

# TSS CONNECT

SUMMER 2016

**Summertime has Arrived!**

**"LIFE AS A GOLDEN BUTTERFLY"**

*Article by Dorothy Baume*

**AND MORE INSIDE!**



**Turner  
Syndrome  
Society**  
of the United States



*Creating awareness, promoting research and providing support for all persons touched by Turner syndrome.*

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*Designed & Printed by Colortech Direct*

**TSS CONNECT**

Summer 2016

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Non-Profit 501 (c)(3)  
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**A LETTER FROM ANDREA SILVER**

*Andrea, the current Nominations Chair for the Board of Directors, shares her story about her daughter’s TS diagnosis and why, six years later, she chose to become more involved with TSS.*

Turner Syndrome and I met for the first time, on a phone call, in December 2009. I was at work, in my office, when the telephone rang. It was the genetic counselor from Children’s Healthcare of Atlanta gently explaining that they had found the underlying cause of my 6 year-old daughter’s medical problems...Turner Syndrome. Honestly, all I really heard during that call was Turner Syndrome, infertility, and an organization called the Turner Syndrome Society. Three things about that day stand out in my memory: First, spinning in my office chair – round and round and round – trying to wrap my brain around what I had just heard; second, feeling completely deflated and overwhelmed; and, third, visiting the Turner Syndrome Society website and immediately noticing a picture of a beautiful little girl with a butterfly painted on the side of her face. Seeing that little girl with the butterfly on her face made me smile because, since birth, the theme of Caroline’s bedroom has been butterflies. On that very first day in December 2009, the TSS website was a beacon of hope and comfort as I slowly absorbed and accepted my sweet little girl’s diagnosis.

Over the past six years, the Turner Syndrome Society has provided invaluable information and support to my family and our personal journey with Turner Syndrome. The TSS annual conference is an event that my daughter and I look forward to each year. It is the one place where I feel truly at peace and home. Watching my daughter (at these conferences) laugh, have fun, and relax brings an immense amount of joy to my heart. I can’t imagine what the last six years would have been like without the support of the TSS organization and its national conferences. Like so many other girls, women, and families, I want TSS to be around for a very long time – to be to others what it has been, and continues to be, for my daughter and family.

It took several years to feel like I was capable and ready to serve in a capacity beyond providing annual financial support to this wonderful organization. In early 2015, the opportunity to “do more” for TSS presented itself when I read a Facebook post on a call for nominations for 2016-2017 open Board of Director positions. I inquired about the open positions and requirements and, after careful consideration, decided to go for it. And, guess what? One year later, I now have the honor of serving as the Nominations Chair for the Board of Directors for the 2016-2017 term.

If you are looking for an opportunity to serve, the Turner Syndrome Society’s Board of Directors has several open Board positions for the 2017-2018 term:

- Secretary
- Member-At-Large, Woman with TS
- Treasurer
- Local Group Representative

For more information on these open positions and requirements, or to obtain a nomination form, please contact me at [andrea@turnersyndrome.org](mailto:andrea@turnersyndrome.org). I would love to talk with you and assist you with the nominations process.

*Andrea Silver*  
 TSSUS Nominations Chair, Board of Directors



**LEFT PHOTO**  
 Andrea Silver, her daughter Caroline Alexander (12), and their puppy Max.

**COVER PHOTO**  
 Dorothy Baume and her Golden Butterfly sisters on vacation in Myrtle Beach, SC.



JULY 22-24, 2016 | CINCINNATI, OHIO | HYATT REGENCY

# TEAM TURNER 106

*Up for the Challenge*



29<sup>th</sup> Annual  
Turner Syndrome Conference

OVERCOMING OBSTACLES & BECOMING A CHAMPION OF YOUR HEALTH!



THANK YOU SPONSORS



# TSSUS ANNUAL CONFERENCE 2016 PRESENTER HIGHLIGHTS

This year we will have over 20 speakers and 40 sessions!



## “Winning at Organizing: Your Gold Medal Game Plan”

**LORI FIRSDON** Forte Organizers

Workshop for Adults | Friday, July 22, 2016 at 2:30 pm

Your home is the hub of your life. Whether entertaining or relaxing, your home should be a haven - not a headache.

In this interactive session, you will discover how to:

- ◆ Organize any room in your home with confidence
- ◆ Use a play by play organizing action plan
- ◆ Apply specific strategies to overcome executive function challenges

Learning these life skills will help anyone feel more calm and in control in their home.

Visit [www.forteorganizers.com](http://www.forteorganizers.com) for more information!

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Lori is a regular Dayton Daily News columnist and has been featured on national television shows focused on organizing, including A&E Television’s popular show, Hoarders.



## “Job Interviews: Communicating Your Skills and Getting Hired”

**BARBARA BISSONNETTE** Forward Motion Coaching

Saturday, July 23, 2016 at 9:45 am

Do you wish that someone would explain the unspoken rules about what to say during an interview? Are you confused about the difference between marketing your skills and lying? Nervous about what to expect?

