

# DSATnews

Down Syndrome Association of Tulsa

July, 2008

P.O. Box 54877 • Tulsa, Oklahoma 74155-0877 • [www.dsat.org](http://www.dsat.org)

## President's Message

Hello. We hope everyone is enjoying their summer. We have lots of change going on within DSAT. We are going to be having a planning meeting in August and we hope you plan to attend. We want to get your ideas on where you think DSAT should be heading. Erin and I have been president/vice-president for six years and we feel that it is time for someone else to be in the leadership position. We have a wonderful new couple that will be filling the President position starting in January, Molly and Danny Ziriak. They are a tremendous asset to DSAT and know they will lead DSAT in a wonderful direction. The Vice-President position is open and we hope to fill that position soon. We also are forming several new committees and need new chairpersons of these committees as well as committee members. If you are interested in becoming more involved with DSAT, please let us know as soon as possible. We hope to get lots of ideas at our August meeting. If you have ideas and can not come, please make sure to let us know so we can share those ideas.

We often have information that needs to be sent out in between newsletters, so please make sure Molly has your e-mail address so you get the regular email updates.

Have a great summer.

*Adam & Erin Paul*

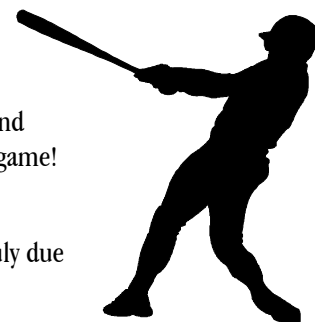


## Driller's Game

On Sunday, July 27th the picnic will start at 1:00 PM to 2:30 PM. The game starts at 2:05 PM This will be fun for the whole family! Every DSAT member gets a free

picnic ticket and ticket to the game. Pick up your tickets outside the front gates at the DSAT table starting at 12:50 PM until 1:45 PM After 1:45 PM please pick them up at will call under DSAT. The picnic will be hamburgers, hot dogs, chips and drinks. We will all sit together at the game! Bring the whole family!

There will be no formal meeting in July due to conference and Driller's game.



## 47 Pieces

What is Down syndrome? If you think of Down syndrome like a puzzle, you have one extra piece of the puzzle. When you first buy the puzzle and notice you got that one extra tiny piece, you scratch your head wondering what you are going to do with it and how it is going to fit into the puzzles that are already complete in your life. This page is the stories of how other families, like you, wondered that same question and how that extra "piece" fit into their lives. [www.47pieces.blogspot.com](http://www.47pieces.blogspot.com)

Thursday, July 24th



Note change: The July D.A.D.S. meeting will be held on the 4th Thursday of the month, **July 24th** at 7:00 PM at the same location, "Fox and Hound Pub & Grille" at 71st & Garnett.

All Dads and Grandfathers are welcome to attend!

**D.A.D.S.**  
Thursday, July 24th at 7:00 PM  
Fox and Hound Pub  
Private Dining Area  
71st & Garnett

**August Meeting**  
Thursday, August 21st at 7:00 PM  
New Haven United Methodist Church  
56th & New Haven  
(between Yale and Harvard)  
Help us plan for the next year!

Thank you TARC for making this newsletter possible!

# 2008 Buddy Walk

Sunday, October 19th

**What:** The Buddy Walk is a multi-advocacy walk in which people with syndrome invite "buddies" to walk with them. Buddies can be anyone from friends to teachers, coworkers and politicians. The Buddy Walk includes entertainment prize giveaways, food and fun activities for the whole family.



**Why:** 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.

**When:** Sunday, October 19, 2008, from 2:00 PM - 4:00 PM.

**Where:** Track at Union High School in Tulsa, Oklahoma. (6636 South Mingo Road). The track is located west of the high school.

**Registration:** You may register online any time at [www.firstgiving.com/dsat](http://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](mailto:Buddywalk@dsat.org) or call Erin Paul at (918) 824-8574.

**Pledges and Donations:** 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](http://www.firstgiving.com/dsat) where you can invite friends and family to sponsor you or your "buddy."

**Sponsorship:** 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](http://www.dsat.org)). If you have any questions, or would prefer a packet be mailed directly to yourself or a company, please contact Erin Paul at 724-8574 or Alana Kennon at (918) 605-9931 or email [buddywalk@dsat.org](mailto: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](mailto: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. We hope to see you there!**

# Time Square Photo Contest

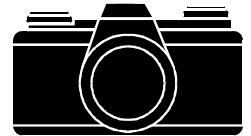
Celebrate the Buddy Walk's 14<sup>th</sup> anniversary by entering the Times Square Video Contest. The video, which showcases individuals with Down syndrome from all over the world, will air on the Panasonic News Corporation Astrovision screen in Times Square on September 28 at 10:30 AM. The New York City Buddy Walk™ will immediately follow the video at the Great Hill in Central Park.

