

# TSS CONNECT

WINTER 2016

## A New Look for the New Year!

“YOU ARE PERFECT  
JUST THE WAY YOU ARE”

*Article by Karen Freedle*

AND MORE INSIDE!



Turner  
Syndrome  
Society  
of the United States



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

**Contents**

- 3** Annual Conference
- 4** Social Matters
- 5** Cover Story
- 6** Medical Updates
- 8** Local Groups & Events
- 10** Fundraising
- 12** Member Article
- 13** Healthy Living
- 14** Honor & Remembrance
- 15** 2015 Donors

**TSS CONNECT**

Winter 2016

Turner Syndrome Society  
 11250 West Road, Suite G  
 Houston, Texas 77065  
 832.912.6006 | 800.365.9944  
 www.turnersyndrome.org  
 tssus@turnersyndrome.org

Non-Profit 501 (c)(3)  
 EIN #41-1596910  
 United Way #021953  
 Combined Federal Campaign #11561

**A NEW YEAR, A NEW LOOK, A NEW PRESIDENT**

*A Message from Your New TSSUS President, Carol Crawford.*



I am excited to be starting my role as the President of the TSSUS Board of Directors after 5 years serving on the board.

Our family had been very active in TS locally after Abigail, my 15-year-old, was diagnosed with TS. However, as always happens in life, I was busy with other things and became less involved. In 2010, Brenda Gruwell, whom I had met at local Atlanta Chapter meetings, called to say that one of us should consider a board position. At first, I was unsure, but I thought about how much the society had meant to me when Abigail was diagnosed and how wonderful it has been to meet other parents and women with TS in Atlanta, so I decided I needed to give back. It was one of the best decisions I have ever made. In 2011, I began serving the TSSUS Board as Treasurer. While I like to think that I've made positive contributions to the Society during my service, I know that the Society has made innumerable

positive contributions to me, Abigail, and all of us in the TS community.

When I was less involved in TSSUS, I lost sight on the larger picture – the need for more TS research, more community support and better clinical guidance on issues Abigail and other women with TS may face in the future. I also lost sight of the connections we all make in the TS community – friendships and bonds that last a lifetime. TSSUS had not lost sight and I feel lucky to now be able to contribute to this work. Looking back on just the 5 years I've served on the board, I can see how much TSSUS has continued to grow. What excites me most is looking at our strategic plan and seeing the exciting work coming up to support our 4 primary goals:

- Ensuring that all girls and women with TS receive quality healthcare regardless of age, location, or finances
- Supporting patients, families, and professionals to ensure successful adjustment to all stages of TS
- Expand the knowledge about TS through research
- Facilitate a heightened awareness and understanding of TS, its effects, and possibilities

Each day so much work occurs in the office supporting these goals – from answering the phones, to helping local groups have meetings, working with the professionals on new TS guidance, helping setup Chasing Butterfly walks, putting on the TSSUS conference, or getting ready to roll out the new TS Registry. The hard work of Cindy, Deborah, Shawn, Stephanie, Cheri, and Barb cannot be overstated – these women are truly dedicated to our TS community.

If you have any questions about TSSUS or the TSSUS Board, please feel free to reach our directly to me at [CarolCrawford@turnersyndrome.org](mailto:CarolCrawford@turnersyndrome.org). Your board is here to serve you, do not hesitate to reach out to me or any board member.

*Carol Crawford*  
 TSSUS President



**RECENT NEWS**

Kinsley Stavino, of The Circles of Hope Foundation, hands Cindy Scurlock a \$20,000 check to benefit TSSUS. Their foundation held their 1st Casino Night.

**COVER PHOTO**

Clare enjoys herself at a TS Annual Event while being held by mom. She will be turning 3 this year - how time flies!



*Up for the Challenge*

## TSSUS 29<sup>th</sup> ANNUAL CONFERENCE 2016!

JULY 22-24, 2016 | CINCINNATI, OHIO

The Turner Syndrome Society of the United States cordially invites you to join us for our 29th Annual Turner Syndrome Conference.

This year, our theme is "Team Turner: Up for the Challenge."

Emphasis will be placed on overcoming obstacles of TS and becoming a champion for your own healthcare.

*TSSUS members! Watch your mailboxes in early March for an informational brochure highlighting the weekend's activities, along with information on the hotel, transportation, youth program and more!*

Be sure to regularly check the conference page at [www.turnersyndrome.org](http://www.turnersyndrome.org) for more detailed information as it becomes available!



PHOTOS FROM LAST YEAR'S NATIONAL CONFERENCE IN KANSAS CITY

Left: Three Butterflies pose after their Thursday evening dinner at Union Station.

Center: The sibling group enjoyed a visit to Science City after decorating t-shirts.

Right: The Lilly Exhibit full of activities.

## SOCIAL COMMUNICATION

A brief overview of the 4 Steps of Communication. Compiled by Beckham Linton M.A., CCC-SLP.



Have you ever met someone who just won't stop talking about themselves or who only responds to you with very short answers, i.e., 'yep', 'I don't know.' Do you know people who are perpetually late or who laugh too loudly or too long? Do you have friends or family members who stand too close or interrupt others in the middle of their conversation? If you answered 'yes' to any of these questions, you may know someone who is experiencing social communication challenges.

Social communication is a complex, multifaceted concept that begins simply with a shared thought. Most people initially think social communication is all about 'talking', but it is a lot more than just talking. It involves looking, thinking, moving, listening, and regulating ourselves based on the thoughts and feelings of others. The process of social communication has at least 4 basic steps. These steps, defined by speech language pathologist, Michelle Garcia Winner, (Think Social Publishing) are as follows:

1. Think about the people with whom you want to communicate.
2. Use your body to communicate your intention.
3. Use your eyes to connect with people as you relate to them.
4. Use your words to relate to people when you talk to them.

These steps happen in order when we first meet someone, but we process and respond to the information we gather about a person through these steps simultaneously as the relationship grows. Let's look at each of these steps more closely.

### Step 1: Think about the people around you and what they might be thinking.

What are their interests, where are they going, and/or how are they feeling? We make decisions about whether we want to join them or their group based on the thoughts we are having about them. Groups are usually formed around common interests, personality type or a previous friendship group, therefore you must make sure your own strengths or interests match those of the people in the group you are wanting to join.

Good social communication requires thinking about the thoughts and experiences of the people you want to be with before trying to join their group, so make sure you think not only about what you have in common with them, but also think about how they have treated you in the past. If you see a group of people whom you admire and would like to get to know better, it's important that you know at least one person with whom you have a positive connection in that group before attempting to join that group. Otherwise, they may not willingly accept you into their conversation.

### Step 2: Use your body language to communicate your intention.

Body language is a common term used to describe the messages we send through our body posture, our physical approach to and from a group, our physical proximity, physical position in space and our body movement. All of these aspects of body language work together to let people know if we are feeling comfortable or anxious, whether we are open or closed-off to communication, what we are going to do next, and/or if we want to continue or end the conversation. For example, a person who stands at an arm's length away with feet, hips and shoulders facing others in the group indicates a strong desire to be included in the group conversation, even if people in the group are not talking very much. On the other hand, a person standing at one arm's length away but with hips, feet and shoulders facing slightly away from the group is sending a message that he/she has little

*continued on page 16*

## BOOK REVIEW: COMMUNICATING NONVERBALLY

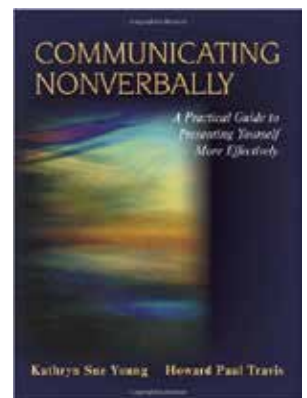
- Thea and Shawn Wier


*Communicating Nonverbally: A Practical Guide to Presenting Yourself More Effectively* is an excellent resource written by Kathryn Sue Young and Howard Paul Travis. It would be very helpful for anyone who wants to improve their communication skills.