In this workshop, you will learn:

- ◆ How employers evaluate candidates
- ◆ How to follow up
- ◆ How to prepare strong responses to anticipated questions
- ◆ Pros and cons of disclosure of a disability
- ◆ Tips for avoiding common mistakes

Barbara will also be offering 15 and 30 minute private consultations during the conference.

Check out her article  
**Five Best Resume Tips on page 14!**



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Barbara is an author, speaker, and career coach who specializes in working with clients with nonverbal communication challenges. She is the principal at Forward Motion Coaching, and will be presenting a workshop on Job Interviews and offering private consultations at the 2016 National Turner Syndrome Conference in Cincinnati.



## “Leadership & Self-Advocacy”

**PRIYA WINSTON** Transitions

Young Adult Seminar (18-25) | Friday, July 22, 2016 at 2:30 pm

A young woman with Turner syndrome will share her story and help young adults assess their strengths, learn about self-advocacy, and build confidence in achieving their goals.

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Priya Winston is one of the program developers and instructors at Transitions, a post-secondary program for young adults with learning differences, and an individual with a disability. She was diagnosed with Turner syndrome and nonverbal learning differences at age 14 and ever since has had to contend with people telling her she would not accomplish her goals. Despite this, Priya is a magna cum laude graduate of the State University of New York – Albany’s Honor’s College, where she attended with full academic-based scholarship. She is now pursuing her master’s degree in Social Work. In addition to her work at Transitions, Priya is a graduate assistant at Project Excel at her university, where she supports first-generation or low-income college students, or students who have a disability, to succeed in their path in college.

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## LIFE AS A GOLDEN BUTTERFLY

- Dorothy Baume



When asked to put together this article, I wondered about what should be included. What was my life like growing up? Would things be different if I were growing up now?

First of all, a little about myself, I am 62 years old and I feel was fortunate enough to be diagnosed at birth. I am what you would say is "Classic". The puffy hands and feet, as well as webbed neck were present, and the blood pressure in each leg was different. After testing, they diagnosed coarctation of the aorta, a narrowing of the aorta which would eventually require surgery. Now, they perform this at a much younger age. During my first year, I had 14 ruptured eardrums. My mom would wake me up and notice that my ear had drained. There were no tubes for them to treat me with. Treatment was radiation of my neck to open the ear canals.

I ended up having the coarctation corrected at age five. Remember, that was 55 years ago! At that time the surgery was new and not being done in many places. When I was ready, we found out it was being done at Henry Ford Hospital in Detroit, where I lived. As the years went on, the short stature became obvious. I consider myself very fortunate to have had a wonderful pediatrician who was there to support my parents, as well as an endocrinologist who monitored my bone age and the estrogen therapy.

I was "chubby" growing up, and since the medical treatment was estrogen and progesterone, he wanted me to lose weight. Right! A kid with my love for food losing weight? Never happened. I ended up starting the estrogen replacement therapy at age 16. I was on very high doses of estinyl and Provera, and began to see gradual changes in my body. The estrogen therapy continued into my early 50's when the GYN I was seeing stopped the therapy.

With the edema, finding shoes was a hard issue. My feet were a double-wide width. Finding Sunday shoes or anything that were stylish was next to impossible. The best shoes for me were what were called "saddle shoes" back then... yes, I'm ancient! Tie shoes with good support, in a wide width. Not exactly easy to find. When I would get a new pair each fall for school, I would end up with a blister that got infected on my right foot. The blister would open and the lymph drained. Off of school for a week, after a trip to the doctor for a penicillin shot you know where!

Socially, I found it hard to relate to others my age. I had trouble with math. My parents worked with me, and I did pass, but overall I was an average student. I did go to college after high school and got my Bachelors Degree in Sociology. Several years later I went on for my Masters in Public Administration with emphasis on Human Resource Management. After a couple of jobs right out of college, I did get a job with the American Red Cross in their Service to the Armed Forces Department. I worked with them for 34 years until I retired at the end of October, 2011. My job involved working with military service members and their command in verifying family emergencies or helping out with particular family issues.

Several years were spent on various military installations, transferring every two years or so providing direct service. Four of those years were in Europe... the rest in the United States. The last half of my time with Red Cross was spent at the Headquarters in Washington DC. I worked with training, policy and provided guidance to the workers in the Chapters throughout the United States and our stations overseas. It was a very rewarding job, with lots of opportunity and adventure. When I retired, I relocated to be near my family in a location that has wonderful health care.

Medically, I've had some issues over the last 10 or so years. I've had strabismus surgery, and I am now the owner of hearing aides. In 2014, I had surgery to replace my aortic valve. Having been followed by a cardiologist for years, I knew that stenosis was slowly progressing and eventually I would need surgery.

