

DSAT *news*

Down Syndrome Association of Tulsa

July, 2007

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

President's Message

We have had very beneficial meetings the past several months. Our potluck was a huge success and we hope everyone enjoyed themselves. Dr. Laura Taylor gave some great information on horseback riding therapy in May and then did a great question and answer session in June. We hope this was beneficial to our members.

We have many exciting events coming up. We really work hard on making this newsletter very news-worthy and try to provide the most up to date information. If you have any information you would like to include, please e-mail us at president@dsat.org. We are working to increase utilization of our website. It is really been a great tool for new parents. We have several e-mails to use to answer your questions more effectively. Please e-mail your questions to the board member that can assist you the most with your question. We will try to get back to you in a very timely manner.

We really encourage you to fill out the family profile sheet included in this newsletter. Please return it and we will get your family featured in upcoming newsletters. This is such a great way to get to know each other within DSAT. We want to have existing families and new families complete this form! We think this will be a great new section to our newsletter. We want to include pictures as well.

We look forward to our annual DSAT event at Driller's park in July! We hope to see everyone there! Enjoy your summer.

Adam & Erin Paul

Next Regular Meeting
Special Olympics
Thursday, August 9th
New Haven United Methodist Church
56th, between Yale & Harvard
7 to 9 PM

Check Out The NEW DSAT Website

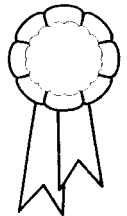
Visit www.dsat.org for lots of great information. You can also tell your friends and family about our donation page! We take credit cards and they can set it up so they can automatically donate each month a certain amount! Take advantage of this great way to support DSAT! Alana Kennon has done an outstanding job on the DSAT IN THE NEWS PAGE. Click on this icon on the website and see just how many times DSAT has been in the news. It is amazing and the articles are very interesting. Thanks for all your work, Alana!



New Parent Packet

We Need Your Stories

Stephanie Keester is putting together our New Parent Packets now. This is a HUGE job and we really appreciate you doing this, Stephanie. DSAT thanks you for your time. Stephanie is updating the packet and requesting people to either update their stories and pictures that have already been written or if you don't have your story in the packet and would like it to be, please contact Stephanie Keester at sakeester@aol.com or 496-3441. This is such an important part of the packet, so please consider writing a story and including lots of pictures.



Applicants Needed

We have only received one teen/young adult/adult information sheet for the Buddy Walk that was included in the last newsletter. PLEASE return this to the PO BOX so we can honor these individuals at the Buddy Walk!

Join The Email List

Molly Zirix is doing a fantastic job on sending out e-mails to our members. There are so many times that information needs to be given to our members in between mailings and so it is very beneficial if we have your e-mail. To join the list, send your e-mail to zirix@tulsacoxmail.com

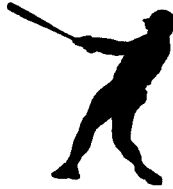
Thank you TARC for making this newsletter possible!



Driller's Night

Friday, July 13th
No Formal DSAT Meeting

Friday, July 13th at 6:00-7:00pm there will be a picnic dinner for all DSAT members. Then we will all sit together and enjoy the baseball game starting at 7:05pm. Please pick up your picnic and game tickets at the DSAT table located outside the front gates starting at 5:50pm- 6:30pm. After 6:30pm, please pick up your tickets at Will Call under DSAT. This is a great time for the **WHOLE FAMILY AND ALL AGES!** Please plan to attend!



August Meeting

Special Olympics

Please Note: The date for the August Meeting has changed to 7:00 PM August 9th (2nd Thursday) at New Haven United Methodist Church.

Special Olympics will be coming to do a presentation on their programs available for ages 4-up. We will also be lucky enough to have some Special Olympics Ambassadors come and speak about their experience with Special Olympics. It is always so neat to hear self-advocates stories! Please plan to attend this meeting to see how you can get involved with Special Olympics. Even if your child is too young to participate, you can learn how to get involved by volunteering and see what is in store for the future!



Save The Date

3rd Annual Couple's Conference - Friday and Saturday January 25 & 26, 2008 in Oklahoma City, Ok!

On The Road Conference - Tuesday, October 16th from 8:30 to 2:30. DSAT is going to help sponsor an On The Road Conference put on by OASIS. This is a FREE conference will include speakers from DHS to answer questions about the waiver and TEFRA, Department of Special Education and many more agencies will be represented. The event will be at the Tulsa Career Tech the Jenks Campus, address is 801 E 91st, on Tuesday, October 16th, 2007. Look for more details to come!

DSAT Morning at TOYS 'R' US at 71st and Memorial - Saturday, November 3rd from 8:00-10:00 AM. Toys R Us is opening up early just for DSAT and the Tulsa Autism Foundation. They will have door prizes, Geoffrey the Giraffe, and donuts and juice for us! They are also planning on having some toys displayed out of their "Differently Abled Kids" toy catalog that are designed for children with disabilities. Plan to do your shopping for Christmas without the hustle and bustle of all the lines. This is going to be a great event, so plan to attend!

