

DSAT *news*

Down Syndrome Association of Tulsa **September, 2008**

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

President's Message

Hello, we had a great time at the Driller's game and appreciate all that came. I know it was a hot day! We hope everyone enjoyed themselves.

We had a very good meeting in August. We appreciate everyone's ideas for the future of DSAT. We have grown so much in the last several years and know that we will continue to do so. Molly and Danny Zirix will be Co-Presidents as of January. We know they will do an excellent job. We still have the positions of Vice-President, Secretary and Vice-President of Development available. If you are interested in serving in one of these positions, please make sure you contact us at erin-adam@prodigy.net as soon as possible. We are hoping to fill the positions as soon as we can to continue the success of DSAT. We also have several new committees forming. We have a social committee that will help with all social activities of DSAT and a New Parents Committee that will help with all aspects of support for our new parents. We are going to start having new parent get together that we hope will help connect our new families. If you are interested in any of these committees, please let us know.

The Changing Lives packets are being delivered and we thank everyone who is helping deliver. We especially want to thank Molly Zirix, Velvet Ahumada, Kay Smith, Stephanie Keester and Teresa McHenry for all the hard work they put into these packets. Thank you for making this a success!! These packets will go to every pediatrician's office in Tulsa to provide a resource tool on Down Syndrome. We will be delivering these to Tulsa area obstetricians, if anyone is willing to help with those deliveries.

Make sure you mark the date for the Buddy Walk - October 19. We are looking forward to another great walk. Please make sure you look at the information enclosed and form a team! We have flags this year for every team formed. Please note that the shirts will be long-sleeve and we have a great new logo so make sure to get your shirts! We are also having a Kick Off Party this year that we hope you will attend when you pick up your registration bags. More information inside!

Hope school is going well everyone and we hope to see you at the next meeting and the Buddy Walk!

Adam & Erin Paul

2008 OKC Buddy Walk

2008 Down Syndrome Association of Central Oklahoma Buddy Walk will be held September 20, 2008. Registration begins at 11:00 AM and the walk begins at 1:00 PM. Events continue until 3:00 PM.

This walk will be that the AT&T Bricktown Ballpark at Reno Avenue and Mickey Mantle Drive in Oklahoma City. Parking will be FREE at Coca-Cola Event Center (East of the ballpark). Tell Attendant you are with the Buddy Walk.

September Meeting
Thursday, September 18th at 7:00 PM
New Haven United Methodist Church
56th & New Haven
(between Yale and Harvard)
Therapy Works presents Sensory Integration



Jump Into the Buddy Walk

Please Join Us at Pump It Up on Tuesday, October 14th. Everyone can jump (parents included) and pick up their Buddy Walk t-shirts, registration bags, turn in donation money and receive your incentive prizes! This should be a fun night! Come anytime from 5:30 PM to 8:30 PM!

Pump It Up is located at 13675 E 61st Street in Broken Arrow. You may go their website at www.pumpitupparty.com for more information about their facility. We hope this will be a fun family time as well as picking things up for the walk. By getting your registration bags early, you do not have to go to the check-in table at the walk. This really helps with the crowd the day of the walk. We hope to see everyone there!

Everyone **MUST WEAR SOCKS** to jump, so slip on your socks and jump with your kids! Let's Celebrate!

Thank you TARC for making this newsletter possible!

Exciting 2009 for DSAT

As Adam and Erin have mentioned, they will be vacating the office of President and Vice President at the end of this year. They have done an AMAZING job these last 6 years. We owe them a lot of appreciation and gratitude for the leadership they have shown and the time they have invested into making DSAT what it is today!

Thank you so much Adam and Erin!

Danny and I are very excited to have the privilege of becoming your new Presidents. We are thrilled to work together with you to continue to meet the needs of our families in the Tulsa and surrounding areas. As our kids grow up, we are faced with new challenges and new opportunities that daily arise and knowing that there are those who have gone before us, paving the way is a huge blessing to us all. And through this we hope that we can help give encouragement, courage and faith to those that are just beginning down this wonderful journey.

We had a great DSAT meeting in August to discuss new ways and fresh ideas on meeting the needs of our DSAT families. We had a great attendance and many wonderful ideas were shared and I think many of you are excited to get involved.

Obviously, we can only accomplish these goals, **with your help!** If you did not have a chance to sign up for a committee, or would like to add your comments please contact us and we can get you connected! zirix@tulsacoxmail.com
We would love to hear from you! Danny and Molly Zirix

Children's Urgent Care

On July 21st, the Children's Urgent Care Clinic will be closing and moving to the ER at SFH. The new name will be **Pediatric Emergency Center**. The good news is that the director will be the only board certified Pediatric Emergency Physician in Tulsa, CeCe Guthrie. The hours will be from 11:00 AM to 11:00 PM daily.

We understand that SoonerCare/Medicaid will now be accepted at the Pediatric Emergency Center!

Jill's Fundraiser for DSAT

Jill Solomon, our DSAT Calendar Photographer, is wanting to do a "fundraiser" for DSAT. Anytime between now and September 30, anyone who schedules a photography session with her and mentions DSAT, she will give 10% of the profit back to DSAT. It can be friends, family, anyone! They just have to mention DSAT so she will know. She now has her photography website up and running so you might suggest that they go to her site and check out her work. www.jillsolomonphotography.com

Please pass this on to friends and family!