Back in 1993, I was feeling pretty unhealthy and unhappy with my life so I went back to Weight

*continued on page 15*

### TSSUS BOARD OF DIRECTORS

Carol Crawford, *President*  
 Emily Havrilak, *President-Elect*  
 TBD, *Secretary*  
 Sarah Sullivan, *Treasurer*  
 Dorothy Baume, *Development*  
 TBD, *Fundraising*  
 Michael Silberbach, MD, *Medical Advisor*  
 Kim Graham, *Public Relations*  
 Andrea Silver, *Nominations Chair*  
 Elizabeth Fontenot, *Member at Large - TS Adult*  
 Mysti Harrison, *Member at Large - Parent*  
 Carrie Odom, *Local Group Representative*

### STAFF & CONSULTANTS

Cindy Scurlock, MA, *Executive Director*  
 Deborah Rios, *Member Services Director*  
 Stephanie Head-Kirksey, *Administrative Assistant*  
 Shawn Wier, *Conference & Resource Coordinator*  
 Barbara Flink, *Staff Consultant*

The Turner Syndrome  
 Society Board of  
 Directors would like to  
 thank

AMANDA  
 ANDERSON

&

CALLIE  
 SHAFFER

for their enthusiasm,  
 dedication, and  
 contributions to the TSS  
 Board.

*We are so grateful for their  
 service and wish them all  
 the best!*

## CONGRATULATIONS 2016 GRADUATES

We are so proud of our beautiful, successful Butterflies!

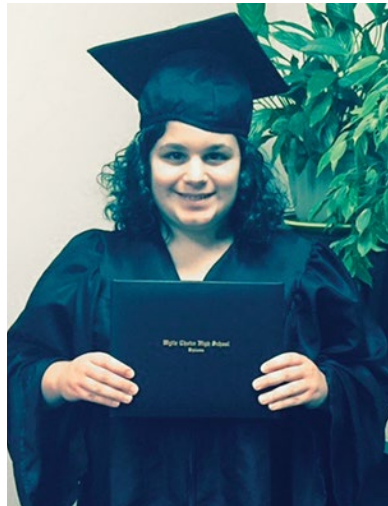


**BROOKE KACZYNSKI** is graduating from Cy-Fair High School and is a member of the Ready, Set, Teach Program, the National Technical Honor Society, and Fellowship of Christian Athletes. She has volunteered over a hundred hours for TSSUS (she is Cindy Scurlock's daughter).

Brooke will attend Stephen F. Austin State University in the fall, and has wanted to be an elementary teacher since she was in second grade.



**JESSIE SATTERFIELD** is graduating from Cherokee High School. This fall she will be attending Georgia Gwinnett College and plans to study Education.

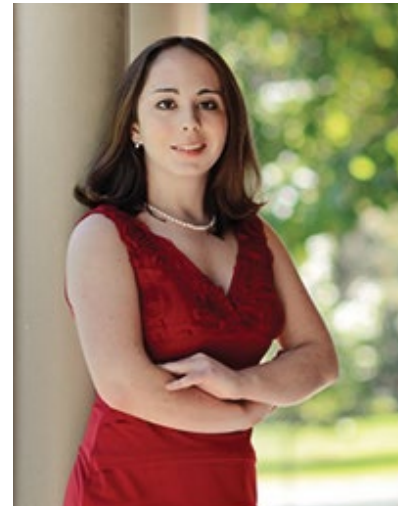


**ALYSSA PALOMBA** was diagnosed with mosaic Turner syndrome at age 15. She walked the stage at her high school graduation on May 27th. Alyssa says that school was a struggle for her and she is glad she was able to get through it. She says, "I've met some great girls through having TS, and I am so thankful for them!"



**MAKAYLA BABCOCK** is a senior at Patrick Henry High School. She is involved in Bowling, Musical, Spanish Club, National Honor Society, and has a part-time job. She is also an Honors Diploma recipient.

Makayla plans to attend Eastern Michigan University, where she will be in the honors program. She plans to double major in Public Relations and Spanish.



**MEGAN GENTLEMAN** is graduating from Perkiomen Valley High School in Collegeville, Pennsylvania. She is a member of the National Honor Society, Student Leadership for Marching Band and Color Guard.

Megan will be graduating in the top ten of her class and her future plans include studying Chemical Biology in the Honors College at Saint Joseph's University in Philadelphia. She hopes to make an impact on the world of genetics.

In her college application essay, Megan wrote, "I refuse to let having Turner syndrome limit my dreams, because I believe in myself and know that I can achieve anything with persistence, determination, and hard work."



Do you have a photo or event you'd like to share with the TS community?

Please send your photos and event highlights to [newsletter@tssus.org](mailto:newsletter@tssus.org)!



## BRINGING AWARENESS TO TURNER SYNDROME

Isani bringing awareness to hundreds of people at Colorado Science & Engineering Fair!

Young researcher and teen with Turner syndrome, Isani Singh, recently presented her high school research project, "Studying the Effects of a Missing X Chromosome on the Liver," and competed against hundreds of high school researchers in the Colorado Science and Engineering Fair (CSEF) held at Colorado State University in April. Isani came in first place in the entire show!

At CSEF, she had the opportunity to bring awareness to hundreds of people about Turner Syndrome, and was interviewed by dozens of judges in the field of medicine. Isani was the only 10th grader to achieve this in Colorado this year. She also came first in her category of research, Medicine and Health, earning cash awards and scholarships.

Isani then advanced to compete at the Intel International Science and Engineering Fair (ISEF) in Phoenix, Arizona held in May, where she competed against finalists from all over the world. She received the fourth place Grand Award in her category of Biomedical and Health Sciences. The 2016 International Science and Engineering Fair featured 1,700 high school students from 75 countries presenting projects to doctoral-level scientists.

