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 teensy tiny room, transformations took place, studies about mice and cats widened eyes and visions of human chimeras 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 Medical Genetics will explain 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 Scuffiok
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 website 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.

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 a recent 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 5% 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 use of 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.

Please join the registry at www.turnersyndrome.org
For 32 years, we have been empowering, educating and supporting the TS community. 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.

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!

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.

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

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.

Which Membership Level is right for you?

<table>
<thead>
<tr>
<th>Membership Level</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual</td>
<td>$45/yr</td>
</tr>
<tr>
<td>Family</td>
<td>$65/yr</td>
</tr>
<tr>
<td>Professional</td>
<td>$75/yr</td>
</tr>
</tbody>
</table>

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)
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 cough, shoulder or neck pain, faintness, and hives.

**Emergency Alert Card**

I have Turner syndrome and I am at risk for dissection of the aorta.

**Please call 911 immediately if any of the following occur:**

- Shortness of breath
- New chest pain
- Back pain
- Shoulder or neck pain
- Faintness
- Hives

**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: Branson 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.
- I have to explain TS to my doctors.
- I feel like people still see me as a child even

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 Carroll, 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 Sourlock, 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.

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

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.
Entertainment:
- Friday, 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: 615-890-4484

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

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

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

Reserve your hotel room soon before the TSSUS block is sold out!
We hope to see you at a TS Days event in 2019! Communications to receive updates as they are released.

Plans are underway for four more TS Days events for 2019 starting in August. Make sure to follow the TSSUS

At the Turner Syndrome Society of the United States, our members and donors are our lifeline. Without the support and experience of those of you who have been represented or affect these individuals, we would not be able to provide vital resources, exciting, supportive educational events, and leading support and directing for Turner syndrome research.

In 2018, hundreds of members of the TS Community attended events were designed to educate about TS health care and provide an opportunity for those affected by TS to connect and not feel so alone.

In every city, there were women who experienced were shared by many others. Suddenly, they did through these engaging meetings, there were those who found and took estrogen. In every city, there were women who also provided an opportunity for those affected by TS to connect and not feel so alone.

For young women with Turner syndrome ages 12-19 and take estrogen. In every city, there were women who also provided an opportunity for those affected by TS to connect and not feel so alone.

Through these engaging meetings, there were those who found and took estrogen. In every city, there were women who also provided an opportunity for those affected by TS to connect and not feel so alone.

The Turner Syndrome Society, ASL, Theater, Zumba, Karaoke, Painting, Doctor’s Panel, and much more.

The Turner Syndrome Society

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.

Many Thanks to Our Donors & Members

At the Turner Syndrome Society of the United States, our members and donors are our lifeline. Without the support and experience of those of you who have been represented or affect these individuals, we would not be able to provide vital resources, exciting, supportive educational events, and leading support and directing for Turner syndrome research.

In 2018, hundreds of members of the TS Community attended events were designed to educate about TS health care and provide an opportunity for those affected by TS to connect and not feel so alone.

In every city, there were women who experienced were shared by many others. Suddenly, they did through these engaging meetings, there were those who found and took estrogen. In every city, there were women who also provided an opportunity for those affected by TS to connect and not feel so alone.

For young women with Turner syndrome ages 12-19 and take estrogen. In every city, there were women who also provided an opportunity for those affected by TS to connect and not feel so alone.

Through these engaging meetings, there were those who found and took estrogen. In every city, there were women who also provided an opportunity for those affected by TS to connect and not feel so alone.

The Turner Syndrome Society, ASL, Theater, Zumba, Karaoke, Painting, Doctor’s Panel, and much more.

The Turner Syndrome Society, ASL, Theater, Zumba, Karaoke, Painting, Doctor’s Panel, and much more.

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.

Many Thanks to Our Donors & Members

At the Turner Syndrome Society of the United States, our members and donors are our lifeline. Without the support and experience of those of you who have been represented or affect these individuals, we would not be able to provide vital resources, exciting, supportive educational events, and leading support and directing for Turner syndrome research.

In 2018, hundreds of members of the TS Community attended events were designed to educate about TS health care and provide an opportunity for those affected by TS to connect and not feel so alone.

In every city, there were women who experienced were shared by many others. Suddenly, they did through these engaging meetings, there were those who found and took estrogen. In every city, there were women who also provided an opportunity for those affected by TS to connect and not feel so alone.