### POSITIVE ELEMENTS:

- \* Provides practical, real-life examples and gives solutions for working through various situations.
- \* Reviews and explains different types of nonverbal communication, such as body language, touch, and personal space.
- \* Gives the reader, through workbook format, the opportunity to think through and analyze their own communication skills.
- \* Text is very straightforward and easy to understand
- \* Includes chapters on nonverbal communication in an educational setting, professional setting, and in interpersonal relationships.

This book would be very helpful for anyone who struggles with Nonverbal Learning Disability and wants to learn to overcome these challenges. The format also lends itself to a group discussion. Local TS groups might enjoy working through this together. ♦



 Find it at [textbooks.com](https://www.textbooks.com) for only \$12!

## PERFECT JUST THE WAY YOU ARE

- Karen Freedle



My story is really pretty typical. I grew up in the suburbs of Boston in a very loving and supportive family. They gave me my love of learning, deep religious faith, optimistic attitude, commitment to serving others, and confidence to be independent.

Unlike most Turner Women, I grew up not knowing I had Turner syndrome. My life proceeded in an ordinary fashion. I loved my family, my church, and school. Learning was fun for me, and I was, and still am, a voracious reader and learner. In elementary, middle school, and high school most subjects came easy to me, with the exception of Geometry.

I always knew that I was slightly different from other people. I found interacting with my peers a little awkward, and sometimes found it difficult to make friends. Although I did have select close friends growing up, with whom I am still in touch today. I was, without a doubt, the shortest person anywhere I went, and was very often teased and bullied for it, too.

I remember being brought to the Height & Weight Clinic at Boston Children's Hospital when I was a young child, as I was nowhere to be found on the growth chart. It's funny, because I remember them offering to put me on growth hormone (at that time growth hormone was desiccated pituitary), but the doctors changed their minds, saying that I would eventually "catch up" to my peers. My reaction was, "Right... I'm never going to grow." I guess I was just that perceptive, even as a kid.

Adolescence hit, and I kept waiting for the expected changes, which seemed to take forever. They finally happened at about 16 years old with normal breast development and very light and extremely irregular periods.

Life continued, and I decided on a career in health care, and was encouraged by my family to enter a career in Nursing at the University of Virginia. My first semester there, I threw myself into my studies. Always an overachiever, I took a Master's level history course, and a business "weed-out" course in statistics. I didn't do well. I failed the Master's level history course and the statistics course. This was pretty hard on me, as I'd never failed in school in my whole life. But, in true Turner syndrome determined fashion, I picked myself up and moved on, and did very well the rest of my time in college. Incidentally, my college roommate, who was also a nursing student, also had Turner syndrome.

After graduation, I took a job working on a Medical Surgical Unit at New York University's Tisch Hospital. Within 9 months, I realized my calling was actually in the field of medicine, so I took a risk and returned home to Boston to take pre-med courses. I took to them like water, earning a nearly perfect 4.0 in the pre-med classes, but the damage to my GPA had already been done due to that first semester in college. My undergraduate advisor told me I would never become a physician, especially not one at a University like I had hoped. He advised me to apply to off-shore medical schools. In some ways, he was right, but again in true Turner determined fashion I was not discouraged. I applied to every medical school and Doctor of Osteopathy school in the United States, but did not receive a single interview. Still undeterred, I then applied to off-shore medical schools and enrolled in Ross University in Dominica, West Indies in August of 1995. Living in a third-world country was a true culture shock, but I did pretty well there both academically and socially. I helped start a tutoring program and a Catholic Students Association, which, I'm happy to say, is still in existence today.

One of the proudest and most defining moments of my life was in February of 1999 when I took the Hippocratic Oath, was hooded, and became a Doctor! This was the culmination of a life-long dream and the beginning of my career in medicine. I also decided that I was meant to dedicate my life to the care and welfare of children, and entered Pediatric Residency in 1999. During Residency, I noted that I had to work a little harder at communication and social interactions than some of my peers. Networking and such things came so easily to them, but I had to work at it. I also realized that I struggled somewhat with physical procedures like blood draws, lumbar punctures, and suturing. Again, I had to practice to do well at what seemed to come so easily to others.

*continued on page 13*

### TSUS BOARD OF DIRECTORS

Carol Crawford, *President*  
 Emily Havrilak, *President-Elect*  
 Callie Shaffer, *Secretary*  
 Sarah Sullivan, *Treasurer*  
 Dorothy Baume, *Development*  
 Amanda Anderson, *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*



### BUTTERFLY SISTER'S PRESENTS

Madi at her endocrinology appointment, showing off her new necklace and earrings she received from a fellow Butterfly Sister. What she lacks in height, she makes up for in spunk and sass!

## NEW ECHOCARDIOGRAM ROOM AT TCH

Two Turner syndrome fundraising groups in North Houston, Leaping Butterfly Ministry and Circles of Hope Foundation, have partnered to sponsor the Echocardiogram Room for Texas Children's Hospital. TCH is building a new hospital in the area and their sponsorship will spread awareness of Turner syndrome to everyone who enters the room with a dedication plaque and artistic mural. ♦



LEFT PHOTO  
Debbie Browne, of Leaping Butterfly Ministry, signs the donation check for the new echocardiogram room at Texas Children's Hospital.



RIGHT PHOTO  
Leaping Butterfly Ministry and Circles of Hope Foundation present a check for \$50,000 to TCH.

## TS RESEARCH PUBLISHED IN JOURNAL OF LYMPHOLOGY



"Describing Lymphedema in Females with Turner Syndrome" was published in the Journal of Lymphology, Volume 48, Issue 3 in December, 2015.

This has been the culmination of research beginning in 2013, when Jana Rothbauer, OTR, CLT-LANA, attended the Dallas, Texas, TSSUS conference. The study gathered information through an online survey about lymphedema as it is experienced in girls and women with Turner syndrome. There were a total of 219

participants from the United States, United Kingdom, and Canada, creating an international representation. ♦

The article may be viewed in its entirety at <http://www.u.arizona.edu/~witte/lymphology.htm>.

## TS RESEARCH REGISTRY TO LAUNCH IN 2016

We're so excited about launching the TS Research Registry this year!



A registry is a place where official records are kept. The Turner syndrome registry will store answers (provided by patients and

families) and allow TS researchers to access them. The unique part of the registry is that the person that fills out the information owns the information. That means that you get to share your answers with as few or many researchers as you choose.

The Turner Syndrome Research Registry is part of a larger registry system called PEER, which stands for Platform for Engaging Everyone Responsibly.

