



TS affects 1 in 2000 Females

We Can Help!

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Rebekah Wallace

My full name is Rebekah Joy Wallace, but I love to be called Bekah. I am 21 years old, and I was diagnosed with Turner Syndrome shortly after my birth. Turner's has presented its challenges and its frustrations, but it has also blessed me with a solid sense of self, fierce determination to triumph over obstacles, and a joy-filled love for the life God is allowing me to live. I live with medical concerns like lymph edema, hypoglycemia, and elevated liver enzymes but, at least in my case, they are not so intense that I have not been able to live healthfully and happily. I have no reason to believe that my future will not be the same. Certain skills and tasks, things that need a high level of coordination and which many (not all) others find to be second-nature, are painstaking for me. I can drive, I can ride horses, I can swim, but these motor skills require every bit of my concentration, and I don't always do them very well. Math was always a struggle in school, too. It took hours of extra practice and studying. Not that I couldn't do it, but it was hard and I still don't like it. Writing, on the other hand, I have always loved. Ever since I was a little girl, I took great pleasure in scribbling down stories and keeping a diary. Writing for me is about discovering. I search for beauty, questions, flaws, and lessons worth sharing. Writing is a way for me to make sense of my thoughts, values, the world I live in, and how they all interact. Yes, you have to know something about a topic in order to write about it, but there is also no better way to learn. I write to stretch myself and hope that in reading what I write, others will stretch with me.

There is, of course, more to my life than Turner Syndrome and writing. I grew up on a dairy farm in western New York, the youngest of four siblings, one of whom has three very lovable children. I graduated from high school in 2012 and am now a Senior at Houghton College in New York. Here I have double-majored in Writing and Spanish, and I am scheduled to graduate with a Bachelor's of Science this coming December. After college I plan to serve as a substitute teacher while beginning online Graduate studies in Psychology through Southern New Hampshire University. My ultimate goal apart from continuing my writing is to become a translator for farms and small businesses who hire migrant workers from Latin America.



Ways to Give

Tribute Gifts

In celebration of:

- *Julia Burke *Fornia Family *Jillian Bednar
- *Terra Shea *Christina Torres *Faith
- *Angilina Russo *Eleanor Tecosky-Feldman
- *Victoria Carolan *Carol Bernabei
- *Schwenk Family *Amanda's Sweet 16

In memory of:

- *Bronwynn J. Davies *Ainslie Meier
- *Dr. Chayim Y. Newmark

TRIBUTE GIFTS

A tribute gift in honor, in memory, or to celebrate a special occasion make thoughtful gifts. A card will be addressed and mailed with your personal sentiment. [Send a tribute gift.](#)

TD BANK AFFINITY PROGRAM

TD Bank customers, existing and new, can benefit the Foundation by assigning Affinity Member Code A3538 to your accounts. TD Bank will make an annual donation based on the number and value of accumulated accounts. There is no cost or risk of privacy issues. Contact your local branch, call 732-706-5460, or [click here](#) for more information.

Online Shopping for a Cause

Donation partners will donate every time you shop & browse using their online portal. Select the Turner Syndrome Foundation and shop online at your favorite retailers! [GoodSearch.com](#)
[Amazon Smile](#)

You can also shop our website at: www.tsfusa.org



Donate a Vehicle Free Towing!

Our new program takes any vehicle, even boats! So if you want to donate your vehicle to an organization you believe in, our new program makes it easy! Anyone, anywhere in the US and Ontario can donate to us. All you need is a clear title, and we'll take care of the rest, including pickup, at no cost to you. Once your vehicle has been sold, you'll be sent a receipt for your tax records, and the sale proceeds will be donated to the Turner Syndrome Foundation. More about the process is detailed in our [FAQs](#), or call for more details: 1-855-TSF-4-CAR.



Good Reason to Support Turner Syndrome Foundation's Annual Appeal

Your support for the Turner Syndrome Foundation's 2015 Annual Fund Campaign can be accomplished with the tax-deductible contribution. *Your gift today will make a tremendous difference by increasing the capacity to improve life for women of all ages who live with Turner Syndrome.*

GIVE A LASTING GIFT:

Make a one-time, monthly or annual donation

Send a tribute card

[GIVE NOW!](#)

Turner Syndrome Foundation's Leading Initiatives:

- ✦ **Research-** TSF Patient Registry established in 2009 for new discoveries and improvements in care.
 - ✦ **Information Resources-** A comprehensive and informative website accessible without fees.
 - ✦ **Medical Education-** A continuing Medical Education program on Medscape entitled, "Identifying and Managing Care of Girls with Turner Syndrome" reached more than 27,000 allied health care professionals and remains a premier teaching tool for medical care providers.
 - ✦ **Education Outreach-** TSF sponsored education outreach at universities and hospitals promoting access to specialized centers of care, early interventions and a community of support.
 - ✦ **TSF Educational Videos-** "The Importance of Early Diagnosis of Turner Syndrome" video is streaming in 2,500 – 6,000 different medical centers every month across the U.S., and has reached 8 million viewers in a three-month period!
 - ✦ **TSF Council on Infertility-** A paper entitled, "Fertility Preservation in Females with "Turner Syndrome: A Comprehensive Review and Practical Guidelines", Journal of Pediatric and Adolescent Gynecology approaches fertility preservation and family planning options.
- Transition from Pediatric to Adult Care-** TSF has contributed to a body of resources to assist providers and families in adapting a plan for transition to adult care.

But wait there's more... Imagine the possibilities born of tireless dedication and stewardship of a mission that can yield changes seen in your lifetime.

[Click here](#) for the appeal letter. [Click here](#) for more information from the TSF website.



Turner Syndrome Progress Begins With You

In just a few minutes and keystrokes, you will have an opportunity to enter your specific concerns and potentially influence program development and outreach from the information that you share. Your privacy is important to us and will never be used for any other purpose than to advocate on your behalf.

Simply [click here](#) to get started:

Remember, we are working towards a better future for all unborn babies, girls and women with Turner Syndrome. We can only achieve the greatest outcome with your involvement and support.



Team TSF at the NJ Marathon

April 30 & May 1

Heel-to-Pavement – We can Make a Difference!

Turner Syndrome Foundation's Team TSF is an official charity and beneficiary of Novo Nordisk's annual New Jersey Marathon! This year's event will be on Saturday April 30 and Sunday May 1, 2016 in Long Branch, NJ. This marks the *seventh year* Team TSF will be participating and continues to be the most successful athletic event to garner support and awareness. The event is always a great success and a ton of fun, and is sure to be this year, too!

There is something for everyone throughout the family fun weekend! Saturday's events include kid's races, a non-competitive 5K and family festival of games, activities, music, and more. Sunday is the big event – the NJ Marathon, Half Marathon, and Half Marathon Relay.

There are so many ways to get involved, from competing to volunteering to cheering and more!

Compete! Run or walk with Team TSF and raise awareness with each step you take.

Volunteer! Show your support by volunteering for the NJ Marathon. Last year, volunteers helped by handing out water bottles to runners and giving out medals at the finish line.

Bake! Each year, TSF hosts a fantastic Treats and Sweets bake sale at the event. Help us by providing sweet treats or by working at the bake sale table.

Cheer! Help raise awareness by being a Team TSF cheerleader! Make signs and t-shirts to cheer on family and friends.

Still not convinced to be a part of this amazing weekend? Turner Syndrome is a common disorder that benefits from an early diagnosis and intervention. The sooner a girl is diagnosed, the sooner she can receive proper care and lead a thriving life. In order to do so, the public needs to be aware of the necessary information to receive a diagnosis. With such a large number of attendants, this weekend becomes an incredible opportunity to educate people and further the mission of awareness. Join us and be a voice for someone living with TS.

Sign up today to participate by logging on to:

<http://www.turnersyndrome.com/events-teamsf.html>

Turner Syndrome Foundation

1 Bethany Rd, Bldg 1, Ste 5, Hazlet, NJ 07730

P. O. Box 726, Holmdel, NJ 07733

(732) 847-3385



New Jersey Marathon's 20th Annual Festival at the Jersey Shore



JOIN TEAM TSF
TurnerSyndromeFoundation.org
(732) 847-3385



- 5 K "Fun" Run/Walk

- Kids' Races

- Kids' Move 1.2 mile Marathon

Saturday, April 30, 2016

Fun starts at 8:30AM until Noon

On the Great Lawn at the Ocean Front Promenade, Long Branch

Shaping NJ 5K Check-in begins at 8:00 AM; Race starts at 8:30 AM

On the Long Branch oceanfront Promenade
Non-competitive, but a timing clock will be set up

For all "ages" – strollers are welcome!