September Meeting

Using Your Computer to Create Materials for Students with Learning Differences... and Other Cool "Need to Know About" Assistive Technology

Kimberly Voss, the author of the award-winning book Teaching by Design (Woodbine House, 2005) will share ways to create high quality customized instructional materials, using your computer, in the most time efficient manner to address visual perception, math, language, communication, reading, handwriting, and self-help. She will also share other wonderful assistive technologies that could enhance your child's learning.

Kim is the mother of 3 girls; her oldest daughter Ashley has Down syndrome and additional disabilities due to a stroke following open heart surgery. Kim is also the creator of School Fonts for Beginning Writing and Transitional Fonts for Emerging Writers both published by Mayer-Johnson. She speaks nationally on the use of computer technology in special education and rehabilitation. Ashley, now 22, works with her mother at their company: Ashley's Mom, Inc. (www.ashleymom.com).

2008 Calendar Update

Sponsorship Deadline Extended

We are finally finished with ALL the 40+ photo shoots! They are all so good! Jill did such a great job as usual! I think this is going to be a great calendar. We are wanting to show the individual natural beauty of each one of them. We have never done a calendar like this one and I think it will be a nice change. We are using a new designer/printer this year also. We are hoping for completion in early September.

However, we still need sponsors!!!! As of June 29, we have received zero sponsorship applications. YIKES!! Please help us with this!! If you don't have a sponsorship packet, you can either contact me or print one off from the website. It is under the forms category on the website. There are two forms. I usually include last years calendar in the packet as well. So if you have extra calendars, you may want to include one. The deadline on the form says July 19, but we are extending it to July 26th.

If you have any questions, please contact me: edward.c.wegener@gsk.com or 355-6999. Thanks for all you help on making our 2008 calendar happen! April Wegener

Exciting Workshops

The Oklahoma Parent Training and Information Center, in partnership with TARC and Oklahoma Parent Center will present parent trainings across the state. Contact Sherilyn Walton for information about different workshops available at 918-582-8272.

Celiac

Celiac Disease: What Is It and Why should individuals with Down syndrome be tested?

Our daughter, Taylor, who is five years old, was diagnosed with Celiac Disease right before her third birthday. We thought it was very important to remind the members of DSAT about Celiac disease again and why your child/adult with Down syndrome should be tested because there is a 20% higher risk of Celiac when the individual has Down syndrome. Taylor has been sick with many different illnesses and infections since birth. Heart and tonsil/adenoid surgery have helped, but she still had general sluggishness

and constipation problems that even medicine didn't help. We visited Dr. Leichtman in August right before she turned three and he suggested Taylor be tested for Celiac disease as part of her annual blood work and evaluation. Our pediatrician ordered a blood test for Taylor. These results indicated that there was a high probability that Taylor had Celiac disease. After a biopsy, it was confirmed that Taylor has Celiac disease.

including irritability, depression, difficulty concentrating and excessive dependence

How is Celiac Disease Diagnosed?

Generally, a simple blood test is the initial indicator of the potential presence of celiac disease. The test is a simple blood test that tests for the presence of antibodies to gliadin. These antibodies are antigliadin (AGA) IgA and IgG. Although these blood tests are generally reliable, there are instances of false positives and false negatives. The best indicator of celiac disease is a small intestine endoscopy/biopsy. In this routine outpatient procedure, the doctor actually takes tissue samples from the small intestine to be tested for damage. For Taylor, her antibody levels were almost 7 times the normal level and the biopsy confirmed the blood testing. Additionally, there is a testing service called Promethius Labs that provides a 5 panel test including DNA rather than the traditional 3 panel test used by most services.

Why is Celiac Disease Important?

Untreated celiac disease can lead to a number of long term conditions including: Osteoporosis & other bone disease, Weight Loss, Epilepsy, Internal Hemorrhaging, Central and Peripheral Nervous system disorders, Pancreatic Disease, Intestinal Cancer, Anemia, Chronic Diarrhea, Infertility, a variety of emotional disturbances, including chronic fatigue and ADHD-type symptoms.

Treatment

There is no cure for celiac disease. The only treatment is adherence to a strict gluten free diet. The diet is not as restricting as Erin and I first thought. There are restaurants now that have gluten-free menus. More food products that you buy in the grocery store (not just at health food stores) are being labeled gluten-free. Every six months, blood work is done to make sure the levels are remaining constant.



Down Syndrome Creed

My face may be different
but my feelings the same.

I laugh and I cry
and take pride in my gains.

I was sent here among you

to teach and to love
as God in the heavens
looks down from above.

