

We are pleased to release the Summer 2013 edition of the Answering TTP Foundation newsletter. Help raise awareness for TTP by forwarding/sharing this newsletter and participating in the upcoming 2013 Walk to Answer TTP Together. Enjoy! Sincerely, Sydney Bryant Kodatsky, Executive Director Answering TTP Foundation. You're receiving this email because of your relationship with Answering TTP. 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.



Newsletter

Summer 2013



Latisha's Story



My name is Latisha Nicole Barefield and I live in Collinsville, IL. I have 2 sons named Bernard (17) and Kevin (14). My son Jason was stillborn at 5 months because of my TTP. I am divorced from my children's father and currently planning a wedding to a

wonderful man named Mike, my light in the darkness of a deadly struggle with TTP.

I was 27 years old, a mother, wife, medical assistant and future doctor until my life changed forever. The day I recall it all began was so nice, I was folding clothes and getting prepared for the arrival of another son! The first sign of trouble was my light headiness and confusion. I was looking at my son Kevin playing and did not know who he was. The second sign something was off was the vomiting and the only thing I could feel was the stomach pains that were so bad that I could not walk. I screamed as loud as possible and thankfully my neighbor heard and was able to call my mother. My mother arrived and proceeded to take me to three different hospitals and at each one I received a different diagnosis, a stomach flu,

In This Issue

- Latisha's Story
- Who Will Help Raise Life-Saving Awareness?
- Be a Team Captain for the 2013 Walk to Answer TTP Together
- Answering TTP Foundation has Launched a NEW Website!
- Volunteer Appreciation Dinner and Award Night.
- What Does 3 in 1 Million Look Like?
- TTP Patient Order Sets Now Available
- Request for Patient and Supporter Stories
- Dollars at Work
- Ongoing Support Initiatives
- Patient Brochure

Register your Team of 10 for the Walk to Answer TTP Together!
 Each team member will receive a wristband!

a stomach virus, nothing related to what was actually wrong. One hospital even called the local police because doctors felt I was a victim of domestic violence, due to the bruising that had taken over half of my body.

After my visit to the three hospitals I was simply given antibiotics and pain medications before being discharged with a follow up appointment scheduled to see my doctor three days later. My mother, my hero, had every doctor, nurse and police officer scared because she knew from my current state that I did not have three days to spare.

Join the TTP community
from anywhere in the world
 on September 21st, 2013
 to improve the prognosis for all TTP patients.

**Participate in the
 Walk to Answer TTP Together**
 to help raise life-saving awareness!
 Form your team today and [Register Here.](#)

She proceeded to take me across the river to Barnes-Jewish Hospital and Siteman Cancer Center while I was in and out of consciousness and my organs were shutting down, that part was later told to her by one of the doctors. My mom was loud and demanding so much so that a new medical student looked in on me and said, "Oh my god I finally get a chance to see a patient with TTP," I was rushed into surgery where they installed a line. They told me in recovery that this line may never come out and that I would need plasmapheresis treatments for the rest of my life. It was at this time I was also told that because of my illness the baby boy I was carrying, my son, did not make it. After the terrible news of losing my baby I was also told that being at the hospital would be a part of the rest of my life and that I would need to be part of clinical studies moving forward if I ever wanted to beat this deadly blood disorder. To date I have 19 doctors that know me and have overseen my struggle with TTP. I now have to take over 25 medications daily and go for plasmapheresis treatments every month which is down from my previous schedule of every two weeks.

I was once told I would not live to see thirty, I AM 38 YEARS OLD. I was told that I would not be able to work, I WORK FROM HOME. I was also told that I would not finish college because of my TTP, I RECEIVED MY SECOND DEGREE IN 2009 WITH HONORS! I was told I would not become a doctor, I HAVE 2 MORE YEARS TO GO.