We are very proud of Isani's hard work and accomplishments, and we look forward to seeing what the future holds for her! ♦

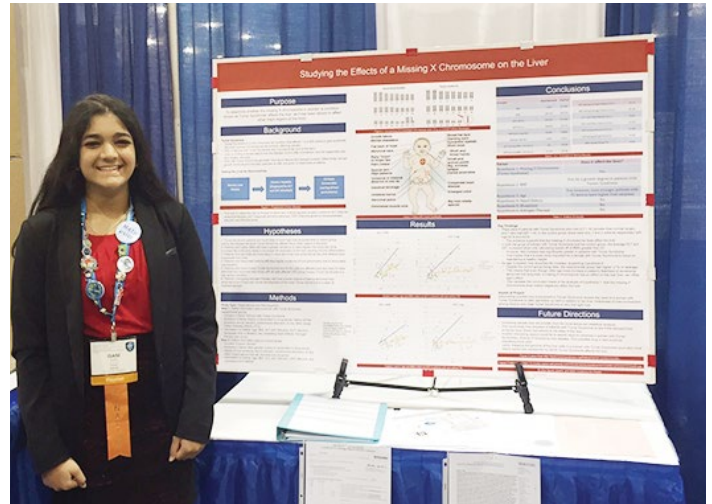


PHOTO  
10th grader, Isani Singh, poses with her award winning research project at the Intel International Science and Engineering fair (ISEF) in Phoenix, AZ in May.

## ON WINGS SHE FLIES

- Bethany Mercer

For years the TS community has been waiting for a documentary that takes an extensive look into Turner syndrome. "On Wings She Flies" is a documentary that is focused on informing doctors, newly-diagnosed patients, and parents just receiving a diagnosis, about Turner syndrome.

As many know, there are still so many unknown and complicated facets to this rare and very complex condition. Unlike the 80's and before, there is now a substantial amount of information on the internet for people to see. The problem with this is that much of the information available online is either misleading or incorrect. Seeing this and watching this community lose six women last year led to a conversation which inspired Mark Phillippe, Scarlett Stuart, Robyn Boaz, The Walk for Ferriell Foundation, and myself to do this documentary.

We are very proud of the work we are doing and hope this will lead to more conversations not only in the medical community, but also in the TS community to be more open about TS and raising awareness. ♦

*Bethany will be attending the 2016 TSSUS NATIONAL CONFERENCE and will be videoing those who wish to participate in this project!*



## ONLINE TS COMMUNITY

*A great way to connect with others!*

Check out our Message Board at [www.turnersyndrome.org](http://www.turnersyndrome.org).

 Follow Us on Facebook

Do you have an article suggestion, content request or want your group highlighted?



Send your inquiries to [newsletter@turnersyndrome.org](mailto:newsletter@turnersyndrome.org)

## DALLAS LOCAL GROUP MEET & GREET

Held at Old Shepard Park, Plano, TX on May 14, 2016

The Dallas area TSSUS Meet and Greet weather was chilly, but the feelings were warm as the group met and greeted each other. It was wonderful to see the many new and familiar faces as the day went on. Everyone had a great time and looking forward to getting together again! ♦



### BUTTERFLIES NEAR YOU

Upcoming Events in 2016!

Grand Rapids, MI . . . . . 6/11  
*June Dinner*

Memphis, TN . . . . . 6/18  
*Meet & Greet*

Newburgh, NY . . . . . 6/25  
*Meet & Greet Breakfast*

Conshohocken, PA . . . . 6/25  
*Meet & Greet*

Charlotte, NC . . . . . 8/27  
*Meet & Greet Lunch*

Cary, NC . . . . . 9/18  
*Annual Pool Party*

*More TSS Events and other information on our website!*

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

## BOSTON INTERNATIONAL TS SUMMIT

The Boston International Turner Syndrome Summit (BITSS) Summer opportunity for teens!

BITSS is a NEW not for profit organization offering a fun summer program in Boston, MA, from July 31st to August 7th, 2016. ♦

For more information, visit [bitssummit.org](http://bitssummit.org)

## IX TS INTERNATIONAL CONFERENCE

At The Westin Resort and Spa Cancun, Mexico from Nov 17th - 20th, 2016.

We are pleased to announce you that the IX Turner Syndrome International Conference will take place in Cancun, Quintana Roo, Mexico. In addition to enjoying a great event, you will also be able to share experiences with people from several countries and of course, enjoy the beautiful beaches and natural attractions this region has to offer.

*Our main goal is to motivate you to face your every day challenges and to provide the tools to take good care of your physical and emotional health.*

This is an event oriented to girls, teenagers, women and health professionals. ♦

For more information, please visit [turnersyndromeinternationalconference.com](http://turnersyndromeinternationalconference.com)

## SAVE THE DATE!

We're excited to announce the Turner Syndrome Research Registry will launch in July!

The purpose of the registry is to support TS related research to advance quality TS healthcare, and your participation is requested to make that happen.