New Ideas for future of DSAT:

Here is a brief outline of the items discussed and the suggestions that were made.

New Parents:

- Start a follow-up program
- New parent get together- 2-3 times a year
- Play group for new parents – help start
- Put new parent packet on a CD- for those with computers

DSAT monthly meeting ideas:

- Financial planning
- "Simply Fun" – games for kids
- ENT, Speech, OT professionals
- Nutritionist
- Lawyer
- Waivered Services
- How to do/improve your IEP (Getting ready for school workshop in the spring)
- Oral Motor skills
- Potty Training
- Activities- what activities are available in the area.
- Small group- break up into small discussion groups
- Universal Design
- Young Adults- activities, issues
Kimberly Myers is interested in this age group, if interested in helping her let her know at myersceo@hughes.net

Fellowship:

- Cookout with all of DSAT
- Family activities
- Christmas party
if you want to help, contact Erin Paul

Fundraising:

- Buddy Walk- need help!! Contact Alana Kennon
- First Downs for Down syndrome new fundraiser with the Union High School football team!
- DSAT Calendars
this helps to promote Down syndrome awareness

Newsletter:

- We are looking into some changes for our newsletter (color, binding etc. . . .)
- Articles needed for newsletter
- Dad's Corner
if interested in submitting an article and picture of Dad and child, contact Molly Zirix.



6th Annual DSAT Buddy Walk Online Registration Presented by McDonald's. Sunday, October 19, 2008 from 2-4 PM Track at Union High School (66th & Mingo)

Buddy Walk brochures will be mailed out in September to all individuals on the DSAT mailing list and information will also appear in the September/October newsletter. But, we wanted you to have information about registration immediately so that you can spread the word about the Buddy Walk and start your fundraising efforts.

Detailed information about the Buddy Walk can be found on the DSAT website at www.dsat.org and click on Buddy Walk.

Online Registration: It really is this easy!!!! To register to walk online, please go to www.firstgiving.com/dsat. If you register to walk online, you do not need to send in a paper registration. You can register yourself, a family and an individual with Down syndrome through this website. You can also create team's as well as a fundraising page that you can mail out to friends and family. Specific instructions are located below, but if you have any questions about registering or need help, please email Alana Kennon at alanakennon@cox.net. Registration is not necessary to attend the walk, but it is encouraged.

All registered walkers will receive a white long sleeve Buddy Walk t-shirt with the new 2008 Buddy Walk and a goodie bag.

Online Registration Instructions:

1. Go to www.firstgiving.com/dsat
2. Click on the Get Started button
3. Click on blue text which reads Buddy Walk 2008 – Tulsa
4. You will be given three choices:
 - a. Register online now – to register online for a family, individual and/or an individual with Down syndrome
 - b. I've already registered by phone or by mail – if you have registered through the brochure (once it is mailed) but would like to create a fundraising page
 - c. I've already registered for this event on this site – click on this if you have already completed step 4a but didn't create a fundraising page and would like to create one now.
5. You are now given choices on who you want to register.

Fill in the correct number of registrations next to the walker type.

 - a. Walker with Down Syndrome - Free – Number of individuals you are registering with Down syndrome. (One person = 1, Two people = 2)
 - b. Walker - \$10.00 – This is an individual walker. One registration per walker. (one person = 1, two people = 2, etc.)
 - c. Family Walkers - \$25.00 – This is a family membership and includes 3 walker registrations. (family of three = 1, family of six people = 2)

Note: You can enter more than one registration type in this section. If you have a family of 5 that you want to register and one of the family members has Down syndrome you would enter them as follows:
(1) Walker with Down syndrome, (1) Family Walker and (1) Individual Walker.
6. You will now need to register with the website.
 - a. If you created an account last year and still remember your password, you do not need to create a new account.
Simply type in your email and your password to continue.
 - b. If you are new to the site, type in your email and your password and you will create an account with Firstgiving.
7. Who are you registering?
 - a. Click on "Yourself" or "Someone Else"
 - b. If you are registering more than one person, you will be given an opportunity to register all individuals. You will just do so one at a time.
8. Once you enter the name and information, pick which time registration type that you are registering at this time, your phone number and the t-shirt size(s) Note: If you are not registering a family then you will only need to indicate one t-shirt size. The one with the red asterisk.
 9. "Are you part of a team?"
 - a. Registering with an existing team -
Pick the team you would like to join and click "select." OR
 - b. Create new team – located to the far right of the screen.
 - i. Team Name – enter a fun team name. Get creative.
 - ii. Organization – please enter DSAT
 - iii. Click add team button
 - c. If you do not want to create a team, then you can click on the "No I don't want to do a team" button at the top of the page.
 10. Confirm your registration
 11. Registration Confirmation
 - a. Write down your registration code and keep it handy.
You might need this number later!
 - b. Print the page for future reference. Bring it with you to the walk!
 12. Create a fundraising page
 - a. Click "Create Your Page"
 - b. Choose a web address – anything you want if it is available
 - c. You can do the following on your page:
 - i. Create a fundraising goal (aim for the stars)
 - ii. Upload a picture of your "buddy"
 - iii. Write a personal message.
 - iv. Once complete, click "continue" at the bottom of the page
 - v. When you are ready, email your friends and family your page link and ask them to support you. You will be surprised how many people will be happy to help you in your fundraising efforts. It seems to be easier for people to ask them to sponsor you over email than it is in person. But remember, if someone wants to write you a check or give you cash, you can turn this money in at the walk and still receive credit for your incentive prizes.
 - vi. For an example of a completed fundraising page, please visit:
 1. www.firstgiving.com/lucykennon
 2. www.firstgiving.com/lucykennon3
 3. www.firstgiving.com/ethanlane
 4. www.firstgiving.com/taylorp

