

DSATnews

Down Syndrome Association of Tulsa

March, 2009

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

President's Message

Hi there! We just got back from the A.I.A. conference in Washington, D.C. where over 300 people representing 90 affiliates gathered to discuss and share ideas from each of our Down Syndrome Associations. You can read more about our time on Capitol Hill, later in this newsletter! It was an exciting place to be and an honor to be representing all of you!

We have some great events coming up this Spring and Summer. Remember that this March, we will *not* have a DSAT monthly meeting, due to Spring Break! We will be having our Annual Easter Egg Hunt on Saturday, April 4th starting at 3:00 PM. We will be having this at Whiteside Park (41st / just west of Yale). You won't want to miss this fun time together and a chance to see the Easter Bunny! Bring your camera!

Our April DSAT meeting, we will have **Curtis Shacklett**, from Barber & Bartz Attorneys at Law, share with us valuable information on establishing a trust fund for our children with special needs, among other options and topics! This is always highly attended, so come early! Free Childcare is always provided.

On Sunday May 3rd, we will have DSAT Day at an ORU Baseball game! This will be fun for the whole family! You must sign up to receive your free tickets. We will have sign ups at our April meeting or you can sign up with us at zirax@tulsacoxmail.com

In May we will have representatives from Special Olympics and in June we will have a presentation for us on nutrition therapy! Don't miss out on getting connected with others walking down the same road as you! There are lots of things to get involved in!

Feel free to contact us if we can be a help to you!

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April Meeting
Thursday, April 16th at 7:00 PM
New Haven United Methodist Church
56th & New Haven
(between Yale and Harvard)
Establishing a Trust Fund

Free Computers

Sooner AMBUCS ASK Project



Sooner AMBUCS is a civic club in Norman, Oklahoma. Our ASK project accepts donations of computers and peripheral devices from individuals

and businesses. We make repairs, load software, and provide systems to people with disabilities. We are not affiliated with any government agency and this project is run by volunteers. We are a 501(c)(3) charitable organization under IRS regulations. Leave a message on our answering machine at 405-360-1521 if you have questions or to request an application form.

Goin' to Kansas City

The Down Syndrome Guild in Kansas City is sponsoring a one day conference this month. Believing in Achieving will be held on Saturday, March 28, 2009 from 8:00 AM to 4:30 PM at the Sheraton in Kansas City. Registration is \$55 each or \$80 a couple and includes breakfast and lunch for the day. For more information or to register call 913-384-4848.



Stars of the Future

The young children of Special Olympics will have their event on Saturday, April 11th at 7:30 AM at East Central High School. Please contact Craig at 272-8009 to register.

Exhibition Run

At the St. Patrick's Day Run on Saturday, March 14th there is an exhibition run at 9:00 AM that any child with special needs can participate in for free. It is so neat. The kids might get a medal for their participation. You must contact Derek Cain at 481-1234 to register. This is a very special event. It only lasts about 10 minutes but is so fun for the kiddos.



Thank you TARC for making this newsletter possible!

Must See Movie

Down Syndrome Association families ARE INVITED to a FREE limited showing of "Praying with Lior". The film will be shown at New Haven United

Methodist Church on May 2nd at 6:00 PM.



"Praying with Lior" is an inspiring documentary about a young man with an extraordinary ability to pray.

Lior also happens to have a developmental disability.

The film chronicles Lior's preparation for his Bar Mitzvah as well as his impact on his family, school and faith family. Visit www.prayingwithlior.com for more information.

New Haven United Methodist Church is committed to children with special needs and their families. Please visit our website www.newhavenumc.org or call 743-6491 to learn more about our Special Needs Ministry.

Please call 743-6491 by April 24 to reserve your place and free childcare will also be provided by reservation only. Like every great movie, popcorn, drinks and goodies are complimentary.



Tax Code

Did you know that tax code information is posted on the IRS website. The following link is specific to people with disabilities. Most of the information in this publication is related to disabled adults (especially if they are working or receiving SSI). The child-related parts of the tax code are not new but we want you to know that there MAY something here you need to know. Please share your situation and this information with your tax advisor.

