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We are pleased to release the Spring 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

Spring 2013

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Gergana's Story



I was diagnosed with TTP six years ago, after a Christmas vacation with my family in Europe. I was excited about the new year - starting medical school and moving in with my boyfriend of 10 years. I had been experiencing some unusual symptoms for a month, headaches, bruising, bleeding gums, I was constantly tired and had trouble staying awake. I knew something was really wrong once I noticed the petichea all over my body. I went to a walk-in clinic and it took an hour to convince the doctor that I needed blood work. He was sure it was just eczema and had prescribed a basic topical cream. I went to a local lab and gave a blood and urine sample. After not getting the test results from the clinic, I called the lab directly and asked that they forward my results to my dermatologist, who I had an appointment with later that week.

When I arrived for my appointment, she was surprised to see me. She showed me my lab results, with a platelet count of 7, and advised that I head straight to the nearest ER. Armed with my test results, I called my boyfriend and asked him to come pick me up. I arrived at the St Joseph's ER

later that night. I waited for about 4 hours and after being seen by an internal medicine specialist, I was sent home.

They were unable to diagnose me and asked me to call the following Monday and

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Register your Team of 10 for the Walk to Answer TTP Together!

Each team member will receive a wristband!

schedule an appointment with a hematologist. I knew that things were getting worse and I had no time to waste. The next morning I was waiting at the ER of the Toronto General Hospital. They repeated my blood work, they asked some questions and then I waited for ten hours, until that evening, when a team of doctors approached me and gave me my diagnosis - TTP.

Join Gergana and 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.](#)

I spent the next five hours battling for my life. I had to receive my life-saving plasmapheresis treatment, however due to my collapsed veins, the doctors could not insert my central line. They had given up on me, I remember hearing the apheresis nurse begging one of the doctors to try again, telling him I had no other chance and that I was dying. Thankfully one of the interns decided to give it another try and he was successful. I don't remember much more from that night. I quickly forgot the excruciating pain; all I remember is how lucky I was to be given another chance at life. I spent the next month and a half in the hospital, and every day of the following six years living with TTP, grateful for my life.

I know that there are others who weren't as lucky as me. I started reading numerous research articles about the condition, desperately trying to find something encouraging. Unfortunately, I soon realized how little was accomplished in research and raising awareness for this disease. I was extremely disappointed, but not discouraged by this fact and was fully committed to changing it. I was fortunate to meet other patients who gave me the support I needed and made my battle with TTP much easier. With your support, we can give hope to patients like myself and maybe one day we will find the answer to TTP.

Gergana Sandeva

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

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Be a Team Captain

A great way for YOU to create grassroots life-saving



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**](#)

Ohio Support Group

June 5, 2013

James Cancer Hospital



Informal dinner and open discussions.

Visit our [website](#) soon for updates from this session.

[**Join the Answering TTP Community**](#)
to receive support group notifications.

[**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.

Walk to Answer TTP Together



awareness in YOUR community!

Each person on your team will get a Walk to Answer TTP Together T-shirt and an awareness bracelet to be worn on September 21, 2013. Your team will also be armed with flyers to distribute while you walk!



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

Events Snapshot

September:
- The Walk to Answer TTP Together

Ongoing:
- 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](#)

Walk to Answer TTP
Together



September 21, 2013

REGISTER TODAY

Join the Movement to Raise
Awareness & Funds for
Research.
Walk in your community for 2

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

hours. Individual and team registration available. T-shirt & custom donation webpage provided.



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

Winnipeg Meet & Greet



On Sunday April 14, 2013, Answering TTP Foundation held its first support group in Winnipeg, MB. About 20 patients and supporters attended the event. It was a successful Meet & Greet that got TTP patients and supporters together to share their experiences with TTP.

Two members of the Patient Advisory board were also in attendance at the meeting to share their stories and present updates from the Foundation. They also made a presentation on how TTP patients and supporters can get involved in their own communities.

To read more about and see pictures from the Support Group check out our [blog!](#)

TTP Symposium in Winnipeg

On Sunday April 14, 2013, Answering TTP Foundation hosted its first TTP Symposium in Winnipeg, MB. The event was held as part of the [Canadian Apheresis Group's](#) Annual Meeting. We had two internationally-recognized doctors who presented an overview of recent developments in TTP, as well as engage the audience of almost 50 doctors and nurses



from across Canada who treat TTP in a collaborative discussion.