The new Turner syndrome registry will be the one place that the entire TS community can use to support TS research with personal records. The Turner Resource Network will approve researchers and support the goals of the registry. The Turner Syndrome Society of the United States will fund the registry needs. Much more information will follow as we get closer to launching the registry survey the first half of 2016. ♦

## 2016 TRN INTERNATIONAL SYMPOSIUM

The 2016 Turner Resource Network International Symposium will take place immediately following the TSSUS conference, on July 24-26, 2016. The TS community is invited to attend the symposium.

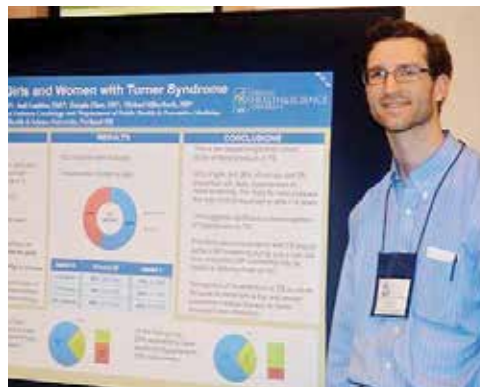
The purpose of the symposium will be to update the Turner Syndrome Clinical Practice Guidelines. This is the document that health professionals should follow to ensure quality care for their patients. The guidelines will be expanded to include important topics that were not included in the previous guidelines, and an additional document will be created so that patients and families will be able to understand the standards of care without having to get a medical degree.

Dr. Phillipe Backeljauw, TSSUS professional advisory board member, and Dr. Claus Graveholt, of Denmark, are chairing the symposium. More than 45 professional and advocacy delegates will convene to determine the best treatment options for those with Turner syndrome. The Turner Syndrome Society and the Turner Syndrome Global Alliance are working together through the Turner Resource Network to co-sponsor the 2016 symposium. ♦



LEFT PHOTO

Dr. Scott Hawley speaks at the 2014 TRN Symposium in Florida.



RIGHT PHOTO

A researcher's presentation on *Hypertension in Women with Turner Syndrome*.

## DID YOU KNOW?

Hearing loss affects a large percentage of the TS population. There are two types of hearing loss that girls and women with Turner syndrome may experience.

**The TSSUS website has added NEW RESOURCES on hearing loss!**

It includes college scholarship information for the hearing impaired, hearing aid financial assistance programs, and learning about hearing loss.

To access these resources, simply visit [www.turnersyndrome.org](http://www.turnersyndrome.org) and select 'Resources' from the menu bar.

## TS PROFESSIONAL AND PATIENT RESOURCES

TSSUS will be mailing out informational cards to you to give or mail to your physicians as a reminder that various TS resources are available!



Shown resources are downloadable at no cost and hard copies are available for small fee.



## WHAT IS THE TURNER RESOURCE NETWORK?

The Turner Resource Network (TRN) is the result of a collaborative effort of scientists, clinicians, and TS advocates (individuals with TS and family members), aimed at improving the quality of health care for those with Turner syndrome. The TRN's goals include establishing TS guidelines and promoting excellence in health care delivery, determining which TS research studies will be coordinated with the Research Registry, and supporting regional centers to provide quality healthcare and research

opportunities. The success of meeting TRN goals is dependent on the collective efforts of the Turner syndrome community (such as advocacy organizations, providers, and researchers) to identify objectives and collaborate on projects that support the timeline and needs within the TRN. ♦

The TRN program can be viewed as an umbrella program assisting in coordinating multiple individual projects that are independently sponsored by a group or person.

Current projects coordinated through the TRN include:

- The Turner Research Network Registry (TRNR); a patient powered registry which aims to be a large database containing, demographic, clinical, imaging and genetic information formed by combining 4 existing TS cohorts as well as limited self-reported data from the TS community.
- In 2017 the registry will aspire to import researcher-obtained data back into the TRNR.
- Quality TS Resource Centers
- Quality care documents for Professional TS Care Providers
- The 2016 International TRN Symposium with the goal of revising the TS Clinical Practice Guidelines.



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

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

## FALL REGIONAL CONFERENCE

Held in North Carolina This Past October



The Turner Syndrome Society's North Carolina Chapter held a regional conference, "Bloom, Grow, Blossom" at the end of October in Charlotte, NC. There were over 110 attendees from all over the east coast including Pennsylvania, Maryland, and Florida.

The children's program included more than 30 participants. They learned about TS and social acceptance. After lunch, 20 girls

enjoyed an afternoon of bowling.

Speakers included Dr. Jessica Lord Bean, Courtney Strauss, Dr. Jennifer Law and several of her colleagues involved with the TS Clinic at UNC-Chapel Hill. Some topics presented were TS & Cardiac Effects, Executive Function, Self-Image, and Auto-Immunity & Infections in Turner Syndrome. ♦

### NEXT YEAR'S REGIONAL CONFERENCE WILL BE HELD IN RALEIGH, NC!

Information can be found on our website beginning in March at [www.tsnorthcarolina.wordpress.com](http://www.tsnorthcarolina.wordpress.com) or the TSSUS events page at [www.turnersyndrome.org](http://www.turnersyndrome.org).



## HB CARES EVENT

TSSUS President-Elect, Emily Havrilak (right) and Dianna Fuller (left) at the HB Cares event in Minnesota.

Dianna, who works with Helms Briscoe, is instrumental in helping us locate and secure our annual conference hotels. Thank you, Dianna, for supporting the TS community! ♦

## PATIENT EDUCATION DAY IN SUNNY CALIFORNIA



The Central and Northern California Turner Syndrome Resource Group hosted their yearly TS Patient Family Education Day on Saturday, November 14, 2015, at Peace Lutheran Church in Sacramento. There were approximately 60 TS girls, women and their families in attendance to listen to Mitchell Geffner, M.D., of Childrens' Hospital of Los Angeles speak on growth, diabetes and metabolism in Turner syndrome.

The other speakers included Catherine Devine, Genetics Counselor, who spoke on "The Genetics of Turner Syndrome," and Mysti Harrison, Parent-at-Large Board Member, who spoke on non-verbal learning disability. Our members also enjoyed a wonderful catered lunch, and this event was made possible by generous funding from Eli Lilly, Genentech, Novo Nordisk, Pfizer, and Sandoz.

These TS Patient Family Education Days have been held over the past 25 years at Lucile Packard Childrens' Hospital at Stanford, Valley Childrens' Hospital in Madera, and Sutter Memorial in downtown Sacramento. The resource group tries to move these information days around to various locations, so that all of our members can enjoy attending and listening to the various speakers. These information days were originally started about 25 years ago by Rosemary Starr Morris, and were first held at Lucile Packard in Stanford. ♦

## FAMILY FUN DAY

The Northwest Panhandle Resource Group celebrated their 2nd Annual Family Fun Day with smiles while raising awareness. ♦





## CELEBRATING THE SEASON TOGETHER

Good food, good friends, and lots of hugs and smiles!



PHOTOS  
The Kansas City Chapter enjoying an evening of fun, accompanied by a plentiful pot-luck feast!

PHOTOS ABOVE

The Middle Tennessee Support Group celebrated at The Gondolier, in Murfreesboro, TN. Along with conversation and laughs, the ladies enjoyed a “dirty santa” gift exchange.



PHOTOS ABOVE

Ladies from the Northwest Florida Panhandle Resource Group enjoy each other’s company at their holiday party, while remembering Amber Gallo.



PHOTO ABOVE

The ladies from the Orange County Chapter enjoyed an evening of holiday festivities!



