

DSATnews

Down Syndrome Association of Tulsa

January, 2010

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

President's Message

Happy New Year!

We trust that you had a wonderful holiday and are beginning to thaw out a little bit by now! What a crazy winter!

We have a lot of great things planned for 2010. Our next event will be attending an ORU Basketball game, Saturday, January 30th. If you haven't picked up a ticket, email us and we can get one for you and your immediate family. Tickets are compliments of Oral Roberts University. We have limited supply so hurry and put your request in!

At our January DSAT meeting we will be having a representative from the Challenger League in Tulsa. She will give us all the information on the exciting opportunities with them and the upcoming events.

In February, we will have a local Dentist come to our DSAT meeting to discuss the specific dental issues that children with down syndrome have.

We are planning our Easter Egg Hunt and will be giving you details about that in the coming months. Yeah, more candy and fun!

We are still trying to start some play groups. If you are interested in leading one or being a part of one, let us or Mindy Beasley know. It is limited planning and lots of fun!

Thank you to everyone who made our Christmas party a great success!

Please let us know if we can be of help to you in any way,

Q3P Molly Zirax

February Meeting
Thursday, February 18th at 7:00 PM
New Haven United Methodist Church

Bring your questions for the dentist.

Tennie

Tennie Cogburn, 25, a precious member of our Down syndrome family from Muskogee, passed away December 14th. By her side at the hospital was her best friend, Michelle Garner, who appeared with her in the 2004 DSAT calendar. She was greeted at heaven's gates by her friend Becca Smith. Tennie had the gift of embracing all who came into her life with love.

An account has been set up at Bank of Oklahoma to help with funeral expenses under her mother's name (Joy Jefferson) or Tennie Cogburn.

ORU Basketball

DSAT Night at the ORU Basketball Game, Saturday, January 30th. Festivities start at 6:45 PM and the game starts at 7:00 PM. ORU has given us some free tickets to enjoy the game. **It is ALWAYS a fun family night out.**

Please email me if you would like some tickets and how many. I will be in the North Lobby just near the escalator from 6:30- 6:45 PM to hand out tickets. So let me know how many you need... we have a limited supply.

This will be a fun evening! They may even mention our group that night and we have good seats. Email to sign up!

ziriax@tulsacoxmail.com

Handwriting

Children who have difficulty writing are at a disadvantage in their schoolwork. Children with disabilities are at risk for writing failure. It is important to monitor writing skill using written language testing. Caution! All tests of written expression are not created equal. Small differences between tests can result in large differences in scores.

In the Special Ed Advocate, Dr. Melissa Farrall explains the importance of measuring specific skills when evaluating writing expression. Learn what areas should be included in a written language evaluation and learn what commonly used tests of written expression measure.

Check it out at:
<http://www.wrightslaw.com/info/test.written.lang.htm>

Thank you TARC for making this newsletter possible!

Disney Days

Life gives us so many feel-good reasons to celebrate: birthdays, anniversaries, reunions and beyond. But this year, Disney Parks is celebrating a new reason and that's the good things we do for each other. So during 2010, we want to inspire one million people just like you to volunteer a day of service to a participating organization in your communities. In turn, we'll celebrate your efforts by giving you a free one-day admission to your choice of a Walt Disney World Resort or Disneyland Resort Theme Park! There's no better time to make a few dreams come true for others... and to let us make a few come true for you. You must pre-register and sign up for eligible volunteer opportunity at disneyparks.com. Ticket quantities for this program are limited. Must be at least age 6 to participate. One ticket per person. Other terms and conditions apply. See disneyparks.com for details.



Here's how the "Give a Day. Get a Disney Day." program works:

Sign up and commit to an eligible volunteer opportunity.
Complete your volunteer service.
Print the voucher we will email to you once your service is verified.
Follow the instructions on the voucher to have a day at the park.
(Or you can donate your ticket to a designated organization.)

CHD Awareness Week

Congenital Heart Defect Awareness Week
February 7th to 14th, 2010

What is CHD Awareness Week? It is a nationwide effort to raise awareness of congenital heart defects. Did you know that approximately 36,000 infants are born each year with a congenital heart defect? That is about 9 out of every 1,000 births (according to the American Heart Association). Additionally, according to Nation Down Syndrome Society, nearly half of all infants born with Down syndrome have some form of congenital heart defect(s).

This year, Mended *Little* of Tulsa would like your help communicating CHD awareness. It might be easier than you think • c..from adding a CHD statement to the signature line in your e-mail, to volunteering at local awareness events, your participation will draw attention to the needs of the congenital heart community.