<http://www.irs.gov/pub/irs-pdf/p907.pdf>

Free Seminar

TherapyWorks now offers nutrition therapy at our pediatric clinic in Tulsa! To introduce everyone to our registered dietitian, Amy Puls, R.D., L.D., and our new services, we will be hosting a **FREE nutrition seminar on Thursday, March 26, 6:30 PM to 8:00 PM** at our clinic. If you would like to attend, please call 918-663-0606, to RSVP. We hope to see you on the 26th!

Calendar

It is already time to think about next year. The 2010 Calendar Profile is included in this newsletter. Please take the time to complete the application and return it quickly as the photo shoots start soon! Sign up to help also... it takes a lot of people to make our calendar the best ever.

Cheer Squad

Tulsa Cheer Academy has started a special athletes cheer squad. On January 31st this team performed at the JamFest Cheer Competition. The 5 girls on this team have been working hard to learn basic cheer moves, jumps, and a dance to the song "We're All In This Together"! The girls went out in front of the lights and an audience of hundreds. They danced and cheered with lots of enthusiasm! What a great job they did! The audience went wild for these girls. After the awards presentation one of the team members said, "This was the best day ever!" Christina Cervantes and Michelle Adams coach the team.



It was so wonderful to see kids that may never get to cheer on a football field be cheerleaders for hundreds! The girls will perform again on March 14th at the Oklahoma Championships here in Tulsa at the UMAC.

The owner of SSB KIDS! is so excited about this team! She said that it was a dream come true to have a group like this come out of their gym.

Michelle Adams, the founder of this team, could not believe that a dream that she had worked on for a year was coming true before her eyes! She knew Tulsa needed something like this. There are special needs dance classes and soccer teams, but not cheer. So many special kids want to be like their peers. This offers them an opportunity to shine before hundreds.

The team is also going to be performing at venues around town. A Tulsa 66ers half time performance is currently in the works.

Classes for the new cheer season will begin in April. TCA Special Cheer is open to any child with a disability ages 4 and up. For more information contact Michelle Adams at 289-1071 or specialcheer1@sbcglobal.net.



DSAT Calendar 2010 Profile

It is time to start working on the 2010 Sharing Our Joy calendar. We would like to include more parents in the many aspects of producing this wonderful project. Please consider which area you would be able to help with as you fill out the profile for your child. Filling out a profile does not secure your child a position in the calendar; it only means they will be considered. All calendar shots will be used in a variety of mediums (print, TV, ads, website, etc.) so if you have objections to signing over rights to **All** areas please **DO NOT** fill out this profile.

Child/Adult's last name _____ First name _____

Parent or Legal Guardian's full name _____

Address _____

City _____ State ____ Zip _____ Email address _____

Phone number (home) _____ (cell) _____

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

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

Organizing profiles _____	Helping with photo shots _____	Making phone calls _____
Distribution _____	Sponsorship packets _____	Accounting for calendars _____
Sponsorship appreciation _____	Sales at Buddy Walk _____	Typing _____ Publicity _____

How many calendars do you estimate you can sell? _____

Do you know a business or individual who would be interested in helping to sponsor the calendar?

If yes, would you contact them for sponsorship? _____

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

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

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

NOTE:

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

Please write a little something about your child below. We may put some of this info in the calendar.

Ex. Sports, hobbies, things they like, brothers, sisters, animals, etc.

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

AIA Conference Summary

Danny and I went to Washington, D.C. in February to attend a Conference called, **"Affiliates in Action"** This is the 3rd Annual Conference. Those who attend are the Leadership (President, Board Members. . .) of any Down Syndrome Association. We had approximately 300 attendees representing 90 Down Syndrome Associations from across the nation. It is a wonderful opportunity to network and find out what other Associations are doing with their groups that are either working or not working. The goal is for shared information, to build a stronger unity!