To Him I'm no different,
His love knows no bounds;

It's those here among you
in cities and towns

that judge me by standards
that man has imparted,

But this family I've chosen
will help me get started.

For I'm one of the children
so special and few

that came here to learn
the same lesson as you.

That love is acceptance,
it must come from the heart;

We all have the same purpose.
though not the same start.

The Lord gave me life
to live and embrace,
and I'll do it as you do

but at my own pace

-Unknown

What is Celiac Disease?

Celiac disease is a genetic disorder in which intolerance to gluten causes damage to the lining of the stomach. Celiac disease is an auto immune disorder. Gluten is the protein found in wheat, oats, rye and barley. In people with celiac disease, the gluten damages the villi in the small intestine. The villi are the small hairlike projections in the small intestine that are responsible for absorbing the nutrients in food. If untreated, the celiac disease will partially or completely flatten the villi. This can lead to malabsorption, meaning the nutrients in food are not absorbed by the body.

Symptoms of Celiac Disease

Following are some common symptoms of celiac disease. It is important to note, that celiac disease is often difficult to diagnose because the symptoms are so varied. Some people exhibit the "classic" symptoms and some people may be asymptomatic.

Classic Symptoms: Infants & Toddlers

Diarrhea, Failure to thrive (-below average weight gain or increase in height), Projectile vomiting, Distended abdomen, Lack of muscle definition throughout the body, Dental disorders, Irritability, Listlessness, Lack of desire to eat, Low levels of calcium, folic acid, and vitamin B12

Classic Symptoms: Children and Adults

Gastrointestinal distress (cramping, bloating, gas), Diarrhea, Constipation, Anemia and other nutritional deficiencies, Weight Loss
Lack of desire to eat, Emotional disturbances

TEFRA - What is it and does my child need it?

My daughter receives Medicaid through TEFRA. Although applying for TEFRA can be a lengthy process, it is well worth the effort and energy. This is a new program offered to Oklahoman's (as of May 2007 only 149 participate in the program), and we have found that many DHS and OHCA (Oklahoma Health Care Authority) employees do not completely understand the benefits, guidelines or application process. Thus, you must be ready to ask questions and have some patience. However, through TEFRA, my child receives her Medicaid card and allows us to receive additional therapies, treatments and medicines that we would not normally be able to afford.

Here is a brief explanation of TEFRA and if you have any questions about TEFRA, I would be happy to share what we have learned and why we think it is a hidden gem to parents of children with disabilities. (Alana Kennon – alanakennon@cox.net)

The information below is taken from DHS and OHCA websites.

What is TEFRA?

TEFRA stands for Tax Equity and Fiscal Responsibility Act of 1982. This act states that states have the option to make Medicaid benefits available to children with physical or mental disabilities who would not ordinarily be eligible for Supplemental Security Income (SSI) benefits because of their parents income or resources are too high.

What services are provided?

Depending on the needs services include:

- Child health and doctor check-ups
- Dental care
- Emergency / non-emergency transport
- Inpatient and out-patient treatment
- Medical equipment
- Occupational therapy
- Pharmacy
- Physical therapy
- Vision
- Speech therapy
- Home based services

Who is eligible for TEFRA?

Individual must be under age 19

Live at home

Meet the SSI definition of disability Child's income is a gross monthly income at or below \$1,737 for 2005 and countable resources at or below \$2,000.

Meet an institutional level of care. Meeting this level of care does not mean a child must be institutionalized

Children Under the age of 3 must be evaluated by SoonerStart and be at least 20% delayed in two or more areas.

After the age of 3, child will be evaluated by a psychologist and results indicate that IQ is less than or equal to 75.

It must be appropriate to provide care to the child at home and

The estimated cost of caring for the child outside the institution cannot exceed the estimated cost of treating the child in the institution

General information about TEFRA

Apply for TEFRA through your Local DHS office.

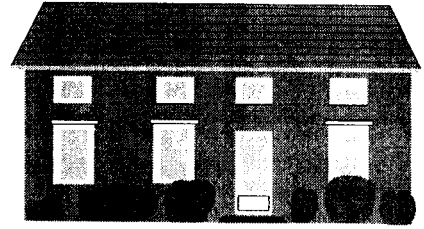
If approved for TEFRA, you will receive a Medicaid card through the Oklahoma Health Care Authority (OHCA) and your child will be enrolled in SoonerCare, the state's managed care system.

If you have a private health insurance, your existing coverage will become your primary insurance company and OHCA (TEFRA/Medicaid) will become your child's secondary insurance.

Your child is still eligible for TEFRA even if they are on the DHSD waiver services waiting list

Receiving TEFRA will not remove your child from the waiting list

TEFRA coverage lasts for 12 months. You will need to be certified for TEFRA every 12 months. (Not as complex a process for renewal)



To apply you will need the following:

Completed TEFRA-1 Form (available through DHS)

Denial letter from the Social Security Administration – (800) 772-1213 and talk to the tele-representative about your child's eligibility.

