tss connect™

Turner Syndrome Society
of the United States
Spring 2019

Turner Syndrome Society of the United States



- National Conference
- Resource & Research Updates
- 2019 Membership Drive
- Chasing Butterflies Walks

Turner Syndrome Society of the United States

The Turner Syndrome Society of the United States advances knowledge, facilitates research, and provides support for all touched by Turner syndrome.

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TSS Connect • Spring 2019
Tuner Syndrome Society
of the United States
11250 West Road, Suite G
Houston, TX 77065
832.912.6006 800.365.9944
www. turnersyndrome.org

The Turner Syndrome Society of the United States is a national 501(c)(3) nonprofit organization dedicated to providing support and health-related information to those with Turner syndrome, their families, and the medical community. TSSUS is the leading authority on the condition.

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Unicorns and Research



It's time to celebrate! The anticipation of seeing and feeling some of our wildest dreams come true is simply exhilarating. Believing in miracles and uniting butterflies is changing history.



"Once upon a time in the land of Turner Town people with rare conditions, doctors and researchers were like animals in the forest, each scurrying alone. Ding, fast forward 25 years. One day, everyone in the land was invited to a meeting in Virginia by a leader in the land – a detail minded fellow, Dr. Silberbach. Scientists and doctors gathered their nuggets of knowledge, and people affected by Turner syndrome danced and prepared because they were being treated as the important people they are. In a teeny tiny room, transformations took place, studies about mice and cats widened eyes and visions of human chimera's and brains in dishes danced in their heads (this is all true – really). By the end of the meeting, the differences among them seemed small compared to the solutions in front of them. For months they worked together to unveil a work like none other, *The Special Issue on the Proceedings of the Turner Syndrome Research Network Symposium*.



The March 2019 issue of the American Journal of Medial Genetics will exclaim to those outside of Turner Town that opportunities are plenty and they are welcome to join.

The moral of the story may be that sharing the information we work hard to gather or have in our possession leads to shared journeys to places we all dream about.

Thanks to the women with TS and parents of girls with TS for sharing your information with the online Turner Syndrome Research Registry.

Thanks to the researchers, doctors and TS organizations for searching for answers.

Specific to TS research, over the next year, TSSUS will summarize the newest research articles and reviews for you. We are finalizing a new online research survey for you to fill out that will ask more detailed health questions than the previous survey. Most importantly we will send out emails and update our website with information that helps you make better decisions about your TS healthcare.

Sincerely.

Cindy Scurlock

Cindy Scurlock, President
The Turner Syndrome Society of the United States

TSSUS Resource and Research Updates

At TSSUS, we are continually creating, updating, and adding new resources to our website at tssus.org and our printed materials. Recently, we've updated the Sexual Development and Hormone Replacement Therapy and Growth and Height pages on the website, and have added videos from past TSSUS National TS Conference sessions throughout.

We've spotlighted twenty amazing personal stories on the TSSUS blog "My TS Story" series during February Awareness Month, and we've introduced a Cardiac Emergency Alert Card that can be ordered and downloaded free.

Research Update

The American Journal of Medical Genetics (AJMG) has dedicated the March issue as a special issue to Turner syndrome. The special issue shares the proceedings from the 2018 Turner Resource Network Symposium, and hard copies will be available for purchase from the TSSUS webstore as soon as they are available.

The following articles are summarized/paraphrased:

The Turner Syndrome Research Registry: Creating Equipoise Between Investigators and Participants

The purpose of the study was to address knowledge gaps about Turner syndrome (TS) associated disease mechanisms, the Turner Syndrome Society of the United States created the Turner Syndrome Research Registry (TSRR), a patient-powered registry for girls and women with TS. More than 600 participants completed a 33-item foundational survey that included questions about demographics, medical conditions, psychological conditions, sexuality, hormonal therapy, patient and provider knowledge about TS and patient satisfaction. The TSRR platform is engineered to allow individuals living with rare conditions and investigators to work side-by-side. The purpose of this article is to introduce the concept, architecture and currently available content of the TSRR, in anticipation of inviting proposals to utilize registry resources.

