

We are pleased to release the Summer 2015 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 the 2015 Walk to Answer TTP Together. Register Today! Enjoy! Sincerely, Sydney Bryant Kodatsky, Executive Director. You're receiving this email because of your relationship with Answering TTP Foundation. Please [confirm](#) your continued interest in receiving email 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.



Audrina's Story

My name is Audrina and I live in Glendora, California. In 2011, I had just graduated with my Doctorate in Physical Therapy, and was very excited to start my career as a Physical Therapist. I was also expecting my first child with my husband. At 26 years old, my life was absolutely perfect.

My symptoms began when I was 38 weeks into the pregnancy. While preparing for a Super Bowl party I was hosting, it occurred to me I had not urinated all day, which at 38 weeks I found very odd. However, I attributed it to not consuming enough liquids and the California heat. When I did urinate that evening it was tinged red (with blood).

The next morning I woke up with a significant headache, tiny red dots (petechiae) all over my legs, and swelling in both of my legs. I attributed all of this to pregnancy; I had an appointment with my OBGYN the next day, so I wasn't too concerned.

The morning of my OBGYN appointment, my headache, petechiae, and swelling had not subsided. In fact, I had new symptoms - my eyes were jaundice and I had bruises all over my stomach. I was still urinating blood, if I urinated at all, and I was very tired. I left the doctor's office with a prescription for Calamine lotion for "the



rash" on my legs, which was petechiae. My husband and I were very concerned, but pushed our worries aside because we had just seen a physician who assured us that all was well. The next morning was no better, I was crying in pain because my head would not stop pounding and my legs hurt so badly. My husband, who is a nurse, called from work to tell me he thought I had HELLP syndrome, and should go to the hospital immediately. I went to the hospital alone as I refused to believe I was ill; I had been healthy my entire life.

I was admitted into Labor and Delivery and labs were drawn. There was no way I could be alive with the results that came back from my blood draw - there had to be a mistake. Time was critical. My body was shutting down, and there were two lives to consider. They needed to get my baby out, but with a platelet count of 4,000, surgery meant a high possibility that one, or both of us, would not make it out alive. I was prepped for a cesarean section and I kissed my family and husband goodbye. I woke up in the ICU breathing with the help of a ventilator, bleeding profusely from my abdomen, bruises all over my body, and I was so swollen I couldn't bend my arm or legs; but I was alive and I wanted to meet my baby. They wheeled her into the ICU and in that moment all of my pain and fear disappeared. After a week of numerous treatments, I was stable enough to be discharged and to follow up as an outpatient.

Join Audrina, her "army", and the TTP community
from anywhere in the world
on September 19, 2015
to raise funds for TTP research!

*Participate in the
Walk to Answer TTP Together
to help raise life-changing funds
for TTP research!*

Register as an individual or team of 10 [HERE!](#)

I nursed my daughter and returned to work, but never felt completely healthy. I had monthly, sometimes weekly, appointments with my doctor. After 5 months of symptoms, I was diagnosed with TTP and again admitted to the hospital where I received treatments for 7 days. Five days after my discharge, my numbers plummeted again, and I was admitted to the hospital for another round of treatment. During this admission to the hospital, my husband revealed that he could not handle all of this, and he no longer wanted to be married. I was destroyed.

For the next two and a half years, I was in the hospital as an outpatient for daily treatments. My daughter grew up in the hospital. She took her first steps in the hospital and by 10 months knew when, and how, to put a mask on for mommy's catheter dressing changes. It took me several hematologists, over 360 plasma exchanges, and over 22 rounds of Chemotherapy, in addition to, countless blood transfusions, immuno-suppressants, allergic reactions, and steroids to enter remission. I stayed in remission for 1 month before relapsing and starting the process all over again.

While my life has turned out to be nothing I could have ever imagined it to be, I am so thankful to be alive and to have the opportunity to raise my daughter, who is now 4 years old. I am currently able to work, and my family and friends have been a great source of support and inspiration during this journey. I am looking forward to banding my support network together again to raise funds for TTP research, education and support on September 19, 2015. The Walk to Answer TTP Together is an amazing event that enables me to help change the future for all TTP patients. I am proud to be the face of the 2015 Walk to Answer TTP Together. Check out the walk trailer on YouTube by clicking below.

