

We are pleased to release the Winter 2017 edition of the Answering TTP Foundation newsletter. Help raise awareness for TTP by forwarding/sharing this newsletter and don't forget - REGISTRATION is now open for Change in Toronto on April 22, 2017. Register Today! Enjoy! Sincerely, Sydney Bryant 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 2017 Newsletter

### Ashlee's Story

My name is Ashlee, I am 27 years old and from California. At the age of 25 my husband and I received some exciting news, we were expecting a baby! We couldn't be happier.



*Ashlee pictured with her husband.*

Around 10 weeks along I started getting bad headaches, bloody noses, couldn't hold anything down and had weird rashes all over my body. I called my OBGYN and they told me to take some time off work, just relax and gave me some nausea medicine. Still feeling ill, I went to a walk-in doctor who diagnosed me with a viral infection.

Two weeks had passed and I was getting worse. I was to the point that drinking water or Gatorade made me sick. We went to our local ER and they drew some labs. Something was abnormal and they thought the test was inconclusive. They drew more blood with the same outcome; something was wrong. After two ER doctors checked me out, talked to me and still could not figure out what was wrong, they transferred me to Stanford Medical Center which was 3 ½ hours away.

I was transferred via ambulance and once I arrived, I already had 5 teams of doctors. I had Kidney, OBGYN, Hematologist, Dermatologist and Primary doctors. That first day was all a blur. I had test after test done. My platelets were 13, hemoglobin 7, kidney failure, high calcium levels and this rash.

All the labs were looking like I had leukemia so they did a bone marrow biopsy. I had X-rays, ultrasounds, an MRI and tons of tests done. The rash ended up being eczema which I have never had before. After the bone marrow biopsy came back negative for

cancer and blood levels kept getting worse, they started treatment for TTP. What is TTP we were all thinking; never heard of this before. Being pregnant, I was scared for my life and my unborn baby's life.

My treatment was plasmapheresis, and high doses of prednisone. I was starting to feel better and my platelets were looking better. Being at a teaching hospital, my hematology team switched doctors and the new doctor wanted to stop plasmapheresis for a day to start weaning me off it. That day had been Thanksgiving and that afternoon I started to feel sick again. Platelets started dropping, treatment was started again and then I started getting better.

After 17 days in the hospital, I was released to outpatient treatment. We had to stay in the area as the treatment I received was not available where I live. Treatment was every other day or every three days. Lab work was still done every day.

I went in for my 16 week ultrasound to find out there was no heartbeat. Just when we thought things were looking up. After recovering from losing the baby, we were up there for another two months to make sure I was completely okay without any blood products.

It was quite the scare and quite the journey. In total I had about 21 treatments which equals around 220 blood donations. I not only had plasma; I also had red blood cells and platelets transfusions.

[Ashlee's full story here](#)

## In This Issue

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## Featured News

### New Research Grants

**Over \$1.5 million committed to research grants through 2018**

Answering TTP Foundation understands the need for biomedical, clinical and population health research and accepts research proposals internationally. We are excited to announce the funding of three new promising international research grants that began in September 2016.

[Deeper insight into the misrouted immune response to ADAMTS13 in acquired TTP - a prerequisite for better patient management.](#)



Prof. Dr. J. A. Kremer Hovinga, Department of Hematology and Central Hematology Laboratory, Inselspital, Bern University Hospital.  
*Photographed by: Tanja Läser, Insel Gruppe AG, Bern, Switzerland.*



[Development of improved assays for the diagnosis of TTP.](#)  
D. W. Chung, PhD, Bloodworks Research Institute, Seattle, WA.



[A prospective randomised controlled trial of low-dose versus standard dose rituximab for prevention of relapses in acquired TTP.](#)  
Dr. M. Thomas, Consultant Haematologist, University College London Hospital, London.

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## PTSD and Depression in TTP Survivors - Journal Article

A [paper on PTSD and depression in TTP survivors](#) was recently accepted for publication in Thrombosis Research. The study was conducted by a Clinical Fellow of Vanderbilt University Medical Center, Shruti Chaturvedi. Answering TTP Foundation spread the word about this very important research. Thank you to those who took part. There is more work to do. [Register for the Answering TTP Community](#) to receive invitations and updates like these.

## How You Can Help

[Join our Community](#)

[Share your Experience](#)

[Donate](#)

[Fundraise](#)

## Upcoming Events



Benefiting



Answering T.T.P.

Thrombotic Thrombocytopenic Purpura Foundation  
[www.AnsweringTTP.org](http://www.AnsweringTTP.org)

# Chance for Change

**Help us Raise \$1,000,000 to Fund Research**

# by Supporting our Annual Chance for Change on April 22nd!



## Fun Games, Fabulous Prizes, Entertainment and Auction!

The Chance for Change event is living up to its name. Since the inception of "Game Night" in 2010 this event has brought in over \$900,000 to fund research, giving TTP patients and supporters hope that one day a cure will be found. No other single resource has made an equal investment in a "chance for change" to improve the prognosis for TTP patients.

