

We are pleased to release the Fall 2014 edition of the Answering TTP Foundation newsletter. Help raise awareness for TTP by forwarding/sharing this newsletter. Good luck to all participants of the 2014 Walk to Answer TTP Together! If you are not registered, consider supporting a team or an individual. Sincerely, Sydney 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 emails 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.



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www.AnsweringTTP.org

Newsletter

Fall 2014



A Supporter's Story

Taken too soon...



On Friday, May 17, 2013, my wife, Joan, woke up with severe pain in the upper part of her stomach that extended to her back. She was nauseous and began vomiting every five minutes.

Thinking it was a stomach virus, I gave her medicine for her upset stomach and fluid so that she would not become dehydrated. But everything I tried seemed to make things worse. Her pain and discomfort seemed to be getting worse and worse. After about an hour, I contacted Joan's internist, who called in a prescription and told me that if she didn't get better in about three hours to take her to the emergency room. She also mentioned that from what I was describing, she didn't think it was just a stomach virus.

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After about three hours with no relief, I took Joan to the emergency room as instructed. Tests were run and then we waited for three to four hours for results. She was admitted to the hospital with the diagnosis of pancreatitis. She was given morphine for the pain and other medications. She was put on a "no food or liquid by mouth" diet until further notice. Blood work and other tests were done daily.

On the third day of hospitalization, they noticed that she was not putting out any urine and that her blood picture was "out of whack". The urology team and a hematologist were called in and she was started on dialysis. After she was put through more testing, she received an additional diagnosis - Thrombotic Thrombocytopenic Purpura (TTP), a rare blood disorder that causes blood clots to form in small blood vessels throughout the body. These blood clots can block the flow of the blood to the body's organs and can result in other very serious health problems. As a retired podiatrist, I had heard of TTP but knew very little about it.

Along with the dialysis, she began plasmapheresis treatments once a day at first, followed by every other day for three weeks, along with red blood cell transfer for anemia. After about ten days with no food or drink, her pancreatitis seemed to resolve, and she appeared to be getting better. She began eating, talking and even walking a little but was still on dialysis because her kidney function had only slightly improved. The plasmapheresis was discontinued and things were looking up for the next three to four weeks. Joan was catching up with friends and making plans for the rest of our summer.

Then she relapsed. Plasmapheresis started all over again. This happened two more times. She would get better, treatment would stop and then she would relapse. Each time, there were new medical changes taking place, such as reduced circulation to her extremities and liver. They also found a cyst on her pancreas, which could not be operated on at the time due to her condition.

Join Staci (Joan's daughter), William (Joan's husband) and the rest of the TTP community from anywhere in the world on September 20th, 2014 to improve the prognosis for all TTP patients.

Donate to a team and/or individual who is walking in the 2014 Walk to Answer TTP Together helping to raise life-saving awareness and



Support Our Efforts!

Donate today to a team or individual who is walking on September 20, 2014 in the Walk to Answer TTP Together.

Join the Movement by Helping to Raise Funds for Research.

Donate Today!

Registration now Open for our Patient Speaker Workshop!

Join us on October 4, 2014 to become a confident patient speaker by learning how to effectively deliver your TTP patient story at our workshop!

Registration is FREE, but required by October 1, 2014!

[Click Here to Register Today!](#)

TTP Awareness Hat



Available for a limited time! Patients and supporters who [share their story](#) officially with the Foundation will be sent a TTP awareness hat.

funds for TTP research!

Donate Today!

There was a period of remission, during which time she was discharged from the hospital and went to a rehabilitation hospital for occupational therapy in preparation for coming home. During the stay, Joan had another relapse and became very sick. She was readmitted to the hospital and diagnosed as septic due to the growth of the cyst on her pancreas. Within a few hours, she was taken to the operating room to drain the cyst and fluid in her abdomen. After the surgery, Joan was placed on a respiratory ventilator and fed through a nasal gastric tube. Her health at this time was on a downward spiral. Two weeks later, on September 25, 2013, she passed away peacefully...To read the rest of Joan's story and others (CLICK HERE)

William & Staci Rutherford

Organize a Fundraiser!