## HOLIDAY PHOTOS

Cover model Clare, and Mom pose for Holiday photos. Clare is now two years old and happy as ever!

## Chasing Butterflies The Walk for Turner Syndrome



### HOW TO GET INVOLVED WITH A WALK IN YOUR AREA

Our fantastically popular program, Chasing Butterflies: The Walk for Turner Syndrome, 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.

#### Want to host a walk?

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

#### Want to just walk?

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

#### 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.

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

#### FOR MORE INFORMATION

800-365-9944  
Deborah@turnersyndrome.org  
TS Walk page: [www.tssus.org](http://www.tssus.org)

## THE NATIONAL WALK

### Chasing Butterflies: The Walk for Turner Syndrome

TSSUS helps individuals organize walks in their own communities to bring awareness to Turner syndrome. These walks benefit the initiatives of research and support and the national office receives 100% of the proceeds after expenses.

We are excited that twenty-one walks were held in 2015, resulting in over 1400 participants and about \$80,000 in registration fees and donations! Because of these wonderful coordinators, TS is more known in these communities and the proceeds were so great. We are grateful to each one, including their teams of volunteers and all the participants. ♦

Ashleigh Dorfman with Nation's Capital R.G.

Sarah Shutt with Central Virginia R.G.,  
Fredericksburg, Virginia

Ashley Abbott, The Villages, Florida

Brittany Rayoum with St. Louis R.G., Belleville, Illinois

Cathy Neely, Lebanon, Ohio

Cheri Svagerko, Conference Walk in Kansas City,  
Missouri

Darlene Hay with Butterflies of S. Florida R.G.,  
Pembroke Pines, Florida

Deanna Carey with Western Oregon R.G. in Auburn,  
Washington

Erica Bautista, Sacramento, California

Erica Melman, Elk Grove Village, Illinois

Glena Gibson with Oregon R.G., Portland, Oregon

Jen Borcena, Redlands, California

Katie Visner with West Michigan Chapter, Grand  
Rapids, Michigan

Kelley Valenzuela, Monahans, Texas

Kelly and Lisa Jasper with Arizona Resource Group,  
Scottsdale, Arizona

Krystina Reeb, Newark, Ohio

Lynda Taylor with Delaware Valley R.G., Newark,  
Delaware

Mikayla Espista, Bryan, Texas

Patty Collins with Boston R.G., Boston,  
Massachusetts

Penni Sheets, Wilksboro, North Carolina

Sarah Sandven, Ft Dodge, Iowa

Tamyka Campbell, Davies, Florida

*R.G. stands for Resource Group (formerly known as Support Groups.)*

## CHAPTER WALKS

Some TSSUS Chapter Leaders also held walks in their communities in which 80% of the proceeds after expenses remained with the Chapter for local goals (over \$37,000) and 20% was retained by the national office for national goals (over \$9,200.) We're grateful for each coordinator and their teams in which over 450 people participated in the walks, raising awareness and funds. ♦

Heather DeRousse, Houston Chapter

Julie Leon, Minnesota Chapter

Lisa Smith, North Carolina Chapter

Tamara Douglas, Colorado Chapter

## FABULOUS SOCIAL FUNDRAISERS OF 2015

A social fundraiser for TSSUS is someone who creates a digital fundraising page for any walk they participate in and who receives donations because they share their story with TS, asking for support of TS and TSSUS. We thank these 187 individuals, whose efforts, combined with the walk coordinators, resulted in over 1,000 donations to the walks in 2015. They truly are Fabulous Fundraisers! ♦

Alison Boettcher  
Amanda Holguin  
Amanda Pennington  
Amy Zambrano  
Ashley Titus  
Audrey Bixler  
Barbara Beck  
Barbara Pannell  
Beth DeCamp  
Brandy Greening  
Breanna Hoadley  
Brittany Rayoum  
Caley King  
Cara Holguin

Carla Darnell  
Carol Crawford  
Cheri Svagerko  
Cheryl Foust  
Christina Rogers  
Cindy Kenward  
Dana Elizabeth Tucker  
Deanna Lail  
Deb Norkus  
Deidre and Kevin Lock  
Dominick Russo  
Donna Rice  
Dorothy Baume  
Elaine Fraizer

Elizabeth Bubelnik  
Erica Bautista  
Erica Haag  
Erica Melman  
Erica Scheuder  
Florrie Katchen  
Heather Anne Gooch  
Heather DeRousse  
Heather Matz  
Jamie Gomez  
Jamie Stowe  
Jean Fischer  
Jen Czarnecki  
Jennifer Lynn Spencer

Jessica Budahn  
Jolene Manternach  
Joni Ensminger  
Josefina Jimenez  
Karyn Willie  
Katherine  
Vivanco-Risner  
Kathy and Ed Boyle  
Katie Breedlove  
Kelley Valenzuela  
Kim Graham  
Kris Fulkerson  
Kristy Holben

*continued on page 14*

## CHASING BUTTERFLIES IN VIRGINIA

1st Annual TS Chasing Butterflies walk in Fredericksburg, VA: Walking for Awareness.

The Nation's Capital TS Resource Group, in collaboration with the Central Virginia TS Resource Group, hosted the 1st Virginia Chasing Butterflies Walk and Picnic on Sunday afternoon, September 27, 2015 at Old Mill Park in Fredericksburg, VA. Approximately 15 people, including 6 girls and women with TS, attended the event. Members were from cities as far as St. Mary's County, MD and Richmond, VA.

To make the walk fun, they posted handmade butterflies, which were made at their previous picnic, with awareness postcards along the route; participants spotted the butterflies and took photos. Other walkers could read about Turner syndrome as they walked by. After the walk, participants enjoyed mingling and eating our potluck picnic in the pavilion. ♦



### PHOTOS

Butterflies and their families from the Central Virginia TS Resource Group joined together this past September. They posted handmade butterflies and awareness postcards at each of the pathway's mile markers.

### ABOUT THE NATION'S CAPITAL RESOURCE GROUP

We are the Nation's Capital Resource Group of the Turner Syndrome Society. It is our mission to assist TS women and girls, as well as their parents/guardians. Our group serves Northern Virginia, Maryland and the District of Columbia. We meet 3-4 times per year, in which we host educational meetings and social events, such as our Annual Potluck Picnic. In 2015, in collaboration with the Central VA Resource Group, we hosted our 1st Annual TS Chasing Butterflies walk in Fredericksburg, VA. ♦

## WALKS AROUND THE COUNTRY



### ABOVE

Chasing Butterflies Walk in Delaware. Walkers hold a 'Thank You' sign for the support they received.

### LEFT

TS Butterflies in North Carolina smiling after their walk and face painting!

### JOIN THE CHASE

Upcoming Walks in 2016!

The Villages, FL . . . . .2/06

Hollywood, FL . . . . .2/20

Birmingham, AL . . . . .2/20

Sacramento, CA . . . . .2/20

Destin, FL . . . . .2/27

Land O' Lakes, FL . . . . .4/16

Ft. Wayne, IN . . . . .5/14

## MAKING MILESTONES: HOW I CAME TO TERMS WITH MY INFERTILITY

- Bailey Lynch



My name is Bailey. I am a twenty year-old, Michigan-born girl living with Turner syndrome. My chromosome number is 45x47xxx, an extremely rare case. Being this rare is both a blessing and a curse. It is a blessing in the sense that I miss out on most of the health defects: I don't have the webbing on my neck, my hands and feet aren't puffy, and I'm pretty much a giraffe at 5'3". It's a curse because when I do have certain health problems, it takes awhile to figure out what is going on because it doesn't happen with most girls with TS. And up

until about a few months ago, I would have considered the infertility that comes along with TS a curse as well.

