charge for the exhibition run or no age requirements. For info about the fun run or the regular run, please call the Special Olympics at 481-1234.



The **Summer Games Registration packet** is on-line. Look for the **orange** button. The Deadline for Summer Games registration is **April 1, 2008**. Don't miss this Deadline!



Remember to send us your video clips (DVD, CD, or mini Digital tapes) from your area events!



Coaches' Certification is required for ALL sports. Each Team must have a Certified Coach training athletes to be eligible to enter athletes in any competition.



Area Spring Games packet for Training Opportunities. Time is running out if you still need to get your sport certification.



Every athlete needs a **new Medical/Release** this year. Be sure your athletes have the current Med/Release form valid from September 2007 through August 2010. These new forms are valid for 3 years. Be sure to submit COPIES and keep your originals on file for each athlete.





Little Hearts Hold Big Hopes.



When a child is diagnosed with a congenital heart defect/heart disease, caregivers may think hope is lost. Often they feel very alone.

Mended *Little Hearts*, a nationwide organization for parents, caregivers and families of children with heart defects/heart disease, provides resources and a caring support network to help families work through overwhelming emotions involved with having a child with a heart defect/heart disease. This organization helps families move forward to find laughter, healing and hope.

Serving families. Serving the Community

Mended *Little Hearts* is a pediatric support program dedicated to inspiring hope in those who care for the littlest heart patients of all. The core goal is to connect families in crisis with others who have survived the shock of learning a child has a heart defect/heart disease, navigated the maze of medical decisions and procedures, and mapped out a plan for the future. Mended *Little Hearts* was developed and is supported by The Mended Hearts, Inc., a national organization with over fifty years of experience serving heart patients and their families.

Purpose of Mended Little Hearts:

- ◆ Offer support to family members and other caregivers of children affected with heart defects/heart disease
- ◆ Offer educational/health resources relating to heart defects/heart disease and well-being
- ◆ Raise awareness in the community about children and heart defects/heart disease and factors that may contribute to this disease



The Facts*

- ◆ 9 out of every 1,000 births will have some form of congenital heart disorder
- ◆ Approximately 36,000 babies are born with a heart defect each year
- ◆ About 1 million Americans born with a CHD are alive today
- ◆ Cardiovascular disease ranks as the number 2 cause of death for children under the age of 15

** According to the American Heart Association*



We are currently forming a
Mended *Little Hearts* group in Tulsa, OK.
For more information, please contact:
Susan Vanderpool at 918-906-2026 or
svanderpool@hotmail.com.



**Mended
Little
Hearts**

A program of The Mended Hearts, Inc.

DSAT Calendar 2009 Profile

It is time to start working on the 2009 Sharing Our Joy calendar. We would like to include more parents in the many aspects of producing this wonderful project. Please consider which area you would be able to help with as you fill out the profile for your child. Filling out a profile does not secure your child a position in the calendar, it only means they will be considered. All calendar shots will be used in a variety of mediums (print, TV, ads, website, etc.) so if you have objections to signing over rights to **All** areas please **DO NOT** fill out this profile.

Child/Adult's last name _____ First name _____

Parent or Legal Guardian's full name _____

Address _____

City _____ State _____ Zip _____ Email address _____

Phone number (home) _____ (work) _____

Child/Adult's birthday w/year _____ clothing size _____

Please check the DSAT areas you would be willing to share your time and talents on:

Organizing profiles ____ Helping with photo shots ____ Making phone calls ____

Distribution ____ Publicity ____ Accounting for calendars ____ Sponsorship packets ____

Sponsorship appreciation ____ Calendar Sales at Buddy Walk ____ Typing _____

How many calendars do you estimate you can sell? _____

Do you know a business or individual who would be interested in helping to sponsor the calendar? If yes, would you contact them for sponsorship? _____

We like to highlight individuals with Down syndrome doing typical activities in the community (girl or boy scouts, 4-H, gymnastics, jobs, sports). Is your child/adult involved in something we should know about? _____

Please write a little something about your child below. We may put some of this info in the calendar. Ex. Sports, hobbies, things they like, brothers, sisters, animals, etc. _____

Please attach a recent **SNAPSHOT OR COLOR COPY OF YOUR CHILD**. It will not be used in the calendar but to plan the photo shoots. It will not be returned. Mail completed sheet and photo to: **April Wegener: 1512 E. Tacoma St. Broken Arrow, OK 74012**

Please contact April Wegener if you have any questions at 355-6999 or aprilwegener@cox.net

NOTE: Please understand that our photographer, Jill Soloman, generously donates her time, talents and materials for our calendar project. It is very important that we work into HER schedule. I know it is difficult for some to take off work, take your kids out of school early, take them during nap time, etc. However, it is also difficult for Jill to accommodate to everyone's schedule. We try to schedule times that will work best for everyone but sometimes it is difficult to please everyone. We do the best we can but when you are scheduling photo shoots for 50+ people, that isn't always easy. Jill has even opened up some of her Saturdays for us this year. Please remember that we need you to be flexible for this one photo shoot. Thank you for your understanding!