Email me if you have any questions – alanakennon@cox.net

We hope to see everyone at the Buddy Walk!

Alana Kennon



6th Annual DSAT Buddy Walk

Presented by McDonald's.

Sunday, October 19, 2008 from 2-4 PM

Track at Union High School (66th & Mingo)

The Buddy Walk is a multi-city advocacy walk in which people with Down syndrome invite “buddies” to walk with them. Buddies can be anyone from friends to teachers or coworkers to politicians. The goal of the Buddy Walk is to celebrate October, National Down Syndrome Awareness month, and promote acceptance and inclusion of people with Down syndrome.

The Buddy Walk includes entertainment, prize giveaways, food and fun activities for the whole family. The Buddy Walk raised more than \$35,000 in 2006 to provide support and services for local families. More than 225,000 people participate nationally each year and more than 1,200 people are expected to participate in the Tulsa Buddy Walk this year.

Don't forget to register to walk at www.firstgiving.com/dsat or send in your registration form by mail.

Form a fun team – get creative with your team names!

WHAT IS A TEAM AND HOW DO I FORM ONE?

A team is a group of people who want to join in the fun and support DSAT and their “buddy.” Start by organizing your friends, family, coworkers, classmates and neighbors. Then, choose a team name and register your team at www.firstgiving.com/dsat. Through this website you can register individual members, build your own fundraising web page and email the link to friends and family.

WAYS TO SPONSOR YOUR BUDDY

We encourage all walkers to raise money for their “buddy.” Money may be collected by:

- Internet: Sponsors may give online with a credit card at www.firstgiving.com/dsat.
- By Mail: DSAT, P.O. BOX 54877, Tulsa, OK 74155. Include walkers name and make checks payable to DSAT.
- Bring to walk: Collect sponsorships and bring on walk day. Turn in at donation table.

All money raised goes to support Down syndrome awareness by creating new parent packets, distributing semi-monthly newsletters, awarding conference scholarships, sponsoring social functions and providing the public with up-to-date information and handouts.

INCENTIVE PRIZES

All registrants raising at least \$50 (not including registration) will receive a Buddy Walk Drawstring goody bag. Other incentive prizes are available for donations at the following levels:

- \$100- \$249 – Coffee Mug
- \$250 - \$499 – above plus Stocking Cap
- \$500 - \$999 – above plus Tote Bag
- \$1000 - \$1,999 – above plus Folding Chair
- \$2000 - \$2,999 – above plus Fleece Jacket

All money must be turned in by 3:00 PM on October 19, 2008, to be eligible for prizes.

WALK DAY INFORMATION

Walk Day Registration begins at 2:00 PM

Buddy Walk begins at 3:00 PM

Post-Walk Activities

- o Ceremony honoring individuals with Down syndrome
- o Food provided by McDonald's;
- o Sound and Music by Bryan & Kendra Pennington
- o Chatters the Clown
- o Carnival Games
- o Face Painting
- o Inflatable games
- o Mascots
- o Arts & Crafts by Camp Fire USA
- o Small animal petting zoo by 4-H Club
- o Animals from Safari Joe's of Adair
- o TheraPETics Service Dogs of Oklahoma
- o Tulsa police and fire vehicles
- o Tulsa Street Scene – cars and more



6th Annual DSAT Buddy Walk Fundraising Ideas Presented by McDonald's. Sunday, October 19, 2008 from 2-4 PM Track at Union High School (66th & Mingo)

REGISTRATION INFORMATION

By Mail: Brochures will be mailed in September and available to download at www.dsat.org.

Online: Register to walk online, build walking teams and create your own fundraising page at www.firstgiving.com/dsat. This website allows you to register yourself and other members of your team, as well as create a web page where you can invite friends and family to sponsor you or your "buddy." If you register online, it is not necessary for you to mail in the paper registration form.

If you have any questions about registering online, creating a team or starting a fundraising website please contact Alana Kennon at alanakennon@cox.net or publicity@dsat.org.

All individuals are ENCOURAGED to register and obtain sponsorships. However, it is not required to attend the Buddy Walk.