- Arts & Crafts Event
- Bake Sale
- Potluck Dinner

Everyone can raise money for TTP this Fall. [Check out our website for more ideas!](#)

Events Snapshot

September 2014

September 20, 2014:
[- Walk to Answer TTP Together](#)

October 2014

October 4, 2014:
[- Patient Speaker Workshop](#)
October 7, 2014:
[- Toronto & Virtual Support Group & Info Session](#)
October 18, 2014:
[- TTP Patient Day in London, UK](#)

Ongoing:

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

Upcoming Support Groups

October 7, 2014 - Toronto & Virtual Support Group & Info Session



On Tuesday, October 7th, 2014, Answering TTP Foundation will be hosting its Annual Toronto & Virtual Support Group and Info Session at 401 the West Mall, Suite 610, Toronto, ON. This support group is open to TTP Patients near and far, to join us in person or via teleconference.

The agenda will include a presentation regarding developments in TTP and a general Q&A session.

Registration is **FREE** but is required by Thursday, October 2, 2014 for planning purposes.

[Click Here to Register Today!](#)

October 18, 2014 - London, UK TTP Patient Day

On Saturday, October 18th, 2014, The Haemostasis Research Unit, Department of Haematology, University College London is holding a TTP Patient Day in London, UK at The Thistle Hotel, Marble Arch.

To find out more about the event, registration and contact information please visit the

event on our website [HERE](#).

Patient Speaker Workshop

Are you a TTP patient who is interested in getting involved with the Foundation? Do you want to share your experience with others to help spread awareness for TTP? Do you feel overwhelmed when sharing your story with others, but want to learn effective ways to overcome this?

If you answered yes or maybe to any of those questions then the Foundation has a great opportunity for you!



Sharing the story of your personal experience with TTP as a TTP patient is the most powerful way to spread awareness, but standing in front of others to tell your story in person can be a challenging task. Especially when you are asked to speak in front of people you don't know or a large group. We understand how difficult this can be and we want to help you to overcome those challenges by arming patients with best practices of delivering your story!

On Saturday, October 4th, 2014, from 10am - 12pm at 401 The West Mall, Suite 610 Toronto, ON, the Foundation is hosting a pilot workshop to help TTP patients learn how to effectively share their TTP experience in public to help raise the profile of TTP and bring awareness of TTP. If successful the Foundation will be looking to coordinate similar events in other cities around the world.

Registration is **FREE**, but required. Registration will close Wednesday, October 1, 2014.

To register please visit our website [HERE](#).

By working together, we WILL find an answer for TTP! See you there!

It's Official We're Published!

That's right, the Foundation has its first published article in the reputable [Transfusion and Apheresis Science](#), the official journal of the World Apheresis Association and the European Society for Haemapheresis. This is a ground breaking step for the Foundation, as it will help to boost the Foundation's credibility with current stakeholders, and extend the reach of the Foundation's charitable programs and research by garnering attention from the international medical community.

The article entitled "A patient's perspective", was an initiative of the Foundation's Patient Advisory Board, spearheaded by Sydney Kodatsky, Founder and Executive Director. The article is a first person account of Sydney's experience with Thrombotic Thrombocytopenic Purpura (TTP), and the important role the Foundation has played to help improve access to treatment options for patients.

The article outlines the success of the Foundation's unified voice for TTP, which helped to bring Solvent Detergent Plasma (SDP) to the Canadian TTP patient community. As our

community grows, the Foundation becomes better equipped to advocate for quality care for all TTP patients.

We are thrilled about this Foundation first, and we look forward to future opportunities to publish articles. If you are interested in joining the Foundation's Patient Advisory Board, please visit our website [HERE](#).

To read the entire article in [Transfusion and Apheresis Science](#) please [Click Here](#) to get to the article link.

To receive a hard copy of the article (while supplies last) please contact us by email at Contact@answeringttp.org.

The Awards are back and up for grabs!!



Will you be the winner of this year's Spirit, Top Individual Fundraiser or Top Fundraising Team Award?

Spirit Award!



Top Fundraising Individual! Top Fundraising Team!



All 3 awards are up for grabs, and with 5 days left until Walk day, there's still plenty of time to raise life-saving funds and plan how you can show your unwavering support for the TTP community by having the most spirited Walk!

Overall Event Goal:



With 5 days left to Walk day we have reached 47% of our goal. We need your help to reach our 2014 goal! [Donate to a team or individual today](#) to help the TTP community!