Supplemental documentation to support information provided on the TEFRA-1 document.

Include a current (within the past 12 months) physician's history and physicals examination, as well as any hospital discharge summaries, psychological evaluations or other information that will help us verify the disability. Even if SSA has established disability, they will need this information to help establish eligibility for institutional level of care.

If under the care of Sooner Start, will need to submit most recent evaluation. Results need to indicate that child is at least 20% delayed in two or more areas to qualify as institutional level of care.

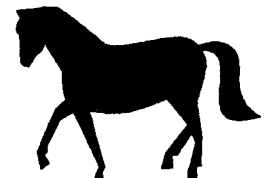
Websites to visit for additional information:

www.okhca.org

(click on Programs and then TEFRA)

www.okdhs.org

(click on Health and Medical and then Tax Equity and Fiscal Responsibility Act)



Sharing Information

There are NEW items available in our Lending Library: Contact Velvet Ahumada at vahumada@cox.net. Keep this handy to access local / national resources and local calendar so that you will not miss out on opportunities for education and fun.

Free Newsletter Subscriptions/ Information

Down Syndrome Congress

1-800-232-NDSC

www.ndscenter.org

Free info about Down Syndrome and a great newsletter.

Disability Solutions

1-503-244-7662

www.disabilitysolutions.org

Free subscription providing information about specific topics.

Down Syndrome Society

1-800-221-4602

www.ndss.org

Free information and newsletter about Down Syndrome.

OK Parent Connection

1-877-553-4332

okparentctr@aol.com

A list of several workshops and advocating for children.

TARC

918-582-8272

www.ddadvocacy.net

Located in Tulsa and provides a great source of info. Monthly support group and newsletter.

Special Olympics

918-481-1234

www.info@sook.org

Get on their mailing list for the latest about Special Olympics.

Training

Stars 1-405-271-1836

www.ah.ouhsc.edu/tolbert/

courses_workshops

Statewide training system for people with disabilities in OK.

National Conference on CD

A copy of the National Conference has all the wonderful speakers on CD.

Horseback Riding Therapy

Hearts and Hooves in Ft. Gibson

918-478-3339

Janice@heartsandhooves.org

Helping Hooves in Jenks

918-261-8112

Neat Products

Band of Angels

1-800-963-2237

www.bandofangels.com

Neat books and notecards of children with Down Syndrome.

Dolls with Down Syndrome

1-888-749-9330

www.downcreations.com

Adorable dolls all with characteristics of a child with Down Syndrome (including a scar from heart surgery!)

Juggling Down Syndrome Kit

The Little Acorn

1-210-256-2177

thelittleacorn1@yahoo.com

A collection of journals for all medical & resource information to help keep you organized... all put together!

Positive Perspectives

508-278-0876

www.apositiveperspective.com

Offers a variety of items that display upbeat messages about Down Syndrome and Inclusion (Notecards, magnets, mugs, pens... everything you can think of.)

Land Of Pure Gold

michaelsart.landofpuregold.com

www.psln.com/sharingds/Michael

www.loveandlearning.com

Michael Johnson, a gifted artist who has Down Syndrome, paints pictures that you can visit at his website. We sent a picture of Taylor in and he painted her picture on a notecard. It is truly incredible. It is under the angel notecards on the site.

Local Groups

Down Syndrome Association of Tulsa

www.dsat.org

Down Syndrome Association of Central Oklahoma

405-330-5025

www.dsaco.org

Group Homes

Faith Homes, Inc.

918-358-2273

www.clevelandcommunitycenter.org

Wonderful group homes in Cleveland.

Motor/Speech Products

Hip Helpers

1-757-481-2407

www.hiphelpers.com

Support shorts for excessive hip abduction due to low tone.

New Visions

1-434-361-2285

www.new-vis.com

A catalog of oral motor programs and items.

Talk Tools

1-888-529-2879

www.talktoolstm.com

A catalog for tools for oral-motor therapy.

Express Train

www.expresstrain.org

CDs to enhance children's speech.

Super Duper Publications

1-800-978-7379

www.superduperinc.com

Fun, educational materials that are speech and reading related. They will send you a free catalog!

Ambucs

405-360-1521

They are creating independence for people with disabilities. Call to obtain an application for a computer for your child.

Books

Down Syndrome and Vitamin Therapy

by Kent MacLeod

He sent us 4 copies of this book to pass around.