A light breakfast will be served after the run and random prizes will be awarded.
Commemorative T-Shirts for all pre-registrants... while supplies last*

Kids' Races For Kids Check-in begins at 8:30 AM; FUN begins at 9:00AM

At 9:15 separate races for kids 2-10+ years old — 20 yards to 440 yards
Mini Fair with Refreshments, Prizes, Carnival Games, Crafts, & Surprises

A festive atmosphere with music and activities
Commemorative T-shirts and ribbons for all pre-registrants... post while supplies last*

The **FUN BUS!** for ages 2-8 www.funbuses.com

MR. SCOTT will be performing at 11:00am - 12pm

Kids Move 1.2 Mile Marathon Check-in begins at 8:30 AM; Race starts at 10:00 AM

"KIDS" (9 & under, 10+ years) will run a 1.2 mile marathon on the Long Branch oceanfront Promenade.

Finishing at the official 2013 NJ Marathon and LB Half finish line.

Commemorative T-Shirts and medals for all pre-registrants... post while supplies last.*

Directions: Garden State Parkway to Exit 105. Go straight ahead on Hwy. 36 East, 8 traffic lights to Broadway. Turn right and follow Broadway to the end. Proceed straight ahead to the NJ Marathon Host Hotel, Ocean Place

Remembering Bronwynn J. Davies "Winnie"



In Memory of Bronwynn J. Davies "Winnie"
A Champion for Turner Syndrome

November 10, 2015 - It is with great sorrow that we share the news of the sudden passing of Winnie Davies. All at the Turner Syndrome Foundation are deeply saddened and she will be dearly missed.

Winnie was instrumental in the passing of legislature in New Jersey by making phone calls and going to Trenton to testify to the Senate on behalf of passing the bill which now is a law declaring the Month of February as Turner Syndrome Awareness Month in New Jersey. She was a great advocate for Turner Syndrome.

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*"Winnie, I will personally miss your energy, kindness, and long talks and having fun with you at the many events we attended over the years. Winnie cared for others and she inspired me to take preventative measures to have a cardiac MRA of my heart. I encourage all to do the same."* – Kym Hall

A celebration of life  
- Winnie Davies -

Saturday, December 12, 2015

Page Funeral home, 302 East Union Street, Burlington, NJ

Visitation at 11 a.m.

A memorial service at noon followed by a reception

The Turner Syndrome Foundation sends heartfelt condolences and prayers to all of Winnies' family and friends. For those wishing to remember Winnie, you may consider making a donation and sending a memorial card.

[Click here](#) to send a tribute card to the family by making a donation and providing mailing instructions.

## Volunteers Make it Happen

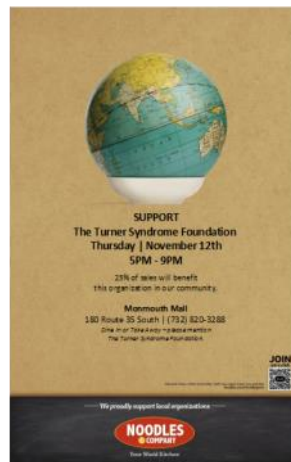
The Turner Syndrome Foundation's National Council of State Leaders are volunteers organized and devoted to improving the lives of patients affected by Turner Syndrome. Many individuals who want to help "Make It Happen" find the volunteer application process much simpler and efficient now that it has been digitalized. If you have an interest in volunteering as part of a state or program area, please take a moment now to complete the volunteer application.

[Click here](#) to learn about the National Council of State Leaders

[Click here](#) to access the online TSF Volunteer Application



You signed up to volunteer and then thought... WHAT CAN I DO?  
Host a Special Event



Just look at the sisters of Alpha Sigma Tau \*Beta Omega\* from Monmouth University. They hosted a Dine-to-Donate at Noodles and Company to support one of their local philanthropies, Turner Syndrome Foundation. Because of their leadership and outreach to a local business, 25% of sales from dinners served were donated directly to Turner Syndrome Foundation. TSF is very thankful to the sisters of Alpha Sigma Tau Beta Omega\*, and especially Gabriella Minieri, for organizing this event.

If you would like to facilitate a fundraiser with a small business or corporation, please contact Gabriella at [specialevents@tsfusa.org](mailto:specialevents@tsfusa.org).

### Tools to help you get started:

- Read the Special Events Guide Fundraising Ideas
- Complete the Special Events Form

TSF will help promote your event as long as 100% of the donated amount is given directly to Turner Syndrome Foundation.

What event or party will you plan? Let us help you get started!

## Newly Published Fertility Preservation Guidelines

A Turner Syndrome Foundation health initiative, Council on Infertility, produced a first of its kind manuscript in the United States entitled, "Fertility Preservation In Females With Turner Syndrome: A Comprehensive Review and Practical Guidelines - Review Provides Guidelines for Practitioners with Turner Syndrome Patients", Journal of Pediatric and Adolescent Gynecology, Oct 2015.

