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We are pleased to release the Rare Disease Day Winter 2018 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](mailto:contact@answeringttp.org) to your address book today.

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



Winter 2018 Newsletter

## Happy Rare Disease Day.

We are pleased to release the winter 2018 newsletter on 2018 Rare Disease Day. This is a day to celebrate our accomplishments for rare diseases to date, and to further our common agendas. You are encouraged to use this recognized day as a day to raise awareness for TTP by talking about the disease, your experience, and our Foundation's initiatives to provide hope. This is the 11th annual international Rare Disease Day coordinated by Eurordis. More information about [Rare Disease Day here](#).

## In This Issue

- [Lataya's Story](#)
- [Updated New Patient Information Piece](#)
- [2018 Chance for Change](#)
- [Virtual Support Group](#)
- [Research Grant Application Deadline](#)
- [One of Our Researchers is Recognized](#)
- [New USTMA Consortium Website](#)
- [aTTP Study Continues Recruiting](#)
- [Save the Date](#)
- [How You Can Help](#)
- [Doctor to Doctor Connect](#)
- [Patient Education Material](#)
- [About the Foundation](#)

## Lataya's Story

My name is Lataya Huckaby, I'm 36 years-old and I live in a small town in Georgia. I'm married to my wonderful husband and have three awesome boys. I was diagnosed with TTP in 2015, while I was working as an Insurance Agent. I currently am a stay at home mom as a result of my condition.



My first diagnosis began when I was admitted to the emergency room with a severe headache and pains in my left arm. I was later admitted to the MICU where I spent 3 weeks. The entire experience was hard both physically and mentally; I rarely got to see my children. I clearly remember one day I was getting treatment and got down to my last six minutes, I am extremely thankful for my nurse who did everything in her power to bring me back.

I was in recovery for a year before I had my first relapse. This time I spent a week in the hospital because my platelets were detected before they dropped below 60,000 per UL. TTP has made a big change in my life and my family's life, too. From the bottom of my heart, I wish I had never visited the ER, but I also knew something was not right with my body. My worst relapse was my second, my count was eight per UL and I had no control of my body at all. I then had my port removed after my outpatient treatment, and after going to what I thought was just a follow-up appointment I was informed that I was entering my third relapse!

TTP has made me spiritually stronger because each day is a struggle. There are a lot of things I can't do now, such as walking without becoming tired, cooking for my family, and being able to go to my boys' athletic events. I have to take afternoon naps just to keep going, and I go to bed early because I'm constantly tired. It's been hard, but I am learning to live with these limitations. I am becoming forgetful of different things, which bothers me, but my family understands that this has now become a part of my personal reality. I am learning my limits and understand I shouldn't exceed them to preserve my health.

[Lataya's full story here](#)

[Help support others affected by TTP and raise awareness by sharing your story. Learn more here.](#)

## Updated New Patient Information Piece

**ANSWERING T.T.P.**  
Thrombotic Thrombocytopenic Purpura Foundation  
INFORMATION FOR PATIENTS & SUPPORTERS

**SYDNEY'S STORY**

I was diagnosed with TTP in 2008 after my mom took life-saving action by seeking out a 3rd opinion. I was extremely lucky to not have experienced a heart attack or stroke due to the delay in diagnosis.

After almost 9 years, 7 relapses, plasma exchange using over 700 blood donations, spleen removal surgery, chemotherapy, and years of immune suppression medications, I am still learning to live with TTP and its effects. I believe that my non-targeted TTP treatments resulted in my subsequent battle with metastatic cancer at only 35 years old.

Despite these years of challenges I have remained hopeful. I founded Answering TTP Foundation because I have big ideas for our small and

**WHAT IS TTP?**

Thrombotic Thrombocytopenic Purpura is a rare blood disorder that is considered a true medical emergency. TTP is diagnosed at a rate of 3-4 in 1 million people per year. Potentially fatal complications can result from internal blood clotting, with damage to critical organs such as the brain and heart.

Due to a deficiency in the ADAMTS13 enzyme, blood becomes "sticky" and forms clots in blood vessels throughout the body. These clots are made up of platelets, one of the elements in blood. Vital blood flow to the body's organs is restricted, placing the organs at risk for damage due to a lack of oxygen and nutrients from the blood. Moreover, since platelets are being used to form numerous unnecessary blood clots, their availability to perform their normal function, which is to seal injury sites to prevent excess bleeding, is compromised.

This trusted brochure has been updated and restructured. The brochure was initially developed in 2013 to help provide information about TTP to those newly diagnosed with TTP, and to provide information about our supportive community. Since that time, there have been significant developments in the understanding of the disease. We are pleased to release the 2018 Information for Patients and Supporters printable information sheet.

Download [here](#).

## 2018 Chance for Change



Benefiting **Answering T.T.P.**  
Thrombotic Thrombocytopenic Purpura Foundation

# Chance for Change

**An evening of fun, fabulous prizes, entertainment and auctions benefiting T.T.P.**  
Saturday April 21, 2018 at Famous People Players. One-time venue. Don't miss out!  
343 Evans Ave., Toronto. Doors open at 6pm.  
Dinner and drinks included. Smart casual attire.  
Early bird admission \$200 each before March 31, after \$235 each.  
*60% of admission price was eligible for a tax receipt in 2017.*

**Purchase Admission Today!** at [www.AnsweringTTP.org](http://www.AnsweringTTP.org)  
Sponsorship & donation opportunities also available.