Bead*Dazzle

In honor of her beautiful niece, Anna Vahrenberg has created this Down Syndrome Awareness Bracelet. The focal point of the bracelet is a freshwater pearl surrounded by twenty swarovski pearls or crystals. Individuals with Down Syndrome classified as Trisomy 21 have an additional twenty-first chromosome. The freshwater pearl along with the twenty surrounding beads symbolizes this twenty-first chromosome. The unique shape of each freshwater pearl represents the special and unique qualities of each child with DS. The freshwater pearl is accented with the National Down Syndrome Society's colors of blue and yellow in Swarovski crystals and with Swarovski rhinestone rondelles. Hanging from the sterling lobster clasp is a sterling awareness ribbon charm.

Anna has donated a beautiful bracelet to our Buddy Walk.

For more information visit Bead*Dazzle or email Anna
http://www.etsy.com/shop.php?user_id=5565839
or email beaddazzlejewelry@gmail.com

Fundraising ideas and ways to celebrate October as National Down Syndrome Awareness Month:

§ **Work**

· **Jeans Day Pass**

o Ask your employer if they will sponsor a Jeans Day Pass to celebrate October as National Down Syndrome Awareness Month.

Employees purchase Jeans Day passes to wear on designated days. Without a pass, they can not wear jeans.

o Options include (but are not limited to):

§ Every day in October

§ Every Friday

§ Friday before Buddy Walk

o Turn in money at the Walk.

§ **School**

· Ask the principal if the teachers and staff in the school can participate in the Jeans Day Pass

· Talk to your child's teacher about a special way to incorporate the Buddy Walk and October as

National Down Syndrome Awareness month into the lesson plan.

· If older children, they might want to do a fundraiser to raise money to support your child.

§ **Social Clubs**

· If you have a bunko group, bridge group, poker night, bowling league or other social club ask them each

to donate \$5/\$10 (or more) instead of prizes.

· Turn in money at the Walk.

§ **Church**

· Ask your church if they will help publicize the Buddy Walk in the church bulletin.

· Make it a lesson in your families Sunday School class. Invite the Sunday school class to join your family at the walk.

§ **Posters and Brochures**

· If you are interested in displaying a poster somewhere or need extra brochures to pass out,

please let Erin (724-8574) or Alana (605-9931) know and we can get them to you.

Good luck and can't wait to see you on Sunday, October 19 at 2:00 PM at the Union High School Track!

Free Music Class Online

Come Children, Sing! Music Classes for Infants and Toddlers

The Come Children Sing Institute is offering free gift certificates for Come Children, Sing! Online Music Classes for infants, babies and toddlers with special needs. The \$35 gift certificate will provide one 10-week Online Music Class. Request a free gift certificate for your child by sending an email to ccs.online@comechildrensing.com. Mention this email article and that you have a child with special needs. Your gift certificate will be sent via email and you can start the Online Music Class at any time.

Come Children, Sing! is a developmental music program that makes learning music as natural as learning language. You can now engage with your little one in music classes online, in your own home and on your own schedule, whatever your musical background, and whatever the developmental level of your child. MP3 files, music activities, and parent tips are all provided online, and you can make Come Children, Sing! portable with an iPod or CD.

Listen to the Free Audio Presentation, "Parenting Music," at http://www.comechildrensing.com/public_pages/presentations.php. Discover the wonder of your little child's musical talent and the kind of activities that most serve musical growth and development.

For further information about Come Children, Sing! Online Music Classes for infants, babies and toddlers, and to view Free Sample Lessons, go to www.comechildrensing.com.

Sibshops

Sibshops? This is a place where children who have siblings with special medical or developmental needs can go to be around other children in the same situation. They get a chance to do fun stuff, interact with other children and just have FUN !!!

It's going to take lot of agencies, parents, volunteers to get this going. We got facilitators, dates/place, funding so now we need to start getting children registered for our sibshops. The first class will be for our 6-9 year old on Saturday October 4, then the 10-12 age group on November 1 and it will continue on until May. Each age group will have 4 sessions, every other month. This is for any child who has a sibling with a special medical or developmental need.

Please pass this along, post everywhere and advertise. We will need some volunteers to help with the classes. Thank you to everyone for your help. This is going to be very exciting for Tulsa.

Lora L. Roberts
OG&E Sapulpa/Drumright Scheduler
(918) 227-6202 office

Dr. Leichtman

Down Syndrome Clinic Coming to Tulsa October 3rd thru October 5th

Dr. Lawrence Leichtman will be back in Tulsa holding another Down Syndrome Clinic. He sees over 1200 kids and adults with Down Syndrome across the United States. He has been coming to Tulsa for several years. If you are interested in having a consultation with him while he is here, please contact their office at 757-425-1969. He does a very extensive evaluation.



This is Dr. Leichtmans' last trip to Tulsa. He will not be traveling after this visit. However, if you are a first time patient he will continue phone visits and can still write prescriptions. If you have seen him in the past, if you come and see him again, he will be able to continue the phone visits and prescriptions as well. Don't miss this chance!

Tulsa Spirit Award

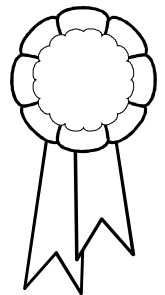
I finally have a few moments to pass on some exciting news to you and DSAT. From over 100 original applicants, I am one of 12 semifinalists in the Tulsa Entrepreneurial Spirit Award. We are using a model of "customized employment" and entrepreneurship to create meaningful employment for Ashley and potentially other young adults with disabilities. The new company is many abilities. We are providing outsourcing of mailing and other small office jobs to companies. Our focus is small to midsize companies.