Down Syndrome: The First 18 Months

by Blueberry Productions

Sometimes Miracles Hide: Stirring Letters from those who discovered God's Blessings in a Special Child

by Bruce Carroll

A Special Kind of Love: For Those Who Love Children with Special Needs

Susan Titus Osborn, Janet Lynn Mitchell

Understanding How Children with Down Syndrome Learn

by Special

Offspring Series Books

www.specialoffspringseries.com or

www.specialoffspring.com

Internet

Dads Appreciating Down Syndrome

www.dadsappreciatingdownsyndrome.org

Down Syndrome Health Issues

www.ds-health.com

Down Syndrome for New Parents

www.downsyn.com

Oklahoma Parent Network

okla-parent-network@yahoo.com

Parents of children with disabilities in Oklahoma gives great ideas about pediatricians, dentists, schools, etc.

List Serve

down-syn@listserv.nodak.edu

Newsgroup

Downs-Heart@yahoogroups.com

Support Network

www.ideallives.com

upsndowns@yahoogroups.com

Special Education Resources

www.reedmartin.com



Publishers

Special Reads

1-513-541-7617

www.specialreads.com

Specially designed books for children of special needs.

Interactive books

918-337-0763

www.booksschool.com

Children love to interact with books.

Interactive Reading Books

661-263-7661

www.greenhousepub.com

These books use velcro to teach basic concepts.

Interactive Reading Books

www.greenhousepub.com

Another company with interactive type books.

Love and Learning

1-313-581-8436

www.loveandlearning.com

Videos, tapes, books and computer games that teach beginners and continue up through school age.

Out of the Box Reading Program

www.outoftheboxreading.com

1-866-922-0055

Woodbine House

1-800-843-7323

www.woodbinehouse.com

Book company that will send a catalog of special needs books.

Tamarack Reading Pages

1-715-549-6187

email: TamarackRP@cs.com

Neat books written by a mother of a child with a disability.

State and National Organizations

Family Voices of Oklahoma

1-800-766-2223 x56910

<http://OKVoices.org>

Lee Mitchener Tolbert Center

405-271-2131

www.ah.ouhsc.edu/tolbert

OASIS

1-800-4262747

www.oasis.ouhsc.edu

Oklahoma's statewide referral service.

OK Department of Human Services

800-522-1075

www.okdhs.org/programs/programs.htm

OK Developmental Disabilities Council

1-800-836-4470

www.okddc.org

Helps to coordinate the efforts of state agencies and organizations in meeting the needs of Oklahomans with developmental disabilities and their families.

OK Commission on Children and Youth

1-866-335-9288

www.okkids.org

To improve services to children by facilitating joint planning and coordination among public and private agencies.

OK Family Network

www.oklahomafamilynetwork.org

Parent to Parent group that provides one on one support for raising children with special needs.

OK Healthcare Authority

1-800-987-7767

www.ohca.state.ok.us

SoonerStart

1-800-426-2747

Provides free evaluation and services to children from Birth to 3 years of age.

Special Education Services

405-521-3351

www.sde.state.ok.us

Supplemental Security Income

1-800-772-1213

www.ssa.gov



Buddy Walk 2007

SUNDAY, OCTOBER 21, 2007

2:00 PM to 4:00 PM

at the Union High School Track

(located west of the school at 6636 S. Mingo Rd. in Tulsa)

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, coworkers and politicians. The Buddy Walk includes entertainment, prize give-aways, food and fun activities for the whole family.

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.

Please notice that there is a change in location this year! We are growing and appreciated that Union was able to accommodate our larger group this year!

You may register online any time at www.firstgiving.com/dsat. Brochures will be mailed to all individuals on our mailing list in September. If you are not on our mailing list and would like a brochure mailed to you, please contact us at Buddywalk@dsat.org or call Erin Paul at (918) 495-2563.

We are going to have a new t-shirt pickup night this year! Be looking for more details! We are going to have it at Average Joe's at 81st and Garnett and have free mini-golf. You will also be able to turn in your money that night and receive your incentive prizes to avoid the lines at the walk!

All individuals are encouraged to register and obtain pledges. However, it is not required to attend the Buddy Walk. Walkers can

create a web page at www.firstgiving.com/dsat where you can invite friends and family to sponsor you or your "buddy."



We have the sponsorship packets ready to go! We have wonderful incentives for our sponsors this year! If you are interested in becoming a Buddy Walk Sponsor or know anyone that might be interested in sponsoring, please let us know. You can download sponsorship information forms from the DSAT website (www.dsat.org) and click on Buddy Walk and Forms). If you have any questions, or would prefer a packet be mailed directly to yourself or a company, please contact Erin Paul at 495-2563 or Alana Kennon at (918) 605-9931 or email buddywalk@dsat.org

Media: If you have any contacts with your local media (TV, Radio, magazines, community papers, church/school papers) and would like a press kit mailed to them, please contact Alana Kennon at publicity@dsat.org. We would like to help feature your child in their local school paper, community paper, local paper (if outside the Tulsa area) or other relevant publications during the months of September and October.