For young women with Turner syndrome ages 12-19 and take estrogen. In every city, there were women who also provided an opportunity for those affected by TS to connect and not feel so alone.

Through these engaging meetings, there were those who found and took estrogen. In every city, there were women who also provided an opportunity for those affected by TS to connect and not feel so alone.

The Turner Syndrome Society, ASL, Theater, Zumba, Karaoke, Painting, Doctor’s Panel, and much more.

The Turner Syndrome Society, ASL, Theater, Zumba, Karaoke, Painting, Doctor’s Panel, and much more.

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.

Many Thanks to Our Donors & Members

At the Turner Syndrome Society of the United States, our members and donors are our lifeline. Without the support and experience of those of you who have been represented or affect these individuals, we would not be able to provide vital resources, exciting, supportive educational events, and leading support and directing for Turner syndrome research.

In 2018, hundreds of members of the TS Community attended events were designed to educate about TS health care and provide an opportunity for those affected by TS to connect and not feel so alone.

In every city, there were women who experienced were shared by many others. Suddenly, they did through these engaging meetings, there were those who found and took estrogen. In every city, there were women who also provided an opportunity for those affected by TS to connect and not feel so alone.

For young women with Turner syndrome ages 12-19 and take estrogen. In every city, there were women who also provided an opportunity for those affected by TS to connect and not feel so alone.

Through these engaging meetings, there were those who found and took estrogen. In every city, there were women who also provided an opportunity for those affected by TS to connect and not feel so alone.

The Turner Syndrome Society, ASL, Theater, Zumba, Karaoke, Painting, Doctor’s Panel, and much more.

The Turner Syndrome Society, ASL, Theater, Zumba, Karaoke, Painting, Doctor’s Panel, and much more.

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.
TSSUS Birthday Society Donors

Barbara Lippe, MD
Megan Littenhouse
Christina Losoya
Evan Los
Heather Lynch
Donna & Taylor Maas
Roberta Marzban
Patricia Marquees Barros
Elizabeth McClaran
Debra Nicole McMichael
Kevin R. Melver & Catherine Ward Melver, MD
Emily & Edward Metcalf
Kim A. Melts
Jennifer Milton
Abby Montag
Patricia Chris Montemeyer
Dean Moody, MD
Season & Donovan Moore
Molly Mours
Kim Nelson
Lesley Ann Niemeyer
Blake C. Nixon
Sean Nolan
Audrie M. Niol
Renée Nowacki
Carrie Odom
Toby Paluffi
Lisa Palomba
Lori & Gene Pawlik
Amy Pietrowski
Hannah Polaseck
Ann & David Pope
Michael Powell
Siddharth Prakash, MD, PhD
Kimberly & Brian Prince
Kymberly & Matthew Pyeatt
Tori Raffel
Sarah Rayburn
David Reedinn
Alison K. Reijle
Mary Reilly
Donna Rice
Danielle Richard
Nikki Risvik
Sarah Rolfe
Lisa & Thomas Romeo
Bonnie Sue Rubie
Victoria Sanchez
Christine Santor
Teresa A. & Robert J. Scarfati
Mary Schroeder
Lisa & Michael Sears
Deimante Selleryte
Veena Sharma
Jarred Sharp
William Shein
Brandy & Thayne Short

TSSUS Board of Directors
Butterfly Society Supporters

Nancy & Jason Bryant
Myist-Harrison
Emily Haertik
Erica Melman
Rosemary Morris
Sarah & Daniel Sullivan

TSSUS Staff

Becky Brown
Deborah & Jimmy Roe
Cindy & Billy Storck
Shawn & Thomas Wier

Billi Jo Stiefel
Claire Simms
Sarah Sitton
Lauren & Brent Silver
Michelle Smith
Sabrina & Eric Smith
Joanna R. Stank
Beth Suchocki
Deanna Swanson
Michaela Teachmon
Debra Terzakis
Susan Thaxton
Christine Thompson
Stephanie & Jon Thompson
Katie Thorson
Dawn Uyehara
Leah Van Hoozer
Ray & Maureen Weronick
Jennifer Anne Wang
Kelly Watson
Kimberly Wawrzonek
Wanda Welch
Laurie Whammond
Jane White
Mary Witsens
Marian Wofford
Ann Marie Wood
Bethey Wood
Lisa Wright
Laura Wuerz