I am to submit a revised business plan to the Spirit Award competition next week and make a second pitch to the judges September 5. The field will be cut to 7 and the winners will be announced in November after more work on the business plan and pitch.

Anyway, thought you all might be interested. We are trying to create a new paradigm with a progressive model by providing integrated and meaningful employment that is so badly needed in the Tulsa community.

Hope this finds you well.
www.ashleymom.com
www.manyabilities.com (coming soon!)

Kim Voss



Rare Disorder Support Group

A new support group for those with Rare Metabolic disorders: Lora Roberts works with the "Oklahoma Family Network" see her story below, it may not pertain to you, but you can pass it on to someone who would like this group.

My son, Jeremy was diagnosed with "severe" FG syndrome on March 25, 2005 after being tested for many different genetic syndromes and metabolic disorders. I joined the FG syndrome Family Alliance and became the Assistant OK/Texas Family Rep and until last year we were the only family in Oklahoma diagnosed with FG. We participated in a research project through Greenwood Genetics Clinic for FG syndrome and on May 15, 2008 I received a phone call that they found Jeremy had a significant change on his L1cam gene and I'm a carrier so he inherited this gene from me. The L1cam gene is located off of the long arm of the Xq 28 chromosome. Jeremy was born with hydrocephalus, agenesis of the corpus callosum and a severe heart defect. Jeremy had major open heart surgery, a shunt revision, a shunt infection, numerous outpatient procedures, frequent physician visits, & all the early intervention he could endure.

The work I do with the Oklahoma Family Network brings me in constant contact with many families, but this past year I started to notice how I was getting more referrals for families who had a genetic syndromes or metabolic disorders and when I tried to match them up in Oklahoma there were no families. The more I talked to these families the more we had in common, we were searching for answers, wondering why our families don't understand what we deal with. Genetics have always fascinated me and each family I would talk to I loved the encounter. I decided one day after talking to a family with a syndrome I have never heard of that this was one of my passions to start a support group for families who had children with rare metabolic disorders or genetic syndromes. They need a "safe" place where they can meet other families who are in similar circumstances, they can learn from each other and resources. I talked with Joni Bruce our Executive director and she put me in touch with two moms from Oklahoma City who wanted to do a support group up there. We decided we would be one group but have two different locations and work it through OFN. I talked to Melissa Ramirez who is one of my moms of many years and we met one Saturday for breakfast and brain stormed our thoughts, we decided to set a date/time, pick a place and work out the details. Melissa and her husband David created our logo and gave us a name so with that "**Extraordinary connections**" was born.

I am PROUD to announce we will have our first meeting in the NE Oklahoma are on **Saturday September 20** at Hardesty Regional Library starting at 10:00 AM to noon. I'm asking if you have family/friends/patients who have a child with a rare metabolic disorder or genetic syndrome please pass this information along to them. We will be doing an article in the Tulsa World the first of September.

Lora L. Roberts (918) 227-1797
NE Regional Coordinator- Oklahoma Family Network



Functional Feet

Therapy Works is offering a **FREE** seminar on Tuesday, September 30th from 6:30 PM to 8:00 PM at their clinic located at 7608 E. 91st St. in Tulsa (on 91st between Memorial and Sheridan. Please call 918-663-0606 or email info@therapyworkstulsa.com to RSVP.

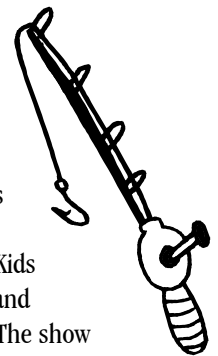
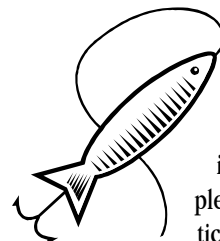
If your child complains about foot pain, constantly sprains his or her ankle, looks "awkward" when walking or running, is clumsy or "toe walks," incorrect foot alignment may be the cause. This seminar will discuss correct foot alignment, causes of foot and knee pain, walking and running style, balance and coordination, youth sports injuries, orthotics, casting and bracing and preventing foot problems as adults. The seminar will be presented by Liesa M. Persaud, MPT, and physical therapist at Therapy Works.

Please pass this along to anyone who might be interested in attending. Let me know if you have any questions or visit www.therapyworkstulsa.com for more information. We look forward to seeing you there!

Troutfishing In America

A grammy winning band whose music caters to kids of all ages. Their shows are very fun and encourage audience participation. Able Kids thought it would be fun to have our friends and

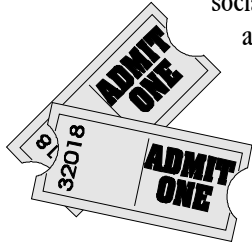
families go together. The show is at the Tulsa Performing Arts Center (PAC) which is located downtown on Saturday, September 20th with the family show at 4:00 PM. If you are interested in attending this fun filled event please let us know ASAP and we will buy a block of ticket (\$10 each) so we can sit together.