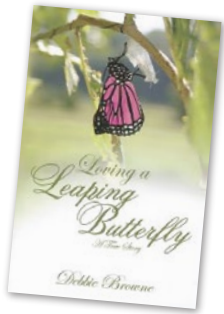
We will share more information by mail, e-mail, website and Facebook to provide with you all the details you will need to participate. ♦





# LOVING A LEAPING BUTTERFLY

- Debbie Browne



Four years ago after the book release of *Loving a Leaping Butterfly*, Debbie Browne wondered what the next step would be. For you see, writing was never in her foreseeable future, but God had other plans in taking her personal tragedy and creating a pathway of triumph. The book soon gained attention from those who had never heard of Turner syndrome. Proceeds from the book were dedicated to help those with Turner syndrome and within four short years, substantial funds

have been raised to make the difference in the lives of those with Turner syndrome.

**“I had no idea where to start,”** Debbie shares. “No one I talked to had heard of Turner syndrome, nor did they seem interested in learning more about it. It had become discouraging at first, but I continued in the next baby step that awaited me.

A year after the book release, a fundraising event was planned and an all-out effort was launched to not only spread awareness, but compassion too. The 1st annual event was planned during National Turner Syndrome Awareness in February, and also the month my daughter who had TS passed away from complications of her condition. Friends rallied around me and we took that step to do something greater than ourselves.

Over 100 people came to the first fundraiser of the new annual Seeds of Faith Celebration and we raised \$33,000 in 2014. The next year we raised \$67,000, and this past year, 2016, \$85,000.

We’ve learned a lesson of faith in not just talking about doing something, but **doing** something, as conference scholarships have been given, support for an echocardiogram room at a local hospital has been secured, and hearing aids for those who need one have been provided. We have also been able to provide much needed support to the Turner Syndrome Society of the United States, helping to fund research and other programs. This is some of the fruit produced from our labor.” She continues with great passion.

**How about you? Where can you start that first baby step of faith?**

Perhaps God is calling you to just trust Him in your life journey and see what He can do through you. Because if He can accomplish great things through Leaping Butterfly Ministry, He can do the same in you. ♦



You may purchase a copy of her book, *Loving a Leaping Butterfly* from the TSSUS online store.

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

Visit the Leaping Butterfly website at [www.leapingbutterfly.org](http://www.leapingbutterfly.org)

**THE THIRD ANNUAL SEEDS OF FAITH GALA WAS HELD IN FEBRUARY AND RAISED \$85,000 FOR TS!**



TOP PHOTO  
The Evening’s Speakers: Dr. Hankins, Robin Harris, Debbie Browne, and Dr. Chen. Robin, a woman with TS, spoke at the celebration. She was wonderful and received a standing ovation.

MIDDLE PHOTO  
Andrian, Jimmy, Billy & Deborah

BOTTOM PHOTO  
Ashley Pope, Mary Anna Kayne and Carla Darnell

## HOW TO GET INVOLVED WITH A CHASING BUTTERFLIES WALK

Our fantastically popular program focuses on community and puts the FUN in fundraising!

Have you been looking for a way to spread awareness and unite people touched by TS in your local community? Looking for a way to contribute that can involve all members of your family, young and old? Then, walking for Turner Syndrome is for you.

Each Chasing Butterflies walk is hosted by local folks who know best about their community. Each event should include a short walk that is noncompetitive and focuses on community. Everyone wins by participating. Before or after each walk, your host might organize games, refreshments, and fun activities which are sure to make you smile and walk away satisfied in knowing you helped create a brighter future for thousands of people living with TS.



### Want to Host a Walk?

Everything you need to begin planning a Chasing Butterflies walk in your community is just one email away.

By thinking about where and when you might have the walk, and deciding who you can ask to help organize it with you, you will be three steps ahead in making a decision about hosting one. We take care of creating and managing your online registrations, ordering t-shirts and mailing you supplies like a banner, butterfly hand fans and buttons, while you can take care of making it a special event for your community.

### Want to Just Walk?

Current and available walks are always on our website under Walk for Turner Syndrome.

Once you register for a walk of your choice, you will be prompted to set up your own personal fundraising webpage. This will enable you to capture your story about how you, or someone you know, is affected by Turner syndrome and share it with your friends, family and coworkers. By explaining why this cause is so important to you, you can raise awareness and vital funds to support the Society's life-changing programs and services.

### Raising Awareness and Funds

The Turner Syndrome Society of the U.S. is proud to have a mission of creating awareness, promoting research and providing support to all persons touched by TS. The Chasing Butterflies Walk has raised great awareness of Turner syndrome across the nation and will continue with your efforts, whether you organize a walk or just walk. All the proceeds from the walks go toward meeting goals like promoting research and supporting people just like you.

Together we can make a difference for every life touched by TS. ♦

For more information, please contact Deborah at [deborah@turnersyndrome.org](mailto:deborah@turnersyndrome.org) or 800-365-9944, or visit [www.tssus.org](http://www.tssus.org) and check out *Take Action/Chasing Butterflies*.



### DID YOU KNOW?

You can set up your own personal fundraising page to support the Turner Syndrome Society!

It's easy to set up, and you can share your link via e-mail, text message, or social media within minutes.

