

We are pleased to release the Winter 2013 edition of the Answering TTP Foundation newsletter. Help raise awareness for TTP by forwarding/sharing this newsletter and don't forget to SAVE THE DATE for our upcoming Chance for Change Game Night, April 12, 2014. 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

Winter 2013



Danielle's Story



My name is Danielle Bourgeois, I am 23 years old and I live in Dieppe, New Brunswick.

In the summer of 2011, when I was about 20 weeks pregnant, all my symptoms began. I was working full time at a senior home doing the graveyard shift (7pm-7am). It never crossed my mind that I was having anything other than typical

pregnancy symptoms - I couldn't eat, I had pains in my stomach, I was very tired, always vomiting and constant headaches.

The morning of August 4, 2011, after I had finished working a 12 hour night shift, I complained to my mom of a really bad headache and that I had noticed unexplainable bruises on my body. She told me to go rest and that she would contact the clinic to schedule an appointment for later in the afternoon. When my mom got home to take me to the appointment, I was still very

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How You Can Help

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

tired and had spots on my face & chest (these turned out to be broken blood vessels).

When we got to the hospital, I still assumed that everything was fine and that everything I had been experiencing was normal. They did some blood work and then sent me home. They said if there was something wrong, they would call us back. My mom and I had just enough time to get something to eat when we received the call that changed everything, telling us to come right back to the hospital! So many things were going through my mind - was it my baby? Was it okay? When I arrived at the hospital, they told me that I would be admitted and couldn't leave. As time ticked away, I became more and more nervous. They ran blood test after blood test and introduced me to several different doctors, who all looked at me with the same bewildered look. Finally after hours of waiting, I was given my diagnosis - TTP. I had no idea what it was but I knew deep down it wasn't good just by the doctors' facial expressions. They told me that my platelet count was at 7 and that I would need to be air lifted to Saint John Regional Hospital to receive aphaeresis treatments.

I remember arriving at the hospital and not knowing what to expect. All I wanted to do was sleep, but I couldn't. Several nurses, doctors and residences were asking me questions to a point where I became completely overwhelmed and was no longer able to answer. I remember my family, who had driven while I was airlifted, finally arriving and I began to feel safe again. At 3 am, I was sent into surgery for the placement of my Hickman line and at 7 am, my first treatment began. After three weeks of treatment, I started to feel like myself again and it was time to go home!

After being home for only a week, I started to feel my body weaken and knew it was coming back. I was right, and once again we made our way to the hospital in Saint John for more treatments. It was confirmed to me during my second stay in the hospital that I was expecting a little girl. The obstetrician also told us that my daughter was smaller than she should be and that he might have to preform a C-section in the next couple of weeks because of my health.

I was kept in the hospital for the remainder of August and had received 24 treatments by the time September arrived. I was released in September but returned for treatments twice a week until October.

On the morning of October 2nd, 2011, I was at home in Moncton when I began feeling very uncomfortable, with pain in my back. I was almost 28 weeks pregnant at this point. My mom decided that I should be taken to the hospital to be checked out. We waited several hours in emergency without being helped; no one seemed concerned when we told them I was a high-risk pregnancy and that I had recently been diagnosed with TTP. My mother and I decided to walk up on the 3rd floor to see if anything could be done. At the front desk, we told them



Please donate this holiday season to brighten the spirit of the TTP community!

[Donate NOW](#)



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 on sharing your story, read the [article below](#) and visit our [website](#).

Events Snapshot

November:

[- Ohio Patient Support Group](#)

April 2014:

[- Change for Change Game Night](#)

Ongoing:

[- Support Programs](#)

[- TTP Denim Days](#)

Holiday Fundraising Ideas

- Bake sale
- Coin collection
- Dress down day
- Dinner party

Everyone can raise money for TTP

the same things we had told the emergency and thankfully they listened. They gave me a bed, hooked up monitors for the baby and did blood work. Once again they were shocked with the results, my platelets were at 5 and I had developed preeclampsia that had turned into HELLP syndrome.

Again, I was sent to Saint John for more treatments and to have a C-section. They had to give me several medications and two apheresis treatments before doing the c-section because they were concerned about my daughter's development. On October 4th, I gave birth to a beautiful baby girl, weighing 1 pound, 14 ounces. The feeling of waking up after the C-section, knowing I was still alive and that I had a beautiful baby waiting to meet me for the first time, was the most indescribable feeling. Olivia stayed in the Saint John hospital for 4 weeks before being transferred to the neo-natal unit at the Moncton City Hospital, closer to our home. Finally, on December 4th, weighing only 4 pounds, she was released. Christmas came early for my family and I that year! I continued travelling to Saint John twice a week for treatments and relapsed again in March 2012. When all the treatments were done, I had received a total of 64 Aphaeresis treatments and 4 Chemo treatments, from August 2011 to April 2012.

Today, I can proudly say that I've been in remission since May 2012. I decided to go back to school to get my GED, I plan on getting my driver's license in September and would like to become a Practical Nurse. My daughter is almost 2 years old and is doing great; she is very intelligent. She is my angel and my reason to always fight for life!