Each year, NDSS receives thousands of photo submissions for the Times Square Video Contest. Because the Buddy Walk™ promotes acceptance and inclusion of individuals with Down syndrome, the winning photographs feature children, teens and adults with Down syndrome working, playing and learning with friends and family. Please limit photos to no more than three per individual with Down syndrome. If more than three pictures are received, only the first three will be considered.

For more information, or to submit a photo, go to [www.buddywalk.org](http://www.buddywalk.org) and click on Time Square Video. The deadline for submitting photos is July 18, 2008.

If you would like to send photos to NDSS for consideration, please mail to the following address:

NDSS Attn: Call For Photos  
666 Broadway, 8th Floor  
New York, NY 10012



NOTE: All photos sent in to NDSS must have a consent form to be considered for the video. To download the consent form go to [www.buddywalk.org](http://www.buddywalk.org). If more than one person is in the photo, please indicate which individual has Down syndrome.



## Up With Down

The Up with Down Center was founded by Frank Baxter after making several mission trips to Voronezh, Russia. While on these trips, God opened Frank's heart to the need that Russia has for children with Down Syndrome. In Russia, these children are rejected by society and generally do not have the opportunity to attend public schools.

This need was made more evident on one of the mission trips when Frank was approached by a woman who had a child with Down Syndrome. She wanted to raise her child to have a normal life and asked for Frank's help in this area.

At the time of the mission trips, Frank was volunteering at The Little Lighthouse. It was at this school that Frank learned about Down Syndrome and discovered his passion for helping kids with special needs. In a step of faith, Frank decided to open the center in Voronezh and allow God to work miracles in the lives of these children and their families. <http://www.upwithdownschool.org/>

# Respite

## Respite Basics

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 can take place in the family's home, the home of a friend or relative, a daycare center or even a church. Respite can be used so that families may visit family or friends, run errands, spend an evening at the movies or for even taking a vacation. Some parents use respite so they can spend time with another child or with their spouse. Others utilize respite so they may attend a conference or retreat. The benefits of respite are many and include reducing stress on the family and improved parenting or care giving.

## Who can provide Respite?



Respite may be provided by a family member, a friend, an agency or another person that is qualified to care for your child, and you feel comfortable with the care they provide.



## How do I find a Respite provider?

Often times friends and family can make recommendations of who might be a good provider for your child. Below you will find multiple resources who provide this service at low or no cost to the family receiving services. (In alphabetical order. By no means is this a complete listing of all services available in our state.)

## How do I pay for Respite Care?

The Oklahoma Respite Resource Network has information on payment.

Respite funding may also be accessed by those families receiving waived services programs such as the Self Directed Services Pilot Program, the Autism Pilot Program, and the Community Based Services waiver through the Department of Human Services Developmental Disabilities Services Division. More information may be accessed by searching [www.okdhs.org](http://www.okdhs.org)

Get creative, find families in your area who might take turns providing respite for you in exchange for respite for their own.

Many high school and college students are required to provide volunteer services to people in the community. Seek out schools in your area to see if they have a program that might allow a student to help out. (Job Placement Service Centers at colleges or counselors in high schools can typically tell you who the contact is.) Many medically-related students seek opportunities to care for children who have disabilities to assist them in preparing for their future career.



## Oklahoma Respite Resource Network (ORRN)

OASIS Information & Referral

PO Box 26901 Oklahoma City, OK 73190

**Main Phone:** (405) 271-6302 **Toll Free:** (800) 426-2747

The network sponsors a respite voucher system - apply through OASIS at 800-426-2747. Families must have an income of less than \$60,000 per year annually and have a child with special healthcare needs. Vouchers are awarded based on availability of funds. Other qualifications may apply. Please contact the agency with questions.

## Boston Avenue United Methodist Church

1301 S. Boston Ave. Tulsa, OK 74199

Main Phone: (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.

## New Haven United Methodist Church

[www.newhavenumc.org](http://www.newhavenumc.org)

They sponsor a Respite Care program on the 2nd Saturday of each month. Also, a "special Friends Sunday School Class" for additional information please call (918) 743-6491.