To learn more about how YOU can make a difference through Social Fundraising, contact:  
[shawn@turnersyndrome.org](mailto:shawn@turnersyndrome.org) or  
[deborah@turnersyndrome.org](mailto:deborah@turnersyndrome.org)

## WALKING WITH TINKERBELL





# CHASING BUTTERFLIES WALK IN FLORIDA

## First Annual Chasing Butterflies Walk & Butterfly Release

“Beautiful weather and many wonderful people. About 74 walkers and about 120 with volunteers and others. We passed our \$2000.00 goal before [that day] in sponsorship and walk registration! Thank you so much to everyone who came out and made our first year a big success!” - Carrie Odom ♦



WANT A SHIRT LIKE THEY'RE WEARING?

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

# KANSAS CITY WALK



### PHOTOS

Chasing Butterflies Walk in Kansas City during the 2015 Annual TSSUS Conference.

## JOIN THE CHASE

Upcoming Walks in 2016!

Vancouver, WA . . . . . 6/25

Wheaton, IL . . . . . 7/25

Cassopolis, MI . . . . . 7/30

Grand Rapids, MI . . . . . 8/6

More Walk info on our website!

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

> Take Action/Chasing Butterflies

## TSSUS ANNUAL CONFERENCE 2016 PRESENTER HIGHLIGHTS continued from page 4



### **“Healthy Snacking on the Go”**

**MIRA M. DESSY** *Grains & More*

Sunday July 24, 2016 at 9:45 am

This fabulous demonstration presentation will show you how to prep healthy snacks to have on hand. Don't reach for a candy bar (disguised as a protein bar), get real food goodness instead.

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*Mira Dessy, The Ingredient Guru, is a holistic nutritionist, popular public speaker, and the author of *The Pantry Principle: How to Read the Label and Understand What's Really in Your Food*. She is a professional member of the National Association of Nutrition Professionals, the Society for Nutrition Education and Behavior, and the American Holistic Health Association. She speaks frequently on how to navigate the grocery store's mammoth packaged food stock, to decipher confusing food labels, understand the relationship of food additives to poor health, and to find real food. She believes it's not just what you eat, but what's in what you eat. Her motto is “Eat well to be well.”*



### **JESSICA KICHLER, PH.D.**

*She will be presenting on “Anxiety, Depression, and OCD,” as well as, “Turner Syndrome and Family Dynamics.”*

Jessica is a pediatric psychologist who specializes in working with children who have chronic medical conditions and their families. She provides individual, family, and group therapy for all ages of children and their families. In addition, she engages in research, education, and training in the areas of adjustment and coping, adherence, and the psychosocial outcomes of chronic illness in children and families.

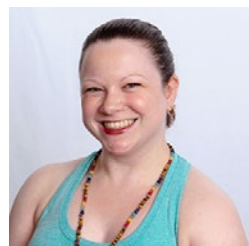
Dr. Kichler is currently an Associate Professor of Pediatrics at the University of Cincinnati Medical School, in the Division of Behavioral Medicine and Clinical Psychology at the Cincinnati Children's Hospital Medical Center in Cincinnati, Ohio.



### **JEANNE JAMES, M.D.**

*She will be co-presenting on “Cardiovascular Concerns in Turner Syndrome.”*

Jeanne James, MD, is an associate professor of pediatrics at University of Cincinnati College of Medicine and is currently the director of the Cardiology Fellowship Training Program at Cincinnati Children's Hospital Medical Center.



### **DANIELLE BEAUPRÉ**

*“The Petite Yogini”*

Danielle is a woman with Turner syndrome who holds master's degrees in English and French from the University of Maine. She teaches French at Maine Maritime Academy and Husson University. She teaches yoga at the Bangor YMCA where she draws on her 15 years of personal practice and trainings in YogaFit and Core Strength Vinyasa.

She aims to help others find the same healing and peace she has found in yoga and to demonstrate that yoga is for all of us. She will be leading yoga for adults as well as the older teen girls.



### **KATHY MONTAG**

*She will be presenting on “Transitioning to School” and “Transitioning to Middle/High School.”*

Kathy and her husband, Sean, are the parents of three children: two sons, ages 24 and 21, and Abby, age 16, who was diagnosed with Turner Syndrome prenatally. She has been an active educational advocate for her daughter since she was identified as a special education student in preschool, and has been recommended by counselors and principals as a resource for other parents of students with special needs.

After many years of working as a stay at home mom and freelancing in marketing/graphic design, she chose a career with Thomas Worthington High School in Worthington, Ohio, where she is a building test coordinator and works with students on a daily basis. She served three years on the Intervention Assistance Team (IAT) at the high school level and continues to advocate for students who are struggling with academics, social issues, and learning disabilities.



# CONFERENCE EXHIBITOR HIGHLIGHTS

For more Conference information, visit the TSSUS website!

