

We are pleased to release the Summer 2017 edition of the Answering TTP Foundation newsletter. Help raise awareness for TTP by forwarding/sharing this newsletter. Enjoy! Sincerely, Sydney Kodatsky, Chair, Answering TTP Foundation. You're receiving this email because of your relationship with Answering TTP. Please [confirm](#) your continued interest in receiving emails from us. To ensure that you continue to receive emails from us, add contact@answeringttp.org to your address book today.

You may [unsubscribe](#) if you no longer wish to receive our emails.



Summer 2017 Newsletter

A Message from the Chair

Dear Friends,

I have TTP. In 2008, I learned how to pronounce Thrombotic Thrombocytopenic Purpura. After almost 9 years, 7 relapses and the building of the Answering TTP Foundation, I am still learning to live with TTP. My non-targeted TTP treatments have resulted in a battle with metastatic Cancer that I am winning.

I have big ideas. That is why I founded Answering TTP Foundation. I do everything I can to support TTP research so that I can watch my daughter grow up. I believe there is hope to improve TTP treatment in my lifetime. I believe that my blood, sweat and tears to fundraise will help TTP research improve and lengthen my life.



I am scared to be turned down by those that don't understand my mission to fundraise for TTP research. Getting a "no" is hard when the "ask" is so very personal. But I can't let my fear stop me. I must be strong. **TTP is scarier.** I believe that I have the power to help change my future by supporting TTP research. I believe that my network of family, friends, and colleagues want to support me.

I believe in our TTP community. I believe that together we can be the change to propel research forward toward a cure. If you believe, [please walk with me on September 16, 2017](#). I've created this walk to connect our geographically disperse community (TTP patients, their families and supporters) to join together to raise funds to support TTP research. I need your help to bring us all hope. We can change

our future together.

I believe that our perseverance will pay off. Thank you to all those who have participated in the walk to date; I look forward to walking with you again this year. Your efforts give me hope. Hope for better treatment. Hope for a cure in my lifetime.

Sincerely,
Sydney Kodatsky ([Sydney's full updated story here](#))



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Sandra's Story

My experience with TTP started in April of 2009. My name is Sandra Stanley and I live in Alsip, Illinois. At that time I was 54, I am now 61 years old and I work as an Administrative Assistant.

One morning I did not feel well, but I decided to go to work anyway. By noon I was home with flu like symptoms. By night time, I could not even stand up, I was delirious and could hardly speak so my family took me to the emergency room. My platelet count was 13,000, but I didn't understand what that meant at the time. Now I know where they should be, as we all do.



I was sent to the ICU and diagnosed with TTP the following day. I had many questions. How did I get this? Is it hereditary? I was told the only thing that could help was plasma exchange. I received it every day until my platelets started to rise. Laying there for 4 hours or more was not easy, but I wanted to get well. I never thought that something like this would ever happen to me. I had to return to the University Hospital in Chicago after discharge for weekly treatments for a month until I was stable. It would be six months recovery before I was finally able to return to work.

The ugly monster came back again in January, 2016. I first went into the hospital with what they thought was a viral infection. Despite being diagnosed with TTP 7 years earlier, I was sent home. The very next day, I thought I was having a heart attack. I was rushed to the emergency room for the second time in the same week. My platelets were at only 6,000. My platelets were being stubborn this time, so it took almost three weeks before I improved.

This was the second time in seven years. Do I have to look forward to another episode

of this in seven more years? I sure hope not. I am doing fine now but sometimes I get very tired. Other times, I feel like I cannot remember things at work that should come easy. Not sure if this is related, but it is scary.

I will continue to stay strong and to pray for some kind of cure, not only for myself, but for all my honorary brothers and sisters out there that have this terrible disorder. Please help me, help us. [Walk on September 16, 2017 to improve TTP care.](#)

[Sandra's full story here](#)

Upcoming Events

*Walk to Answer TTP
Together*



Saturday, September 16, 2017

Registration NOW OPEN

**Join the Movement to Raise Awareness &
Funds for Research**

This is an INTERNATIONAL event. Walk anywhere in your community for 2 hours. Individual and team registration available. 2017 Walk Button & custom donation webpage provided. REGISTRATION \$20 each or \$150 per team of 10.