TTP has changed my life because of the limits my physicians put on me, I have to take a lot of precautions because of my illness and my doctors advise me to slow down, I do, but I still live and love life for my family! The pain, weakness, loss of hair, medications, and everyday struggle of TTP can drive us mad but all TTP patient's need to remember we are a select group and each of us has a purpose. We might not see it now but with our



Answering TTP Foundation is arming teams of 10 in the Walk to Answer TTP Together with awareness bracelets and T-shirts this year. These will help get the conversation started to raise awareness for TTP to help save lives.

REGISTER NOW

How You Can Help

- [Register for the Walk to Answer TTP Together](#)
- [Join our the Community](#)
- [Share your Experience](#)
- [Donate](#)
- [Fundraise](#)
- [Participate in Support Groups](#)
- [Raise awareness for Blood Donation](#)
- [Volunteer Opportunities](#)



Share Your Story

As patients and supporters, we encourage you to share your stories with us. We will publish your submissions online and/or in our newsletters and educational materials to raise awareness and help others facing similar challenges.

For instructions and tips visit our [website](#).

Events Snapshot

September:

- [The Walk to Answer TTP Together](#)

Ongoing:

stories, we can show the world that we are strong; we will speak for the babies who are not yet born, for the medical student who chooses a career in Hematology because of TTP. There is a light at the end of the tunnel and if we work together we can get there quicker! KEEP SHINING.

TTP is not a death sentence! And I want all newly diagnosed patients to know that they should not give up.

Latisha Barefield

[More Patient Stories \(click here\)](#)

- [Support Programs](#)
- [TTP Denim Days](#)

Blood Donation

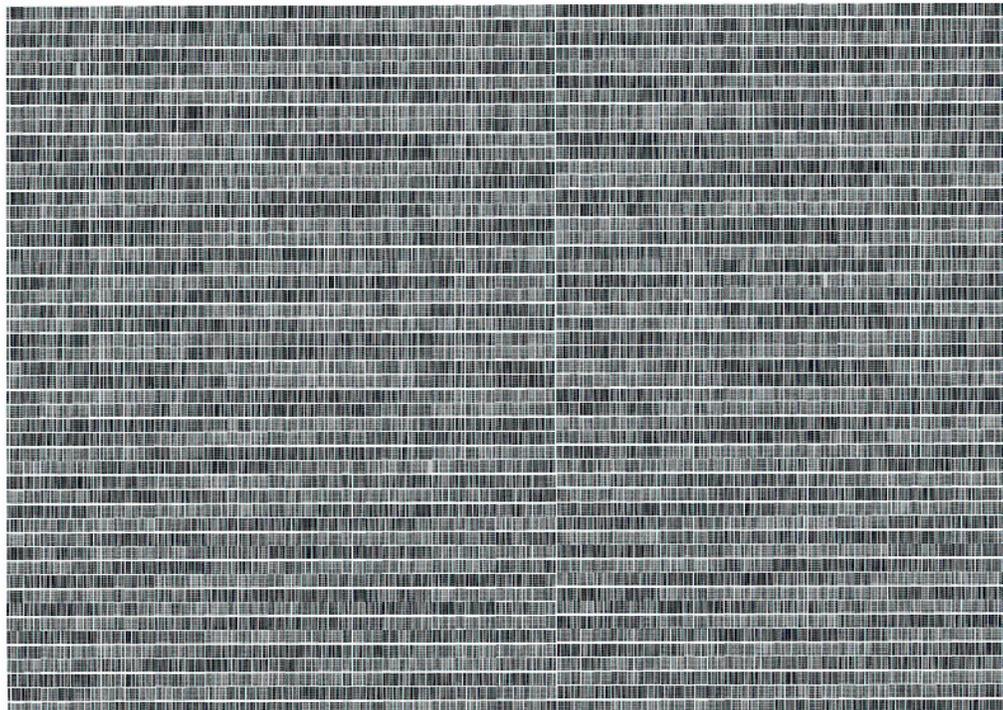
Engage your community, wherever you are to donate life-saving blood!