~ Audrina Caine



[READ AUDRINA'S FULL STORY HERE](#)

THE 2015 TTP Dinner Symposium



On Tuesday, June 23, 2015, Answering TTP Foundation hosted the 2015 TTP Dinner Symposium. The evening provided a unique platform for international TTP medical and research professionals to come together to share best treatment practices and learn about TTP research being done around the world, while paving the way for collaboration opportunities in the future.

Over 50 international TTP medical and research professionals attended the evening. These leading TTP experts took part in discussions that were robust and opened doors for international collaboration in future TTP research. Several exciting opportunities were identified throughout the evening, including the action items that were noted by the moderator in her closing remarks:

- 1. We should be looking to provide TTP patients with individualized "TTP Survivorship Plans" similar to what is being done in oncology.*

2. *An evidence-informed consensus statement on the escalation of therapy for a TTP crisis is needed.*

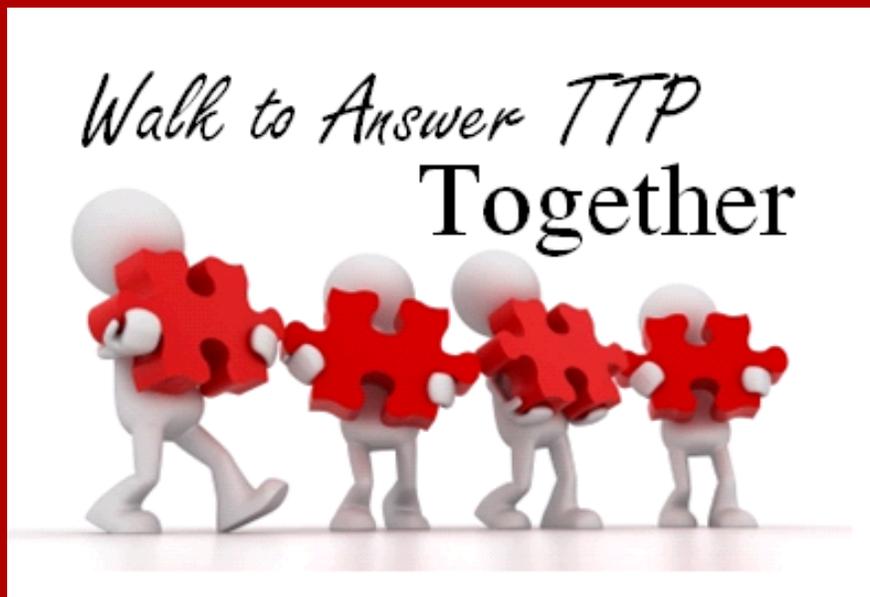
3. *Rare blood disorders such as TTP should be looking to develop and implement a successful "Comprehensive Care" model.*

The Foundation is looking forward to publishing the complete proceedings of the Symposium in a reputable journal in the coming months, *to ensure information generated during the Symposium* is shared with a wider TTP professional audience.

We thank all those who participated in the Symposium and will keep the Foundation's community abreast of updates to the action items.

[SEE MORE PICTURES FROM THE EVENING](#)

REGISTRATION NOW OPEN FOR THE 2015



Saturday, September 19, 2015

**This is an INTERNATIONAL event.
Walk anywhere in the world for 2 hours.**

**EARLY BIRD REGISTRATION PRICING IS ONLY
AVAILABLE UNTIL AUGUST 14!**

\$35 each or \$250 per team of 10. After August 14th, registration goes up!

Register TODAY, as an individual or team of 10, and start FUNDRAISING for your Walk! Then, on Saturday, September 19, 2015, join the TTP community around the globe as we **MAKE STRIDES TO SAVE LIVES** by walking for 2 hours!