**If You Believe,
Walk With Us to Raise \$30,000!**

5 EASY STEPS to register and participate in the
2017 INTERNATIONAL Walk to Answer TTP Together!

STEP 1: [Register](#) as an individual or as a team of 10.

STEP 2: Set up your fundraising page.

STEP 3: Share your fundraising page with EVERYONE you know!

STEP 4: Pick a starting location and time for your Walk on Saturday, September 16th. Your front door is a great option!

STEP 5: Walk for 2 hours anywhere, any distance, any speed on Saturday, September 16th!

For more information, please visit the event website [HERE](#).

**This is your chance to contribute to the TTP movement!
Simply walk and share your donation page to raise funds for TTP research
because you believe life with TTP can be better.**

[Register TODAY](#)



Featured News

NEW TTP Animation Video

A video animation of the TTP mechanism has been added to our [TTP Overview page](#). Many thanks to ABLYNX for developing and sharing this educational video.

Phase III Study Completes Patient Recruitment

On May 2, 2017, Ablynx announced that it has successfully completed patient recruitment in the multi-national, double-blind, placebo-controlled Phase III HERCULES study of caplacizumab to treat acquired TTP. If approved, this drug will be the first therapeutic specifically indicated for the disease.

[*Read full press release*](#)

Primer on TTP is Published in Nature Reviews Disease Primers

The [article](#) published April 2017 in Nature Reviews Disease Primers will serve as a reference resource for experienced researchers and a useful broad introduction to the field for early career researchers and medical students. Two of the five authors are

Chance for Change Celebrates Milestone Year

\$1,000,000

Raised for TTP over 8 years



Benefiting
Answering T.T.P.
T. Trachtenberg Therapeutic Program Foundation
www.answeringttp.org

Chance for Change



An evening of fun carnival style games, fabulous prizes and auctions to benefit TTP.

Visit www.AnsweringTTP.org for pictures, event movie and updates for the April 22, 2017 event.

To conserve resources, charitable receipts are issued yearly in time for tax season.

The 8th Annual Chance for Change Game Night marked a momentous milestone this year as we crossed over the \$1,000,000 milestone for funds raised through this event since inception. To commemorate this accomplishment, the committee surprised guests with an impromptu celebration complete with stilt walkers and tears of joy!



The event is the Foundation's life-blood fundraiser, bringing in over 85% of all the donated funds towards our charitable programs. This event would still be a small fundraiser in Sydney's basement if it wasn't for our talented and dedicated committee of volunteers comprised of Sydney's friends and family, all of whom have contributed to the success of the event in an effort to provide hope to the Bryant family. They're inspired by Sydney's commitment to fund research in an effort to find a cure for TTP.

Our sponsorship has grown to include 31 very generous businesses contributing sponsorship funds that have a huge impact on the Foundation's ability to support research grants. Many of these businesses have supported Chance for Change for a number of years, for which we are very grateful. A special thanks goes out to those sponsors who are able to join us at the event and support Sydney and the Bryant family beyond the monetary value of their contributions. It means so much to us that you share these evenings with us.

We continue to also be grateful to the large number of donors contributing to our auction. Our guests compliment our committee year over year on the quality of contributions and we take pride in being able to offer items that are 100% donated to ensure the Foundation benefits from your auction bids.

The feedback we received this year indicates that our guests had a spectacular evening and are excited about future events. Their enthusiasm for Chance for Change Game Night inspires our committee and all the volunteers of the Foundation to continue our hard work all year long. We can't wait to offer our guests even more to enjoy in the future.

Thank You to everyone who participated in this year's event.

[CHECK OUT EVENT PHOTOS HERE](#)

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Congratulations to Robyn Artem!
Winner of the Feedback Survey Participation Draw

How You Can Help

Join our Community

Share your Experience

Donate

Fundraise



Submit your story officially to receive our TTP Awareness Hat. Limited supply available.

Submit Your Patient / Supporter Story!

Are you looking to take the first step to get involved with the Answering TTP Foundation?

