

DSATnews

Down Syndrome Association of Tulsa

May, 2008

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



D.A.D.S. Special Meeting Tuesday, May 27th

Exciting News! Our next D.A.D.S. (Dad's Appreciating Down Syndrome) meeting, Tuesday, May 27th at 7:00 PM. will have a special guest speaker. **Jimmy Gonzalez, Director of Football Operations with Oklahoma State University**, will be coming to speak to us!

Jimmy Gonzales came to OSU after a two-year stint as the Director of Player Development at Notre Dame. He has also served on staffs at Texas and Oklahoma in administrative capacities, and prior to that he coached for almost 15 years at Duke, Northwestern, Wisconsin and Tulsa. He also coached at Texas Lutheran, Tulsa and Southwest Texas State.

He and his wife have three daughters: Danica, Lea and Mya Nicole. Mya has down syndrome. He will be coming to share his experiences with raising a daughter with down syndrome and the foundation that they have developed.

Please plan on attending, we want a great crowd. Invite grandfathers, friends, uncles, anyone you think would benefit from this special guest speaker.



Driller's Night Sunday, July 27th

This is for the whole family! Come out on Sunday, July 27th and enjoy a day at the ball field. DSAT will be providing a free picnic lunch (hot dogs, hamburgers, chips and drinks) for the family from 1:00-2:30 and the game starts at 2:05 PM. We will all be sitting together. We hope you can come join us! Please pick up your tickets at the DSAT table that will be located outside the front gates starting at 12:50 PM until 1:45 PM. After 1:45 PM, please pick your tickets up at Will Call under DSAT. Hope to see everyone there!

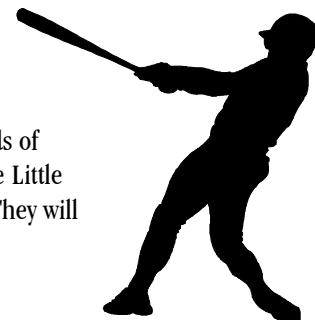
There will be no formal meeting in July due to the National Conference and our Driller's outing!

Please Share

If you take the opportunity to attend a Conference and want to share a few things about what you learned, please email Molly Ziriak at ziriak@tulsacoxmail.com and we would love to include it in our next newsletter. We can't all attend every conference, and this is a good way to pass on the information you receive! Thanks, Molly

Little Lighthouse

Some of you may already know... the Little Lighthouse is growing! They have purchased the Saint Anthony's Presbyterian Church next door and the Church will come down for an expansion of the Lighthouse. They are working to get kids into their services sooner. The two-year waiting list shows the need for this growth. The new building will allow them to double their enrollment. The facility will serve as a teaching environment for more than 200 children and hundreds of volunteers. If you have not visited the Little Lighthouse, stop by and take a tour. They will be glad to show you around.
36th & Yale in Tulsa



D.A.D.S.

Tuesday, May 27th at 7:00 PM

Fox and Hound Pub

Private Dining Area

71st & Garnett

May Meeting

Thursday, May 15th at 7:00 PM

New Haven United Methodist Church

56th & New Haven

(between Yale and Harvard)

Frank Baxter and his school in Russia

Thank you TARC for making this newsletter possible!

St. Francis

Children's Hospital & Urgent Care

St. Francis has completed their move into the new Children's Hospital. There are many nice things now available for family's who unfortunately need to spend time here. There are new security measures as well, so if you are visiting you must check in at the front desk in the lobby of the Children's entrance. They have also moved the After Hours Clinic and you also enter through the new entrance and ride the Children's elevators down to the new clinic.

Also, from Lora L. Roberts: I just found out from our last trip to the St. Francis after hour clinic that the Oklahoma Health Care Authority WILL NOT PAY for any expenses from the clinic. If they send you to radiology Medicaid will pay because it's billed through the hospital. You need to be aware of this if you utilize the facility and if you utilize Medicaid. You will be required to pay the co-pay at the time of visit which I had grown accustomed to not doing. If you have straight Medicaid the entire balance will be your responsibility and if Medicaid is secondary like it is for us when your insurance pays their part you are going to be required to pay the balance. I talked to Terrie Fritz, Director of Child Health at Sooner Care, and told her that for Tulsa families this is tough because that is our after hour pediatric clinic for our area and they are aware of the situation and they are addressing it. As ridiculous as it sounds the bottom line is until they get this resolved and do something this is just how it will be. Don't get mad or frustrated with St. Francis this is not their fault.

I recommend that if this affects you contact your State elected officials and voice your concern to them, the more voices that are heard can only be a good thing. Thanks!