TSSUS Butterly Society Donors

In Honor of
Ashley Adams
Amanda Agricola
Rylee LeighLane Anthony
Dorothy Baume
Emma Grace Beal
Macy Boggs
Alex Boyle
Lucy Bragg
Jenna Brennan
Elle Brown
Nancy Bryant
Brittani Burtstand
Campbell-Relitto Hilary
Emilia Gardosi
Abbie Carlson
Elke Coci
Lottie Crawford
Brooke Deway
Ashlyn Elton
Addison Capri Doyle
Brittani Ethrom

Lauren Patronis
Gracie Popeovern
Winifred G. Powell
Sophia Remy
Tessa Roach
Caio Russo
Sophie Shonette
Michal Silverbach, MD
Sarah Sullivan
Cate Rose Sullivan
Elin Timmermann
Pamela Tinsley
Charity Watson
Abigail Webb
Karihle Wedding
Mikahlih Whitrow
Gray Winters
Jacquelyn Woolridge
Brannon Workman
Sydney Worshy
Sopha Zambrano
Emery Doreier Zoller
Brenna Nage
Sarah Page

Alyssa Elnik
Elizabeth Fontenot
Ashdon Ford
Mira Franz
Taylor Giannoni
Christina Gonzalez
Alicia Graham
Kate Haberkorn
Myist Hamilton
Emily Haviat
Brittany Hinesey
Chloe Lilian Howard
Tyrone Howard
Jeff Hynes
Clare Hynes
Ashley Jachob
Dena and Jonok
Brooke Kaczynski
Flome Katchen
Hazel Joynes
Jacqueline Woodyland
Brandon Workman
Mary Louise Hartley
Jenna Hernandez
Mary E. Wait
Emenyelle Grace Warford
Rebecca Weaver
Kelli West
Pram Valhaker

In Memory of
Talma Baratz
Edyth G. Barry
Katie Blaze Beyer
Ella Ann Debo Blagg
Mary Louis Bolton
Noel Marie Chandler
Eliora Cordova
Baby Girl Cortez
Milly Costigan
Agatha Paul Romano
Hope Schultz
Karla Stilin
Sharon Marie Stair
Emma Silva Trevino
Mary Lou Valley
Barbara VanCott
Mary E. Wait
Emenyelle Grace Warford
Rebecca Weaver
Kelli West
Pram Valhaker

Sisca R. Lind
Leslie Matuschka
Carrie Faye McDaniel
Baby Girl Medina
Robin Murasso
Tim Merit
Alex Ann Nunn
Morgan Daisy Peterson
Poppy Pratt
Claire Evelyn Reibert
Anita Paul Romano
Hope Schultz
Karla Stilin

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.turnerssyndrome.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.

February 2019 Winner
Rylee Kambach

March 2019 Winner
Cathryn Pyeatt

Barbara Lippe, MD
Megan Littenhouse
Christina Losoya
Evan Los
Heather Lynch
Donna & Taylor Maas
Roberta Marzban
Patricia Marquees Barros
Elizabeth McClaran
Debra Nicole McMichael
Kevin R. Melver & Catherine Ward Melver, MD
Emily & Edward Metcalf
Kim A. Melts
Jennifer Milton
Abby Montag
Patricia Chris Montemeyer
Dean Moody, MD
Season & Donovan Moore
Molly Mours
Kim Nelson
Lesley Ann Niemeyer
Blake C. Nixon
Sean Nolan
Audrie M. Niol
Renée Nowacki
Carrie Odom
Toby Paluffi
Lisa Palomba
Lori & Gene Pawlik
Amy Pietrowski
Hannah Polaseck
Ann & David Pope
Michael Powell
Siddharth Prakash, MD, PhD
Kimberly & Brian Prince
Kymberly & Matthew Pyeatt
Tori Raffel
Sarah Rayburn
David Reedinn
Alison K. Reijle
Mary Reilly
Donna Rice
Danielle Richard
Nikki Risvik
Sarah Rolfe
Lisa & Thomas Romeo
Bonnie Sue Rubie
Victoria Sanchez
Christine Santor
Teresa A. & Robert J. Scarfati
Mary Schroeder
Lisa & Michael Sears
Deimante Selleryte
Veena Sharma
Jarred Sharp
William Shein
Brandy & Thayne Short
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
supporter, please visit https://www.turnersyndrome.org/butterfly-society,
call 800.365.9944, or email becky@turnersyndrome.org.