I am very much aware of the fact that nearly all women with Turner syndrome have ovarian failure, and as a result, cannot conceive naturally. An extremely small percentage of women with TS are granted the ability to have kids. I would consider this a miracle for how unusual it is. These statistics don't change the fact that coping with this inability can be very difficult. It certainly was for me, for the longest time. As women, we are raised believing that one of the biggest things that we will do, if not the biggest thing, is to become pregnant and have children. As a kid, I often wondered about who my children would look like more-me, or my husband. This idea is essentially ingrained into our minds, simply because we are female. Because we are women, we are immediately expected to reproduce someday.

When something complicates this, it's not hard to draw the conclusion that we aren't "real" women. I remember the day when I first really understood the concept of infertility. I was thirteen years old. I was in a doctor's appointment and my mother and I were in one of those back rooms, waiting for the doctor to come in and talk to us about the possibility of jaw surgery for me. There had been a lull in conversation, and I was once again contemplating my future kids and who they might resemble more. I put this thought into words, and that was when I learned the truth: I did not have any eggs left, and therefore could not be a biological mother. This hit me hard. I felt like someone had taken a cinder block and pressed it onto my chest, creating an unmeasurable amount of pain. One of my childhood dreams had been taken away from me. I've never liked crying, and I especially don't like doing so in a public place where people might see me and hear me, but I couldn't force down this overwhelming amount of grief. I burst into a mess of hot tears. My mother held me as I fought to regain composure in time, before the doctor arrived. I managed to calm down, but I was dismal during the entire appointment and only uttered a maximum of five words every time I talked. I depended on my mom to do the talking for me.

I struggled with this insecurity for a long time. Sometimes I would keep it to myself, suffering silently. Sometimes I would vent to my mom. This usually consisted of lots of tears and almost yelling from my end. My mom would offer me advice and remind me that there were other ways of being a mom, but I didn't listen. I couldn't listen. I was too focused on the fact that I couldn't do what I'd most wanted to do: be a biological mother. I'd become ashamed of the fact that I could not be a mother the "natural"

way, and I held on to any string of hope that I might be able to be a biological mother, even if it was the slimmest chance in the world. I've never been good at accepting the fact that there are things beyond our control.

A big part of the issue also stemmed from a fear of judgement. What if people judge me for not being able to have kids? What if they say I won't be a "normal" mother? And here was the real zinger: What if my boyfriend/fiancé/husband leaves me because we can't have a family the "natural" way? As irrational as it sounds, this was one of my biggest fears, and I still sometimes worry about it, to be honest. One day, though, everything finally clicked.

I was lying on my bed in my dorm room, scrolling through my Facebook feed, when I came across a political compare-and-contrast cartoon. It showed one couple that appeared fit to have a family and wanted to adopt, but yet they were denied by the agency because they were a same-sex couple. The other couple was a man and a woman, but the major difference was that the house was in poor condition, and that when the man wasn't abusing the kids, the children were running around and causing ruckus because the mother cared more about her well-being than the kids'. Yet, they had a seal of approval from an adoption agency. I remember looking at this and thinking "Gosh, that is no way to treat a kid; I would be a much better parent to those children than those parents right there."

Suddenly, it clicked. It didn't matter how the child was related to the parent: biological, surrogate, or adopted. That child is a person, and deserves to be loved and have wonderful parents. One of the things that my mother always told me was that when you first see your child, it doesn't matter how they're related to you; the only thing you feel at that moment is how incredibly happy you are to not only be a parent, but to be that child's parent. And it finally held true with me—I knew that I would love my kids unconditionally, no matter how they came to me, be it biologically, via a surrogate mother, or by adoption. I switched my mindset from "I can't" to "I can." I was emotionally drained and exhausted after years of seeing my infertility as a curse, when in reality, it's a window of opportunity. A good friend of mine offered to be a surrogate mother for me when the time comes. There are plenty of wonderful children out there, waiting for someone to adopt them, and I am more than willing to be the parent for a few of them someday. My infertility does not make me any less of a woman, and adopting kids or having a surrogate does not make me any less of a "real mother." The people who really love you will understand this and accept you as you are. My friends who know about my infertility, along with my family, have made it a point to remind me how much they love me by helping me deal with this insecurity.

This major switch in perspective has made me feel so much more comfortable in my own skin. I had a choice of attitude here, and I finally opened my eyes and chose the one that would benefit me more. Sometimes, you might not have control over the situation itself, but you can definitely choose how you react. I want to live a happy life, so I accepted the fact that I cannot change my infertility, and decided to look at it in a more positive light. I would be an awesome mom to some pretty special kids. There will be those who cannot see this, but I choose to not surround myself with these people. I have a wonderful, supportive group of people in my life who love me for me. I only have one life to live on this earth, so I'm going to make the best of it. ♦

## GOALS, NOT RESOLUTIONS

- Mira Dessy, The Ingredient Guru



*The problem with resolutions is that we go about it the wrong way. We write down the results we are looking for not how we plan to get there.*

In order to be successful with your anticipated changes for the new year set goals instead of creating resolutions. Goals are a desired outcome as opposed to a resolution which is more finite. If we do not live up to our resolutions frequently we are left feeling discouraged and possibly have a loss of self-appreciation or self-confidence. With goals the end result is planned for but not mandated. Along the way there may be reasons that you did not achieve your goal which you can examine and reconsider. With goals we use qualifiers in order to think about how we will achieve our desired outcome. Be prepared to think all the way through the goal to increase awareness and mindfulness.

### STAY FOCUSED

**Stress.** Don't overwhelm yourself by setting too many goals at once. If you decide that in the next two weeks you are going to lose 20 pounds, start a new high-intensity exercise program, and give up your daily fast food run you may find yourself feeling overwhelmed. When we try to do too much all at once we can be setting ourselves up for failure. Reasonable expectations and a wellthought out plan will be the cornerstone to your success.

**Be Kind To Yourself!** A goal is a hoped for achievement. If you do not master your goal it is not because you have failed. It simply means that you were not able to get to where you thought you might. This mindset gives you the ability to be flexible with your goals. It's not an all or nothing proposition.

**Review.** Remember to stop occasionally and look back at how far you've come. Change is a positive thing and you need to celebrate your successes. Review your plan and take a moment to acknowledge your achievements as you keep working towards your goals. ♦

## HEALTHY RESOURCES

### Stay Active

The American College of Sports Medicine recommends 30 mins moderate activity 5 days/week or 20 mins vigorous activity 3 days/week to stay healthy and reduce risk of chronic disease.

### Keep Calm

Reducing stress can help to support the immune system.

### Mindful Eating

Slowing down when you eat makes you more aware of portion sizes, can increase meal enjoyment, is more nourishing, and helps you get out of negative, automatic food habits.

### Focus

Tracking your goals allows you to see your progress and gives you the focus to reach them.