Swing over to the Foundation's [Blog](#) for a look at last year's winners and to get [ideas](#) to

make your 2014 Walk bigger and more successful than ever!

5 Days to Walk Day = 5 Days to Surpass your Fundraising Goal!

In 5 days, teams and individuals will lace up their sneakers and **Make Strides to Save Lives** in the 4th Annual Walk to Answer TTP Together. This means there are still 5 days for individuals and teams to challenge themselves to surpass their fundraising goals! Funds raised by teams and individuals will make an impact on the global TTP community by helping the Foundation to fund life-changing TTP research and to operate support and education programs. Did you know that through events such as this, the Foundation has raised and committed \$499,607 toward TTP research through 2016?

As a team or individual who is registered to participate in this year's Walk, you may be reading this thinking, "But I only have 5 days. What can I do in 5 days to reach my goal?" To that we say "lots!" There is lots you can do to surpass your fundraising goal in just 5 days and we want to help you! Below are 6 tried and tested ways you can help you and/or your team surpass your fundraising goal and go that extra step to help the TTP community!

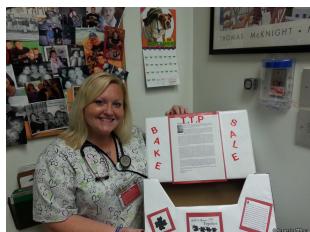
1. Customize your Personal Donation Page - It's not too late to customize your personal donation page. Did you know that **you registration includes a customizable donation page to help you raise funds?** You can personalize your page to share important information with possible donors about how TTP has touched your life. Let people know why you need their help to raise funds! If you have trouble accessing your page please review the participant instructions [HERE](#). For additional support, email events@answeringttp.org.



2. Email - If you haven't already, send an email with a link to your personalized donation page to all your friends, family, coworkers, etc. informing them about the Walk you are participating in, why you are participating, and why it is important to you! If you have sent an email to your network, try sending them another "nudge". They may want to donate and thought they had more time to do so!



3. Social Media - It's one of the most powerful tools out there for reaching people within our networks. Remember to post your personalized donation page link on all your Social Media accounts!



4. Bake Sale - Make up some baked goods to bring into work or bring to the day of your Walk to sell to help raise funds. This works well on Walk Day if you plan a central location to begin your Walk and spend a little time before or after your Walk holding a Bake Sale.



5. Coin Collection - Why not decorate some containers that you and/or your team display on your desk at work before the Walk and then carry during your Walk. People are often willing to donate the spare change they have in their pockets and this small change can add up really quickly!



6. BBQ or Dinner Party - Call up some friends or family for an impromptu dinner party or BBQ on Friday night or Saturday after your Walk. You can even theme the event as a celebration of your Walk for TTP! It doesn't have to be a big to-do, just a small get together! Ask attendees to bring a donation for your Walk instead of a gift for the host/hostess.

Visit our blog [HERE](#) to read what some teams are doing to "up" their game and raise more funds for their Walk! For more small event ideas that you can hold in support of your Walk, visit our website [HERE](#) and scroll to the bottom for a wide variety of event ideas!

Not registered to participate in the 2014 Walk to Answer TTP Together? There is still time to **Support Our Efforts** by donating to a Team or Individual [HERE](#). Every donation enables the TTP Community to assert action to fight back and improve the prognosis for all TTP patients.

Volunteer Appreciation Dinner and Awards!

On Tuesday, August 19, 2014, volunteers and board members gathered for Answering TTP Foundation's Annual Volunteer Appreciation Dinner and Awards! This is a special night for the Foundation as it gives us a chance to celebrate our dedicated volunteers near and far, as volunteers who were unable to attend in person called in to participate in the speech and award part of the evening.



To view all pictures from the event visit our photo book [HERE](#)

This year's event went off without a hitch! We were able to enjoy great food and great company! The weather was perfect for us and allowed us to spend the evening in the comfort of Margie Castiglione's Oasis of a backyard. A BIG thank you to Margie

Castiglione, a dedicated volunteer of the Foundation, who knows how to host one stunning event!