Able Kids Playhouse

Presents: Act It Out! A Dramatic Approach to Social Skills

This group, facilitated by Wendy Huckeba, PhD, Pamela Moore MOT, OTR/L and Karen Raines MA, CCG-SLP will utilize dramatic and improvisational exercises as a vehicle for practicing social skills. Students will work on the application of self-awareness, cooperative activities, and communication (using voice, emotions and movement).



We end each semester with a show for parents, family and friends. This year we are hoping to do this on a real stage. There will be two groups class offered this fall

meeting from 5:30-6:30 Mondays or Wednesday. A limit of 5 kids will be accepted in each group. For more information contact ablekidstherapy@yahoo.com or call 918-622-6599.

Special Able Kids Programs

Able Kids is offering a picky eaters group for kids & their parents. This group will meet monthly. Homework programs are part of this group & necessary for a level of success to be achieved.

Overnight campout at the Coop De Ville. This fall Able Kids will host an overnight campout experience for kids & their Families. It will be on a farm in Carthage, Missouri where there will be many outdoor activities offered for the kids and parents, together & separate.

Halloween Haunted House Party information will be coming soon!

Drop In Game Nights We will have a board game night 2-3 times each semester for kids & parents. Just plain FUN!

For more information contact ablekidstherapy@yahoo.com or call (918) 622-6599.

Sunday School Class

Faithful Friends & Teachers at New Haven United Methodist Church on Sundays from 9:40 AM to 10:40 AM is a class designed so that children and their families may attend church and Sunday School. If you plan to visit, please call the church first so that they will be expecting you. For additional information please contact, New Haven United Methodist church at 918-743-6491.



Meet Annie

Hello everyone!

My name is Heather Scharlau-Hollis and I have a daughter with DS who will turn 3 in September. I am from Wisconsin and have participated in the Buddy Walk in Madison. My daughter Annika (Annie) has had 10 surgeries so far and will undergo a final heart surgery this month (August 14th). For therapy for myself (which we all need!), I wrote a children's book with Annie as the main character. The book shows and teaches acceptance of children with DS. I sent it out to 5 publishing companies and it was picked up by Tate Publishing in Oklahoma! I couldn't believe it! *'Meet Annie'* was released on March 11th and is available all over the world! *Meet Annie* is a first in a series of children's books with more on the way! My goal is to get this book in clinics and hospitals! I have sold out at book signings, my book has been featured in newspapers and I have been on WIBA radio in Madison, WI talking about DS and my book. I am on a mission to educate and promote awareness! I just wanted to let everyone know! Feel free to contact me via email or phone for questions! I will be starting a library tour in the Fall and I am also planning for speaking engagements to spread awareness! Feel free to forward this to anyone whose family has been blessed with an extra chromosome! Thanks for your time, you can find my book at <http://www.tatepublishing.com/bookstore/book.php?w=978-1-60462-148-8>



Up For Reading 2009

We are thrilled to announce Up for Reading 2009 - the second year of our fun and educational sponsored reading campaign for children of all ages and abilities. You can take part in Up for Reading at home, at school or with friends.

Taking part in Up for Reading is an easy way to raise money for Down Syndrome Education International's work for young people with Down syndrome everywhere. By supporting Up for Reading, nurseries, schools and support groups can also raise money for their own activities. Many famous children's authors are supporting Up for Reading - and you have the chance to win some fantastic prizes by getting involved.

To find out more visit www.up-for-reading.org

Online Updates

Down Syndrome Online has been updated to simplify navigation and to introduce a cleaner layout. We have also introduced a new search system - powered by Google - across our web sites, making it easier and quicker to locate information.

This update also paves the way for the release of new online editions of the *Down Syndrome Issues and Information* education series and adult series of books over the coming weeks.

Speech, language and communication for individuals with Down syndrome - An overview, by Sue Buckley, is now available in full online. This book examines what is understood about speech and language development for young people with Down syndrome and the principles of effective intervention and teaching support.

This is one of many books in the *Down Syndrome Issues and Information Education Series*. Further online editions will be available over the coming weeks.

Shining Stars Cheerleading

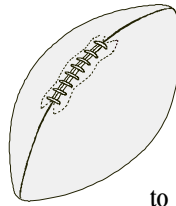
Tulsa Cheer Academy is one of the first to offer special needs cheerleading in our area! TCA Shining Stars cheer team is a competitive cheer squad for special needs athletes ages 5 and up. Competitive cheerleading builds coordination, self-confidence, and discipline. There will be trained adult coaches as well as junior coaches, who are also TCA cheerleaders, working with your child. The junior coaches will be on the floor with the Shining Stars during their all-star competitions to assist where needed.

There is some commitment when joining. Team members will practice on *Fridays*. The starting date is to be determined soon. There will be approximately 3 or 4 competitions the team will compete in. (Most will be local) More information will be given at a later date. The cost is \$120 for uniform rental and bloomers and \$45.00 per month for tuition (4 week session). There will be additional competition fees.

Everyone "makes" the team! Everyone can succeed at cheerleading. We will have athletes with many different disabilities. All will be able to participate at their own level!