Don't forget to include a recent photograph of your child!!

Caring for Your Loved One



A FREE seminar for caregivers of children or adults with disabilities, physically disabled adults, and seniors ...

Providing... HOPE - answers are available

...HELP - people, organizations, & resources

The Grace-Ability ministry of Grace Church is pleased to announce its 2nd annual "Caring for Your Loved One" FREE seminar to provide you with information and resources to help make the care decisions necessary for yourself or your loved one. Representatives from state and local agencies, community nonprofit groups, and disability-related businesses will be present, including Ability Resources, Life Senior Services, MDA, Tulsa Area Agency on Aging, Center for Individuals with Physical Challenges and more.

FREE health screenings available

Topics include:

Programs and services available in the Tulsa area

What information to keep - How to get organized

Considering nursing home care - What to look for

Issues with nursing home care - What to do

Family dynamics with a disabled child

- How to head off trouble

Need help staying at home/leaving nursing home care

- Who can help

Sudden trauma or crisis

- Grief assistance and steps you can take

I'm disabled

- How do I represent myself and my own interests?

Is there anything fun to do?

- Community and Recreational Options

Date: Saturday, March 15

Time: 8:30 am to 1 pm

**Place: Grace Church Edge Building
9610 S. Garnett Rd
(use south parking)**

**No transportation, no respite care, and
no childcare provided**

RSVP preferred: www.gracetulsa.com

Registration also available at the door



**No Regular Meeting in March
due to the Easter Egg Hunt**

**April 17th
Regular Meeting
7:00 PM**

New Haven United Methodist Church

Challenger League will come do a presentation about the activities they have to offer. This is for ages starting at five thru adult. They do all kinds of sports and activities: basketball, baseball, swimming, arts and crafts, and drawing, you name it. They have unified sports and they have teams that go to Special Olympics. You won't want to miss this information no matter how old your child is. It is a wonderful program.

**May 15th
Regular Meeting
7:00 PM**

New Haven United Methodist Church

Frank Baxter, who teaches at the Little Lighthouse, will come and give his inspirational story about how he started a school in Russia for kids with Down Syndrome. He will talk about how he started this school and how wonderful it is for these kids. He will also talk about how we can help. Please plan to attend and show Frank how much we appreciate and support what he is doing in Russia. You won't want to miss his story!

**June 19th
Regular Meeting
7:00 PM**

New Haven United Methodist Church

Susan Vanderpool from "Mended Little Hearts" will share about their program, which is a support group for parents with children who have congenital heart defects/heart diseases and also **Sherilyn Walton** from TARC will talk about what TARC has to offer and the programs and services they offer.

July- Annual DSAT Driller's Day- more details to come.

**July 10th to 13th
NDSC National Conference in Boston**

Plan to attend! This is a great opportunity to be encouraged, to network and to gain valuable information!

April 17th
7:00 PM at New Haven United Methodist Church
Challenger League

P.O. Box 54877
Tulsa, Oklahoma 74155-0877

Down Syndrome Association of Tulsa

DSAT news

DSAT Board of Directors

President	Adam Paul	495-2563	erin-adam@prodigy.net
Vice-President	Erin Paul	495-2563	erin-adam@prodigy.net
Treasurer	Beth Soderfelt	272-3926	soderfelt.ea@juno.com
	April Wegener	355-6999	edward.c.wegener@gsk.com
	Kim Wofford	622-6906	woffordnate1@cox.net
	Alana Kennon	745-2398	kennon.alana@unionps.org

DSAT Committee Chairs

Governmental Affairs	Chris Wegener	355-6999	edward.c.wegener@gsk.com
Calendar Chair	April Wegener	355-6999	edward.c.wegener@gsk.com
Parent Advocate	Kim Wofford	622-6906	woffordnate1@cox.net
Publicity	Alana Kennon	745-2398	kennon.alana@unionps.org
Newsletter	Kendra Pennington	477-2999	kendra@soonerstart.com
Lending Library	Velvet Ahumada	794-5861	vahumada@cox.net

To add your name to our email reminder list please email:
ziriaux@tulsacoxmail.com