Blood donation saves lives and participating as part of the Answering TTP Team helps raise awareness for TTP to save even more lives. Each TTP crisis is a medical emergency and early diagnosis is key to mitigating the risk of irreversible complications, or death.

[CLICK FOR DETAILS](#)

Who Will Help Raise Life-Saving Awareness?



Can you spot the 3 TTP survivors and their supporter's? The image of 1 million dots above, represents 1 million people. Three of these dots, and their immediately surrounding neighbours have been highlighted to represent the 3 in 1 million touched by TTP and their neighbours (family, friends and other supporters).

Not that easy is it?

We need to rally the help of all those touched by TTP. On Saturday, September 21st, 2013 join the Answering TTP Foundation along with TTP survivors and supporters around the world, in the push for global awareness, education and research for this medical emergency.

TTP affects only 3 in a million, it is OUR responsibility as a minority group spread around the world, to come together and give TTP a voice. Together we are stronger!



[Click HERE to register.](#)

[Join the global TTP movement on September 21st, 2013.](#)

(Registration closes September 1)

Continue reading to learn more about the picture above and to see a closer view of where the TTP patients are hidden.

And The Winning T-shirt Design is

Last month we asked our **[Facebook](#)** community members to tell us what words they associated with TTP, and the response was overwhelming!

These words helped us create two incredible t-shirt designs, so amazing that internally we could not decide which one to use. We

Be a Team Captain

Walk to Answer TTP
Together



A great way for YOU to create grassroots life-saving awareness in YOUR community!

Each person on your team will receive a [Walk to Answer TTP Together](#) T-shirt and an awareness bracelet to be worn on September 21, 2013. Your team will be armed with educational TTP flyers to distribute while you walk!



Your team will have a donation page to consolidate your fundraising success! Donors will be able to give to a team member's page or to the

team as a whole.

5 EASY STEPS to register your team:

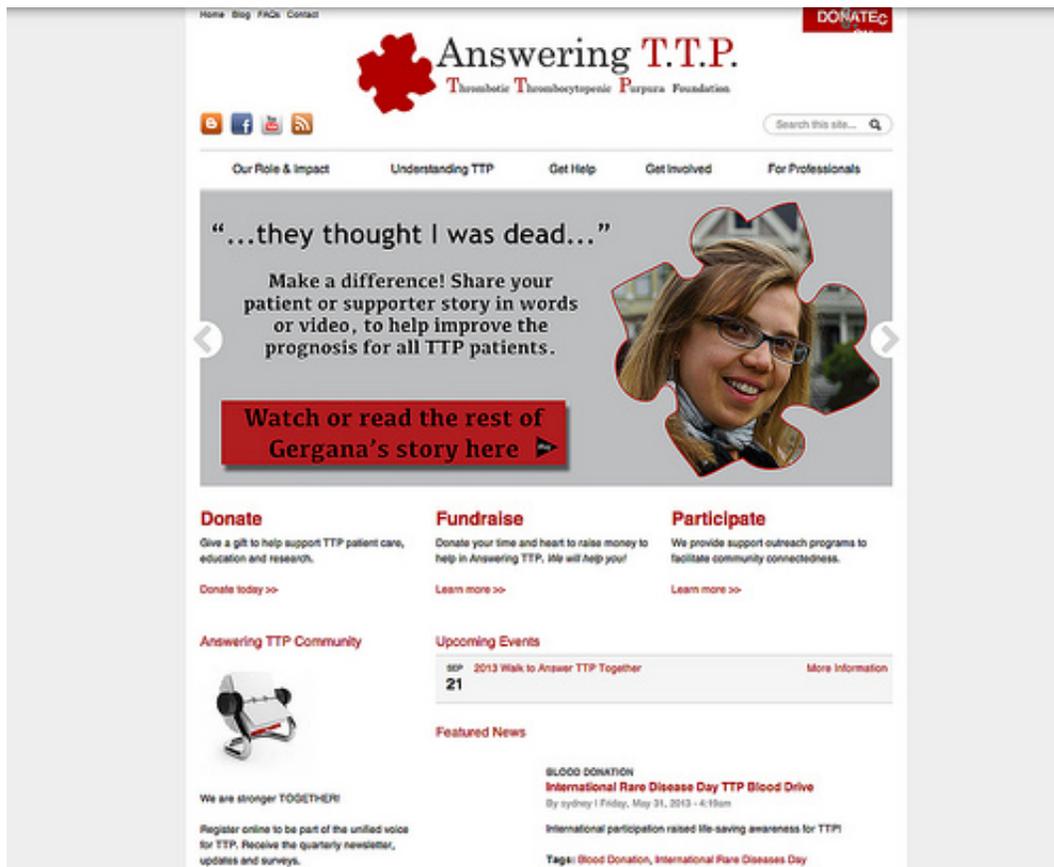
1. Think of 10 people in your community that will join you: family; friends; co-workers etc.
2. Register your team [HERE](#).
3. Customize and share your team donation page with your team so that everyone can circulate the page to all potential supporters.
4. Pick a starting location and time for your walk on Saturday, September 21, 2013, and let your team know.
5. Take lots of pictures on the day of your event to share with the Answering TTP Community.