Answering TTP Foundation | 22 Prince George Dr. | Toronto, ON | M9A 1Y1 | [Contact@AnsweringTTP.org](mailto:Contact@AnsweringTTP.org) | Charitable Registration # 84600 4802 RR0001

## Featured News

### Virtual Support Group

Answering TTP Foundation was thrilled to pilot a virtual peer support group series moderated by a professional social worker. These themed sessions enabled participants to learn about a session topic and share their experiences in a meaningful and collaborative environment.



The fall session received rave reviews and we are planning another 6-session weekly series in the spring.

This is a first-come first-served initiative. Fill out the [registration form](#) to indicate your interest in joining an upcoming group.

Participation is capped (8-10 persons) to facilitate meaningful conversation. Participation is open to the international TTP Community. The session will be held in English. All participants will be required to accept the [Virtual Support Group Guidelines and Waiver available here](#). More information, and registration form [here](#).

### Research Grant Application Deadline

April 1 is the Foundation's deadline for research proposals. We recognize the need for biomedical, clinical and population health research. We promote international collaboration to speed research for our small and geographically dispersed patient population.

Answering TTP Foundation will consider research proposals that demonstrate a direct link to TTP. Complete the form for access to or our Grant Guideline and Grant Submission instructional documents.

## One of Our Researchers is Recognized

The Foundation would like to congratulate Dr. Zheng for being recognized with the 2017 Research Innovation in Scientific Excellence (RISE) Award from the American Association of Blood Banks (AABB). More about the award [here](#). Dr. Zheng began an Answering TTP Foundation funded research project entitled "The Role of Complement Factor H Abnormality in Pathogenesis of Thrombotic Thrombocytopenic Purpura" in 2014. More about his Foundation funded research [here](#).



## New USTMA Cosortium website

*Author: Dr. Spero Cataland member of the Medical Advisory Network for Answering TTP Foundation.*

### The United States Thrombotic Microangiopathy (USTMA) Clinical Consortium

was founded in 2014 as a grassroots movement by several hematologists to increase research efforts into these disorders. The term thrombotic microangiopathies or TMA encompasses several rare blood disease that includes congenital and immune-mediated TTP. Advances in clinical research into TTP have been hindered by the rarity of these conditions that prevents single centers from being able complete clinical research studies in a reasonable period of time.



The USTMA consortium was formed to address this issue and allow for increased collaborative clinical research among investigators and sites across North America. Since its founding, the USTMA consortium has grown to include investigators from over 15 academic centers in the United States, with these centers accounting over 80% of the United States enrollment for the recently completed Hercules Study of Caplacizumab in TTP.

Building on this success, the USTMA is preparing to launch a study to evaluate the prevalence of long-term complications in patients with a prior diagnosis of TTP. This

research will also include lab-based studies to try and understand why these complications occur in TTP patients, with the hope that this information will translate into improvements in the treatment and prevention of these complications.

## aTTP Study Continues Recruiting

A healthcare research continues to recruit patients who have been diagnosed with acquired thrombotic thrombocytopenic purpura (aTTP) and live in the Continental US. This research focuses on understanding your experience with aTTP as well as evaluating a questionnaire designed for use in patients with aTTP. This research may help improve how the patients' experience is accounted for in clinical trials for new treatments.

For more information and for participation instructions click [here](#).

*NB: Mention of any treatment products associated with this study are provided for information only and their inclusion is not an endorsement of a particular product or company by Answering TTP Foundation.*

## Save The Date

**SAVE THE DATE SATURDAY, SEPTEMBER 15, 2018** Gather your Friends, Family and Coworkers to Raise Funds and Awareness to Improve the Prognosis for all TTP Patients

Last year, on Saturday, September 16, 2017, one hundred and fifty registered participants took part in the 7th annual Walk to Answer TTP Together. Participants walked internationally, in their local communities to help raise life-saving awareness and funds for TTP! We did it! Together we surpassed our \$30,000 fundraising goal. We raised over \$40,000!



Be a part of something truly special. Save the date for the 2018 Walk to Answer TTP Together. Participate from Anywhere. Walk Any Distance. Raise funds for TTP.



2017 Walk to Answer TTP Together Video



[CHECK OUT 2017 EVENT PHOTOS HERE](#)



## How You Can Help

Join our Community

Share your Experience

Donate

Fundraise

	<p><b>Submit Your Patient / Supporter Story!</b></p> <p>Are you looking to take the first step to get involved with the Answering TTP Foundation?</p> <p>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.</p> <p>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.</p> <p><a href="#">LEARN MORE.</a></p>
	<p><b>Organize a Fundraiser</b></p> <p>Help support TTP research, education and support. Organize your fundraiser today. From bake sales to galas. Every dollar helps and every person touched by TTP can help.</p>

## 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](mailto: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. Older version translated and available in French, Italian, Simplified Chinese, Russian, Portuguese, Punjabi, German and Spanish from [www.AnsweringTTP.org](http://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](#).

## 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](mailto:Contact@answeringttp.org) | [www.AnsweringTTP.org](http://www.AnsweringTTP.org)

STAY CONNECTED:



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