## Respite Care of Sapulpa

Director: Julie Evans P.O. Box 1718 Sapulpa, OK 74066

Contact: Carol Matthews (918) 224-3400 ext: 15

Siblings are included.

## Respite Care Referral Tulsa ARC

16 E. 16th Street, Suite 405

Tulsa, OK 74119-4447

918-582-8272

Provides referral to respite care providers for individuals with developmental disabilities.

## Friday Night Owls

Kirk of the Hills Presbyterian Church

This is a fun night for children with special needs and their siblings, designed so parents can have a night out. Times are from 6:00 - 9:00 PM. We ask that you please RSVP 5 days in advance to Crystal Fulda, [cfulda@thekirk.com](mailto:cfulda@thekirk.com) Phone: (918) 494-7088, x210.

## Special Kids Weekend Respite Program

<http://www.specialkidsare.org/>

Special Kids offers before & after school and evening respite, vouchers accepted

## Oklahoma Life Skills Association

4921 S. Yorktown, Suite 103, Tulsa, OK 74105

918-836-9464

## First Baptist Church Respite & Special Needs Ministry, Growing together

Mike Dodican 200 S. Elm Sapulpa, Okla. 74066

Ph: (918) 224-4100 [miked@fbcsapulpa.com](mailto:miked@fbcsapulpa.com)

Friday nights on the town from 6 to 8:30 PM

# Support Groups In Northeast Oklahoma

## Sapulpa

### **Support Group for Families of Children with Special Needs**

Support group serving Sapulpa and the greater Creek County area. Meets on the third Tuesday of each month at 6:15 PM at the Sapulpa Public Library-Frank Room, 15 N. Poplar in Sapulpa. This group is co-sponsored by TARC, United Cerebral Palsy, and Sooner Success. For information contact Mindy Littlefield at 918-378-5632.

## Claremore

**“You Are Not Alone”** Rogers County has formed a support group for children with chronic conditions, their parents and siblings, 3<sup>rd</sup> Thursday of the month, at 6:30 PM at the First United Methodist Church, 1615 N. Highway 88, Claremore, OK. In the group the children and adults meet separately and then come back together. The children have an opportunity to meet other kids who are coping with a chronic condition and letting them know they are not alone. For siblings the important issue is letting them know they are not forgotten when their brother or sister are coping with an illness. Parents get assistance in navigating services for their child’s condition and meet others coping with the same situation. More information can be found at [www.ourcourageouskids.com](http://www.ourcourageouskids.com).

## Muskogee

**Muskogee Autism Support Network** meets the 3<sup>rd</sup> Monday of each month at 6:30 PM at Believer’s Christian Fellowship, 4520 Neosho in Muskogee. We have temporarily suspended daycare until I can find a more qualified child care person.

## Grove

**Grand Lake Autism Support Network** monthly meetings are held on the second Thursday of every month beginning at 6:00 PM at Cornerstone Church located at 501 East 13th Street in Grove, OK. However, check the website occasionally as there may be changes from time to time. Parents, guardians, caregivers, grandparents, aunts, uncles, teachers, aides and other support personnel are all welcome to attend. Can’t find a babysitter? No problem. We can always accommodate our little ones. For information, call Gina Dollarhide at 918-964-0477 or log on to [www.grandlakeautism.com](http://www.grandlakeautism.com)

## Coweta

**Coweta Autism Support Network**, 3<sup>rd</sup> Thursday of each month, 7 to 8:30 PM, at New Home Free Will Baptist Church, highway 51 and (Midway Rd) 257th East Avenue (childcare is provided) [www.Cowetaautism.com](http://www.Cowetaautism.com) (918) 857-3161.

## Bartlesville

**Bartlesville Autism Support Network** meets at 7:00 PM the 3<sup>rd</sup> Tuesday of every month at the First United Methodist Church (5th and Johnstone) in Bartlesville. You can call Kim Brooks at (918) 876-0363 or email Brandy privately if you need information. [brandy-marquez@cherokee.org](mailto:brandy-marquez@cherokee.org)

## Tulsa

**Moms & Dads Support Group** is a long-standing support group for parents of children with developmental disabilities. Its mission is to nurture and support families, to encourage positive strategies in dealing with challenges, and to share in the joys of raising our children. This group meets on the last Thursday of every month from 7 to 9 PM at Kirk of the Hills Presbyterian Church, 4102 E. 61st St., Room B-8. The group is co-sponsored by TARC and UCP. For more information, contact Sherilyn at 918-582-TARC.