This review was led by Kutluk Oktay, M.D., Ph.D., professor of Obstetrics and Gynecology of the School of Medicine at New York Medical College (NYMC) and world-renowned infertility specialist along with Karen Berkowitz, M.D., Richard Bronson, M.D., Peter McGovern, M.D., Lubna Pal, M.D., Gwendolyn Quinn, Ph.D., and Karen Rubin, M.D. In addition, Giuliano Bedoschi, M.D., and Banafsheh Kashani, M.D., contributed as fellows.

Contacts of the authors are highlighted on the announcement.

[Click here](#) to read the TSF Council on Infertility Announcement.

[Click here](#) to read more on reproductive health.

On October 21 and 21, the National Organization for Rare Disorders held their annual Rare Diseases and Orphan Products Breakthrough Summit in Arlington, VA. The event is the largest of its kind, featuring numerous leaders from the FDA, NIH, Industry Groups, Payers, and Research Institutions. Keynote speakers included Jono Lancaster, a rare disease patient and advocate, Dr. Chris Austin, Director of the NIH, and Dr. Janet Woodcock, Director of the FDA. This year, the group convened to address rare disease diagnosis, genomics, drug development, patient engagement, patient-centered research models and product approvals. The event is a wonderful opportunity to network with the most brilliant leaders in the community to inspire you or your work. The content of the summit has three focused tracks for treatment developers, medical care providers, and patient advocates. The summit is open to all and we would love to see you there in 2016!

I represented Turner Syndrome Foundation at the NORD Summit and was most moved by the messages given by the speakers advocating for themselves. Patient and caregiver panelists shared personal experiences and challenges. Jono Lancaster travels around the world to meet face to face with others to let them know they are not alone, and spread a message of acceptance. Maddie Shaw, a pediatric panelist spoke about being a 16 year old girl and the difficulty not being able to do things with friends. The suggestion to "Use social media to create room for advocates to speak in their own voice" was stated by Lauren Smith Dwyer.

TSF has a Facebook page available in every state to allow the girls to be heard. The Turner Syndrome Foundation was begun because of a mother's love for a daughter with Turners. We are here to help you advocate and become empowered by using the resources available that we obtain through continued education and research.

## NORD Rare Summit 2015



## TS Tips & Trips

This month's tips will help make living with non-verbal learning disorder easier. Check out these sites for more information.

\*[University of Michigan Health Center](#)

\*[Smart Kids](#)

\*[NVLD and Jobs](#)

\*[Noodle](#)

## TS Links and Resources

\*[Imaging of cardiovascular risk in patients with Turner's syndrome](#)

\*[Clinical guidelines](#)

\*[What is Turner Syndrome—An Animated Video](#)

\*[TS, Estrogen, and Bone Health](#)

\*[Amy Cimorelli Talking About Her Turner Syndrome At The 2015 Global Genes Gala](#)



Jillian Rohlfing isn't letting TS get in the way of her love of volleyball!!!

[Click here](#) to watch the video!!

[Click here](#) to read more!



### ***Thank you Turner Syndrome Foundation***

"Being apart of your organization is important to me because it really is the only connection or memory I have of my daughter since I lost her in utero to Turner Syndrome. Giving to this organization gives me some peace because Skylar's memory is helping others.

I will be making a donation in Skylar's name for Christmas.

Thank you for all your hard work in bringing awareness for Turner Syndrome to others and giving support to people like me. You do not know how much this organization has helped me deal with this terribly sad situation.

So, on behalf of my family, thank you and Happy Holidays." - Kristen B.



## Contact Us

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Administrative office:

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Hazlet, NJ 07730

Toll-free: 1-800-594-4585

Fax: 1-800-594-3862

Email: [info@tsfusa.org](mailto:info@tsfusa.org)

### Add Us to Your Whitelist

To ensure delivery of our monthly e-newsletter, you should add Turner Syndrome Foundation to your whitelist.

### What is a whitelist?

A whitelist is a list of e-mail addresses and/or domain names from which an e-mail blocking program will allow messages to be received. Often, a spam blocker will allow a few junk emails through and block messages. For example, the Turner Syndrome Foundation monthly e-newsletter. Whitelisting is specifically allowing emails from a certain source to be allowed into your email inbox.

For a helpful resources on how to whitelist by server type – Yahoo, Gmail, Mac Mail, AOL, etc. click [here](#).

### Whitelist Domain Name (All)

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

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

### Whitelist Email (All)

[info@turnersyndromefoundation.org](mailto:info@turnersyndromefoundation.org)

[info@tsfusa.org](mailto:info@tsfusa.org)