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



This is your chance to contribute to the TTP movement! Get involved and raise live-saving awareness and funds for TTP research!

Did you Notice Something Different at AnsweringTTP.org?



That is because our new website went live this week, and we could not be more excited about it! Over the past few months our dedicated volunteer IT Manager, [Ian Wilson](#), has worked tirelessly to help design a new website for the Foundation, which is easier to navigate and much more stylish than our previous one. We are very excited about the functionality of this new site and the new pages we have added. Such as:

Our Volunteers: This page will display short biographies of all of the Foundation's amazing volunteers. The page will be updated frequently as new volunteers come on board.

Our Photobook: This page is still in the works and requires a little more tweaking before it goes live, but we are just as excited to launch it in the next couple of months. This page will showcase pictures taken at various events (i.e. Blood drives, Support Groups, Conferences and Fundraisers).

[Click on the picture above to check out AnsweringTTP.org's new look!](#)

Volunteer Appreciation Dinner and Award Night



On Wednesday, July 3, 2013, Answering TTP Foundation held its annual Volunteer Appreciation Dinner and Award Night. A night where board members host volunteers, both local and abroad to celebrate the accomplishments of the Foundation over the past year, and discuss future initiatives. Thank you to the host of this year's dinner, one of our amazing volunteers [Margie Castiglione](#).

A new tradition for the Foundation was started this year with the presentation of the Heather Leckie Bryant Award. This award is very special to the Foundation as it is dedicated to the memory of [Sydney Kodatsky's](#) (the founder of Answering TTP Foundation) mother, for her determination and immense contribution to the Foundation. Every year this award will be presented to the volunteer who goes above and beyond the call of duty as a volunteer.

This year the 1st recipient of the Volunteer of the Year Award is [Tammy Robertson](#). Tammy has dedicated much of her spare time since the Foundation's formation to ensure the success of events from blood drives to fundraisers. Tammy has chaired the [Chance for Change](#) event for the past two years and was instrumental through her leadership and dedication in this past February's Chance for Change event being so successful and well attended.