TSRR
Turner Syndrome Research Registry
Please join the registry at www.turnersyndrome.org

Research priorities of people living with Turner syndrome

Despite major discoveries, traditional biomedical research has not always addressed topics perceived as priorities by patients and their families. Patient-centered care is predicated on research taking such priorities into account. The present study surveyed 543 women with Turner syndrome (TS) 18+ years, 232 parents of women with TS, and 232 parents of younger daughters with TS, and 563 parents of daughters 18 years and younger with TS, regarding their priorities for research. The overwhelming majority of all surveyed (84% and higher) rated both biomedical and psychological research in TS as "very important," yet only approximately 9% of published research focused on psychological aspects of TS. Despite the majority rating research as very important, only about half rated participation in research as similarly important. The majority of respondents in all three groups indicated they would "very likely" participate in research pertaining to eating or nutrition, quality of life, or genetic studies in TS. Substantially fewer expressed similar eagerness to participate in studies involving the study of a new medicine or medical device. Increased engagement of patient and family stakeholders in research requires investigators select topics of study important to that community.

"Donating our bodies to science": A discussion about autopsy

This review highlights strategies to promote autopsy and tissue donation in the TS community, and to develop an action plan for overcoming formidable barriers to increasing autopsy rates. The potential value of autopsy and tissue donation extends to TS patients, families and stakeholders who can benefit from end-of-life planning, and Turner Resource Network (TRN) researchers, who stand to benefit from the analysis of autopsy data and specimens. Discussions about autopsy were primarily initiated by women with Turner Syndrome and their advocates, who have long recognized the scientific value of autopsies and tissue donation. These topics may also be broadly applicable to other rare disease communities with similar priorities.

(This topic will be presented at the 2019 TSSUS National Turner Syndrome Conference in June, 2019)



Join now or renew your membership and get the new TSSUS Member T-Shirt

From March 1st through June 30th, TSSUS is holding a membership drive with an exclusively-designed, member-only t-shirt! Each new or renewing TSSUS member will have the opportunity to order one 2019 limited edition member t-shirt for just the cost of S/H ($5). Members can order additional shirts for household members at the regular cost of $18 each (S-XL) and $22 each (2XL-3XL).

TSSUS believes in making the latest information on TS healthcare and research available to the entire TS community, regardless of one's TSSUS membership status. When you choose to support the Society by becoming a member, you're making an impact by helping us make these resources available to everyone! Together, we are Turner Strong!

For 32 years, we have been empowering, educating and supporting the TS community.

Every year we'll unveil a new member-exclusive t-shirt design.

These shirts are sure to become collectors' items!

Our mission is to advance knowledge, facilitate research, and provide support for all those touched by Turner syndrome. **We can't do it without you.**

You can be a Mission Partner by becoming a member, renewing your membership, or becoming a monthly Butterfly Society Donor/Member.

Turner Syndrome Society of the United States

We are stronger together.

Together, we are Turner Strong!



Proudly show your TSSUS support with the exclusive 2019 Member t-shirt.

Please join us by becoming a member of the Turner Syndrome Society TODAY.

Terms & Conditions: This program runs from March 1- May 30, 2019.

Turner Syndrome Society of the United States

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Houston, TX 77065
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becky@turnersyndrome.org
deborah@turnersyndrome.org

Which Membership Level is right for you?

Individual	$45/yr
Family	$65/yr
Professional	$75/yr

Individual, $45/yr: Includes membership and discounted conference registration for one person, and one 2019 Member t-shirt for $5 S/H.

Family, $65/yr: Includes discounted conference registration for each household member; and one 2019 Member t-shirt for $5 S/H.

Professional, $75/yr: Includes discounted conference rate, bulk discounts on resources, review of study opportunities, email distribution by TSSUS (pending approval), listing in TSSUS online Provider Directory, and one 2019 Member t-shirt for $5 S/H.

Butterfly Society Monthly Donor

TSSUS Butterfly Society, Monthly Donor: Minimum recurring donation of $10/or more per month includes a free Individual Membership (family membership upgrade $20).

Includes benefits of Individual Membership and one 2019 Member t-shirt for $5 S/H.

The TSSUS Butterfly Society is the exclusive monthly giving society of the Turner Syndrome Society of the United States. Find out more about the Butterfly Society here: https://www.turnersyndrome.org/butterfly-society.