**Connections Asperger’s Group** is a social skills group for adolescents and young adults with Asperger’s syndrome, bringing them together for games, discussions and snacks in a relaxed setting where they can meet others with similar interests and practice positive social skills. Connections meets on the fourth Wednesday of each month from 4:30 to 6:00 PM at the Hardesty Regional Library, 8316 E. 93<sup>rd</sup> St. For more information, contact Sherilyn or Amie at 918-582-TARC.

**Families in Transition** is a support group for parents of adult children with developmental disabilities. The group provides information on topics of interest such as housing, guardianship and providers as well as support from parents in similar situation. The group meets quarterly. For more information, dates, and locations of meetings, contact Amie at 918-582-TARC.

**“¡Juntos!” (Together!) Hispanic Parents Support Group** is a support group for Spanish-speaking parents of children with developmental disabilities. Juntos! meets on the last Monday of each month from 7:00 to 8:30 PM. Child care is available. The group is co-sponsored by TARC, United Cerebral Palsy, Ability Resources, DSAT and SoonerStart. For information, contact Zaida at 918-582-TARC.

**Links** is a support group for adults with Asperger’s syndrome, providing speakers on topics of interest, support, social skills building and activities. Links meets on the third Wednesday of each month from 6:30-8:00 PM. at the Brookside Library, 1207 E. 45th Pl. For more information, contact Amie at 918-582-TARC.

**Down Syndrome Association of Tulsa** group meets the 3<sup>rd</sup> Thursday of the month at New Haven United Methodist church (56<sup>th</sup> and between Yale and Harvard). Childcare is provided at no cost. The group does not meet in July but other than that they have a monthly meeting.

**Mended Little Hearts** meetings are the 2<sup>nd</sup> Monday of the month, (unless otherwise noted). The location of the meetings are at St. Francis Hospital in the basement of the Heart Center, Classroom A. Meetings being at 6:30 PM and continue until 8:00 PM 6151 S. Yale, Tulsa, OK. Contact Susan Vanderpool @ [tulsadk@hotmail.com](mailto:tulsadk@hotmail.com)

Continued

Also listed M.E.N.D... description next to our calendar

# National Down Syndrome Congress



Released May 8th, 2008

We are excited to share that the NDSC, in partnership with local and regional associations, has formed an alliance to better serve our Down syndrome community. The official title is the NDSC Partnership Alliance. The Alliance consists of a council of local and regional associations and has the potential to impact the nation.

Several things have played into the timing of our decision to establish the Alliance — the successful implementation of our strategic plan as well as the specific request for national leadership. The request for more deliberate national leadership came from local and regional associations attending the Affiliates in Action event in Arizona earlier this year.

We heard you and we want you to know we are responding. The Alliance will allow a true partnership. We know we will work smarter by working together and by providing regional and local associations a national platform. By forming the NDSC Partnership Alliance we can develop opportunities and resources that only a national can provide. In a future E-Brief we'll introduce those who have agreed to serve in the Partnership Alliance. Be sure to take time to have a face-to-face conversation with them in Boston at the annual convention.

We value each and every one of our local partners. You are doing the hands-on work of daily meeting the needs of families in your neighborhoods, cities, and states. We want to help. By working together we will be much closer to creating a climate in which all people will recognize and embrace the value and dignity of people with Down syndrome.

Sincerely,  
David Tolleson  
National Down Syndrome Congress  
email: [sue@ndscenter.org](mailto:sue@ndscenter.org)  
phone: 770-604-9500; 800-232-6372  
web: <http://www.ndscenter.org/>

## Training by the Dept. of Ed.

If you or someone you know has a child 12 years or over, this is the training for you! I have attended this and it was extremely helpful. Most of those who attended the one I did, were professionals. I found it great to hear their feedback and loved that they got to hear mine as a mother of a 15 year-old. The information is invaluable. You'll learn about the new documentation and law. You'll be a step ahead of everyone else.

Joni Bruce, Oklahoma Family Network 405-203-8745

## Out of the Box Reading has closed its doors...

It is with great sadness that we inform you Out of the Box Reading has closed its doors forever. Fortunately, Denise MacDonald, co-founder of Out of the Box Reading has moved forward with a new business called 'eReadingPro'. Now, with eReadingPro, you can still enjoy all of the benefits of Out of the Box Reading products!