- ◆ Grains & More [www.grainsandmore.com](http://www.grainsandmore.com)
- ◆ Young Living Essential Oils [www.youngliving.com](http://www.youngliving.com)
- ◆ Transitions [www.transitionsusa.org](http://www.transitionsusa.org)
- ◆ Lilly [www.humatrope.com](http://www.humatrope.com)
- ◆ NovoNordisk [www.norditropin.com](http://www.norditropin.com)
- ◆ The Butterfly Store
- ◆ Greater Cincinnati Turner Syndrome Association
- ◆ Cincinnati Children's Hospital [www.cincinnatichildrens.org](http://www.cincinnatichildrens.org)
- ◆ Forward Motion Coaching [www.forwardmotion.info](http://www.forwardmotion.info)
- ◆ Heartland Social Learning [www.heartlandsociallearning.com](http://www.heartlandsociallearning.com)
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*Nutrition Consulting and Coaching  
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Support your health with the perfect foods for your bio-individual body.

Your body is unique, exceptional, one of a kind. While we all share basic nutritional requirements, your body has a blueprint all its own; distinct and special requirements for food, herbs, nutrients, and more. I call this your bio-individual body.



*Essential oils have also been used  
for thousands of years for  
cosmetic purposes, as well as  
for their spiritually and*

emotionally uplifting properties. Young Living has always been at the forefront of bringing this ancient tradition to modern users, introducing millions to a total mind/body wellness they may never have dreamed possible.

Primarily extracted through careful steam distillation but also through cold pressing, the purest essential oils are far more powerful than the botanicals from which they were extracted. Any time you hold a bottle of our powerful essential oils, you are holding nature's pure essence.



*Students and young adults with  
disabilities often need extra  
preparation* in order to live independently and achieve success in higher education and careers. To

address that need, the Transitions program teaches Apprentices the skills necessary to make those goals realities.

Crafted from evidence-based programs, our curriculum is grounded in internationally recognized approaches that will set students on the path toward college and career success. Our curriculum and learning environments are specially tailored to give all students equal opportunities to learn and thrive.

## Heartland Social Learning Center LLC

The services offered at Heartland Social Learning Center LLC include *cutting-edge Social Thinking Groups* that bring

together students of all ages and abilities for weekly sessions focusing on helping them engage in the important process of building healthy relationships.

The concept of Social Thinking is a philosophy of teaching pioneered by speech language pathologist Michelle G. Winner, who teaches students to 'think about their own thinking, as well as the thoughts of others' during play, school, work, and home activities, so they can apply related social skills effectively.' This is a language-based learning approach which is best taught to students with near normal to way above normal verbal intelligence, who have the ability to talk about their thoughts and can generally regulate their own behavior in a group setting.



Odyssey Learning can help you develop important executive functions to accomplish your goals. By *identifying and utilizing*

*your strengths*, you can improve your effectiveness in planning, organization, time management, self-regulation, and social interactions to help you feel in charge of your life.

With over 25 years of experience in education, Diane McLean, M.Ed. provides life coaching and executive functions training by phone, through online video chat, or in person for those in the Kansas City area. Diane is committed to helping children and adults realize their potential and experience success.

## FIVE BEST RESUME TIPS

- Barbara Bissonnette



Whenever I speak about this topic, I engage a member of the audience to help me unfold 25 resumes that I have taped together. Then I watch the faces of the other participants as they watch several feet of paper unfurl!

My intention is to underscore (in a dramatic way) the importance of a resume that clearly communicates how a job seeker fills an employer's need. A single job opening can generate hundreds of resumes from candidates.

Even if screening software is used, at some point a human being will look at a stack of resumes and decide who to call for an interview. According to numerous studies, human resources and hiring managers spend about 10 seconds screening a resume.

Whether you are nearing graduation and seeking your first job, or are an experienced worker looking for a new position, here are my five best tips for writing an effective resume.

### #1 INCLUDE AN OBJECTIVE OR SUMMARY OF QUALIFICATIONS.

The person reading your resume should understand what you do ... immediately. Avoid a vague objective such as, "To obtain employment with a reputable business where I can apply my education and experience to an employer's benefit." This says nothing about your skills or the type of position you are looking for.

Make it easy for the employer to know how you will contribute, as in this example: "To apply the knowledge acquired through a bachelor's degree in marketing and communications and two summer internships at a public relations agency to an entry-level marketing or PR position."

### #2 EDIT CONTENT TO MATCH THE JOB YOU WANT NOW.

A resume is a marketing document. Its purpose is to highlight skills and accomplishments that are relevant to the job you are seeking. It is not a review of every task you have performed at every job, or every course you took during college.

In most cases, your resume should be one page, unless you are seeking a more senior role, where two pages are necessary.

Avoid empty phrases and qualifiers. "Was trained in, and performed, the administrator job" is an empty phrase that states the obvious: employees are assumed to be trained to carry out job duties. Qualifiers modify your proficiency in a certain area: "limited experience with;" "some knowledge of." If you feel the need to qualify a skill, it probably shouldn't be on your resume.

Whenever possible, include skills used and results achieved. There is a big difference between saying, "operated a cash register," and, "accurately handled an average of 35 transactions per hour."

### #3 USE PLAIN LANGUAGE.

Very formal prose and esoteric words make you seem pompous and unapproachable. Employers want to hire people who work well with others. Can you imagine trying to interact with someone who is, "Seeking heretofore an opportunity so oriented as to incorporate numeric acumen that will ultimately lead to application of more rarefied facets of financial management?!"