Additional t-shirts available for $18/each (S-XL) $22 (2XL-3XL)

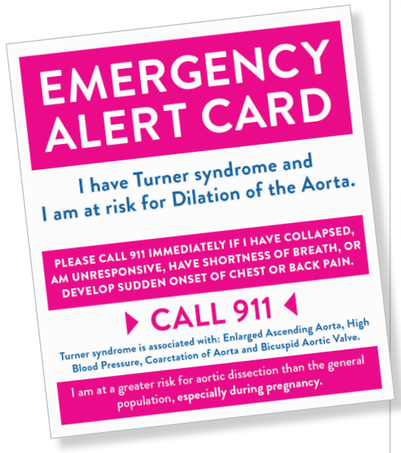
Purchase or renew your membership and order t-shirts by mail or online at:
https://www.turnersyndrome.org/member-benefits

How to Use the New Cardiac Emergency Alert Card (CEAC)

The purpose of the NEW Cardiac Emergency Alert Card is to alert care providers, hospital staff, and first responders that you have Turner syndrome and are at risk for dissection of the aorta and that you require careful monitoring after any surgical procedure and during pregnancy.

The new TSSUS Cardiac Emergency Alert Card (CEAC) can be used in several ways. The primary purpose is to share this card with hospital staff if you or your child has symptoms that could be heart-related. The card will help emergency and hospital staff understand you or your child's potential unique needs associated with Turner syndrome.

Printing and carrying the card will also serve as a reminder to those with TS and their families that taking care of your heart health, following recommended cardiac screenings, and remembering that Turner syndrome is related to an increased risk of cardiac issues is important. A physical card in a wallet is a reminder to stay current with appointments, and serves as reassurance that if in the rare chance that you experience an aortic aneurysm, you will know what to tell someone.



SYMPTOMS OF AORTIC DISSECTION

Can be variable, relatively minor, and nonspecific. **Chest pain** is the most common symptom, but pain can also occur in **the back and/or the abdomen.** The pain may be described as severe or vague, constant or intermittent, migratory, tearing, tightness, or fullness. Other signs and symptoms can include **cardiovascular instability, pulselessness, parasthesia, paralysis, syncope,** or a sense that "something is terribly wrong."

A normal X-ray does NOT rule out the possibility of aortic dissection.

The most definitive tests for aortic dissection are:
CT Scan · Transesophageal Echocardiogram · MRI
Choose one that is most readily available, and expertly performed and interpreted.

Please do not discount aortic dissection until it has been definitively ruled out.

Turner Syndrome Society of the United States
11250 West Road, Suite G, Houston, TX 77065
Important information for medical professionals available. Please contact us today.
www.tssus.org | 800.365.9944

PLEASE NOTE: Women with TS require careful monitoring after any surgical procedure.

EMERGENCY ALERT CARD

I have Turner syndrome and I am at risk for Dilation of the Aorta.

PLEASE CALL 911 IMMEDIATELY IF I HAVE COLLAPSED, AM UNRESPONSIVE, HAVE SHORTNESS OF BREATH, OR DEVELOP SUDDEN ONSET OF CHEST OR BACK PAIN.

CALL 911

Turner syndrome is associated with: Enlarged Ascending Aorta, High Blood Pressure, Coarctation of Aorta and Bicuspid Aortic Valve.

I am at a greater risk for aortic dissection than the general population, especially during pregnancy.

MY NAME:
EMERGENCY CONTACT:
EMERGENCY CONTACT'S PHONE:
MY PHYSICIAN:
MY PHYSICIAN'S PHONE:
MEDICATIONS / KNOWN HEART CONDITIONS / NOTES:

TSSUS Chasing Butterflies Walks for Turner Syndrome

TSSUS Chasing Butterflies Walks are happening in several cities and communities across the country, thanks to the many volunteers, women with TS, group leaders, and parents who are working with us to make them happen!

Walk coordinators may request 50% of funds raised at a Chasing Butterflies Walk be used to support their local TS community for needs aligning with the TSSUS mission, such as scholarships for membership, the TSSUS conference, life experiences, or for local events.

The Chasing Butterflies Walks are the most highly-attended TSSUS events, and bring together hundreds of girls and women with TS and their friends and families in cities and communities across the country in a supportive and fun environment. They raise awareness and important funding to support TSSUS programs and resources for the whole TS community.