Live your life

I would like to thank all my family and friends for all of their support and prayers during my dark moments. Also, a big thank you to the team at Saint John Regional Hospital, Dr. D, my three amazing nurses A.M, V.C and S.M, and Dr. F in Moncton - I owe you my life.

Danielle Bourgeois

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

this holiday season. Check out the article **[Donations Instead of Gifts.](#)**

SAVE THE DATE

April 12, 2014 in Toronto



It's a night you don't want to miss, full of professional style gaming, silent and live auctions, as well as great raffle prizes!

SAVE THE DATE

September 20, 2014 world-wide



Updates to the WEBSITE



Check out our brand new **[Photobook](#)** and **[Research Grants](#)** Pages!

www.AnsweringTTP.org

Blood Donation

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

[CLICK FOR DETAILS](#)

2013 Walk to Answer TTP Together is a Wrap!

\$33,408 raised for TTP research, education & support!
Check out the article Dollars at Work for information on how your efforts are making a difference today.

315 international registered participants raised life-saving awareness!



Check out all the 2013 Walk pictures that have been submitted [HERE](#).

Congratulations and special mention to the winners of this year's awards! To read more about individuals and teams' that won click on their names below!

Top Fundraising Individual was awarded to [Mina Rajan](#)



Mina Rajan

Top Fundraising Team was awarded to team Walking for Trevor
(Team Captain: Kathy Downs)



Walking for Trevor

Spirit Award was awarded to team Island Walkers
(Team Captain: Pam Smith)



Island Walkers

Thank you to all of those who participated in, and donated to, the 2013 Walk to Answer TTP Together!

Save the date for next year's Walk - September 20, 2014!

Walk to Answer TTP
Together



Dollars at Work

To date, Answering TTP Foundation has raised over \$500,000! Your donor dollars have been put to work on groundbreaking projects including: patient support and education; outreach and advocacy; and medical research and collaboration.

The Foundation has recently started funding two new exciting research grants:

The Relationship of Complement Activation to Clinical Outcomes in Patients with Acquired Thrombotic Thrombocytopenic Purpura Mediated by Severe ADAMTS13 Deficiency

This research is dedicated to studying the role of the



Dr. Spero Cataland

complement system in the initiation of an acute TTP episode, the early and late recurrence of a TTP episode, and the risk of dying from an acute episode of TTP. The goal of this study is to define the relationship of complement activation to clinical outcomes in patients with acquired TTP mediated by severely deficient ADAMTS13 activity who were treated with combined plasma exchange therapy (PEX) and immune suppressive therapy.



Dr. Frank Jirik

Developing novel preclinical models of Thrombotic

Thrombocytopenic Purpura

This research is a scientific approach looking at potential factors that may trigger the onset of TTP when ADAMTS13 levels are very low. The research revolves around the Adamts13 gene-deficient laboratory mouse, and is primarily concerned with the investigation of two potential factors that may trigger TTP: blood vessel inflammation due to the immune system; and decreased production of nitric oxide by the inner lining cells (endothelium) of blood vessels. A goal of this research is to develop novel preclinical models of TTP that can be used to test therapies that will prevent and/or treat attacks of this disease. Genetically-engineered mice will also be created to allow researchers to carry out real-time, live animal visualization of platelets using bioluminescence imaging, as well as visualization of interactions between platelets and blood vessels via intravital microscopy imaging.

More information at AnsweringTTP.org/our-role-impact/our-research-grants

Donations Instead of Gifts....

With the holiday season upon us, Answering TTP Foundation asks you to consider getting involved by turning your Holiday shindig or office events into ones that benefit the Answering TTP Foundation.

Need some inspiration???

Bake Sale - why not bake some holiday treats to bring into work and ask your coworkers to make a small contribution of \$0.25 -\$2.00 in turn for the mid-day holiday snack?

Loose Change Collection - festively decorate a container for TTP donations and put it in a common area (lunch room, break room, etc.) or your desk at work and ask people to

kindly donate their change over the next few weeks. You'd be amazed at how well this one does!

TTP Denim Days - for the month of December, why not get your office to participate in TTP Denim Days when one day a week the office can dress down for a small contribution (\$1-\$2)?

Dinner Party - invite your friends and/or family over for a dinner party, but instead of bringing a hostess gift, why not ask them to donate to the Answering TTP Foundation?

Cookie Decorating Contest - a great way to get children involved! Why not have a Cookie Decorating party with your children and some of their friends? Instead of asking the other parents to chip in for the supplies, ask them to send their child with a donation to be made to the Answering TTP Foundation.

There are lots of other great ideas listed on our website [HERE](#), or you can brainstorm your own unique fundraising event or activity to benefit TTP!

If you would like the Foundation to provide support (creative for posters, provide awareness ribbons, or list your event on our website), just fill out the Fundraising Event Guidelines and Event Proposal Forms [HERE](#) and email us at Contact@AnsweringTTP.org to get started!

Help brighten the spirit of those affected by TTP this holiday season by donating generously!