FOR MORE INFORMATION  
[www.grainsandmore.com](http://www.grainsandmore.com)

## PERFECT JUST THE WAY YOU ARE *continued from page 5*

Then, out of the blue, came another defining moment. At 31 years of age my periods just stopped. I waited 3 months, 4 months and... nothing. I knew something was off, as there was 0% chance I was pregnant. I also knew the most likely reason why; early ovarian failure and Turner syndrome. I discussed my concern with a trusted friend and colleague (a fellow Pediatric Resident), who also happened to have Turner syndrome. With her support and encouragement, I made an appointment with the geneticist to have my blood drawn for a karyotype. The results (Isochrome X and Turner syndrome) didn't surprise me much. Looking back, the diagnosis made sense to me, and helped me understand myself better: the short stature, difficulty with geometry, challenges with social interactions, late puberty and irregular periods, difficulty with physical procedures, etc.

My diagnosis of Turner syndrome hasn't stopped me in my career. I became a Pediatric Allergist working at prestigious academic universities, and a published author of both research and a children's book. My passion is educating and empowering peers and patients. I feel it is important to provide patients with the tools to help themselves improve their own health, and I love helping future physicians develop the skills they need to be superb clinicians.

My diagnosis of Turner syndrome hasn't stopped me in my personal life,

either. I have always had a loving family, and have developed several close and long-lasting friendships. And happily, a few years ago, I was blessed with meeting the most amazing and loving man, whom I married. My husband has helped me in so many ways to understand and accept myself for all that I am.

Ultimately, Turner syndrome is just one part of who I am. It doesn't define me, or any other woman with Turner syndrome for that matter. It will also not keep me from continuing to live my life in service to others, or keep me from striving to chase the next dream.

I hope reading my story will encourage mothers of girls with Turner syndrome. To those mothers who are awaiting the birth of their daughter, who may fear for their daughter's future, I hope my story helps you see that women with TS can and do lead full, happy, and productive lives. To those mothers who are parenting a child with TS, I hope that you, too, can see that we women with TS can accomplish whatever we set our minds to with love and support! I also hope my sisters with Turner syndrome will find my story gives them hope and courage that they too can continue to reach for, and expect to fulfill, their dreams. You, my sisters, are perfect just the way you are! ♦

## WE HONOR & REMEMBER

TSSUS proudly thanks everyone whose gifts make awareness, research and support happen.

**In Honor of:**

Abbey Kartak  
Abby Bleich  
Abby Lemieux  
Abigalle Crawford  
Addison Doyle  
Adeline Nolan  
Alani A.  
Alani Borcena  
Alex Boyle  
Alexandra Terry  
Alicia Graham  
Allison Schwartz  
Andrea Centeno  
Andrea Karagolian  
Anna Thompson  
Anneke Wolpert  
Ashley Elizabeth Carlson  
Ashlyn Dixon  
Ashlyn Zieba  
Ashton Ford  
Audrey Andersen  
Avery Farrell  
Baby Girl Busscher  
Bella Davidson  
Bonnie Griff  
Bradi Ann Reigle  
Brenna Giblin  
Brianna Williams  
Brittany J. Abbott  
Brittany Taylor  
Brooke Kaczynski  
Caitlin Gibbs  
Caitlin Sullivan  
Caleb Lyle  
Caroline Alexander  
Carolyn Gibbs & Mike McCully  
Cathy Moore  
Cece Russo

Chloe Lilian Howard  
Claire Allen  
Claude Sitton  
Cosette Dover  
Dave Goddard  
Deanna Lail  
Delaware TS Community  
Donna Rice  
Dorothy Baume  
Drew Narum  
Eileen O'Neill  
Ella Brown  
Ella Manternach  
Ellie Brown  
Ellie Kay Ragland  
Emily Enciu  
Emily Pawlowski  
Emma Jones  
Erica Lambert  
Erin Timmermann  
Felicia Mullins  
Gabby Budauy  
Grace Lawlor  
Grace Umbarger  
Gracie Budahn  
Gracie Gulyas  
Hailey Fresquez  
Hannah Brooks  
Hannah Hayes  
Helen Sokol  
Hope Dawn Kistner  
Hope Lorenz  
Isabella Matz  
Isabella Rose Terence  
Jenna Brennan  
Jenna Culin  
Jennifer Glazer  
Jennifer Kennelly  
Jessica Peters  
Jodin Jordin

Josefina Jimenez  
Josephine Hearn  
Jules Romeo  
Julia Holguin  
Kailyn Gomez  
Katreena Subramanian  
Kaydence Smith  
Kim Kelly  
Kimberly Gamson  
Kinsley Stavinoha  
Kristy Holben  
Kylee Hay  
Lauren Flemming  
Lauren Patris  
Lauren Robinson  
Lottie Crawford  
Madeline Schlaman  
Madison Briggs  
Maggie Wingerter  
Makenzie Norkus  
Marisa Hagar  
Marsha Davenport  
Mary Kay & Sal Carta  
Mattie McCarthy  
Mckaylyn Pennington  
Mckenzie Edwards  
Megan Einck  
Megan Willeford  
Mia Kayne  
Nancy Kay Elizabeth Sanders  
Natalie Bunch  
Natalie Cronberg  
Naveah Zamora  
Nicole Bonfig  
Nola Marie Douglas  
Nora Grace Lock  
Nyssa-sky Mima  
Olivia Zeni  
Pamela Finson  
Rachel Harris

Rebecca Hailey  
Robin Engle  
Rosemary Morris  
Rosie Lawson  
Sarah Braun  
Sarah Evans  
Sophie Reay  
Sophie Zambrano  
Stella Ward  
Susan Jennings  
Sydney Ann Mandeville  
Sydney Short  
Sydney Svagerko  
Talya Toker  
Taylor Czarnecki  
Taylor Shellhammer  
The Frazier Family  
The Sperlazzo Family  
Thea Wier  
Tori Sheets  
Tula Coleman

**In Memory of:**

Ainslie Lynn Meier  
Alaina Anne Campbell  
Allie Usher  
Amber Gallo  
Angela Morel Mejia  
Annie Ruth Kelly  
Avery Layne Farrell  
Baby Atteberry  
Brianna Raye Biethman  
Bronwyn Davies  
Carol Walters  
Carrie Faye McDaniel  
Catherine Joan Genetti  
Daria Colucci  
David William Hill  
Deborah Dimm Guidry  
Edyth G. Berry

Elaine Boisvert  
Elyza Jane Noble  
Emerylle Grace Warford  
Emilia Gail Brender  
Grace Elizabeth Blair  
Grandma Nourie  
Heather Frederickson  
Herbert Holguin  
Hope Schultz  
Jami Penny  
Jennifer Scott  
Jim Booth  
Joyce Sousley  
Julia Carlson  
Karen Bruwelheide  
Kellie Fernandez  
Lauren Harris  
Laverne Turner  
Lilian Skiver  
Lily Anderson  
Linda Tremain-Agnew  
Mary Beth Fortunate  
Mary Lou Bolton  
Melvin Bueckler  
Molly Costigan  
Our Lost Baby Girl  
Poppy Pfaff  
Raegan Jo Gay  
Rashawne Good Friedenson  
Reagan Bienz  
Robert Harris  
Sarah Horowitz  
Sarah Marinoff  
Sue Harrington  
Suzanne Bowman  
Violet Stanczyk  
William Murray

## FABULOUS SOCIAL FUNDRAISERS OF 2015 *continued from page 10*

Kymerly Pyeatt  
Laura Becker  
Lisa Smith  
Lorena Fresquez  
Lori Coleman  
Lynda Taylor  
Lynn Huber  
Margaret Vargas  
Martha Lawlor

Mary Anna Kayne  
Marybel Good  
Meghann Poku  
Melody Sinclair  
Molly Van Gilder  
Nakia Mima  
Nancy Bryant  
Penni Sheets  
Rebecca Hailey

Sara Folsted  
Sarah Hearn  
Sarah Narum  
Sarah Sharp  
Sarah Stechschulte  
Sarah Sullivan  
Shelly McCormick-Lane  
Steve Fronck  
Tamara Douglas

Tevis Thompson  
Theresa Dlugopolsky  
Thomas Boros  
Tiffany Jones  
Tonnie Zezulak  
Tressie Bach  
Wendy Rykowski

## 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)

# THANK YOU DONORS

TSSUS proudly thanks everyone whose gifts make awareness, research and support happen.