According to MacDonald, the creation of this new business was *"due to an overwhelming need to make the reading program more readily available for everyone and to lower the cost - particularly for parents of children with special needs"*.



eReadingPro makes the tools for teaching reading more available in many ways. New electronic, downloadable versions of the program (eBooks) are now available at a fraction of the price of the original Out of the Box Reading complete kit. By purchasing an eReadingPro eBook you will not only save money on the purchase price, you will eliminate the need for shipping AND you will be able to purchase smaller portions of the program. The original 14-month program has been broken down into smaller segments, each representing one-third of the program. Printing of any or all of each eBook is optional.

eReadingPro will be happy to respond to any questions from individuals using the former Out of the Box Reading program. Please pass on this email to any individuals that may currently be using the program! Email any questions to [info@ereadingpro.com](mailto:info@ereadingpro.com).

## Grants Available

For Families Struggling with Child Health-Related Expenses

UnitedHealthcare Children's Foundation (UHCCF) has announced that new grants are available to help children who need critical health care treatment, services, or equipment not covered or not fully covered by their parents' health benefit plans.

UHCCF provides grants to families to help pay for child health care services such as speech therapy, physical therapy, occupational therapy sessions, prescriptions, and medical equipment such as wheelchairs, and eyeglasses.

Parents and legal guardians may apply for grants of up to \$5,000 each for child medical services and equipment by completing an online application at the UHCCF Web site. To be eligible for a grant, children must be 16 years of age or younger. Families must meet economic guidelines, reside in the United States, and be covered by a commercial health benefit plan. (Not available to Medicaid/SCHIP recipients). ([http://www.uhccf.org/apply\\_applicant.html](http://www.uhccf.org/apply_applicant.html))

# The Better To See You With

## SPECS4US Inc.

Hello, my name is Maria Dellapina and I am writing to inform you about an opportunity to enhance the lives of the children we spend our lives advocating for. I am a mother of a nine-year-old daughter with Down Syndrome and have struggled through out her life to fit her properly in eyewear. Being an optician for over 25 years, I was constantly searching for frames that fit her unique needs. After realizing early on that I was fighting a losing battle, I took it upon myself and my experience as an optician, to design and create a special line of frames that dramatically enhances her abilities to function in eyeglasses.

I am proud to say that recently I was able to partner with a manufacturer who has developed my design into a workable frame for children with DS and other special needs.

SPECS4US Inc., Superior Precision Eyewear for Children who are Special, is my vision to bring



specially formatted frames to enhance the life of not only my daughter, but the lives of all the special children struggling with this problem every day. I have fitted a dozens of children in the frames, and have seen tremendous improvement in the lives of all of them.

Parents are e-mailing and calling me to express their gratitude for enhancing the quality of their children's vision and ultimately their day-to-day lives. As I am only one mother attempting to advocate for such a large community, I would appreciate your help in spreading the word to those I might not be able to reach. Please check out my webpage, [www.specs4us.com](http://www.specs4us.com), to learn more about my cause. Thank you in advance for your time and support.

Sincerely,  
Maria Dellapina  
Founder SPECS4US Inc.  
[mdellapina@specs4us.com](mailto:mdellapina@specs4us.com)

SPECS4US Inc. FACTS - Order online at [SPECS4US.com](http://SPECS4US.com) - Available in a variety of sizes and colors, with more styles and sizes coming soon. Fits your child... custom designed to fit the unique facial features of DS children with shortened temples (arms), extra wide frame fronts, and a lowered bridge are ideal for our children. Fits your lifestyle... made from titanium and memory flex that creates a flexible bridge and temples that spring out 180 degrees to keep up with our children's lifestyles. Fits your budget... priced less than traditional frames. Please feel free to pass this information along to your local optometrists or ophthalmologists or provide me with their contact information as I can provide additional information for kit purchases available for their optical offices.

<http://www.specs4us.com/index.html>

## Solo Bambini

The Solo Bambini™ proprietary frames for infants, children and now include adults are made in the USA with FDA approved, hypoallergenic materials and colors that are very durable and are available in 6 sizes, Itsy Bitsy, Teeny Weeny, Toddler, Scout, Eagle Scout and Scout Master. You will also find on our website frames such as the Portofino, the Alexandre and the Sophia which are made exclusively for Solo Bambini™ by European craftsmen known for their quality work and attention to detail. We will continue to add new styles that we feel fit our quality standards and color choices.

We also import and distribute the Comoframe from Italy which is available in 8 sizes, the Newborn, Baby, Babe, Baby-2, Junior, Sport, Sport-M and the Sport-L we stock the complete line in all available colors.