### #4 AVOID "THE DREADED DISCONNECT."

Greg's resume began with the following summary of qualifications: "Experienced researcher and writer of historical biographies. Skilled at utilizing census data, biographical dictionaries, deeds, wills and other archival material to produce richly detailed narratives." Next, under the heading of Work Experience he listed "Sales Associate, Fashion Rite Clothing."

Screech! That is the sound of incongruity stopping a reader in his tracks. Greg's job as a sales associate was not related to writing. He made the mistake of sticking with the common, chronological resume format even though it didn't work. Greg and I reworked his resume so that Writing Experience was the first heading after his objective. He had written many articles on a volunteer basis for publications and Web sites. His current job at the clothing store was de-emphasized under the heading Other Experience.

### #5 PROOF READ CAREFULLY.

It is imperative that your resume is free of typographical errors and formatting inconsistencies. Such errors communicate to an employer that you are a careless worker, and will probably disqualify you as a candidate. I have seen many resumes from clients that mention "detail orientation," yet contain several typos! Ideally you will have two or three people review your resume for errors.

### Bonus Tip.

Your email address should be professional, such as your first initial and last name. People sometimes resist this advice, insisting that clever or unusual addresses make them unique. It is fine to use an address such as BikerDude@ for your personal correspondence. But do create a separate email for your job search activities.

*Learn more about her coaching services at [www.forwardmotion.info](http://www.forwardmotion.info)*

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## ON THE OUTSIDE LOOKING IN

- Shawn L. Wier

I watch them laugh, talk, share their day.  
I wish they'd look at me and say  
What about you, how are you today?  
But still I watch and sit again and again,  
a stranger on the outside looking in.

I try to join their conversation.  
They just move on... no recognition  
of my desire to join their group...  
to be a part.. to just fit in.  
I'm still on the outside looking in.

I get the looks, not sure what for.  
Is it anger, annoyance, I'm never quite sure.  
My brain can't understand all these cues that they give.  
For me, this is such a hard way to live.  
"I shouldn't have to tell you," they seem to say.  
But yes, I need you to communicate this way.  
For then I know what you want me to do  
and I can communicate easier with you.

Sometimes it hurts that no one gets me.  
I'd be such a great friend if they'd just let me.  
But it takes time for a relationship to grow,  
and things just take longer for me, I know.  
But how I long for the kind of friend,  
who opens their heart and lets me in.

I forgot again... I get so overwhelmed.  
So many things to keep up with.  
Why won't my brain cooperate?  
It makes me lose things, it makes me late.  
They all seem to have it together,  
but for me, even simple things seem to take forever.

I try so hard, but they can't see.  
I look so normal, if you look at me,  
but inside my mind is so confused.  
All the things that others can do...  
read faces, body language, social cues.  
So much harder for me it is to read...  
I wish I knew all the rules to succeed.  
There's so much, where do you begin,  
when you're on the outside looking in?

I love who I am, the person inside,  
I only wish others could see...  
Each person has gifts... each person has strengths.  
Each one is different in the way that she thinks.  
I may have to work harder to get where you are,  
but I'll get there, determined.. no matter how far.  
Because I have a Father who created me when  
He was on the outside looking in. ♦

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## LIFE AS A GOLDEN BUTTERFLY

*continued from page 5*

Watchers for the 3rd or 4th time. This time was the charm. I lost my weight, made my goal, and have kept it off for over 20 years now by being active and watching my intake. Yes, there have been times, especially holidays, when I've not been as careful, and have paid for it, but I continue to get back on, because I am determined to take care of myself. The cardiologist has said that I went through the surgery really well, and recovered fairly quickly because I was in good shape.

Over the years I've learned how important it is to listen to your body, and when something is not right, get it checked out. One of the benefits of having TS and reaching this age is that I've developed a pretty good radar when it comes to doctors. In every transition, whenever I needed to establish myself with a new doctor, I would ask questions that would give me a sense of how they practiced and what their knowledge of TS was. Were they going to listen to me when I shared what was going on? Did they take the conservative approach, or did they just feel surgery was always the answer? Would they look at the total picture - me as a person? Those things are important to me.

What medical issues do you have? What areas do you need to follow up on? Is it ears, eyes, heart, lymphedema or some other area? At this stage, I feel I know my body the best. True, I'm not medically trained, but I do know what my body responds to, when I'm having a "crisis," and what those crises are.

Everyone's life has its challenges. We're no different. Ours may be little more complex, but I always try to look at the total picture. Our bodies are unique and are affected in different ways.

This is my story. I can't say enough how much going to the conferences and connecting with my special TS sisters has helped. Get involved. We have nothing to be ashamed of. Enjoy life and do what you can while you can. My wish is for everyone to have an enjoyable life full of love and happiness. Who knows what the road ahead may bring... but bring it on, one day at a time... ♦

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of the United States

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Butterflies of all ages get to meet and build friendships at the annual TSSUS National Conference.  
*Photo from the 2015 Conference in Kansas City, Missouri.*