It's a great time to plan a Summer or Fall Chasing Butterflies Walk!
It's fun, and we can help you every step of the way! Call or email Deborah Rios for more information, or to start planning your walk today.
deborah@turnersyndrome.org or 800.365.9944



2019 Chasing Butterflies Walks

Sacramento, CA
February 9, 2019
Walk Coordinator: Rosemary Morris

Fresno, CA
March 9, 2019
Walk Coordinator: Rosemary Morris

Los Angeles, CA
May 18, 2019
Walk Coordinator: Rosemary Morris

Birmingham, AL
May 25, 2019
Walk Coordinator: Natalya Winters

Lynchburg, VA
May 25, 2019
Walk Coordinator: Iris Campbell

McKinney, TX
June 1, 2019
Walk Coordinator: Kimberly Prince

Vancouver, WA
June 8, 2019
Walk Coordinator: Glenna Gibson

Almeda, CA
June 22, 2019
Walk Coordinators: Haley Rodden & Rosemary Morris

Cassopolis, MI
July 13, 2019
Walk Coordinator: Brandy Shelby

Grand Rapids, MI
August 17, 2019
Walk Coordinator: Katie Visner

Wooster, OH
October 12, 2019
Walk Coordinator: Branon Workman

The 2019 TSSUS National Turner Syndrome Conference

Find Your Voice!

The theme of the 2019 TSSUS National Turner Syndrome Conference is ***Find Your Voice***. The theme was inspired by the voices of the TS community we hear via social media and calls to the National Office. Many feel alone, disregarded, frustrated with their health conditions, bullied, uneducated about Turner syndrome, or frustrated that their doctors don't know enough about TS. Many women and teens battle depression and anxiety as well. Here are some comments that have been shared with us over the phone and on social media from the TS community:

- People make me feel like I can't do anything.
- I'm fearful every day of messing up.
- I feel like people don't take me seriously.
- I feel like people still see me as a child even though I am an adult.
- I have to explain TS to my doctors.
- Our insurance denied growth hormone for my daughter.
- People treat me as if I am not there. Sometimes I feel invisible.
- How can I improve my self-confidence?
- My doctor won't order an MRI ... what can I do?
- No one seems to know about Turner syndrome.
- My daughter has a difficult time making and keeping friends.
- People always tell me I can adopt, but we can't afford it.

The 2019 TSSUS National TS Conference general and breakout sessions will address these concerns, and empower girls, women, and family members to speak up for themselves, feel confident, and advocate for the best health care possible. Our exhibitors will provide insights and tools to help attendees along their TS journey. Some of our speakers will even be on hand to offer one-one-one consultations with attendees.

Through education, connections, and entertainment, the 2019 TSSUS National Turner Syndrome Conference will change lives! We hope you will join us!

2019 conference sessions will cover important medical topics such as:

- Thyroid Disease in Turner Syndrome- Dr. William Russell - Monroe Caroll, Jr., Children's Hospital at Vanderbilt
- Congenital Heart Abnormalities Related to Turner Syndrome - Siddharth Prakash, MD, PhD - Houston
- Turner Syndrome Research Updates- Siddharth Prakash, MD, PhD, Dr. Cheryl Maslen, Cindy Scurlock, MA, LPC, Michael Silberbach, MD
- Talking with Your Doctor About TS - Barbara Duffy, NP
- Hormone Replacement in Adults with TS - Dr. Melissa Wellons- Vanderbilt Medical Center
- Hearing Loss and Disease of the Middle Ear- Dr. Patricia Johnson-UNC
- All About Hearing Aids- Sarah Wyatt- AuD,CCC-A
- What Are Bioidentical Hormones?