5 Easy Steps to Register and Participate in the 2015 INTERNATIONAL Walk to Answer TTP Together!

STEP 1: Register as an individual or a team of 10. **HINT:** Ask friends, family and/or coworkers to join you by registering!

STEP 2: Set up your fundraising page. Individuals and teams of 10 get a customizable page that will help them to raise funds for TTP research. **HINT:** Customize your page with information about why you are walking and why people should donate to you!

STEP 3: Share your fundraising page with EVERYONE you know! People can't donate to you if they don't know about your Walk and fundraising page! **Hint:** Share your page through email, social media, etc.

STEP 4: Pick a starting location and time for your Walk on Saturday, September 19, 2015. If you are walking with a team, be sure to let them know! **HINT:** ALERT THE MEDIA! Inviting local media to take part in your walk by interviewing you and taking pictures is a great way to spread awareness about TTP and why people should donate!

STEP 5: Walk! Don't forget to take lots of pictures and video on the day of your

event to share with your supporters and the Answering TTP Foundation! **HINT:** If you are hoping to win the coveted **SPIRIT AWARD** this year, you must send in your pictures!

REGISTER TODAY

Have you heard of PARTNERS?

Patient Assisted Research Transforming National Effectiveness in Rare Diseases (PARTNERS) is encouraging Canadian rare disease patient involvement.

PARTNERS is a proposed SPOR (Strategy for Patient Oriented Research) Network in Chronic Disease that has a vision of working together with Canadian rare disease patients and their families to implement a clinical care and research strategy that will improve outcomes and reduce the burden of rare disease by the year 2021. They are encouraging patients to get involved by:

1. Completing the survey **HERE**.

OR

2. Attending a group interview. Find a session local to you **HERE**.

LEARN MORE HERE

TTP Patient Education Day



WHO SHOULD ATTEND: International TTP patients, supporters and medical

professionals.

WHEN: November 7, 2015 | 8am - 5pm

WHERE: Holiday Inn Toronto International Airport Location, 970 Dixon Road Toronto, ON, CA

WHY: Our Patient Education Day is designed to help bring the international TTP patient, supporter and physician community together to share, learn and strengthen the TTP community. The day will offer an update about developments in TTP treatment and research globally, workshops and the opportunity to provide feedback to the Foundation as it develops a comprehensive care document to assist in standardizing the care for people with TTP.

TRAVEL GRANTS: A limited number of Canadian travel grants are available.

LEARN MORE & REGISTER HERE TODAY!

EVENTS SNAPSHOT

Upcoming events **YOU** don't want to miss!

Saturday, September 19, 2015

5th Annual Walk to Answer

TTP Together



This is a global event! Walk anywhere in the world, any distance for 2 hours to raise life-saving awareness and funds for TTP! Individual or Team Registration available!

REGISTER TODAY

Spring 2016

7th Annual Chance for Change Game Night

Saturday, November 7, 2015

Patient Education Day



International TTP patients, supporters and medical professionals are invited to register to participate in our upcoming Patient Education Day. Join us to share, learn and strengthen the TTP community.

LEARN MORE & REGISTER

You Pick The Date!

You Pick The Event!



This Toronto, ON event boasts entertainment, fun games and an extensive selection of auction items and prizes.

[LEARN MORE](#)



Get involved by organizing a fundraising event in your community! Big or small, every event helps to raise life-changing funds and life-saving awareness for TTP! Bake Sale or Gala, were here to support you!

[LEARN MORE](#)

SUBMIT YOUR PATIENT / SUPPORTER STORY!



Now, for a limited time, when you submit your story officially, you will receive our TTP Awareness Hat!

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](#)



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!
- developing **TTP education materials** and distribution initiatives to educate the public and the medical community to speed diagnosis and save lives.
- maintaining a **consolidated information platform** to disseminate information to the geographically dispersed community.
- 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.
- providing a **unified voice** to ensure access to the safest and most effective treatments.

We need your help to improve the prognosis for TTP patients. Help us find the answer to TTP.

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See what's happening on our social sites.



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