TouchMath Workshop

The Down Syndrome Association of Central Oklahoma is sponsoring a workshop on Saturday, May 3rd in Oklahoma City. TouchMath is an innovative math-learning system specifically designed to help young students develop math skills. TouchMath works because students interact directly with numbers. They see, say, hear and touch the numbers in order to arrive at the correct answers, without guessing! And through the use of auditory reinforcement and flashcards, children learn the math facts they need to succeed.

This is \$20 for parents and family members and \$80 for teachers. For more information please contact Juanita Killingsworth at jbk3360@sbcglobal.net or (405) 348-6770.

Getting Involved

Recently, a few of us attending a "Joining Forces Conference" in Oklahoma City. It was a first of its kind. The objective was to join forces with Family representatives and Government Agencies in support of disability services. Attending were about 175 people representing parents, professionals, agencies. Some of the agencies represented were: OK State Department of Human Services, OK State Department of Education, OK State Department of Health, OK State Department of Rehabilitation Services, OK State Department of Disability services... and many more. At this Conference, all of these governmental agencies were represented by the Director of these departments and sub-departments; Sooner Start, Office of Medicaid, Office of Waivered Services etc...

It was an exciting day to see the governmental agencies come together with parents and professionals to discuss what we can do to improve the services offered. We were able to meet in a round table discussion format with all of these agencies. They each shared about many committees that are in need of parent members. If you are interested, please let me know and I can put you in touch with one of these departments. In my experience, the Agencies represented were very interested in listening to us and learning about how they can better serve us. It was a great opportunity and I am glad that DSAT was represented by myself, Danny Zirix, Monica Barbour and Rebekah Fish. Molly Zirix

6th Annual DSAT Buddy Walk October 19th

We will once again meet at the Union High School Track from 2 to 4.

Sponsorship Information: Sponsorship packets have been mailed to all previous sponsors. If you know of a company or individual that might be interested in sponsoring the Buddy Walk, please email their information to Alana Kennon at alanakennon@cox.net or publicity@dsat.org. She will be happy to send out a sponsorship packet to them, or send you one so you can present it to them in person. Sponsorship information is also available on the DSAT website at www.dsat.org and click on Buddy Walk. To be listed on brochure, commitment forms must be received by June 1.

Registration/Brochure: Registration will be available online again this year at www.firstgiving.com/dsat starting in June. Brochures will be mailed out in the fall.

2nd Annual Buddy of the Year Award: We are looking for nominations for the 2008 Buddy of the Year Award. The Buddy of the Year Award was developed to honor individuals who help promote inclusion and acceptance of persons with Down syndrome. If you know of someone who exemplifies these qualities and would like to nominate them, please send the attached nomination form to Alana Kennon at alanakennon@cox.net or to DSAT, PO BOX 54877, Tulsa, OK 74155 by June 1, 2008.

Affiliates in Action Conference

Last February, April Wegner and I were given an opportunity to attend a conference called, "Affiliates in Action" (AIA). This was an attempt to unify Down Syndrome chapters across the country. There were approximately 60 Down Syndrome Associations represented and over 200 people attending representing their organization. It was a great opportunity to share with other groups and make connections and gain valuable information on what other Associations are doing to create awareness and raise funds for down syndrome. We came away with many ideas and a great vision to see our own Down Syndrome Association of Tulsa grow and develop into a place where families can come for support, resources and friendships!

The AIA's goal is to bring a sense of unity and "one voice" to our mission of getting the word out that our children are "more alike than different". We need to unite in order to become "one voice" to our government in funding and research. Currently, there are approximately 350,000 people with down syndrome and only 14 million dollars are given to research and funding. We need more! We deserve more!

We attend several workshops pertaining to how to improve our organizations. We came away with several ideas about fund-raisers (ie. Dimes for Downs: having a fund-raiser in local schools, collecting dimes (or any coins, dollars) for down syndrome from each class in a school and the class that collects the most wins a prize (pizza party, movie day, McDonalds etc...)) This is a great awareness campaign and an easy fund-raiser). And expanding Buddy Walk.

Another great workshop was on **Communication**. How we communicate with our children. (this is geared towards older children, however you can be the judge on what your child can handle)

Here are a few tips:

- * 10 second rule: wait 10 seconds for a child to respond to you from a question or comment.
- * Don't talk too fast: so many of us talk too fast and our kids can't always process and respond that fast. We don't give them time! (10 second rule)
- * Wait for a response: give them the courtesy to wait for a response. They may be thinking of one and trying to verbalize it, and we just simply answer for them, or move on in conversation.
- * Don't give needless interruptions or demands. When you ask your child to do something, don't keep interrupting them and giving them additional information or demands. Give them a chance to accomplish the original task and goal.
- * Foster independence:
- * don't over prompt. Give them an opportunity to follow directions without over prompting. Para's should be working towards independence, by eliminating prompts. Ask your para to not give them every detail they need to accomplish the task and you might be amazed at how much they will learn and remember and do.