We attended many wonderful workshops and gained some great ideas on building a stronger DSAT. We are on the verge of growing in numbers and we want to be able to provide you with the most effective services and programs. Please feel free to contact us with any ideas that you may have!

The first day of the Conference was spent on Capitol Hill where we took a whole day to

meet our Senators and Congressman and ask them to support 2 very important bills that affect our kids with Down syndrome (ABLE Act of 2009; Kennedy-Brownback Bill). Danny and I met personally with Oklahoma Congressman David Boren, who was VERY interested in our group and was willing to join our campaign. We also met with both Oklahoma Senate offices and several other Oklahoma Congressman. It was a great opportunity for us. We gave each Senate/Congressman office a copy of



Danny and Molly with Congressman Patrick Kennedy. He has been extremely supportive in all disability legislative.



Molly and Congresswoman Cathy McMorris-Rodgers She is instrumental in co-sponsoring the funding for the Kennedy-Brownback Bill. She also has a 2 year boy who has Down Syndrome.

our DSAT Calendar, and they loved the pictures of our kids!! Thank you for sending us to represent you all at this Conference and on Capitol Hill, it was truly an honor!

I am including a wonderful summary article from a journalist, Pat Bauer that was able to capture the day on Capitol Hill. I thought she did a wonderful job and I wanted you to be able to read it.

Down syndrome advocates lobby on Capitol Hill

Patricia E Bauer

When more than 300 Down syndrome advocates from 35 states gathered at the U.S. Capitol last week, their stated mission was to seek federal funds to help spread accurate information about prenatally diagnosed disabilities.

But for many the goal was much more personal: To put a human face on a condition they feel is misunderstood and even stigmatized by the general public.

Recent advances in medical technology, coupled with strong business incentives, have been driving a broad public perception that Down syndrome is largely preventable through prenatal diagnosis and selective termination.

These advocates, from 85 local groups and representing some 400,000 Americans with the condition, hoped to leave their elected

representatives with a different impression. They want legislators to see their loved ones with Down syndrome as valuable, worthwhile people who are respected and cherished members of happy families.



"We want them to know that we are here, and we are striving to make sure that our kids are part of our community — not hidden away like in the past," said Theresa Grant, a mom from Reno, Nevada, whose 11-year-old son Elliott has Down syndrome.

"They are making strides and they are succeeding in school."

"We can stand up for ourselves," said Lydia Orso, a young woman with Down syndrome from St. Louis, at left with Rep. Patrick Kennedy (D-RI). "We can be advocates and have a voice."

Kennedy Brownback Bill

Representatives of Down Syndrome Affiliates in Action (DSAIA) called on Congress to allocate \$25 million over five years to implement the Prenatally and Postnatally Diagnosed Conditions Awareness Act, known as the Kennedy Brownback Bill.

The bipartisan measure calls for providing accurate, up-to-date information and support for parents who receive a diagnosis of Down syndrome or other disabilities such as spina bifida or cystic fibrosis either prenatally or up to a year after the birth of their child. It passed both the House and Senate without dissent and was signed into law last fall.

The intent of the measure was to create a sensitive and coherent process for delivering factual information about a diagnosis of disability. Down syndrome advocates say medical professionals too often give prospective parents inaccurate and

Advocates lobby on Capitol Hill continued

incomplete information, leaving parents anxious and fueling irrational bias against people who have the condition.

The measure provides for compiling data about the lives and development of people with Down syndrome and other conditions, as well as providing support to parents and assembling a list of families who wish to adopt children with disabilities.

“It’s important to understand that this is not about pro-life or pro-choice” but rather about providing parents with needed data & support, said Indianapolis dad Joe Meares (back row, left), whose daughter has Down syndrome.



“The worst presenters of a diagnosis of Down syndrome unfortunately today are medical professionals because there are no mechanisms to train them, to teach them how to deliver that diagnosis and to present the options, all of the options.”

It is estimated that some 90 percent of American women who receive a prenatal diagnosis of Down syndrome have an abortion.