For more information regarding CHD Awareness Week, how you can help, or where you can receive help, please contact Mended *LittleHearts* of Tulsa (ML). ML is a support program for families of children with heart defects. Mended *LittleHearts* a support network, resources, etc. and connects families in crisis with other parents who have survived the shock of learning a child has a heart problem.

National Mended *Little Hearts*
www.MendedLittleHearts.org
(888) HEART99
mlh@mendedhearts.org

Mended *Little Hearts* of Tulsa
www.MendedLittleHeartsTulsa.org
(918) 289-5587
tulsaok@mendedlittlehearts.org



A program of The Mended Hearts, Inc.

Parent Study

My name is Kayli Cross, and I am a graduate student in the Marriage and Family Therapy program at Texas Tech University. I am currently assisting with a research project entitled, "My Kid Has More Chromosomes Than Yours!": *The Journey to Resilience and Hope in Parenting a Child with Down Syndrome*. The project coordinators are Nicole Springer, Ph.D., Texas Tech University and Briana Nelson Goff, Ph.D., Kansas State University, both parents of children with Down syndrome.

This research project will include online surveys completed on a voluntary basis by parents. Qualitative interviews will then be held with selected parents, based off of their answers to the survey. Even though they are being selected to participate, their involvement in these interviews is still voluntary. Questions will explore the journey to

resilience and hope experienced by families with a child with Down Syndrome (DS). This research will identify the key resilience factors in families who have successfully navigated this difficult transition and provide important information and resources for families facing this journey in the future. Specific questions will ask participants how they coped with their child • fs Down syndrome diagnosis, about their relationship as a couple, and their hope and satisfaction with life. In addition, qualitative questions will ask more about their initial response to the diagnosis, their current attitude about the diagnosis, and other specific experiences they have had as a parent to a child with DS.

We anticipate two primary outcomes from this project: 1) academic publications and presentations based on the research data, and 2) a consumer media publication for families with children with DS. The consumer media publication for new parents of children with DS will include the experiences of parents, in their own words, as well as several key resources to help parents in this journey.

The following is a link to our online survey for parents: <https://surveys.ksu.edu/TS?offeringId=148766>. If you would be willing to allow us to post this link and information concerning our project on your website, or to email this information to the members of your organization, please let me know. I have also attached a copy of our informational flyer, both in PDF and Publisher format. Your support will be much appreciated!

If you have any further questions or concerns, you can contact me at kayli.cross@ttu.edu, Nicole - nicole.springer@ttu.edu, or Briana - bnelson@ksu.edu.

Thank you in advance for your consideration of our project.

Kayli Cross
Marriage & Family Therapy Clinic Coordinator
Texas Tech University
Human Sciences, Rm. 164A
Box 41210
Lubbock, TX 79409-1210
(806) 742-3074 ext. 243
Email: kayli.cross@ttu.edu



Down Syndrome Family Research Study

"My Kid Has More Chromosomes Than Yours!":
The Journey to Resilience and Hope in
Parenting a Child with Down
Syndrome

<https://surveys.ksu.edu/TS?offeringid=148766>

About the Study

This research project will include online surveys and qualitative interviews with parents that will explore the journey to resilience and hope experienced by families with a child with Down Syndrome (DS). This research will identify the key resilience factors in families who have successfully navigated this difficult transition and provide important information and resources for families facing this journey in the future.

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Who do I contact with questions?

The researchers are both parents of children with Down syndrome.

You may contact either Briana or Nicole with questions about the study:

Dr. Briana S. Nelson Goff

119 Justin Hall, School of Family Studies and Human Services
College of Human Ecology
Kansas State University, Manhattan KS 66506
Bnelson@ksu.edu, 785-532-1490

Dr. Nicole P. Springer

Department of Applied and Professional Studies
College of Human Sciences, MS 1210
Texas Tech University, Lubbock, TX 79409
Nicole.springer@ttu.edu 806-742-5050 (Ext. 267)

What is Required?

The research will be conducted through the following online survey questionnaire and will require approximately 30-45 minutes of your time.

Some participants will be invited to provide additional information in a follow-up interview. If selected for a follow-up interview, phone interviews will be conducted that will require approximately 60-90 minutes of your time. Interview participants will receive a small incentive for their participation.





CHD Awareness Week

February 7, 2010 thru February 14, 2010

Jonathan
Bixby, OK



Ava
Tulsa, OK

What Can I Do . . .

- Support the Congenital Heart Futures Act
- Raise awareness in the community by sharing educational material
- Share your CHD experiences
- Support family and friends with CHD's
- Join CHD related causes (in person, Facebook., etc.)
- Post links to newspaper articles, TV segments, and other related media
- Update your electronic signatures to include a CHD related topic

I Need Help . . .