These are just a few ideas of what was presented. The AIA plans to continue a yearly conference of sharing ideas and becoming one voice. The next conference will be in Washington, DC in February '09. There will be opportunity to meet with Congress and speak on behalf of the down syndrome community.

If you are interested on serving on a Task Force committee to help further this cause, please contact me. ziriax@tulsacoxmail.com

Molly Ziriaux

Partners in Policymaking

I strongly encourage you to seriously consider taking the class. I know many of you have taken it in the past and some of you have sent in your application for this year. My passion is to see many families from our area take this class, something the speaker said this weekend that stuck in my mind is, "I may not win the battle today, but you knocked one more stone out of the way". We all know there is unity in numbers and we may not always win the battle but just think if we all keep knocking them stones out of the way, that wall has got to fall.

If you have a child with developmental disabilities, you work with families who have a child or people with developmental disabilities or you wonder what issues they deal with turn in your application. This class will take you farther in your thought process than you would have imagined, there has been so many ways my thinking has been changed. The current Partners class graduates on Sunday, April 27 and I will be among the graduates.

I have heard about Partners for many years but my thought process was I work full time and can't attend class or do any homework. I work 40 hours week at OG&E, 30 hours a month for Oklahoma Family Network, still advocate for Jeremy and I only missed one class due to Jeremy being sick after dental surgery and I got all my homework done. I can tell you the only regret I have taking the class is that I didn't take it sooner. You will have orientation on a Sunday afternoon in August and then class starts in September, you go one weekend a month, you get December off and go twice in April. Class is Saturdays 9:00 AM to 7:30 PM, and then Sunday 9:00 AM to 2:00 PM. The Oklahoma Developmental Disabilities council will pay for your motel room on Saturday night, they have a continental breakfast but you get a really good meal for lunch and dinner. I don't live far enough to qualify for the motel room on Friday night but we get the same rate/room and we pay for it ourself. I can't get up early enough on Saturday morning to travel to OKC and be there by 9:00 AM They will reimburse your mileage. If you have any questions about the class give me a call or email me.

Lora 227-1797

Dad's Corner



By Trace Weldon

When Molly asked me to write an article about Owen for the D.S.A.T. newsletter, I told her sure, I'd be happy to do it, after all he is one of my favorite subjects. I didn't realize that I would have so much difficulty. It's not that I can't come up with enough to write, it's just the opposite. I have too much I want to say.

Owen was born on June 22, 2006 and spent the first two weeks of his life in the N.I.C.U. at St. John Medical Center. This was due to a heart defect. He was diagnosed with Down syndrome and the heart defect about five months into the pregnancy, so at this point, none of this was a surprise. After two weeks, they sent us home to take care of a child with special needs. Ever since the diagnosis, I had wondered if we would be able to do this.

We had tons of support, family and friends were great. We had already become part of the D.S.A.T. group, so if we ever had questions, we knew where to find somebody with answers.



We found out just how giving people can be. There were a lot of days made easier just because someone would call to see how we were doing. One of my friends was so impressed with the reading we had done, and getting in touch with the D.S.A.T. group, he told me that Owen was lucky to have us as parents. We have never felt like we are in this alone, there has always been somebody there to lean on when we were having a bad day.

When we finally got Owen home and it was just Marci and I there to take care of him, we slowly began to get over our fears of raising a child with special needs. Now I see it differently; instead of raising a child with special needs, we're raising a special child. To think that I was once worried about the things that he wouldn't be able to do. I guess it's a good thing that Owen doesn't know anything about limitations, he thinks he can do anything. Sometimes that gets him into trouble.

Owen is very outgoing and loves to socialize. He enjoys playing with his dog, Riley and he is especially fond of his little brother, Dane. He's in the Orange class at The Little Light House. He loves going to school and playing with his friends Morgan, Caleb, and Aiden. They have the greatest teacher in the world, Miss Kate. Every evening when I get home, here he comes across the floor doing his bear crawl as fast as he can, with that big Owen grin on his face. I look back now and wonder what we were so worried about.

As I said we had a lot of support, but there's one person who is always able to convince me that things are going to turn out alright; one person I can always lean on when the day isn't going so well. All I have to do is pick him up and hold him. Thanks Owen! Your Momma and I are the lucky ones.