The latest addition in the Baby frames is the distinctive "Vulkani Baby" imported from Germany. This frame has a double laminate construction, with the dominant color on the front and softer silicone material on the inside and adjustable temples with matching soft comfort cables. It is available in one size 38mm in five(5) beautiful colors. The temple length adjusts very easily by removing the cables, cutting the temple to the desired length and reinserting the cable.



The **Solo Bambini**™ website offers all of our eyewear products with detailed descriptions for on line purchase in an encrypted and safe environment. We have also made it simple for you to order most prescription lenses and prescription sunglasses for any of the frames you find interesting.

The **Solo Bambini**™ frames offer the ultimate solution to correct infant refractions when first detected which can contribute to early resolution of many early childhood visual maladies. The softness and delicate feature of these frames present a comfortable alternative to traditional stiff metal or hard plastic frames that are ill fitting and awkward looking.

The large sizes SCOUT, EAGLE SCOUT and SCOUT MASTER from **Solo Bambini**™ and the Junior, Sport, Sport-M and the Sport-L from Comoframe offer a welcome alternative to traditional frames in that they have no hinges or screws to be concerned about when you are camping, fishing, hunting or conducting any outdoor activity. In other words, they are completely care-free. If you, for instance, fall asleep with them on, or should you by accident sit on them, No problem they will not misshape and cause you to loose sleep over them.

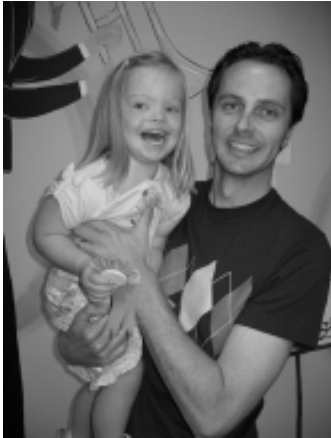
<http://www.solobambini.com/>



# Dad's Corner

By Jason Kennon

## Heroes among us...



In today's television and internet age it is very easy to be provided heroes' on a plate. We have golf heroes (Tiger Woods), football heroes (Go Sooners!), and other stars in almost every sporting event that are often looked upon as heroes. Not that there is anything wrong with sports heroes, but my hero lives at my house and she is almost three years old. I am speaking of my beautiful daughter Lucy Alaine Kennon.

I have to admit, like all parents that received the news indicating that your child may be a little different than the "typicals," the beginning was an emotional roller coaster.

But very soon after her birth, and I mean very soon, pretty much from the moment we were able to bring her home after 16 long days in the EOPC at Saint Francis, she has continually amazed me.

I truly didn't know what to expect in the beginning, but I sincerely believe that as I am blessed enough to witness each and every accomplishment and milestone that Lucy reaches, I am one of the luckiest men in the world. It has been a very rewarding three years and every time she calls me "DeDe" it warms my heart again.

Yes, there have been challenges, but as you realize that there really is no such thing as perfect, your own daily experiences become the new "normal" and if you just allow it, happiness and your new "normal" go hand in hand. So, if we could all recognize that our heroes and inspiration are closer than we think, the world would be a happier place.

P.S. The title of my article was intentionally plural, because I wanted to give special recognition to one of the most loving and steadfast people that I have ever had the privilege to be around, my wife, Alana. She truly is an amazing mother! Her lucky husband and Lucy's Dad (Holden's too), Jason Kennon (aka "DeDe").



## Help DSAT

Christmas Time will be here before we know it! Our Annual DSAT Christmas Party is scheduled for Saturday, December 13th at 10:30 AM to 12:30 PM. We will be doing a brunch again this year! It seemed to work out great last year. However, we are needing to form our committee now so we can get a gameplan going. Please let us know if you are interested in helping in ANYWAY... big or small. E-mail [Erin-Adam@prodigy.net](mailto:Erin-Adam@prodigy.net) or call 298-0428 if you are wanting to help. We need someone to help with centerpieces, food, decorations, games, and much more! Please help!

Changing Lives packets are READY to be DELIVERED! We have changed our plan for the packets. Instead of doing presentations, we are delivering all pediatrician offices and OB offices with a great basket of goodies. It has our packet, calendar, candy, pens, post-it notes and other goodies. We are needing people to help deliver these packets to the offices. It won't take long at all. We will tell you exactly what to say and give you the exact locations. Please let us know if you can help deliver even one of these packets. We really want to get these packets delivered as soon as possible. Contact Erin Paul at [Erin-adam@prodigy.net](mailto:Erin-adam@prodigy.net) or 298-0428 if you can help in anyway!