We will work with each athlete to develop their own level of cheer and tumbling skills. Tumbling skills are not required. All we ask is a willingness to learn, follow directions, have a positive attitude, and maintain good attendance.

For more information or to sign up, please call Michelle Adams at SSB KIDS at 289-1071 or email specialcheer1@sbcglobal.net



First Downs for Down Syndrome

Union High School Football teams have joined with us to raise money for public awareness. Look at their website www.unionredskinsfootball.com for donation information.

Thank you Union High School for this support!



Resources

DRS Disability Resource Guide

Find local, state and national disability information on Employment and Training, Specialized Educational Services, Financial Assistance, Housing, Transportation, Health, Disability Law, Legal Aid, Support Groups, Accessibility, Assistive Technology, Rehabilitation, Personal Assistance, Disability Organizations, Sports and Recreation. Go online and search for a topic or simply explore chapters that interest you. www.okdrs.gov or 1-800-845-8476

Zac Browser Eases Frustration for Children that allows children to play games, listen to music and do a variety of activities without the worry of violent or adult websites and distractions such as pop ups. The Zac Browser is free and available online for anyone to use. It can be downloaded or run directly from www.zacbrowser.com

Up with Down is a school in Russia that is for children with Down Syndrome. Frank Baxter started this school and continues to make it grow every year. He does this ALL on donations alone. The UP with DOWN, Inc is having their 2nd Annual Golf Tournament on September 27, 2008. For more information call 918-355-8856. We hope we can show Frank our support. He is doing such a wonderful thing in Russia for all of these children. He can't do it alone! You may go to upwithdown1@netzero.com to ask for more info as well.

Miracle Flights is a program providing out-of-state for medical care. We have heard that they have been VERY helpful with these stressful trips. For information go to www.miracleflights.org

36th Annual NDSC Convention

I attended the Convention with my daughter (Ben's older sister) Michelle. We stayed at the Boston Renaissance Waterfront Hotel which was within walking distance of the Trade Center where the Convention was held.

I signed up for a pre-conference workshop that was held on Friday. We were supplied with complimentary coffee and ice water. The workshop was about inclusion in a regular classroom. It is not the first workshop I had attended about inclusion but as long as it's a different speaker, I always learn new things. ! We then attended the reception that night... wow! It was beautifully decorated and tables all over the ballroom were loaded with great food! To top it off, they had set up a sweet and salty bar with chocolate covered pretzels, chocolates, jelly beans...! Bags were supplied so we could load up! I managed to save some for Ben!

Saturday, when all the workshops started, my daughter and I went our separate ways. She went to workshops that pertained to her relationship with her brother and I went to workshops about Ben's education and behavior.

I was impressed with the Mock IEP workshop. A mock panel of an IEP team first put on a skit about a "worst nightmare" IEP meeting and then followed up with a "Dream IEP". The first made me want to cry and the second...well, made me laugh! It was great, I am sure everyone with a school age child has had one somewhere in between. What is sad though is a lot of their material was pulled from actual IEP meetings!.

The last day, I attended a behavior (Behavior and Down Syndrome) and found it was not what I had expected nor did the speaker hold my interest. I need to be entertained! (LOL) Anyway, the great thing about the workshops is that you could just go drop in on another one!

We absolutely enjoyed ourselves. The Convention being in Boston was just icing on the cake! We are so very thankful for the scholarship!

Velvet Ahumada and Michelle De Bie

Dear DSAT Family,

We would like to thank DSAT for providing the scholarship that made it possible for us to attend the NDSS Convention in Boston. This was an amazing opportunity for us and we would not have been able to go without the generous gift from DSAT. We were able to meet other families from across the nation who experience the same things we do. There were some of the most knowledgeable speakers who spoke about very important topics specific to our Down Syndrome families, and the exhibitors were a great resource as well. Probably our favorite part was hearing the self-advocates speak. Even though our daughter, Baylee, is only seven, the self-advocates encouraged and inspired us to set high goals for her future and once those are met, set even higher goals.

We just can't say enough about how much we enjoyed the convention. The fact that it was in Boston was just an added bonus! We are so grateful for all of the work that is done by DSAT. We feel very privileged to get to be a part of such an amazing group.

Jason & Kelli Bennett

The National Down Syndrome Association meeting in Boston was an awesome experience. I am so thankful to the local chapter for sending me. Truly we can see that "We're More Alike Than Different."

I attended meetings on behavioral management and expectations, teaching reading to children with Down Syndrome, medication and other issues with Down's children, and teaching math. All sessions were absolutely fabulous and I learned something in every one.

Behavior is such an issue and Dr. Capone from Johns Hopkins feels that we are seeing that there are also other issues, such as autism, OCD etc., with Downs more than previously thought. He said we need to choose our battles, be consistent, keep the rules the same, use positive words as much as possible, and if need be, get help from a behavioral specialist. He stressed catching children being good and praising them for the correct behavior. He had much advice about medications and children depending on what issues they have along with Downs.

Sue Buckley, from the Down Association International, UK, gave very practical advice about teaching reading to children with Down Syndrome. She stressed the importance of using visual strategies with these and ALL children. Over 80% of people learn visually, therefore it makes sense to incorporate these strategies for everyone.