TherapyWorks

Changing lives for over 25 years, TherapyWorks provides speech, occupational and physical therapy in our outpatient pediatric clinic and in schools throughout Northeastern Oklahoma. TherapyWorks recently started a seminar series for parents, grandparents, caregivers, teachers, etc. who are interested in learning more about various therapy related topics. Our first presentation on sensory processing and integration will be presented at our September meeting.

On **May 22 at 6:30 PM**, they are presenting, "Easy Eating for Pediatric Feeding Problems," at our outpatient pediatric clinic located at 7608 E. 91st St. Is your child a picky eater? Are mealtimes a battle? Do you avoid restaurants? This seminar will discuss myths about eating, causes of feeding disorders, how to identify problem eaters and how to make mealtime fun. Kathy Soland, CCC-SLP, speech therapist at TherapyWorks, will be presenting.

The seminar is FREE but we do ask everyone to RSVP so we have an idea of how many people to expect. We look forward to seeing you on May 22! To learn more about TherapyWorks, visit www.therapyworkstulsa.com.

Special Programs Coordinator

The OU Health Sciences Center has a position opening for Tulsa County Special Programs Coordinator for Sooner SUCCESS. The job works with the Tulsa Alliance on Disabilities helping to coordinate the meetings as well as work with individual families to navigate and connect them to services within the community. Applicants must be a resident of Tulsa County. This is a 20 hour per week position with benefits. Apply online at: <https://jobs.ou.edu/applicants/jsp/shared/frameset/frameset.jsp?time=1208272049121>

The job code is: **Req #5185**

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

Jason & Alana Kennon

Burt & Stephanie McLachlan

Michael & Lora Conte

Donations

Michael & Lora Conte

Matching Gifts

ONEOK Foundation

Williams Companies

Wings

Special Needs Adult Community

An Oklahoma Christian based nonprofit 501 (c)(3) corporation, has been working to realize the dream of friends, family and supporters of adults with disabilities in Oklahoma. Our mission is: "To provide a Christ-centered community where adults with special needs can live and thrive within an environment guided by the principles of the Bible and Christ-centered leadership."

Phase I of the Wings community is currently underway. We have secured a location just 30 minutes north of Oklahoma City area, along the I-35 corridor, and are in the midst of a \$7,000,000 fund-raising campaign to help bring Phase I to completion. To help you understand more feel free to contact us at (405) 436-1865 or via email at WingsOK2007@gmail.com We would love the opportunity to share personally about Wings and the future of this project. Our website is www.wingsok.org

Wynter L. Olson, Program Coordinator



(DSAT members: A DVD, brochures and business cards will be a part of the lending library, if you are interested in checking it out.)



May 15th Regular Meeting 7:00 PM

New Haven United Methodist Church

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

May 27th D.A.D.S. Meeting 7:00 PM

Fox & Hound at 71st & Garnett

Jimmy Gonzales will be a guest speaker. Come support our new group. Remember that grandfathers are welcome also.

June 19th Regular Meeting 7:00 PM

New Haven United Methodist Church

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

July

No regular meeting due to the Driller's Game.

July 10th to 13th NDSC National Conference in Boston

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

July 27th Driller's Game 1:00 PM Lunch 2:05 PM First Pitch

Driller's Stadium at 15th & Yale

DSAT will provide a Free Lunch for members and their family and tickets to the game. Please bring everyone and join in a fun afternoon at the ball park.

May 27th D.A.D.S. Group
7:00 PM at Fox & Hound

April 15th Frank Baxter
7:00 PM at New Haven UMC

P.O. Box 54877
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Down Syndrome Association of Tulsa

DSAT news

DSAT Board of Directors

President	Adam Paul	298-0428	erin-adam@prodigy.net
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DSAT Committee Chairs

Governmental Affairs	Chris Wegener	355-6999	edward.c.wegener@gsk.com
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Publicity	Alana Kennon	745-2398	kennon.alana@unionps.org
Newsletter	Kendra Pennington	477-2999	kendra@soonerstart.com
Lending Library	Velvet Ahumada	794-5861	vahumada@cox.net

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

National Conference

We're More Alike Than Different

July 11th to July 13th

Just a reminder to register for the **National Conference** as soon as possible, and make hotel reservations (you can always cancel hotel reservations without obligation), so if you are remotely thinking about going to Boston in July... make reservations. This is a **WONDERFUL** opportunity to learn more about our children, how we can be a part of their education and also meet new people, I know it is an expense to you, but it is well worth the investment.

Online registration is available:
<https://www.ndscenter.org/convention08/>

If you are not comfortable registering online, you can download the printed brochure from our website, and use that to register by mail or fax.