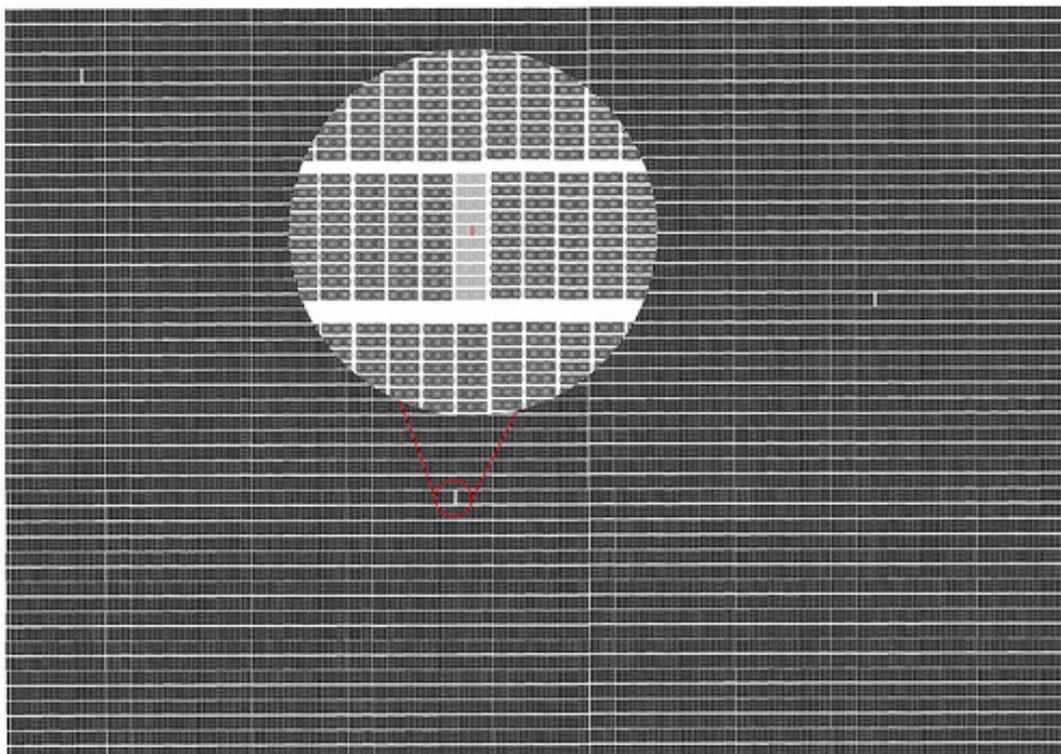
(From left) Tammy Robertson, Sydney and Heather Kodatsky and Alexis Levine

Aside from the food, fun and awards, a thank you address was given by [Alexis Levine](#), Chair & Secretary of the Board of the Answering TTP Foundation. If you were unable to attend or call into the event [Click Here](#) to hear the address.

If you are interested in getting involved with the Foundation we have lots of opportunities available for all dedication levels! [Click Here](#) to check out some of the opportunities available or if you have an idea of how you can contribute to the Foundation outside of what is advertised please contact us at Contact@AnsweringTTP.org. We would love to hear from you!

Thank you again to all of our amazing volunteers! None of what has been accomplished so far would have been possible without you, volunteers are truly the life-blood of this Foundation!

What Does 3 in 1 Million Look Like?



This picture is a depiction of what one million people together would look like (using dots, Yes, that is one million tiny dots)! Of the 1 million dots, three of those are red (TTP patients) and around the three red dots are 99 grey dots (TTP supporters or people who could be aware TTP exists because of that one patient).

Awareness is higher the closer you are to a TTP patient. But who will generate awareness among the millions of other people around the world who know nothing about this deadly 3 letter medical emergency if you don't?

That is why we need YOU! As a TTP community member (patient or supporter) we need your help to raise life-saving awareness around the globe. Participate in the 2013 Walk to Answer TTP Together! The event is designed for all athletic abilities for everyone in the world. Walk ANYWHERE in the world, ANY DISTANCE for 2 hours on Saturday, September 21st, 2013. Take as many breaks as you need. Walk alone, with another participant or form a team.

Research is Hope / Awareness is Low / Early Diagnosis is Key

[Register Today!](#)

TTP Patient Order Sets Now Available

[Answering TTP Foundation](#) is excited to announce the release of a tool to help speed diagnosis for TTP and share best practices for treatment. Distribution of these order sets will be piloted in the Fall to over 500 ERs and walk-in clinics, in addition to being

distributed to Answering TTP Foundation's list of TTP treatment centers.