2019 conference sessions will also cover important topics related to daily living with TS:

- Living with Nonverbal Learning Disability - Dean Mooney, PhD, LCP
- Managing Multiple Diagnoses-TBA
- Fitness Tips for Women with Osteoporosis - Sarah Brown, DPT
- Top Nutrition Tips for Thyroid Health- Mira Dessy, The Ingredient Guru
- Job Interview and Workplace Etiquette - Monica Irvine, The Etiquette Factory
- Self-Care After Your Child's Diagnosis- Natalie Bonfig, Author/Blogger, Mom of daughter with TS
- Improving Executive Function Skills with Games- Shawn Wier, National Event and Resource Manager, TSSUS
- Breaking the Silence: Living with the Pain of Infertility – Emily G. Pardy, LMFT, PMH-C

2019 Youth Program will offer talks from various speakers, as well as crafts, games, and a special outing for ages 11-17. Topics will cover:

- Sugar Bingo w/ Mira Dessy, the Ingredient Guru - Mira will use sugar cubes to help the youth SEE how much sugar is in certain foods that we eat.
- Yoga and meditation : Natalie Bonfig will teach the girls how to relax their minds and bodies to help relieve stress and anxiety. (Friday/Saturday)
- Fitness Tips with Natalie Portway, Youth Leader, Woman w/TS, foster mom, and personal trainer
- Dealing with Bullies and Learning Assertiveness- Kimber Bishop-Yanke, Kids Empowered
- Teens will hear from keynote speaker, Jessica Janniere, as she talks with them about dealing with life's challenges.
- Youth ages 11-17 will visit the Frist Art Gallery in downtown Nashville (Saturday)
- Etiquette Coach, Monica Irvine will share the secrets of social skills and etiquette.

More activities will be added in coming weeks. For a complete list of sessions and speakers, please visit tssus.org

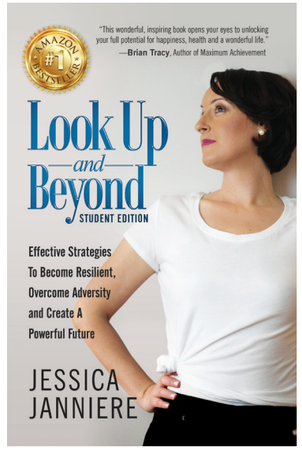
Keynote Speaker:
Jessica Janniere, Overcoming Adversity Expert

Keynote Presentation: "Look Up and Beyond: Use Your Voice, Know Your Worth, and Live with Purpose"



Jessica Janniere is a child abuse and rape survivor on a mission to help people realize that negative past experiences do not equal a negative future, regardless of the level of trauma they've faced. She is a best-selling author, and the founder of the award-winning personal development organization, Look Up and Beyond Inc. She is committed to helping people overcome the pain of their past and current circumstances to live purpose driven and fulfilling lives. One of her greatest passions is working and speaking with women and youth who have challenging backgrounds to help them realize there is more to life than what they see in front of them.

More Conference

















Conference continued

Entertainment:

Friday Night, Cimorelli Concert & Meet & Greet

Saturday, TS Choice Awards with "Talent Show" Performers, followed by Dancing

Conference Hotel:
Embassy Suites by Hilton
Nashville SE Murfreesboro
1200 Conference Center Blvd
Murfreesboro, TN 37129

Phone: 615-890-4464

Reserve your hotel room soon before the TSSUS block is sold out!



	TSSUS Member Early Bird Discount (Feb. 1- April 15)	TSSUS Member (after April 15)	Non-Member	Late Registration (online after June 23 and on-site)
Full Conference Fees				
Adult	$270	$320	$365	$370
Pre-teen/Teen (Ages 11-17)	$225 *	$280 *	$315	$330
Child (Ages 3-10)	$150 *	$190 *	$220	$245
Conference Meal Pass Only **	$175	$180	$195	$205
Saturday-Only Fees				
Adult	$185	$235	$285	$290
Pre-teen/Teen (Ages 11-17)	$160 *	$200 *	$230	$260
Child (Ages 3-10)	$130 *	$165 *	$199	$210
Saturday Evening Banquet Dinner Only **	$65	$65	$65	$65

* With Family Membership
** Must be a family member of a registered attendee. (such as spouse, parent, grandparent)

Conference Schedule at a Glance

Thursday, June 27
1-5 pm: Optional Tours
3-6 pm: Exhibitor Set-Up
4-7 pm: Attendee Check-In/ Late Registration
5:30 pm - 7:30 pm: Hotel Manager's Reception in Hotel lobby
7-9 pm: Cupcake Decorating Class (Adults Only)
7-9 pm: Butterflies and Brushes Paint Night –
(Sign up on Activities Page)