The following lists include general and annual campaign donors. Additionally, we appreciate the hundreds of donations given to walks, and those gifts given anonymously, by corporations and by small businesses.

*If we have inadvertently omitted or made an error in the listing of your name, we apologize. Please contact us at [tssus@turnersyndrome.org](mailto:tssus@turnersyndrome.org) to correct your record.*

Rebecca Abbott	Wendy Bunch	Tamara Douglas	Genetech	Emma Jinkerson	Alyssa Lynn Malmquist
Susan Adams	Sally Burk	Troy Douglas	Michael Genetti	Lindsay Johns	Carolyn Manning
Angela Albarran	Leslie Burrows	Gigi Dover	Mary Gentleman	Revon Johnson	Karen Mccabe
Alyssa Dawn Albee	Martha Cain	Gail Dowling	Connie J. Gheen	S. B. Johnson	Denise Mccaney-
Jorge Alvarez	Pat Campbell	Kim Drake	Helen Gibbons	Diane Jones	Whitmore
Susan Jacobsen	Tom Campbell	Robyne Beth Drexler	Carolyn Gibbs	Gary Jones	Andrea Mccarthy
Mary Ann & Joel	Italo A. Cardenas	Sharon Duffy	Mary Gladden	Leslie Jones	Trudy Mccarthy
Andersen	Deanna Carey	Maureen Dunlevy	Stan Glazer	Stacey L. Jones	Joanne S. Mcclelland
Amanda Anderson	Brenda Carlson	Marjorie Durst	Lisa Glenn	Lauren E. Jue	Mr. & Mrs. Ellicott
Rick Anderssen	Teresa Carlson	Jean C. Eakin	John Gordon	Josh Kaczynski	Mcconnell
Yvette Appel	Richard Carmassi	Eastern Star of	Gary Gould	Nancy Kaczynski	Kim McFall
Monica Autrey	Thomas Carmen	Missouri	Ronald & Deborah	Linda Kalb	Stephen McGillivray
The Borgman Family	John Carta	George & Renee Eberly	Govin	Kimberly Kane	Susan McNamara
Juana Baez	Sue L. Casacia	Joyce Eberly	A. R. & H. G. A.	Dawn Karagosian	V. A. McWalters
Cheryl Bailey	Soraya Casanova	Ann Edwards	Graham	Panagiotis Karatzas	Jennifer Meinert
Jo Bailey Sitton	Frank Cesare	Mark Edwards	Peggy Graham	Margaret Kartak	Terry Meisinger
Melissa Ballagh	CFC	Megan Edwards	Greater Milwaukee	Joan Katz	Catherine Ward Melver
Sandy Baptiste	MN Chapter	Sue Einck	Foundation (Wiberg)	Joanne Kaufman	Glenda Melvin
Stephen Sartori	Sharon Chleboun	Eli Lilly & Company	Elayne Green	Susan Louise Kempler	Emily Metcalf
Catherine Baume	Tim & Sue Chlopowica	Michelle M. Ellsworth	Sharon Grube	Cindy Kenward	Narcisa Meza
Dorothy Baume	Jim Choi	Dorothy Engle	Ebru Kadriye Gultekin	Michael Keselica	Carolyn Michielutti
Cathleen Beggy	Chrissy Stavinoha	Eleanor Epstein	Catherine Gulyas	Carol Keyser	Aaron Miller
Claudette Beitaharon	Judy Clark	Leanne Ethridge	Sanjay Gupta	Donna Kirk	Janet Susan Miller
Cindi Benfield	Timothy Claxton	Barbara Etzin	Frankie Gurganus	Bradley Klussmann	Laila Minter
Jane Berne	Karina L. Coffe	Evelyn Evans	Sandra Haack	Lee Koffler	Diane Misener
Andrea Beyke	Sarah Connolly	Kerry Fairchilds	Michel Habashy	Karen Krane	Sue Monaco
Rael & Mary Blair	Jessica Conroy	Lawrence & Taralyn	Carol Hagan	Leigh Kratka	Diana Moore
Ruth Boerner	Beverly Cook	Farrell	Elizabeth Hall	William Lafranchi	Barbara Moraczewski
Gregory Bolton	Michael Costigan	Lois Feller	Kathy Sue Haney	Stephen Laner	Rosemary A. Morris
Natalie B. Bonfig	Anne Crawford	Lynn Ferguson	Patricia Haniford	Barbara Larsen	Patricia Mosher
Margaret Booth	Carol Y. Crawford	Mary Jo Finley	Edrie Harrington	David Laurel	Molly Moursi
Melissa Sue Booth	Nancy Crawford	Patrick Finley	Lesley Harris	Maria Lawson	Felicia Dawn Mullins
Lois Borgman	Donna Crivaro	Mary Fisher	Peggy L. Harris	Leaping Butterfly	Roland Mullins
Peter Bowman	Richard Cronberg	Kathryn Fitzpatrick	Emily Havrilak	Ministry	Isabell Munoz
Janine Braman	Catherine Crouch	Sean Fleming	Mary Hayden	Peggy Lebrun	Leticia Murillo
Katie Braman	Janice Crow	Flemings - St. Louis	Jim & Joy Haynes	Kathleen Lelonek	Sarah Beth Murphy
Rhonda R. Brame	Dennis Culin	Community Fdn.	Stephanie Hedbor	Julie Lemieux	Ron Musselwhite
Beth Brampton	Colleen Curby	Barbara Flink	Heddy Murphey Brown	Carol Lench	Anne Naber
Robert Bratman	Ann Currie	Lisa Florack	Patricia Heflin	Carmen Lesieur	Stephanie Naccarato
Katie Braun	Keith W. Curtis	Mike & Heather Flynn	David Hendrickson	Glenn Lewis	Jean Naeger
Elizabeth Brazier	Colleen Daman	Elizabeth Fontenot	The Hibert Company	Sheri Lewis	Brittany Nelson
Teresa Brazil	Ann Danner	Joanne Foodim	Janel Hofler	Angela Lin	Janet Neyens
Elizabeth Brender	Tania Danner	Vicki Ford	Eleanor Hoke	Barbara Lippe	Fatima Nieves
Michelle Brennan	Wanda Davenport	Candace Forte	Paula Holmes	Craig Liska	Kim Niggeman
Bonnie Brenner	Jenifur Davidson	James Forti	Amanda Holquin	Katie Liszkay	Kara F. Nolan
Janet Breuer	Carol Davis	Robert Fortunate	Andrea Horner	Kassandra Livingstone	Sean Nolan
James Brobin	Randal Dawson	Jeannine Freudenberg	Tyrone C. Howard	Keenan Lorenz	Novo Nordisk
Vallye Brooks	Stephanie Debellis	Donna G. Frey	Susan Hoy	Christina Losoya	Jeremy Boss
Heddy Brown	Phil Denino	Toby Friedman	Brendan Hupf	Karen Lundholm	Marianne Nucci
Helen Brown	Leslie Depiero	Steve Fronck	F. Husky	Heather Lynch	Janelle O'connor
Karen J. Brown	Mira Dessy	Gamers For Cures	Michael Husky	Catherine Lyon	Carrie A. Odom
Kathy Brown	Elisa Romano Dezolt	Steven Gamson	Jeffrey Hynes	Rosanne Macdonald	Trisha Estes
Melanie Brown	Michelle Dharte	Angelica Garcia	Maria Imbalzano	Victoria Macdonald	Craig & Patricia Orcutt
Selma Brown	Mildred Diehl	Javier Garcia	Scott Jameson	Diana Mack	Money Order
Jessica Brumbach	Nancy Doering	Leslie Garrison	Rebecca Jenkins	Stacey Macko	George Ouellette
Madeline Bryson	Douglas Dolan	Ryan Gaylord	Janet Jensen	Kathleen Maley	Andrew Dunn