Together with PatientOrderSets.com's Clinical Research and Development team, and an international panel of TTP expert physicians, Answering TTP Foundation has developed two order sets, and an associated supporting document to support the first response investigation and treatment of TTP.

Over the course of multiple virtual meetings, expert knowledge to treat TTP from experts in Canada, USA and Europe was integrated to produce these finalized order sets. The documents are designed to provide evidence-based recommendations for the diagnosis and management of TTP.

Answering TTP Foundation will continue to work with PatientOrderSets.com, and the expert group to keep these documents relevant and aligned with TTP treatment innovations.

The Foundation would like to acknowledge and thank the prestigious international community of expert TTP physicians that worked with us on the development of these order sets: Dr. Katerina Pavenski (Toronto), [Dr. James George \(Oklahoma\)](#), [Dr. Spero Cataland \(Ohio\)](#) and Dr. Marie Scully (UK).

To read more about the TTP order sets and the need for awareness check out the August 2013 edition of [Hospital News - Canada's Health-Care Newspaper](#), Page 14.

14 Focus EMERGENCY SERVICES/CRITICAL CARE/TRAUMA/EMERGENCY PREPAREDNESS:

TTP Diagnosis saves lives

Shedding light on a rare autoimmune blood disorder that is considered a true medical emergency

By Taryn Byrne

There was nothing that could be done; the diagnosis came too late and Gergana Sandeva was fighting for her life in the emergency department. It just one of the three doctors that had seen her before finally being diagnosed with TTP (Thrombotic Thrombocytopenic Purpura). Taryn had access to direct information about diagnosing TTP – such as patient order sets which are evidence-based checklists used by medical professionals to ensure that patients are diagnosed and get the appropriate treatment more quickly – but experience may have been different. She could have been diagnosed on her first visit to the walk-in clinic. She could have been started on treatment before her veins collapsed. She could have avoided becoming a near-fatal medical emergency.

The Answering TTP Foundation, together with Patient Order Sets and Hematology with TTP experts from Canada, USA, England, and Australia, has developed a set of order sets as well as a decision document to help speed the diagnosis of TTP.

Join the movement to help

save lives, by adding these TTP order sets to your hospital's working library.

Gergana is just one of the countless TTP patients who were not diagnosed and a few almost too late. Unfortunately many other TTP patients continue to suffer from irreversible complications, such as kidney disease, stroke, heart attack – or even death – because their veins' diagnosed was too slow.

TTP is a rare autoimmune blood disorder with three out of one million people diagnosed each year and is considered a true medical emergency. TTP is caused by small blood clots made up of platelets forming throughout the body restricting vital blood flow placing organs such as the brain, heart and kidneys at risk for damage. Since platelets are being used up to form these sometimes unnecessary blood clots, their availability to perform their normal function is also compromised, and life-threatening bleeding can occur.

If TTP is suspected it is crucial that a hematologist is consulted immediately and plasmapheresis treatment is begun without delay. This treatment can mean the difference between life and death for patients suffering a TTP

crisis and offers them the best chance for survival.

The Answering TTP Foundation was formed in 2009 by a patient, her parents and families of those affected by TTP. Since that time, Answering TTP Foundation has incorporated and gained charitable status in Canada. Answering TTP Foundation is a Canadian charity run by volunteers both in Canada and internationally.

The Foundation is committed to creating and connecting the TTP community

to further common goals while creating life-saving resources and raising funds for research to find a cure.