If you haven't been to a Buddy Walk this is something you won't want to miss. It is a great time to celebrate and have a lot of fun with your whole family. Be sure and look at our website under photos for pictures from the 2006 Buddy Walk. We hope to see you there!

Visit our website at www.dsat.org and click on Buddy Walk for the latest information!!

Gifts: Mothers Reflect...

Review taken from the Down Syndrome News

Gifts: Mothers Reflect on how Children with Down Syndrome Enrich Their Lives

Edited by Kathryn Lynard Soper with a foreword by Maritha Sears, RN

Gifts has 63 personal essays from mothers of children with Down syndrome. The mothers are from a wide range of families, backgrounds, experiences and places. They write of raw grief and palpable pain; hope; struggle; and rich rewards that are far more satisfying than they had ever dreamed. They share their stories of the gifts of respect, strength, delight, perspective and love that come from having a child with Down syndrome. These are the unexpected gifts that many of us never imagined we would receive when we heard the diagnosis of Down syndrome.

ETL

ETL is effective, teaching and learning.

This is a program addressing the needs of individuals with developmental disabilities as well as their families and team members across the state. We personally just started using ETL. The in-home support waiver pays for it in entirety (depending on your amount available). There is a waiting list (we waited a few months) If you are interested, talk to your case manager with DHS about this program. They come to your house and teach "coping" skills and behavior modifications to your child/young adult/adult with disabilities. They follow you for sometimes up to a year or more. Their website for more information is www.etl.org or e-mail them directly at info@etl.org The number is 918-749-8717

Attention New Parents

If you have not received a new parent packet (that has so much valuable information and resources). a book entitled, The New Parents Guide to Down Syndrome and a DVD entitled, Down Syndrome: The First 18 months, please contact Stephanie Keester at sakeester@aol.com or 496-3441. DSAT provides all of these items totally free. PLEASE contact us. They are such a great resource and answer so many questions.

Forming A New Position

We are looking for someone to write for and find information for our newsletter. There are only 6 newsletters a year so it is not that time consuming. Kendra Pennington actually puts all the information together that we send her and does the newsletter itself. All we need for someone to do is to find good information for the newsletter and e-mail it to Kendra at the end of every other month. If you are interested in doing this, please contact Erin-Adam@prodigy.net or 495-2563. If you want to just HELP in finding information for our newsletter, that would be very helpful, too. I am running out of ideas!

Respite?

What is Respite?

Respite is the temporary short-term relief for families and caregivers who need a break from the responsibilities of caring for a family member or loved one with a disability or special health care need. Respite can range from a few hours to a week or more, depending on the needs and resources of the family and take place in the family's home, the home of a friend or relative, a daycare center or even a church. Some parents use respite so they can spend time with another child or with a spouse. The benefits of respite are many and include reducing stress on the family and improved parenting or care giving. What are a few of the places that respite is provided?



Boston Avenue Methodist Church

1301. S Boston Ave Tulsa, Ok 74199

918-583-5181

Respite care provided to families at no charge for their child with special needs and their siblings Care is provided on the second and fourth Fridays of each month.

Oklahoma Respite Resource Network (ORRN)

OASIS Information and Referral

PO Box 26901 Oklahoma City, OK 73190

Toll Free- 1-800-271-6305

E-mail: oasis@ouhsc.edu Internet: www.okrespite.org

Program Information: Controlling agency Oklahoma Areawide

Services Information System Hours: Monday-Friday 8-6pm

Service Description: ORRN is a partnership of public and private agencies and organizations working to improve support for families and caregivers by increasing the availability of respite care.

The network sponsors a respite voucher system- apply through OASIS at 800-426-2747.

Qualifications: Families must have an income of less than \$60,000 per year annually and have a child with special healthcare needs.

Vouchers are awarded on based on availability.

Respite Care of Sapulpa

1500 E Dewey Sapulpa

Director and Contact: Carol Matthews 918-224-3400

Hours: Tuesday 4:30-8:30pm (siblings included)

Every other Tuesday 4:30-8:30pm (no siblings)

Every other Saturday from 10:00am-4:00pm (no siblings)



Friday Night Owls

Kirk of the Hills Presbyterian Church

This is a fun night for children and young adults with special needs and their siblings, designed so parents can have a night out. Parents of the church and the community are invited to drop off their children and siblings for a night of activities. It is held the 4th Friday of each month. They have movies, video games, snacks, crafts and more. Times are from 6:00-9:00pm. We ask you please RSVP 5 days in advance to Crystal Fulda at cfulda@thekirk.com Phone: 918-494-7099 x210

Special Kids Weekend Respite Program

<http://www.specialkidscare.org>

Special Kids in Tulsa offers additional programs such as evening respite. Respite Vouchers Accepted | Before and After School Program

Parent Night Out

Oklahoma Life Skills Association

4921 S Yorktown, Suite 103, Tulsa, Ok

918-836-9464

A Night on the Town

First Baptist Church

Respite and Special Needs Ministry, Growing Together

6-8:30pm Friday Night 200 S Elm Sapulpa, OK

Mike Dodican 918-224-4100 miked@fbcapulpa.com



Are You On The List?