Dr. Spero Cataland presented *Long-term Patient Outcomes in TTP* (which was so well received by the medical professional audience that it was later shown again at the Annual Toronto and Virtual Support Group and Info Session to patients and supporters). [Click to watch the video.](#)

Dr. Han-Mou Tsai presented *ADAMTS13: How it impacts on the diagnosis and management of microangiopathic disorders*. His presentation opened the floor for much important discussion amongst the audience. Since his presentation in April, Dr. Tsai has become a distinguished Professor of Medicine and Deputy Chief Executive Officer at I-Shou University College of Medicine and Medical Centre in Taiwan.

To read more about the event and to see more pictures check out our [blog!](#)

Annual Toronto & Virtual Support Group & Info Session

On Wednesday, May 8, 2013, Answering TTP Foundation held its annual Toronto & Virtual Support Group & Info Session. It was only the second time we integrated the virtual option to allow TTP patients and supporters to connect globally and it went great!

A pre-recorded video presentation was shown called *Long Term Outcomes After Successful Treatment of TTP*. The video was supplied by Dr. Cataland, who is the Clinical Associate Professor of the Division of Hematology and Oncology at The Ohio State University College of Medicine and Public Health. In the video, Dr. Cataland discussed the patterns being recognized by TTP specialists in patients since diagnosis, and some analysis that has been performed on these patterns to date. Included were the results from a study investigating memory deficiencies in patients - a topic that comes up at every support group. [To watch the video click here.](#)

Patients and supporters were then broken into smaller groups to share their stories, which lead to some great discussions! To read more about the Toronto and Virtual Support Group & Info Session check out our [blog](#).

Rare Disease Day TTP Blood Drive

On [Rare Disease Day 2013](#), February 28, Answering TTP Foundation held its annual international blood drive to help engage friends and family to give blood, and to raise awareness for TTP in the process.

The initiative resulted in 2 remarkable media stories featuring [Pam's story](#) as a reason to give blood.



Radio interview on CBC in PEI as a result of the Rare Disease Day TTP Blood Drive. Click on <http://www.cbc.ca/islandmorning/episodes/2013/02/25/blood-drive---pam-smith/>



Radio interview on CJOB
in Winnipeg with Karen Black! Click on <http://www.cjob.com/other/audiovault.html>.
Date: February 20th Hour: 5pm
Scroll to 5:53pm

TTP Patient Order Sets Now Available

Answering TTP Foundation is excited to announce the release of a tool to help speed diagnosis for TTP.

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).

Medical Professionals: Please consider joining the movement, by adding the TTP order sets to your hospital working library! Find them here.

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.

Awareness Campaign

TTP awareness wristbands are being given to donors while supplies last.

Answering TTP Foundation is arming donors with awareness bracelets to help get the conversation started to raise awareness for TTP to help save lives.

THIS IS A LIMITED TIME INITIATIVE. For every \$25 donated, 1 awareness wristband gift will be mailed. Donate \$25 to receive 1 wristband gift; \$50 to receive 2 wristband gifts; \$75 to receive 3 wristband gifts etc

DONATE TODAY (click here).



TTP Awareness Wristband

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 Gergana'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, our purely volunteer Answering TTP Foundation has incorporated nationally and gained charitable status. We volunteer to represent one strong common voice of action for our patient group, and to most effectively raise funds to support research initiatives not tied to one hospital. The Foundation provides a platform 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 has engaged professionals to develop a TTP standard order set with direction and guidance from a team of international hematologists 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 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.

Call for Research Participation

Dr. Spero Cataland and Dr. Jennifer Saultz are looking for TTP or aHUS patients to enroll and take part in a study they are conducting to look at headaches after diagnosis of TTP or aHUS. Interested participants must live in or near Columbus, OH.

The Participants will be required to fill out a simple, roughly 10 question survey. The purpose of the study is to examine headache prevalence and severity in patients with a history of TTP or aHUS.

If you are a TTP patient who lives in or near Columbus, OH and are interested in participating please contact Dr. Jennifer Saultz by email at Jennifer.Saultz@osumc.edu.



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

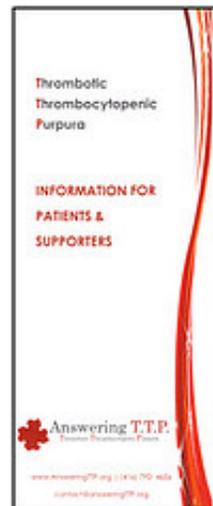
The TTP Patient Informational Brochure is designed to help new patients and families understand a TTP diagnosis and direct them to Answering TTP for further support.

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

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