Prenatal testing

The appearance on Capitol Hill last week of faces bearing the signs of Down syndrome was particularly timely, coming just days after a story in the Washington Post heralded the expected arrival of a new generation of prenatal tests for the genetic condition.

A handful of biotech companies are competing to be the first to unveil a safer test that would spot fetuses with the condition earlier in pregnancy. Whichever company wins is expected to gain a strong advantage in the multi-billion dollar international market in prenatal testing.

News of the tests has sparked a renewed discussion about prenatal testing and selective termination for Down syndrome, a condition in which people generally have three copies of the 21st chromosome instead of the usual two. It is most commonly associated with mild

to moderate intellectual impairment and a higher risk of some medical problems, including heart defects.

Advances in medical care and improved access to education have dramatically improved the outlook for people with Down syndrome in recent years. For example, their average lifespan has increased from 25 years in 1983 to nearly 60 years today, and doctors say it is rising.



Following the passage of federal law guaranteeing access to education, people with Down syndrome are increasingly completing high school, working, volunteering, and seeking to lead productive and purposeful lives in their communities. Disability advocates say these gains have not been adequately documented, and have been largely overlooked by the public.

Tax-Free Accounts

DSAIA members also pushed for a bill to encourage individuals with disabilities and their families to save, tax-free, for disability-related expenses. Called the ABLE Accounts Act, the legislation is intended to help people with all kinds of disabilities become more financially independent. It would allow them to save money without jeopardizing government disability benefits.

The accounts would be similar to college savings accounts, IRA’s, and other instruments that let people to put aside funds tax-free for education, medical needs, and retirement. Presently, people with disabilities may not use such accounts because to do so would jeopardize their federal disability benefits. Under federal rules, they lose eligibility for benefits if their assets exceed \$2,000.



“I am a productive member of society. I work, volunteer, vote and pay taxes,” said Jessica Green, a young woman with Down syndrome from Indianapolis (fourth from left). “I would

like to see Congress support a bill that would help me have a full and meaningful life.”

“We see this as a first step to breaking the cycle of poverty that’s basically been forced on people with disabilities,” said Steve Beck of Fairfax, Virginia, whose nine-year-old daughter Natalie has Down syndrome. “They want to be able to earn money and save it like everybody else. They have the ability, but restrictions that are placed on them have been preventing them from doing so,” he said.

Lydia Orso and Jessica Green were among about twenty people with Down syndrome who were part of the DSAIA group. They spent a busy day scurrying around Capitol Hill shaking hands, swapping business cards, and meeting with such legislators as Rep. Cathy McMorris Rodgers (R-WA), Sen. Sam Brownback (R-KS), and Rep. Patrick Kennedy (D-RI).



McMorris Rodgers, herself the mother of a little boy with Down syndrome, had tears in her eyes as she addressed the group at a packed breakfast meeting in the Rayburn Office Building. (At left, with advocates Heather Hancock and Craig Blackburn)

“I’m so thankful to you who have walked this path before me for the tremendous gains that have been made, and the tremendous progress that has been made. And I believe that my son has more opportunities than ever because of many of you in this room who have been plowing this road before me,” she said. “But we still have a lot more to do. That’s why I’m so thrilled that all of you are here. “It’s important that you are here, and important that you make your voices heard.”

Medical research and health care

The bipartisan Congressional Down Syndrome Caucus, co-chaired by McMorris Rodgers, invited the advocates to present expert testimony on the needs facing Americans with Down syndrome and other disabilities. Among the presentations were assessments of the need for improvements

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

Susan Cowart
Debbie Brown
Kay Crawford
Sandra Shults



Advocates continued

in medical research, health care, employment and education. While advances in medical technology have dramatically improved outcomes for people with Down syndrome, the full benefit of these gains has not been realized because promising medical research on Down syndrome is going unfunded, said Dr. Brian G. Skotko, chair of the clinical advisory board of the National Down Syndrome Society.