The Foundation needs your help to improve the prognosis for TTP patients, and you can do this simply by adding the TTP order sets to your hospital's working library. **B**

Taryn Byrne is Charitable Programs Director at the Answering TTP Foundation. www.answeringtpp.org



Answering T.T.P.
Thrombotic Thrombocytopenic Purpura Foundation
www.answeringtpp.org

Thrombotic Thrombocytopenic Purpura

A patient's perspective

By Gergana Sandeva

For a month I had been experiencing unusual symptoms: headaches, bruising, bloody gums and constant fatigue. But I knew something was really wrong when I noticed spots that all over my body. I decided to go to a walk-in clinic, where I had to convince a doctor that I needed blood work because he was sure it was just a virus. After days of not hearing back from the clinic, about the blood test results I called the lab directly to ask that they forward my results to my hematologist, who I had an appointment with later that week.

They were surprised to see me when I arrived for my appointment. They showed me my lab results, which showed a platelet count of seven and advised that I head straight to the nearest emergency department. Armed with my test results, I arrived at the ED but they were unable to diagnose me and sent me home suggesting I schedule an appointment with a hematologist the following week. I knew that things were getting worse and time was not on my side. The next morning I went to the ER of another local hospital. They requested my blood work, asked some questions and then I went off for ten hours. That evening a team of doctors gave me the diagnosis – TTP. I spent the next five hours waiting for my life. I needed to receive life-saving plasmapheresis treatment, however due to my collapsed veins the doctors could not insert my central line. They had given up on me but I remember hearing the physician come begging a doctor to try again, telling him I had no other chance and that I was dying. Thankfully he decided to give it another try and was successful. I don't remember much more from that night. I quickly forget the excruciating pain – all I remember is how lucky I felt to be alive. Not a day goes by now that I don't feel thankful for my life and feel lucky that my diagnosis wasn't too late. **B**

Gergana Sandeva is a patient advisory board member at Answering TTP Foundation.

www.hospitalnews.com



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HOSPITAL NEWS AUGUST 2013

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In The News

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HOSPITAL NEWS AUGUST 2013

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Doctor to Doctor Connect

Are you a medical professional with a challenging TTP case? Would 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, method of contact you would like us to reach you at). We will then connect you with an appropriate member of the Medical Advisory Network.

Request for Patient and Supporter Stories

Are you looking for a way to contribute to and get involved with the Answering TTP community but you don't know where to start?



Why not share 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.

We are looking for TTP patients and supporters to share their stories with us, to help strengthen the voice of the TTP community and raise life-saving awareness for TTP. Your submitted story will be published on our website and/or used like Latisha's story on the front page of our newsletter to help others facing similar challenges as well as adding a face to this rare blood disorder.

To learn more or to get tips on how to start telling your story visit our [Story Submission Page](#).

For more information about getting involved and volunteer opportunities visit our [website](#).

Why Answering TTP Foundation?

TTP can affect anyone at any stage of life. One day you are a healthy individual and the next you are in a hospital bed fighting for your life. You, nor anyone you know, have never heard of Thrombotic Thrombocytopenic Purpura before and never imagined needing massive amounts of donated blood product. Because TTP causes small blood clots to form throughout the body, you may live with irreversible damage to your heart, brain, and/or kidneys for the rest of your life. 20% of patients will not recover. And if you do recover, you may relapse. You don't know when you might relapse or how to mitigate the risks. Little is known about TTP. This diagnosis makes you one of 3 in 1 million per year.

Answering TTP was formed in 2009 to raise funds for TTP research and care at St. Michael's Hospital in Toronto. Since that time, Answering TTP Foundation has incorporated nationally and gained charitable status. We represent one strong common voice of action for our patient group, and provide a platform to effectively raise funds to support research initiatives not tied to one hospital. The Foundation provides a foundation for the TTP community to further common goals including: access to new drugs and safer treatment options, TTP education, patient support, and furthering TTP research to ease treatment and ultimately find a cure.

Visit our [website](#), [Facebook page](#) and [blog](#) for additional information about our organization.

Dollars at Work

To date Answering TTP Foundation has raised \$.5 Million! Your donor dollars have been put to work on groundbreaking projects including:

- **Patient Support & Education:** face-to-face and virtual support groups, patient connect program, quarterly newsletter, educational brochures, website and social media channels help connect and support the geographically dispersed patient and supporter population.
- **Outreach and Advocacy:** blood drives, roadshow, awareness campaign and the Patient Advisory Board raise life-saving awareness for this rare disorder and

encourage access to the safest and most effective treatment options.

