

# Spotlight



DOWN SYNDROME SOCIETY OF WICHITA, INC.

2nd Quarter 2011

## Advocacy



With budget cuts potentially affecting special education and funds available to individuals with disabilities and their families, advocacy must be placed in high regard. Our children, families, and all those with disabilities need a voice.

The Down Syndrome Society of Wichita is excited to welcome Anita Raghavan as the Advocacy Chairperson. Those of you who have had the pleasure of meeting Anita know her to be a strong, vocal woman who advocates regardless of a designated position. She has advocated for her son, Tavrick, to be in the most inclusive education environment, and now she extends her

advocacy towards bringing post-secondary education to Kansas for those with special needs. Anita also fulfills an advocacy role in her involvement with the Sedgwick County Developmental Disabilities Organization (SCDDO).

Since accepting the position of Advocacy Chairperson in February, Anita has already attended the Buddy Walk in Washington, D.C. while meeting with several representatives, and has advocated at the state level in Topeka. She looks forward to keeping everyone up to date on issues affecting the Down syndrome community and those with disabilities. If you have questions for Anita, you may contact her at [anitaraghavan@sbcglobal.net](mailto:anitaraghavan@sbcglobal.net)

### Grant Writing Experience?

Do you or anyone you know have experience with writing grants? If so, please contact Rebecca at [president@dsswichita.org](mailto:president@dsswichita.org). Being the recipient of a grant would allow DSSW to further our mission, provide more support and activities to those with Down syndrome.

## Thanks to Gracious Donors

The Down Syndrome Society of Wichita graciously acknowledges the following recent donations:

Don Yoxall Memorial—in memory of Thane Van Eaton's grandfather

First Church of the Brethren—in honor of Ava Jensen

IBM Employees—monthly contributions

Thank you!

### Upcoming Events:

- APRIL 9TH—MEETING, SHARING SESSION
- APRIL 9TH—NEW PARENT BREAKFAST 9 A.M. (BEFORE MONTHLY MEETING)
- MAY 14TH—MEETING MARTI JOHNSON, SPECIAL NEEDS PLANNING
- JUNE 11TH—ANNUAL PICNIC AT HIGH PARK

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# Family Spotlight

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## Johanna Thome



Proficient fingers on her pocket-sized hand gently pushed a persistent lock of fawn-colored hair from her slightly slanted doe-shaped eye. Staring intently at the newsroom scenario of one of her favorite television programs, the Mary Tyler Moore Show (classic TV.), she suddenly broke into a violent giggle complete with three short-lived snorts. "Mary is so funny," she genuinely offered without taking her chocolate-brown eyes from the screen.

Her favorite movie is Disney's "Beauty and the Beast" and life would be just perfect for her if she could watch it while eating her favorite food of scrambled eggs and ketchup. Almost 27 year old, Johanna Thome likes to dance (without moving her feet unless it is a kick now and again), watch soap operas (has all the lines memorized from "All My Children" for years now) and go to KidZoogie at church. Even at 27 years old, Johanna is mentally about 8 years old. The church has no problem with her participating with the 8-10 year old Sunday school group. She has a tough time with pronouncing words and usually has to repeat herself to make others understand her speech. She has memorized the T.V. guide - really! She can tell you any day, any time of the day what is on any channel!

Beyond obvious handicaps, she would surprise many with her quick wit and unusual sense of humor. Chortling once again, she unexpectedly said, "Manda told me that if I didn't wash my face in the shower, I would get zits!" Hoping triumphantly for this (late) teenage rite of passage, she asked to be checked out for these prize blemishes.

Johanna sleeps in her stuffed animal-filled (purple) room with two night-lights. Cautiously leaning over, careful to look about, she deliberately whispered, "There is a scary monster in my closet!" Therefore, we all lovingly perform the nightly ritual of checking between the clothes and securely closing the closet door.

Having four older siblings and now a niece, Ainsley who is 9 years old, she did not have much time to fall behind in her continuing education. She sings in the shower. She sings in the car. She sings in church (even when the organist is not playing). Typically, she thinks her niece Ainsley is just "a pain in the neck" and she likes to make funny faces to entertain family. She is very protective of "her space" and you must ask permission to enter her room or touch her things. If asked, she will probably give you about anything you want, but those eyes are telling you to make sure it is given back soon!

When questioned about the recent incident of the self-done haircut she quickly and strongly justified, "I just wanted my hair cut, OK?" Her guilty expression regrettably remembered the multi-length coif she sported for several months. At the time, she was hoping to go unnoticed, but mom found the once-attached evidence hidden under the bathroom sink, and the gig was up.

Johanna generously hugs anyone (and everyone) whose waist is in reach and will be the first to apologize for any mishap, her fault or not. She probably doesn't notice when others impolitely gawk at her handicaps and doesn't understand when parents pull their children away from her at the playground as if her condition is contagious.

Mainstreamed at Buckner Elementary, for every daily good report from her fifth-grade teacher, she proudly placed a sticker on the calendar. When a week was full of stickers, I would reward her with dinner at McDonald's (which we can no longer do since she was diagnosed with Celiac Disease a year ago....no wheat!) She graduated from Chisholm Life Skills School at the age of 21. We tried KETCH and ResCare for a few years, but now with the strict diet concerns and healing intestines, Johanna proudly announces that she is "retired" with mom!

We find ourselves, missing the Y.E.S.S. program activities and yearly renewed friendships, but she now looks forward to "The Looking Glass" twice a week. It is an artists delight day for those with disabilities. In addition to art projects, participants go shopping, cook, and make day trips to the museums. We recently participated in the DSSW Family Game Night and Johanna had such a good time and a recent inquiry yielded a friendship from high school which will offer frequent lunches out for Johanna with an old classmate.