Why not start by sharing the story of your personal experience with TTP as a patient or, if you are a supporter, the experience of a loved one you stood by as they went through or are going through TTP.

Sharing stories will help to strengthen the voice of the TTP community while raising life-saving awareness! Your submitted story will be published on our website to help others facing similar challenges as well as adding a face to this rare blood disorder.

[LEARN MORE.](#)

Helping Hands

Volunteers are needed to help stuff and stamp Walk to Answer TTP Together mailings. A time will be chosen during the weekend of



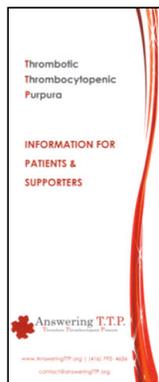
September 2-3 according to volunteer availability. Email Contact@AnsweringTTP.org for more information and to help out. Many hands make lighter work. This event will take place in west Toronto, Canada. This event qualifies for high school students looking to meet their charitable volunteering requirement.

Doctor to Doctor Connect

Are you a medical professional with a challenging TTP case? Would you like to discuss this case with one of the members of the TTP Medical Advisory Network?

If so, please send an email to us at Contact@AnsweringTTP.org providing your contact details (name, hospital/office name of where you practice, and preferred method of contact.) We will then connect you with an appropriate member of the Medical Advisory Network.

Patient Education Materials



Patient & Supporter Information Brochure Patient Resource

Available for download in English, French, Italian, Simplified Chinese, Russian, Portuguese, Punjabi, German and Spanish from www.AnsweringTTP.org



SDP Brochure Patient Resource



In an effort to spread understanding of this product, Answering TTP Foundation has produced a SDP education piece. This educational brochure is available for free download from our [website](http://www.AnsweringTTP.org) to everyone.

Attention Doctors

Please download and circulate our educational materials to your patients. More information on our physician and researcher programs [here](http://www.AnsweringTTP.org).

About TTP and The Foundation

A diagnosis of TTP, Thrombotic Thrombocytopenic Purpura, is scary and complex. Many patients have never heard of this 3-letter acronym before, nor do they have any idea as to its ramifications. Moreover, patients are told over and over that we "just

don't know":

- why it happens
- what may trigger a relapse from remission
- why some patients relapse and others do not
- what the long term prognosis is
- how to ease treatment
- how to cure TTP

These questions remain unanswered because research is limited. TTP is an orphan disease that afflicts 3 in 1 million people per year. It is too rare to make it economical for pharmaceutical companies to specialize research to find a cure. The purpose of Answering TTP Foundation is to help find answers to these questions by connecting patients and supporters. Together, we can raise awareness and raise funds to support patients, treatment and research.

Answering TTP Foundation provides the Canadian national TTP community with a supported platform to further common goals including:

- supplying [fundraising support and guidance](#) to raise funds for effective TTP research to ultimately find a cure;
- providing [patient support](#) to alleviate the feeling of isolation that accompanies the diagnosis of a rare disorder;
- inspiring TTP patients and supporters to [share their stories](#) to help enrich the TTP community and garner public support for TTP;
- maintaining a [consolidated information platform](#) to disseminate information to the geographically dispersed community;
- providing a [unified voice](#) to ensure access to the safest and most effective treatments; and
- developing TTP education materials and distribution initiatives to educate the public and the medical community to speed diagnosis and save lives.

We need [your help](#) to improve the prognosis for TTP patients. Help us find the answer to TTP.

Answering TTP Foundation | Contact@answeringttp.org | www.AnsweringTTP.org

STAY CONNECTED:



You are receiving this email in compliance with Canada's new anti-spam laws. While the anti-spam legislation does not apply to most communications by [Answering TTP Foundation](#) as a registered charity, we would like to obtain your consent to continue to send you important information from us, such as our newsletter containing news, updates and donation requests. You may withdraw your consent at any time by simply [clicking here to unsubscribe](#). We respect your right to receive only those emails you expressly consent to in writing. We also undertake not to share your information with anyone as per our [Privacy Policy](#). If you have any questions, please contact us for more details at Contact@answeringttp.org.