Make sure you are signed up on the waiting list for the In-Home Support Waiver. This is **NOT** based on your family's income... it is based on disability and Down Syndrome usually qualifies. Contact 918-560-4700 or 1-800-522-1075 for more information. You can even get on the waiting list as soon as your child is born! However, it is NEVER too late... and is for .

What is the waiver? They are Medicaid funded programs. For children ages 3 to 17 years, the In-Home support waiver services are respite, in-home care (that can be provided by family members, friends or an assigned person and they get PAID!) , modifications to the home, family training, adaptive equipment and specialized medical supplies

(pull-ups are paid for and delivered to your house after the age of 3). You will also receive a Medicaid card that can be used for co-pays, prescriptions and to pay for therapies (that accept Medicaid). The waiver for 18 years or older covers respite, adaptive equipment, audiology, psychological counseling, occupational, speech and physical therapy, transportation, family training, medical supplies and services, nursing services, dental exams, employment services and much more. Immediate family members that are taking care of their adult over the age of 18 can actually qualify as their in-home care and get paid themselves!

Please make the call today to get the paperwork! It is so very helpful!

You're Not Alone in the Universe...

Growing up, I learned how to handle many situations that most of my friends never encountered. I must admit that I was pretty proud and felt like I had a special talent. After attending my first NDSC Brothers & Sisters Conference four years ago (oh, how time flies!), I realized my "talent" was just another side benefit of having a sibling with Down syndrome. I'd never realized before that every odd thing I did to help my sister out - singing and dancing in the mall to help persuade Lindsey to emerge from the Apple store, waking up at 7 am to music blasting from the room next to mine, or watching *High School Musical* for the eighth time that week - seems completely normal to all the awesome people who show up every year at the Brothers & Sisters Conference. I'm not alone in the universe. Everyone seems to face the same problems in one way or another. The weirdest part is that these odd things come up while working in a group as a sidetrack to the main conversation. But, when everyone else at the table you're sitting at can relate to what you do, these things become a lot less weird and actually feel normal!

When I'm with school friends (who don't face these odd things), they give me really weird looks if I happen to share that I woke up (again) to the *High School Musical* soundtrack. It's nice to "come home" to the conference and talk to people who provide a more supportive reaction.

I remember my first conference...it was kind of like the first day of kindergarten. I walked into a big room filled with strangers. Picking a table to sit at was awkward, and the silence that followed was worse. Then, after an icebreaker or two, I already had at least two best friends and was set for the weekend. After

that, I learned that if I sat down anywhere and started talking to people, it felt a lot less awkward. (You also get a blast from the past after running into that kid you met two years ago, whose name is on the tip of your tongue. After a brief intro, you're back to being friends.)

Unlike talking to your parents, you can ask questions about anything that you need to know.

Besides all the people you meet, and all the great times you experience, you also come home with more knowledge about DS and what is in store for you and your sibling in the future. Unlike talking to your parents, you can ask questions about anything that you need to know - from what kind of job your sibling could have to why they enjoy watching the same movie over and over. You can even get an answer to the popular question, "Why does

my sister (or brother) hold a conversation...with herself?" Overall the Brothers & Sisters conference has been an incredible experience for me and I *definitely* recommend it to anyone who has a brother or sister with DS. There's no need to be scared of making good friends; and, I know it's summer, but a little learning never hurt...right?

By Austin Sabattis, Age 15, Annandale, NJ Reprinted from 2006 Convention Issue, Down Syndrome News

The NDSC is holding their conference August 3-5 in Kansas City. They will again offer workshops for Brothers & Sisters. The sibling must be entering the 6th through 12th grade to participate. The fee is \$75.

For more information on the NDSC Conference, contact them at www.ndsccenter.org.

DSAT IS STARTING A NEW SECTION OF THE NEWSLETTER: GETTING TO KNOW OUR DSAT FAMILIES

Please fill out the requested information below and return it to the P.O. Box so we can put it in one of our upcoming newsletters. We want your profile whether you have been in DSAT for years or you have just learned about our association. We want to get to know EVERYONE IN DSAT!! We would love to hear about individuals of all ages

We also would like you to include a picture of your family. You can do this by e-mail to Erin-Adam@prodiqy.net with the subject line **DSAT photo** or mail it along with your form and we will scan it for you.

Please write your 'Getting to Know You' profile exactly as you want it to appear in the newsletter. There is no limit on space, so feel free to include as much or little information as you feel comfortable providing. We would love to hear about your journey. We want to hear all the successes you have had and maybe some challenges. These really help people feel inspired.