Friday, June 28
8 am-4 pm: Attendee Check-In/ Late Registration
9 am-12 pm: Youth Theatre Workshop for ages 8-17
10-11 am: General Session:
Conference Welcome w/ Live Music
11-11:30 am: Mandatory Parent Meeting w/Children
Lunch on Your Own
12:45-5 pm: Youth Program
1-2 pm: General Session
2:30-4:45 pm: Afternoon Breakout Sessions
Dinner on Your Own
5-7 pm: TSSUS Butterfly Society V.I.P .Reception, light hors d'oeuvres (Invitation Only, Adults Only, Child Care Provided)
7-8 pm: Cimorelli LIVE Concert
7-8:30 pm: Line Dancing Lessons
8-10 pm: Open Mic
8:30-9:30 pm: Cimorelli Meet & Greet (tickets $15)

Saturday, June 29
7:30 am-12 pm: Attendee Check-In/ Late Registration
9 am-4:30 pm: Youth Program (Broadlands A/B and Mirabella I-J)
10:30 am-11:30 am: Breakout Sessions
(4-6 concurrent sessions)
12-1 pm: Lunch Buffet
1:30 pm-2:30 pm: Breakout Sessions
(4-6 concurrent sessions)
2:30-3 pm: Coffee Break
3-4 pm: Breakout Sessions (4-6 concurrent sessions)
5:30-7:30 pm: TS Choice Awards Dinner Banquet and Show
8 -11 pm: After Party/Dancing (cash bar)
8-10 pm: Youth After Party (for ages 11-17)
8-10 pm: Kids After Party (for ages 6-10)
8-10 pm: Childcare for 5 and under

Sunday, June 30
Breakfast on Your Own (Hotel Offers Complimentary Cooked-to-Order Breakfast)
9:30-10:30 am: Breakout Sessions (4-6 concurrent sessions)
10:45-11:45 am: Breakout Sessions
(4-6 concurrent sessions)
12-12:30 pm: Closing General Session
12:30 pm: Exhibitor tear-down
1-6 pm: Optional Tours

July 21st -29th, 2019 ✦ Teens 12-19 years

Don't Just Fly... SOAR

...with us at camp in 2019!



Program Highlights for our 25th Anniversary

- We're going to Disneyland!
- Theatre Workshops & Excursions
- Swimming in the beautiful campus pool
- Beach Days
- Dance Party with Hollywood DJ
- Presentation by Mitchell E. Geffner, M.D.
  Professor of Pediatrics
  Division Chief of the Center for Endocrinology, Diabetes, and Metabolism
  Children's Hospital Los Angeles
- Counselor-Led Rap Sessions
- Salon Day at Vidal Sassoon Academy
- RNs on campus
- Professional Camp Director, Jan Radnoti
- Counselors are camp alumnae
- College Dorm Experience

THE NATIONAL TURNER SYNDROME CAMP, INC.

Mount Saint Mary's University
10 Chester Place
in University Park, a historical district of Los Angeles

Register now at
NTScamp.org/registration

The National Turner Syndrome Camp, Inc.
Beverly Daley, PhD • Beverlyd4tscamp@outlook.com • 818.209.2220 • NTScamp.org

The National Turner Syndrome Camp, Inc. is a non-profit 501(c)(3) organization dedicated to enabling teens and young women (12-19 years) with Turner Syndrome to gain confidence and realize their potential. The camp activities provide fun in a safe community that inspires long-term friendships, discovery of the arts, and healthy living. Tax ID: 47-149407

TS Days 2019

- August 2019 - Seattle, WA
- September 2019 - Chicago, IL
- October 2019 - Phoenix, AZ
- November 2019 - Ft. Lauderdale, FL





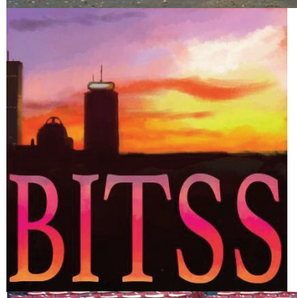


In 2018, hundreds of members of the TS Community attended TS Days events in cities across the country. These single-day events were designed to educate about TS health care and provide an opportunity for those affected by TS to connect and just have fun spending the day together.

Many of the girls and women who attended had never been to a TS event and had never met another person with TS. Through these engaging meetings, there were those who found out for the first time they needed to have regular heart checks and take estrogen. In every city, there were women who realized the anxiety, job challenges, and social difficulties they experienced were shared by many others. Suddenly, they did not feel so alone.