The Buddy Walk is fast approaching! Mark your dates for Sunday, October 19th from 2-4 at the Union High School Track. You won't want to miss it! If you know anyone that wants to sponsor our event, please go to [www.dsat.org](http://www.dsat.org) and click on Buddy Walk for all the details. We also need help collecting prizes for our drawing. It is so easy. We have folders that have a list of places to go on them. All you have to do is hand deliver the letter and be the contact for that place. Easy as that. The letters and locations to go are all ready for you. If you want to help, please contact Erin Paul at [Erin-adam@prodigy.net](mailto:Erin-adam@prodigy.net) or 298-0428. We need lots of help on this to make the baskets even better this year!

## Mended Little Hearts

Parents with children who have been diagnosed with a heart defect or heart disease need to know that they are not alone, and that there is hope in the midst of their crisis. However, even well-meaning family, friends and compassionate medical staff may not be able to offer them the strength and comfort that they are looking for.

By speaking with a trained parent volunteer whose family has survived the same difficult situation, parent in crisis can work through their overwhelming emotions they focus on the vital medical decisions at hand.

Through the support system and educational resources of Mended *Little* Hearts, families will be able to develop an immediate connection and begin to build a sense of hope for the future.

<http://mlhtulsa.org/>



# Oklahoma House of Representatives

## Legislative Studies Include Focus on Autism

June 20th, 2008



OKLAHOMA CITY – House Republican leadership announced today that three interim studies approved for this fall will deal with autism in Oklahoma.

“Interim studies provide legislators a valuable opportunity to gain broader knowledge of complex issues, and several House members have asked to focus on autism this year,” said House Speaker Chris Benge, R-Tulsa. “I believe these three studies provide the best opportunity for a focused examination.”

The first study was requested by Rep. John Wright and will look at the services already offered in Oklahoma for parents with autistic children to determine which ones are redundant, beneficial or could be refined.

Reps. Susan Winchester and Tad Jones will head another study looking at the possibility of creating a school especially for autistic children, allowing them to receive the specialized treatment and care they need on a daily basis. The school would be modeled after schools like the Oklahoma School for the Blind in Muskogee and the Oklahoma School for the Deaf in Sulphur.

The final study will be a comprehensive look at different solutions the state can consider when it comes to autism treatment. Led by Rep. Kris Steele, the study will look at what other states are doing, discuss possible options for Oklahoma and will hear from those in the community dealing with this issue firsthand.

“As policymakers, we have an obligation to look at the big picture, and this comprehensive study will allow us to take a broad snapshot of what is being done elsewhere for children with autism in order to see what might translate successfully here in Oklahoma,” said Rep. Steele, R-Shawnee.

Rep. Susan Winchester has worked diligently to get a lab school for the hearing impaired at the University of Science and Arts in Oklahoma in Chickasha, which will educate deaf children while also training teachers around the state to better teach deaf students. Winchester said USAO has shown an interest in modeling a school for autistic children on the same concept.

The lab school would have a training component as well so special education teachers from across the state could come and augment their skills to better teach children with autism.

The school would have a residential and commuter element to it, and would be easily accessible to parents from Oklahoma City to Lawton, said Winchester, R-Chickasha.

Currently, the only option for residential placement for children with autism is out of state, far from home and at considerable expense.

The interim study will also look at other options for a school dedicated solely to autism, such as looking at the RISE School of Stillwater which is already working with children with various disabilities.

Research would also be a component of the school studied this fall, said Winchester as lawmakers look for ways to root out the causes of autism and the reason for the growing number of children being diagnosed with the condition.

“This would be a concentrated effort with a variety of educators in the mix to give each child the best education possible,” said Winchester. “A team approach with a multitude of resources is the best way to reach these children before it is too late.”

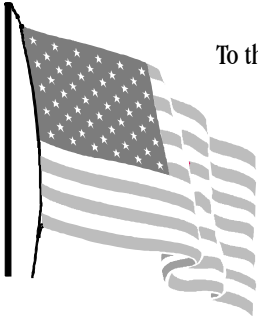
Rep. Jones said children with autism need specialized care and educational attention that in some instances would likely best be met in a separate school dedicated solely to that cause.

“Like the schools for deaf and blind students, an autism school would meet a very specific need for the growing number of children suffering from this condition,” said Jones, R-Claremore. “We want to look at the issue to determine if such a specialized school would be utilized and beneficial for these students.”