Data from the National Institutes of Health shows NIH allocated only \$40 for each person with Down syndrome in 2008, far less than its allocation for other medical conditions. By contrast, \$3,000 in research money is being allocated for each person with cystic fibrosis, and about \$1,500 toward each person with Fragile X syndrome, Skotko said. Both conditions are far less common than Down syndrome, but have better organized lobbying efforts. Skotko called for an increase in federal funding and collaboration on research into Down syndrome, as well as the creation of a national registry of people with Down syndrome to provide a ready data source for researchers.

He also urged the creation of more specialized clinics to serve the 400,000 Americans with Down syndrome. There are approximately 40 clinics across the country.



Employment

Dr. William E. Kiernan, director of the Institute for Community Inclusion at the University of Massachusetts Boston, reported that people with disabilities are disproportionately likely to be unemployed, isolated, and living in poverty.

Calculated as the number of persons working as part of the total number of persons of working age, he said, only about 36 percent of people with disabilities are working, compared with 70 percent of people without disabilities. For people with intellectual disabilities, the number is even smaller: only about one in four people with intellectual disabilities are working. Kiernan called on legislators to explore simplifying and streamlining the "convoluted" federal policies that discourage people with disabilities from working, and build expectations that people with



April 4th
Easter Egg Hunt
3:00 PM at Whiteside Park
41st & Yale



Bring your Easter basket to collect eggs & do not forget your camera.

April 16th
Trust Funds
7:00 PM at New Haven United Methodist Church
56th & New Haven

Come hear Curtis Shacklett speak on the importance of a trust fund for our children with special needs. He is a lawyer with Barber and Bartz law firm. Free childcare!

May 3rd
ORU Baseball
1:00 PM at ORU Johnson Stadium
81st & Lewis

Sign up for your FREE tickets for the whole family! Email Danny or Molly at ziriax@tulsacoxmail.com or sign up at the meeting. This will be lots of FUN!

May 21st
Special Olympics
7:00 PM at New Haven United Methodist Church
56th & New HavenN!

June 18th
Nutrition and Feeding
7:00 PM at New Haven United Methodist Church
56th & New Haven

We will have a registered Dietitian and a Speech Therapist give us a free seminar on nutrition therapy and oral motor skills. Great information you will not want to miss.

disabilities are employable, want to work and deserve to be employed.

"It is unconscionable to think that we would leave three out of four persons with intellectual disabilities standing on the sidelines of the labor force, not allowing them to fulfill their opportunity, their promise, to have what you and I have," he said.

Education

Ricki Sabia, associate director of the National Down Syndrome Society Policy Center, called for a reevaluation of rules that allow local school districts to divert federal special education funds for other purposes.

The Individuals with Disabilities Education Act (IDEA) allows local districts to divert up to 50 percent of any federal funding they receive that exceeds the amount received in the previous year. Thus, Sabia said, whenever the federal government provides extra money, half of it can be used for other purposes even when the district and the state are not in compliance with the IDEA.



April 4th Easter Egg Hunt
3:00 PM Whiteside Park

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

DSAT news

Down Syndrome Association of Tulsa

DSAT Board of Directors

Presidents	Danny & Molly Ziriak	496-1873	ziriak@tulsacoxmail.com
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Secretary (interim)	Danny Ziriak	496-1873	ziriak@tulsacoxmail.com
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Calendar Chair	April Wegener	355-6999	aprilwegener@cox.net
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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
or to get more involved in DSAT
please email: ziriak@tulsacoxmail.com

Advocates conclusion

“This is particularly disheartening to parents of children with Down syndrome who spend an enormous amount of time battling the effects of this noncompliance,” she said. “We need to tie this flexibility to compliance and fully fund the IDEA.”

Patricia E. Bauer is a journalist who has served as senior editor of the Los Angeles Times Sunday Magazine; special assistant to the publisher of the Washington Post; reporter and bureau chief at the Washington Post, and pundit on public affairs television in Los Angeles. Her articles have appeared in the Washington Post, the New York Times and many other publication.

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