- **Patient Order Set:** The Foundation is excited to release TTP order sets developed by a team of international TTP experts with a special interest in the management of TTP. The order set will be shared to speed diagnosis and provide information about treatment options for TTP.
- **TTP Medical Research Collaboration:** The Foundation brings together TTP experts to share current research outcomes and to foster collaboration.
- **TTP Patient Registry:** The project will provide a foundation to achieve better understanding and potential treatment strategies through an accurate and detailed registry.



Ongoing Support

Every person touched by TTP provides further insight into this complex disorder and Answering TTP Foundation's support programs are consistently growing to reach more patients. Sign up for the [Answering TTP Community](#) to ensure you receive invitations to participate. Other support initiatives include:

Patient Connect: Both newly diagnosed TTP patients and more seasoned TTP patients are encouraged to [click here to register](#) for this new program designed to connect patients to provide peer support. Help break down geographic boundaries to share your experience to help others.

Local Support Groups: These groups are currently running in Vancouver, Calgary, Toronto and Saint John. The Quebec Roadshow promises to connect the Answering TTP Community with Quebec centres to begin additional sessions. For information about organizing a session in your community visit www.AnsweringTTP.org.

New TTP Patient Brochure: This informational source outlines TTP in easy-to-understand terms, and informs patients that Answering TTP Foundation is here to support them. The brochure has been translated into French, Spanish and German and is available for download in these languages from www.AnsweringTTP.org.

Facebook: The [Answering TTP Facebook page \(click here\)](#) is an online support forum to enable the Foundation to connect with TTP patients around the world and raise awareness for TTP within the social media space. On this site, we discuss current topics and answer questions from the patient perspective. Posts can be circulated to your Facebook friends by simply clicking on the "Like", "Comment" or "Share" buttons.

Website: www.AnsweringTTP.org was created to be a resource for the TTP community, and a place to raise awareness for TTP. Patient stories listed on the site help personalize the complex condition to help other TTP patients. Stories also garner interest and support from the public to raise awareness. Also, links to other educational resources are listed.

Answering TTP Foundation is committed to supporting those touched by TTP. We are growing our sustainable initiatives through our Roadshow connections and medical community relationships.

Patient Brochure

Patient Resource

NEW - available for download in French, Spanish and German from www.AnsweringTTP.org

The TTP Patient Informational Brochure is designed to help new patients and families understand a TTP diagnosis and direct them to Answering TTP for further support.

The brochure includes an overview of the disorder, a patient story and information about Answering TTP in an effort to relieve some of the anxiety felt by new patients.

The brochure is available to new Canadian patients from their doctor.

Attention Doctors

If you would like to order copies of the brochure, at no cost, please [register with us](#). We would be more than happy to ensure that you receive copies of this educational piece to distribute to TTP patients.



Connect Online

We are raising awareness for TTP through social media. Follow [the blog](#) and connect via [Facebook](#).

Visit our blog

Like us on Facebook 

Share posts with your network to help raise awareness.



A diagnosis of TTP, Thrombotic Thrombocytopenic Purpura, is scary and complex. Many patients have never heard of this 3 letter acronym before, nor have they 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 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 provides the Canadian national TTP community with a supported platform to further common goals including:

- 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;
- developing TTP education materials and distribution initiatives to educate the public and the

- medical community to speed diagnosis and save lives;
- supplying **fundraising support and guidance** to raise funds for effective TTP research to ultimately find a cure!

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

Answering TTP Foundation
www.AnsweringTTP.org
 22 Prince George Dr.
 Toronto, ON M9A 1Y1
 416 792 4656 | toll free. 1-888 506 5458
Contact@AnsweringTTP.org

www.AnsweringTTP.org

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