Plans are underway for four more TS Days events for 2019 starting in August. Make sure to follow the TSSUS communications to receive updates as they are released. We hope to see you at a TS Days event in 2019!





Boston International Turner Syndrome Summit

July 28 - August 4 2019, Boston MA
For young women with Turner syndrome ages 12-19

Highlights Include: Plimoth Plantation, New England Aquarium, USS Constitution ship, ASL, Theater, Zumba, Karaoke, Painting, Doctor's Panel, and much more.

www.bitssummit.org / info@bitssummit.org



Many Thanks to Our Donors & Members

At the Turner Syndrome Society of the United States, our members and donors are our lifeblood. Without the support of those of you whose names are represented here, we would not be able to provide vital resources, exciting, supportive educational events, and contribute leading support and directives for Turner syndrome research.

Every dollar, every membership, and every donation counts. Whether you are a TSSUS Butterfly Society monthly donor, a Chasing Butterflies Walk participant, a TSSUS member, or one who donates during the Annual Campaign, your donation impacts those living with Turner syndrome and their families each and every day. Thank you for your support and generosity of spirit.

Individual Donors

(Sep 2, 2018 - Mar 20, 2019)

Rebecca Abbott
Carole Adams
Brianna & John Adams
Wendy Agricola
Beatriz Amador-Martinez
Mary Ann & Joel Andersen
Rosie A. Arevalo
Roxanna Askam
Huma Aslam
Carolyn Aspinall
Janice Ballak
Jennifer Ballard
Nora Baratto
Cris Barrere
Kristi Battisfore
Dorothy Baume
Jennifer Beal
Magen Benedetto
Ellen Berez
Jane Berne
Joanne Blyskal
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Amelia A.J. Bond
Natalie & Steven Bonfig
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Joyce Eberly
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Dr. & Cat Farquharson
Michael Fell
Jennifer & Sean Fleming
Barbara Flink
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Charles Friel
Lauren E. Gee
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Brigid & Michael Genetti
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Gayle Goldsmith
Myra Gonzalez
Karen Goodman
Beth Gould
Heather G. Graham
Heather & Trevor Graham
Shannon R. Gray
Dr. Worth N. & Elayne D Green
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Alyssa & Peter Hanna
Susan Harrigan
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Benson Hayse
Kathryn & David Hearn
Laurel Henkel
Adrian Herrera
Cathy Hickling
Erica Hill
Ron Hinson
Lila Mae Hinze
Sara Hogan
Mary Holing
Emily Holley
Dawn Hopkins
Francis X. & Jacqueline A. Hynes
Jessica & Jeff Hynes
Susan Jenkins
Dana Johns
Josh Kaczynski
Nancy Kaczynski
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Mary King
Michael Kingery
Nicole & Thomas Knisley
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Jennifer Lafferty
Diane & Wayne Lambert
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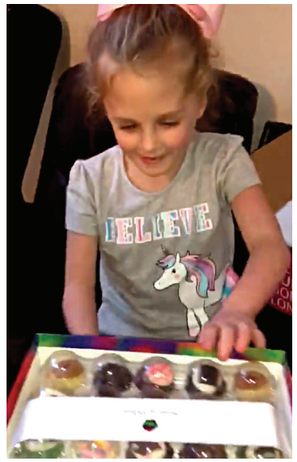
February 2019 Winner
Rylee Kambach

Have you registered for the TSSUS Birthday Society?

This fun program celebrates you on your special day! All you have to do is register online at www.turnersyndrome.org by either creating or editing your profile, and selecting "I want to join the TSSUS Birthday Society" in the custom fields section.

Each month a box of Baked by Melissa bite-sized cupcakes will be delivered to the doorstep of the lucky winner.

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Cathryn Pyeatt

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www.turnersyndrome.org

Reception

TSSUS Butterfly Society V.I.P. Reception

at the 2019 National Conference on
Friday, June 28, 2019 from 5 pm to 7 pm.

This invitation-only event is open to active, current
TSSUS Butterfly Society monthly supporters as of June 1, 2019.
For information about becoming a TSSUS Butterfly Society monthly
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