But before lawmakers can know what is needed, they must determine what services are already offered for children with autism in Oklahoma. Rep. Wright’s study will compile information on what is currently offered for these families.

“It is common sense to take an inventory of current services before expanding any offerings,” said Wright, R-Broken Arrow. “We must see what services are available and are being used to get a true idea of the specific needs within the autism community.”

# Divine Intervention



To the DSAT Family...

Divine Intervention on behalf of DSAT (via me) happened this morning. I am at the airport; leaving for more training all week in NC and I saw Rep. John Sullivan in the book store. I came up an introduced myself (I've called his office a hundred times, but of course have never

got him) and gave him a DSAT calendar (I always keep a couple in my computer bag), and he proceeded to tell me a story about his own experience with prenatal testing and expecting a child with DS (of course he said "Down Syndrome child", but we can educate him later). His story was touching in that he had done so much research on DS that he said he was actually a little disappointed when he found out they weren't going to have a baby w/DS). Pretty Cool.

Well I told him it would save me a call if I could just tell him the message — so I did. I just asked him if he was familiar with (H.R. 4188), he said no and to tell him about it so I did and asked him to co-sponsor the **IDEA Fairness Restoration Act (H.R. 4188)**. He said he always votes to fund these kinds of bills (great news) and he told me to contact **John Rainbolt** in his D.C. office. So I'm asking all of you to do the same. I gave him a card and also told him about the Buddy Walk in October. He gave me the name of the local contact that I needed to talk to (Liz in Tulsa) to get it on his schedule. I just felt that it was definitely a God "thing" and wanted to share with everyone.

Praise the Lord, God Bless and have a great day! Chris Wegener



## Support Groups continued

### Tulsa

**M.E.N.D (Mommies Enduring Neonatal Death)** offers a variety of support to couples who have lost a baby through miscarriage, stillbirth, or neonatal death. Our regular support groups meet every Third Tuesday of the month at Canyon Crossing, 1651 E. Old North Road, Sand Springs, OK (Exit N. 81st W. Ave. off of Hwy 412/64. Go north one mile. Canyon Crossing is on the NW corner at the stop/yield sign.) Our meeting time is 7-8:30 PM. Moms and dads are invited to participate. Additional services offered are care bags to those who recently lost their babies, Walk to Remember in October, recognition of baby's birthday, social gatherings, and many more. Groups will eventually expand to include subsequent pregnancy support and infertility after loss. For more information, please call Michele Wilson at 918-694-4325 or email her at [michele@mend.org](mailto:michele@mend.org).



### July

No regular meeting due to the Driller's Game.

### July 24th

#### D.A.D.S Group

**7:00 PM Fox and Hound Grill**

71st & Garnett

Note the date change. All Dads and Grandfathers are welcome to attend!

### July 27th

#### Driller's Game

**1:00 PM Lunch 2:05 PM First Pitch**

Driller's Stadium at 15th & Yale

Every DSAT member gets a free picnic ticket and ticket to the game. Pick up your tickets outside the front gates at the DSAT table starting at 12:50 PM until 1:45 PM After 1:45 PM please pick them up at will call under DSAT. The picnic will be hamburgers, hot dogs, chips and drinks. We will all sit together at the game! Bring the whole family!

### August 21st

#### Give Us Your Ideas

**7:00 PM New Haven United Methodist Church**

56th & New Haven

This is one you won't want to miss. We are using this meeting as a planning meeting to get ideas for the direction you want DSAT to move. Please bring ideas and come to help discuss ways we can make DSAT even more successful. We are looking at all kinds of new ways DSAT can get involved. If you are interested in chairing a committee, being on a committee, holding a leadership position or wanting to just give some ideas, please plan to attend. If you want to get involved, but can not attend, please let us know!

### September 18th

#### Therapy Works: Sensory Integration

**7:00 PM New Haven United Methodist Church**

56th & New Haven

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

### October 19th

#### Buddy Walk

**2:00 PM**

**Union High School Track**

### December 13th

#### Christmas Party

**10:30 AM**

July 24th D.A.D.S. Group  
 7:00 PM at Fox & Hound  
 July 27th Driller's Game  
 1:00 PM Driller's Stadium  
 August 21st New Ideas  
 7:00 PM New Haven UMC

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

Down Syndrome Association of Tulsa

# DSAT news

## DSAT Board of Directors

President	Adam Paul	298-0428	erin-adam@prodigy.net
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	Alana Kennon	745-2398	kennon.alana@unionps.org

## DSAT Committee Chairs

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