Did you know there is support available to families in need? Mended *Little Hearts* is a pediatric support program dedicated to inspiring hope in those who care for the littlest heart patients of all. The core goal is to connect families in crisis with others who have survived the shock of learning a child has a heart defect/heart disease, navigated the maze of medical decisions and procedures, and mapped out a plan for the future. Mended *Little Hearts* was developed and is supported by The Mended Hearts, Inc., a national organization with over fifty years of experience serving heart patients and their families. The purpose of Mended *Little Hearts* (MLH) is to offer support to family members and other caregivers of children affected with heart defects/heart disease. MLH offers educational/health resources relating to heart defects/heart disease and well-being. MLH also raises awareness in the community about children and heart defects/heart disease and factors that may contribute to this disease.

Mended *Little Hearts* Contact Information

National Mended *Little Hearts* - www.MendedLittleHearts.org ; (888) HEART99 ; mlh@mendedhearts.org

Mended *Little Hearts* of Tulsa - www.MendedLittleHeartsTulsa.org ; (918) 289-5587 ; tulsaok@mendedlittlehearts.org

What is a CHD?
Congenital Heart Defect

Did you know . . .

- 9 out of 1,000 births will have some form of a congenital heart disorder
- Approximately 36,000 babies are born with a heart defect each year
- About 1 million Americans born with a CHD are alive today
- Cardiovascular disease ranks as the number 2 cause of death for children under the age of 15

According to the American Heart Association

www.americanheart.org



Ryan
Sand Springs, OK



Zyron
Tulsa, OK



Solomon
Broken Arrow, OK



Max
Jenks, OK



Taylor
Sapulpa, OK



Logan
Owasso, OK



Hailea
Tulsa, OK



Brinlee
Dewey, OK



Sarah
Tulsa, OK



McCartney
Tulsa, OK



Jackson
Owasso, OK



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 & LJ Daylor
Barry Lewis
Kelli & Jason Bennett
Douglas & Virginia Baldrige
Paul & Marilyn Stanton
Angie & Alan Shaull
Dorothy Endrizzi
Virginia Cervantes
Jacque Canady

Donations

Kelli & Jason Bennett to Becca Smith Memorial Fund
Genevieve O'Connor in honor of Morgan Ziriak
Janice Bratzler in memory of Joseph Cervantes
Ron & Shari Graham in honor of Kyle Graham
Ron & Beth Blackwell in memory of Gaylord Thomas
Myra Fadley and friend in honor of Makayla Wilson
Cimarex Energy
Patrick Meziere
Virginia Baldrige
Jacque Canady
Kohls - Owasso



Calendar

January 21st
Regular Meeting
7:00 PM at New Haven United Methodist Church
We will draw for the scholarship winners!

February 18th
Regular Meeting
7:00 PM at New Haven United Methodist Church
Meet the dentist.



STARS Workshops

The Statewide Training and Regional Supports (STARS) program is pleased to announce our 2010 calendar. Visit www.ah.ouhsc.edu/tolbert/courses_workshops for a listing of the courses and how to register. These workshops are free of charge to parents of children involved in SoonerStart or on an IEP with their school. Registration is available throughout the year. For more information email stars@ouhsc.edu or write to:
STARS,OUHSC
Department of Rehabilitation Sciences
PO Box 26901
Oklahoma City, OK 73126-0901

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

Down Syndrome Association of Tulsa

DSAT news

DSAT Board of Directors

Presidents	Danny & Molly Ziriak	496-1873	ziriak@tulsacoxmail.com
Vice-Presidents	Ashley & Mindy Beasley	445-2623	anbeasley@aep.com
Treasurer			treasurer@dsat.org
Secretary (interim)	Danny Ziriak	496-1873	ziriak@tulsacoxmail.com
Publicity	Alana Kennon	745-2398	publicity@dsat.org
General Members:	Kim Wofford	622-6906	woffordnate1@cox.net
	Chris Wegener	355-6999	edward.c.wegener@gsk.com
	April Wegener	355-6999	aprilwegener@cox.net

DSAT Committee Chairs

Governmental Affairs	Chris Wegener	355-6999	edward.c.wegener@gsk.com
Calendar Chair	April Wegener	355-6999	aprilwegener@cox.net
New Parent Contact	April Wegener	355-6999	aprilwegener@cox.net
Newsletter	Kendra Pennington	477-2999	kendra@soonerstart.com
Lending Library	Velvet Ahumada	764-8329	velvetahumada@att.net

To add your name to our email reminder list
or to get more involved in DSAT
please email: ziriak@tulsacoxmail.com