For starters, please include the following:

Names of family members and ages along with the birthday of the child/adult with Down syndrome

All activities, hobbies and interests of your child/adult with Down syndrome

If the adult is employed, we would love to hear about their employment experience..

We would like to hear all accomplishments and major milestones of your child/adult.

If you would like to include any medical challenges you have faced, that would be helpful to other parents.

List any particular reading programs, speech programs or things that you have felt to be helpful along the way.

Thank you so much for your help. We hope this will be helpful and enjoyable to all DSAT families!! Please return your information so we can do this in every newsletter. If we get a great response, we will do several in each newsletter!!

Thank You!

A great big thank you to all of the following for their support of DSAT.
We could not do this without you.

Dues Paid

MS or LJ Daylor

Donations

MS or LJ Daylor

Tish & Andy Andrus in honor of Taylor Paul

Barnes & Noble

(donation received for % spent at our event)

The Williams Companies

(matching funds)

OneOK Foundation for \$1,000

(matching funds)

Average Joe's Classic Eatery

(donation received for % spent at our event)

In Honor and Memory of Joseph Cervantes

Dora & Gary Durland

Treasurer's Tidbits



How Do I Benefit from DSAT Funds?

During 2006 -

DSAT paid over \$3,200 to provide social opportunities for DSAT members of all ages and their families.

DSAT provided over \$9,000 so members could attend beneficial conferences & seminars both locally and nationally.

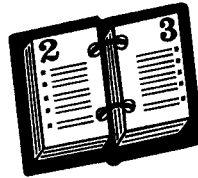
DSAT provided New Parent Packets to families in our area at a cost of \$1,500.

Thanks to all those who pay dues, support calendar sales or the Buddy Walk to help DSAT continue it's mission to enhance the lives of individuals with Down syndrome, their families and caregivers.

Our financial statements are a matter of public record. If you wish to review a copy of DSAT's financial statements, please email treasurer@dsat.org.

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 August 27th for the September newsletter. 477-2999 or kendra@soonerstart.com



No Formal Meeting in July

July 13th

DSAT at Driller's Stadium

6:00 Picnic Dinner

7:05 Enjoy the Game

Dinner and game tickets are Free to all DSAT members.

July 29th

Mini Golf at Average Joe's

from 11:00 AM to 11:00 PM

Mini Golf is Free to all DSAT Friends and Family.

August 3rd, 4th & 5th

National Down Syndrome Congress Convention

Westin Crown Center in Kansas City, MO

Visit www.ndsccenter.org for registration information.

August 9th

Regular Meeting on Special Olympics

Special Olympics Ambassadors will speak about their programs and experiences.

September 20th

Regular Meeting with Kim Voss

Using your computer to create materials for students with learning differences... and other cool "need to know about" assistive technology.

October 16th

On The Road Conference by OASIS

Tulsa Career Tech - Jenks Campus

8:30 AM to 2:30 PM

This is a FREE conference will include speakers from DHS to answer questions about the waiver and TEFRA, Department of Special Education and many more agencies will be represented.

October 21st

Buddy Walk

2:00 PM to 4:00 PM

Please notice the change in location... Union High School Track, just west of the school.

November 3rd

DSAT Morning at Toys 'R' Us

71st & Memorial

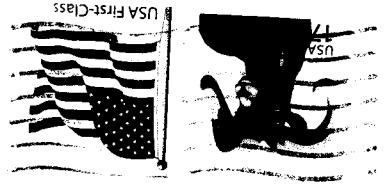
8:00 AM to 10:00 AM

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Driller's Night July 13th
Mini Golf @ Average Joe's July 29th

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



DSAT news

Down Syndrome Association of Tulsa

DSAT Board of Directors

Oklahoma People First

Are you a NEW Parent? Please contact Kim Wofford at 622-6906 or email her at woffordnate1@cox.net

Oklahoma People First is a statewide self-advocacy group run by and for people with developmental disabilities. There are 13 chapters within the state.

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
Calendar Chair	April Wegener	355-6999	edward.c.wegener@gsk.com
Governmental Affairs	Chris 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

- The mission of Oklahoma People First is:
- To promote equality
 - To assist each other in speaking for ourselves
 - To educate our communities
 - To hold meetings to educate ourselves
 - To support self-advocacy in Oklahoma; and
 - To create public support for People First

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

Several of our young adults and adults with Down Syndrome are involved in this group. If you are interested in contacting them and getting more info, contact 405-271-8001 Ext 46804 E-mail at nancy-ward@ouhsc.edu or go to the website at www.oklahomapeoplefirst.com

Free Mini Golf

Average Joe's at 82nd & Garnett has great hamburgers, don't miss this chance to try one. On Sunday, July 29th, tell them you are with DSAT and your entire party can play Mini Golf for Free. And if you try that hamburger or other great meal, they will donate 20% to DSAT.