From left: Sydney Kodatsky (Board Executive Director), Heather Kodatsky, Margie Castiglione (Event Host) and Sherri Sullivan (Board Vice-Chair)

This year's recipient of the Heather Leckie Bryant Award presented to the Volunteer of the Year, is our dedicated IT manager, Ian Wilson. Ian has played a tremendous role in the background of the Foundation in keeping all the Foundation's IT running smoothly. He is also the creator of the Foundation's "new" and much improved website that went live last August. We are very thankful to have him on our team!



From left: Sydney Kodatsky (Board Executive Director), Heather Kodatsky, Sherri Sullivan (Board Vice-Chair), and Ian Wilson (Volunteer of the Year)

The Foundation's Vice-Chair, Sherri Sullivan, gave a speech to thank all the Foundation's volunteers, near and far. If you missed it you can visit our Youtube channel [HERE](#).

Are you interested in getting involved with the Foundation?

We are always looking for volunteers to help! We have many opportunities and have made it really easy for you to get started on the path to volunteering with us. Simply visit our website [HERE](#) to fill out the [Volunteer Information Form](#). Upon receipt of your submission, we will contact you to discuss opportunities that we think might be a good fit for you!

It is only by working together that we will be able to find an answer for TTP!

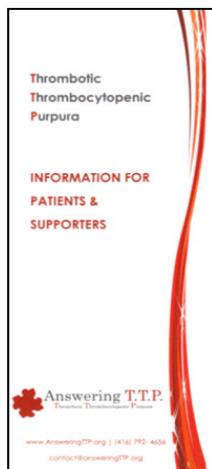
Thank you to all of the Foundation's AMAZING volunteers! None of what the Foundation has accomplished to date would have been possible without your hard work and dedication!

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 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.

Patient Education Materials



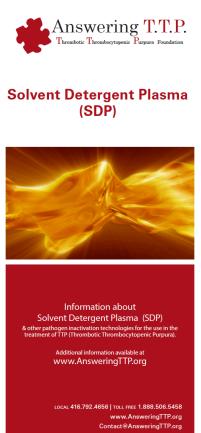
Patient & Supporter Information Brochure

Patient Resource

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 Foundation, in an effort to relieve some of the anxiety felt by new patients.

Available in print in English and French. Available for download in English, French, Italian, Simplified Chinese, Russian, Portuguese and Punjabi from 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 to everyone.

The Foundation is enthusiastic to see that SDP has become more available. We hope that this momentum is continued to enable access to SDP for all TTP patients that may benefit from it.

Available in print and via download. We are in the process of translating ... Check back soon.

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.

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 William'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](#).

Now, for a limited time, when you submit your story to us officially you will receive our TTP awareness hat!



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 with each other to provide peer support. Help break down geographic boundaries by sharing your experience to help others.

Support Groups: Local groups are currently running in Vancouver, Calgary, Toronto and Saint John. The Ontario East Roadshow promises to connect the Answering TTP Community with treatment centres to begin additional sessions. The next Toronto & Virtual Support Group will take place at 401 The West Mall, Suite 610, Toronto, ON. A call-in option is available for those who are not local but would like to participate. For more information or to register for the Toronto & Virtual Support Group visit our website [HERE](#). For information about organizing a session in your community visit [www.AnsweringTTP.org](#).

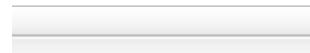
Patient Education Materials: The Patient & Supporters Information Brochure and the Solvent Detergent Plasma (SDP) Brochures are materials the Foundation, with the help of our Medical Advisory Network, has created for patients. These informational brochures contain easy-to-understand terms, and inform patients that Answering TTP Foundation is here to support them. The Patient & Supporter Informational brochure has been translated into French, Italian, Simplified Chinese, Russian, Punjabi and Portuguese 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.

Twitter: The Answering TTP Foundation has joined Twitter! The Foundation's Twitter account, [@TTPFoundation](#), allows the Foundation and its community around the world the ability to interact in real time. We reach out to the community with questions and links to news and interesting facts relevant to the TTP community. Be in the know about what the Foundation is up to and what we are talking about by [following us](#) on Twitter! [Tweet us today!](#)

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.



Connect Online

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

[Visit our blog](#)

[Like us on Facebook](#) 

[Follow us on](#) 

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 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:

- 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; and,
- 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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Contact@AnsweringTTP.org

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