So, life goes on. At bedtime with the fearless night-lights aglow, Johanna rolls over between her "Beauty and the Beast" cotton sheets and flatly states, "I think I need a snack." "What kind of snack?", I ask. "Eggs and ketchup" she says hopefully through the shadows, and then we wait for tomorrow to begin again.

*Originally written by Johanna's older sister, Megan, while in high school. She has since gone on to be a copy writer for K & Company. Johanna is so proud of her sister!*

# Community Spotlight

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## Summer Activities

Spring is here and summer is just around the corner. If you are anxious to find activities to keep your children active - both mind and body, there are a lot of activities offered in Wichita, including for children with special needs. Here is a list of upcoming activities you may be interested in.

- **Y.E.S.S. (Youth Education & Summer Socialization) Program** – a 9 week program offered by the ARC of Sedgwick County which includes a half day of classroom education and a half day of summer fun in the community. This program serves individuals with disabilities from 5-21. For more information please visit the website at [www.arc-sedgwickcounty.org/YESS.html](http://www.arc-sedgwickcounty.org/YESS.html)
- **Dance Reflections**—For more info visit [www.dancereflections.org](http://www.dancereflections.org)
- **Lose The Training Wheels** – The week of June 27 – July 1 the Independent Living Resource Center will be hosting “Lose the Training Wheels”. This program has successfully taught individuals (8 years and older) to master riding a bike during the week long event. In years past, the Wichita program has reached capacity quickly. Please visit the website at

[www.losethetrainingwheels.org](http://www.losethetrainingwheels.org) for more information. If interested in registering for the event please visit the Independent Living Resource Center website at [www.ilrcks.org](http://www.ilrcks.org) and download the application. **Applications must be returned by May 6<sup>th</sup>.**

- **Miracle League Baseball/T-ball** - Games are played each Saturday in May. Registration is due April 22nd. [www.MiracleLeagueofWichitaKs.org](http://www.MiracleLeagueofWichitaKs.org)

### Lending Library—New Books!

- \* “Off We Go” series (Dentist, Grocery Store, Hair Cut)
- \* New DVDs from NDSS (including Time Square Video)
- \* First 18 months (Spanish, English, Vietnamese, Arabic, Chinese)
- \* Discovery Pathways to Better Speech for Children with Down Syndrome

## Local Easter Egg Hunts

- ◆ The For the Love of Chance Center has organized an Easter Egg Hunt for children with special needs on April 23<sup>rd</sup> from 11:00 to 1:00 at the Andover Central High School softball field (in case of rain – move to ACHS gymnasium). The Easter Bunny and Eggbert will be present so bring your cameras and baskets. A \$3 donation is suggested. Please RSVP to [Sports4allkids@rocketmail.com](mailto:Sports4allkids@rocketmail.com).

- ◆ Easter Eggstravaganza at Sedgwick County Zoo is April 23<sup>rd</sup> from 8:30 a.m. to 3 p.m. There will be Easter themed activities throughout the zoo as well as giant hidden Easter eggs. There will also be a special needs activity at the Eggstravaganza at 1 p.m.. RSVP's are requested by April 8<sup>th</sup> for the special needs activity. For more information visit [www.scz.org](http://www.scz.org) and view “Signature Zoo Events”.

## Celebrations

The Down Syndrome Society of Wichita would like to congratulate and welcome five beautiful babies and their families! Welcome Olivia, Jordyn, Jaxon, Blaisi Mae, and Luis! We can't wait to meet you and watch you thrive!

Is your son or daughter with Down syndrome graduating from High School or College? Please email Michelle Sanchez at [michelle0317@cox.net](mailto:michelle0317@cox.net) . We would like to recognize their achievements.



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## Newsletter Requests?

Do you know of anyone who would like to receive the DSSW Quarterly Newsletter? Grandparents, extended relatives, grown siblings, teachers, etc. may enjoy reading about and staying connected with DSSW events through our quarterly newsletter. Please email Lisa at [secretary@dsswichita.org](mailto:secretary@dsswichita.org) to receive future quarterly newsletters. Please include your name and address.



Written by: Lisa Umbehr

Wichita is fortunate to have a one of a kind performance group called "The Laughing Feet Performers". As part of the *Music Theatre For Young People* (MTYP), this theatre group was created to inspire relationships between individuals with special needs and their typical peers. Through musical and artistic expression, 60 students (half of which have special needs) ranging in age from 12-25 years from the Wichita area sing and dance to pop music.

In preparation for the performance, participants practiced up to four days a week for six weeks depending on their desired level of participation for the show. Those who want more roles in the actual performance therefore practice more than those who only want to participate in one act.

Having attended the performance during the weekend of March 4th, I can attest to the incredible talent that our community possesses. I was moved to tears by the

energy, dedication, and acceptance. This is not a performance you will want to miss next year.

If your son or daughter is interested in participating with "The Laughing Feet Performers", you may contact Jenny Mitchell, the founder & director, at [laughingfeetperformers@yahoo.com](mailto:laughingfeetperformers@yahoo.com). If you provide your email she will place you on the mailing list and keep you updated regarding next years performance. Those with special needs, as well as their siblings and regular education peers are encouraged and welcomed to participate. Those wishing to volunteer may also contact Jenny. This past year the enrollment fee was minimal at \$25. It is hoped that a grant will be received that will allow the enrollment fee to remain low.

DSSW would like to give special recognition to Will Simpson, Megan Armstrong, Sammy Rader, and Courtney Logan.