Dana Halle, Down Syndrome Foundation in Orange County, CA, showed ways to incorporate math concepts into everyday activities. Again, she stressed using visual strategies and hands on materials to help children learn daily routines and math concepts.

One of the best workshops I attended was with Kathleen Feeley, Long Island University. This session concentrated on working with specific impairments as early as possible. She stressed that our children have a deficit in requesting skills and gave recommendations on how to work with this issue. She stressed that for expressive language we need to teach the words/phrases required in a given situation to increase the likelihood he/she will use them. She said we need to identify the desired behavior, create a visual to represent that behavior (there are those visuals again), go over what the child should be doing using the visual. (This could also include a video or photographs of children doing the appropriate action.) We use social stories at school. We write a short script with pictures or PowerPoint to show what we expect with a story. Parents can take these stories with them to pull out—like at the grocery store or other places where they have difficulty. Children with Down Syndrome have difficulty with short term memory, impacting learning in many areas. We should drill: touch your head and your nose; stamp your feet and touch your head, go get your coat, backpack, and shoes.

The exhibits were a buffet of temptation. I purchased three books about using visual strategies at home and school and one book on behavior. I highly recommend these: Making Visual Supports by Jennifer Savner. This book is packed with pictures of visual supports that really work with children with many disabilities. It has great ideas for parents to use at home. Visual Supports for People with Autism by Marlene Cohen and Donna Sloan is also very good. There are good ideas for parents and professionals as well. Power Cards by Elisa Gagnon is basically the idea of social stories with a little more added. The book on behavior was not that great. There were so many more I wanted to purchase and I brought home brochures on several.

The conference was a great way to network, share ideas with other parents and teachers, and brush up on skills. It is such a supportive system for parents. I have so many ideas floating through my head about things I want to do for my students and parents this next year. I am thankful for the opportunity to hear from so many professionals and find new ways to present information to my children. Thanks DSAT! It was such a blessing.

Carolyn Cantwell

Carolyn.cantwell@jenksps.org

What another great National Down Syndrome Conference in Boston! If you haven't been able to attend a conference, I hope you get to experience what it is like. It is an unbelievable feeling to be in the same room with so many people that have similar experiences as you. For that weekend, you don't have to explain to anyone and everyone just loves to see all the kids and adults.



Adam and I enjoy hearing the self-advocates as they are very inspirational. The workshops are beneficial and we learn so much. We went to several behavior workshops with Dr. Capone and if you are need of behavioral advice, he is a great resource. He does take appointments at John Hopkins in Baltimore. Another great resource is Dr. Sally Shott. She is an ENT that has a grant to work with children with Down Syndrome. She is at the Cincinnati Children's Hospital. We actually have had a DSAT member see her and then have surgery at that hospital.

We have the whole conference on CD-ROM and we strongly encourage you to check it out of the lending library and listen to these fabulous speakers. Make sure you check out the Specs4US glasses. They are specifically designed for kids with Down Syndrome. The information is info@specs4us.com or 1-800-586-1885.

Adam and Erin Paul

SAVE THE DATES

Saturday, March 7th - A State-Wide Down Syndrome Conference in Oklahoma City. DSAT is a sponsor of this conference. It will be from 8:00 AM to 4:00 PM. We will send out more information as it gets closer.

Saturday, March 28th- Kansas City will have a Regional Down Syndrome Conference. This will be a one-day conference as well with national speakers. More information to come!



September 18th
Therapy Works: Sensory Integration
7:00 PM New Haven United Methodist Church
 56th & New Haven

Therapy Works is coming to do their Sensory Integration Presentation. This will deal specifically with kids/adults with Down Syndrome. This will be very informative.

October
No Formal Meeting

October 12th
Buddy Walk Baskets
1:00 PM New Haven United Methodist Church
 56th & New Haven

Help us assemble the registration packages and auction baskets. This is a very big undertaking and we could use helpers. Please help us prepare for the biggest event of the year!

October 14th
Buddy Walk Pre-Registration
5:30 PM to 8:30 PM at Pump It Up
 13675 East 61st Street in Broken Arrow

Wear your socks, pick up your shirts and bags, turn in donations and receive your incentive prizes. Then JUMP, kids of all ages welcome!

October 19th
Buddy Walk
2:00 PM to 4:00 PM at Union High School Track

November 20th
MUSIC
7:00 PM at New Haven United Methodist Church
 56th & New Haven

December
No Formal Meeting

December 13th
Christmas Party
10:30 AM to 12:30 PM

September 18th Therapy Works 7:00 PM New Haven UMC
 October 14th Pre-Registration 5:30 - 8:30 Jump It Up
 October 19th DSAT Buddy Walk 2:00 to 4:00 PM Union High School Track

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

Down Syndrome Association of Tulsa

DSAT news

HELP US

Sunday, October 12th starting at 1:00 PM

WE NEED YOUR HELP

Please come help put together the door prize baskets and fill registration bags for the Buddy Walk. We will be doing this on Sunday, October 12th starting at 1:00 PM at New Haven United Methodist Church. If you can even come for just an hour, we would greatly appreciate your help. There will be lots of work to be done. Please come help us out!



DSAT Board of Directors

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