This year we'll be striving to exceed total funds raised of \$1,000,000 by the Chance for Change event, and we invite you to be a part of our celebration!

Start the new year with a couple of stretch goals:

- Break out of your comfort zone and ask your friends, family, neighbors and colleagues to attend the Chance for Change event with you this year. Purchase your tickets [here!](#)
- Bravely ask for donations from your company, business associates, neighborhood businesses, friends and even family. You may be surprised what people have to offer! You can log your commitments for donations on our [website](#) and let us help you bring them home!
- Not from the GTA? Support us anyway by donating [here!](#) If you're reading this newsletter, you're a part of our community and this is our chance to demonstrate the impact of that community.

Answering TTP Foundation is motivated to fund new research grants of over \$1.5M and we need your help to ensure the research efforts of world renowned investigators can continue. Without you, there is no funding for their research because pharmaceutical companies have nothing to gain by investing in rare diseases. They appeal to the masses, and therefore, we need the masses to appeal to us!

## Purchase Your Admission Today!

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

# Chance for Change

AN EVENING OF FUN GAMES, FABULOUS PRIZES, ENTERTAINMENT AND AUCTIONS BENEFITING T.T.P.

**Click here to purchase your Early Bird Admission.  
Prices go up on March 31, 2017.**

April 22, 2017 at the Old Mill Inn, Toronto | Doors open at 6pm | Smart casual attire | Tapas and Drinks Included.  
Early Bird Admission \$200 each before March 31, after \$235 each

Sponsorship & donation opportunities also available.



Silent Auction and Raffle Items  
come in all shapes, forms and sizes.  
Send yours NOW!

[Click here](#) to read more  
about the Chance for Change  
event and take a look through  
the photos of our past events.  
We hope to see you this year,  
and if distance keeps you  
away,  
[organize a local fundraiser](#) in  
your community.

## Walk Results Are In!

### 2016 Walk to Answer TTP Raised Just Under \$33,000 for Research, Education and Support!

147 International registered participants from around the world!  
Check out our [website](#) to see how your efforts are making a difference  
today!

THANK YOU to all those who participated in and supported the 2016 Walk to Answer  
TTP Together! Your support is helping the Foundation to support international research  
and other programs for the TTP community.



### Congratulations to the Walk Award Winners!

2016 Top Fundraising Team went to Toronto Walkers  
(Captain: Sydney Kodatsky)

# 2016 Walk to Answer TTP



Top Team Fundraiser - Toronto Walkers

2016 Spirit Award went to Team Cindy Moes  
(Captain: Melissa Angermeier)

# 2016 Walk to Answer TTP



Spirit Award - Team Cindy Moes

Thank you to all of those who participated in, and donated to,  
the [2016 Walk to Answer TTP Together!](#)

Save the date for next year's Walk - September 16, 2017!

## Get Involved



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?

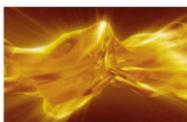
Why not start by sharing the story of your personal experience with TTP as a patient or, if you are a supporter, the experience of a loved one you stood by as they went through or are going through TTP.

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.](#)



Solvent Detergent Plasma (SDP)



Information about Solvent Detergent Plasma (SDP) & other pathogen reduction technologies for the use in the treatment of TTP (Thrombotic Thrombocytopenic Purpura)

Additional information available at [www.AnsweringTTP.org](http://www.AnsweringTTP.org)

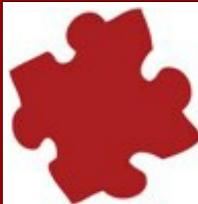
1-800-391-4054 (toll free) 1-800-536-5434  
[www.AnsweringTTP.org](http://www.AnsweringTTP.org)  
Contact@AnsweringTTP.org  
Charitable Registration #89591 89591 89591

### Help refresh our educational materials

The Foundation would like to create more printable friendly versions of our [educational brochures](#). We would like treatment centers to easily print information for patients from our website, rather than store physical brochures.

The brochure files are in Adobe InDesign.

Email [Contact@AnsweringTTP.org](mailto:Contact@AnsweringTTP.org) if you are qualified and interested.



### Helping Hands

The Foundation relies solely on volunteers in order to maximize funds spent on charitable programs. Volunteers are needed to help stuff and stamp annual mailings for donors. Email

[Contact@AnsweringTTP.org](mailto:Contact@AnsweringTTP.org) for more information and to help out.

Many hands make lighter work. This event will take place in west Toronto, Canada on February 11, 2017. This event qualifies for high school students looking to meet their charitable volunteering requirement.

[LEARN MORE.](#)

## 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 in print in English and French. Available for download in English, 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

If you would like to order copies of the brochure, at no cost, please [register with us](http://www.AnsweringTTP.org). We would be more than happy to ensure that you receive copies of these educational pieces to distribute to TTP patients.

## 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 | 416-792-4656 | Toll Free 1-888-506-5458 |  
[Contact@answeringttp.org](mailto:Contact@answeringttp.org) | [www.AnsweringTTP.org](http://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](mailto:Contact@answeringttp.org).