## SOCIAL COMMUNICATION *continued from page 4*

desire to communicate. Thinking about your own and others body language will help determine what messages you are sending and receiving in a variety of situations

### Step 3: Use your eyes to think about people as you relate to them.

Our eyes are the 'window to our thoughts' and are the most powerful nonverbal clue that indicates our desire to communicate. Even if our physical presence sends the message that we want to communicate, others are still not sure until we connect with our eyes. For example, if we want to join a group conversation, we must slowly walk up to the group and listen with our eyes to the conversation by 'bouncing' our eyes from person to person while following the comments of those speaking in the group. Next, we 'lock our eyes' on someone while listening to them so they know our desire to enter the conversation. Once they see our eyes, the person will usually pause and ask a question or just wait until we interject with a question or a comment.

Conversely, too much eye contact can leave the wrong message with people. If we consistently stare at someone from across the room without approaching them, it may make them feel like we are stalking them, however directed and constant eye gaze at work communicates a sense of urgency and is totally acceptable when an important message needs to be communicated, whether a person is standing alone or walking with others.

### Step 4: Use your words to relate to people when you talk to them.

Once we read the thoughts and intentions of others around us, use our body language and our eyes to connect with others, our language helps us make connections with others around us. We use language in lots of different ways to connect with others and build relationships with them, however some people have significant difficulty figuring out what to talk about with others. One strategy in social language involves showing

interest in others, even when they are not very interesting. People don't always remember what you say, but they always remember how you made them feel, so when you ask on topic questions and/or comment on what they are talking about, you will leave a positive impression with your new acquaintances.

Here are a few suggested topics for starting a conversation with others:

1. Seasonal topics: holidays, vacations, annual events (i.e. Super Bowl), etc.
2. Current Events: News events, sporting events, school related events, etc.
3. Commenting on what we observe going on around us: People walking by, buildings or shopping centers going up, weather events, traffic patterns, etc.
4. Common interests or shared memories: This requires having a little knowledge or past experience with a person but if you don't know someone well, asking questions to learn more about a person's interests is a good place to start.

Social communication can be tricky for many of us, but the 4 Steps of Communication provide helpful strategies for becoming a more effective social communicator across a variety of settings and situations. ♦

*If you would like to learn more about the 4 Steps of Communication, you may find more in depth information in the following books.*

*Socially Curious and Curiously Social: A Guidebook for Bright Teens and Young Adults; Second Edition; 2009. Written by Michelle Garcia Winner and Pamela Crooke.*

*Social Thinking At Work; Why Should I Care? A Guidbook for Understanding and Navigating the Social Complexities of the Workplace; 2011. Written by Michelle Garcia Winner.*

## THANK YOU DONORS *continued from page 15*

Lisa Diane Pack	Kathryn Kay Powell	Jenn Rothwell	Brent Skiver	Mary Beth Terry	Carolyn Webber
Tobey L. Pafundi	Michael Powell	Carl Royal	Nikole Slagal	Debra Katherine Terzakis	Philip Webber
Margaret Palmer	Shelley Pryor	Peter Saad	Karen Smith	Robert Tew	John Webster
Phyllis Pan	Loretta Quick	Theodore Saito	Stephen Smith	Stephanie Tharp	Maria Whamond
Mary Papp	Michael Ragland	Hope Salazar	Nancy Sobelson	Michael & Donna Thralls	Joyce Wheeler
Alison Patterson	Dulmati Ramrattan	Angel Sanders	Christine Solanos	Corwyn Tiede	Scott M. Whitlock
Karoline Patterson	Raoutie Ramrattan	Valerie Sands	Chris Spott	Robert Tremain	Shawn Wier
Lori-Ann Pawlowski	Jace Rauman	Cathy Schreiber	Maureen Staley	Dianna Trentham	William Wigley
Danette Pelletier	Brad Reay	Jeffrey Schreiber	Gary Stanczyk	Carmella Trodden	Susan Wilkins
Patricia Pennewitt	Lisa Reff	Shannon Schroeder	Beth Statman	Susan Trotman	Eileen Williams
Elizabeth Perley	Allan Reiss	Delores Schulte	Claudia Stensland	Charlotte VanErman	Priya A. Winston
Michele Pertle	Greg Ricketts	Tiffany Schulte	Diane Stewart	Deborah Vanlittersum	Sandy Winter
Adrienne Peterson	Kara Rigby	Karen Schultz	C. J. Stinson	Zabelle Vartanian	Lynn Wogtech
Randall Petr	Gayle Risley	Joan Schulz	Courtney Strauss	Bridget S. Vaughn	Melissa Wolfenbarger
Stacey Pfaff	Lauren Robinson	Denise Schwab	Katherine Stronk	Nique Villegas	Phillip Woods
Pfizer, Inc.	Linda Robinson	Paula Schwartz	Paula M. Nagle	Carole Volz	Sherry Wright
Mary Phelan	James & Cheryl Rodgers	Doreen T. Sciulla	Whimsy Art Studio	Pamela Walker	Virginia Wright
Alex Piccirillo	Joyce Rogers	Cindy Scurlock	Anne Sullivan	L. B. Walters	Laura Wuertele
Pitney Bowes	Licenia Rojas	Sheron Shafer	Regina M. Sullivan	Regina Walters	Robert & Glenda Wunderlich
Cynthia Planeaux	Lisa Romeo	Joan Shalikhshvili	Sarah E. Sullivan	Chris Linda Ward	Carol Brown Yam
Ann Pope	Alex & Rebecca Rosen	Kelly L. Shellhammer	Cheri Svagerko	Jenyne Ward	Lynne Zelonis
Leslie Popielarcheck	Janis Ross	Brenda Short	Arlene & Bob Swerdloff	Laura Warford	Roxann Zeni
		Dr. Michael Silberbach	Virginia Sybert	Anita Warner	Sheila Zimmerman
		Amy Sinclair	Carolyn Leepe		
		Tracey Sinclair	Katrina Terence		