Canadian Blood Service Staff Awards

On Tuesday, September 24, 2013, [Sydney Kodatsky](#), Answering TTP Foundation's Founder and Executive Director, was invited to be the guest speaker at the [Canadian Blood Services](#) (CBS) staff service awards ceremony. The Ceremony took place at the brand new state-of-the-art blood services facility in Brampton, ON and was attended by CBS employees who have dedicated their life's work to ensuring that safe and sufficient blood supply is available to those in Canada who need it.

[Sydney](#) shared her story of how blood, collected and processed through [CBS](#) helped to save her life during each one of her TTP relapses. She thanked all employees for their hard work that helps to save lives daily. Her presentation was well received and even helped to spread awareness of TTP.

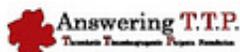
Read more about Sydney's story and our tour of the facilities on the Answering TTP Foundation [Blog](#).



TTP Patient Order Sets Now Available

Order sets are evidence-based checklists that medical professionals use to speed the diagnosis of patients. [Answering TTP Foundation](#) is excited to announce the release of two TTP order sets and a discussion document to assist first responders to more quickly diagnose and seek out appropriate treatment for patients with suspected TTP, and to spread best practice treatment practices amongst TTP treaters.

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.



PATIENT INFORMATION

Document allergies on approved form and ensure medication reconciliation has been reviewed as per organizational process

| Suspected Thrombotic Thrombocytopenic Purpura (TTP) First Response - Initial Investigations Order Set (Order Set # 1) | | ACTION |
|---|--|-----------------------------|
| ***TTP is Life Threatening; Urgent consultation with an MD with TTP specific expertise is required*** | | |
| Refer to Associated Document: Thrombotic Thrombocytopenic Purpura (TTP) Information | | |
| ***for first response treatment of suspected TTP, MD to refer to the First Response Treatment of Thrombotic Thrombocytopenic Purpura (TTP) Order Set (Order Set # 2)*** | | |
| Lab Investigations | | |
| Lab Investigations to be done to Screen for TTP | | |
| <input checked="" type="checkbox"/> CBC, including Platelet count, Smear | <input checked="" type="checkbox"/> Reticulocyte count | Reproduction is prohibited. |
| <input checked="" type="checkbox"/> Coagulation Screen: APTT, INR, Fibrinogen | <input checked="" type="checkbox"/> Direct Antiglobulin Test (DAT) | |
| <input checked="" type="checkbox"/> Group + Screen | | |
| <input checked="" type="checkbox"/> Electrolytes | <input checked="" type="checkbox"/> Creatinine | |
| <input checked="" type="checkbox"/> BUN | <input checked="" type="checkbox"/> Glucose | |
| <input checked="" type="checkbox"/> LDH | <input checked="" type="checkbox"/> Thromb... | |

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).

Distribution of these order sets has begun. The order sets are available on our website for free download, and have been uploaded to PatientOrderSets.com platforms (used by 270 health care organizations), and volunteers have mailed them to over 500 emergency rooms in Ontario, with plans to distribute country-wide in the next year.

Medical Professionals: Please consider joining the movement to help first responders consider TTP. Add the TTP order sets to your hospital's working library! [Find them HERE.](#)

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.

Annual Correspondence Packages



Table of materials to stuff packages with help from volunteers.

On, October 13, 2013, Answering TTP Foundation sent out its Annual Correspondence Packages to Canadian TTP treaters as well as all of the treatment centres who have registered at AnsweringTTP.org to receive updates.

Each Annual Correspondence Package contained English and French information brochures for TTP patients and supporters, our new Solvent Detergent Plasma (SDP) brochures, an awareness ribbon to be worn to help generate awareness and support for TTP, a copy of the new TTP [patient order](#)

[sets](#) to help speed TTP diagnosis, along with a copy of an article focusing on the TTP patient order sets, recently published in [Hospital News](#).

If you are a medical professional and would like to receive a copy of our Annual Correspondence Package, please visit AnsweringTTP.org/medical-professionals to register your treatment centre.

Our New SDP Brochure

Solvent/detergent-treated human plasma (SDP) is a form of virus-inactivated plasma product. The inclusion of the SDP treatment during the manufacturing process potentially reduces the risk of adverse events during plasma transfusion, including transmission of some viral infections, transfusion-related acute lung injury, and allergic reactions.

(Source: Canadian Agency for Drugs and Technologies (CADTH) publication entitled Guiding the Optimal Use of Solvent/Detergent-Treated Human Plasma).

SDP is a type of pathogen inactivated plasma. Pathogen inactivated plasma been used for many years. Some countries such as the UK, Finland and Ireland, have completely switched to using SDP. At the present time, SDP plasma is used routinely in Germany, Israel, Norway, France, Switzerland and Portugal. Some of these countries have used SDP since 2002.

(Source: Allain JP. 10 years of pathogen reduction/inactivation (PR/PI) Transfus Today 2009; No 6:pg. 5.)

In January 2013, the US FDA approved a SDP product to treat patients with congenital or acquired TTP. According to Karen Midthun M.D., Director of the FDA's Center for Biologics Evaluation and Research, "this product provides a reduced risk of certain viral transmissions."

(Source: <http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm336009.htm>)

In Canada (except Quebec), as of July 30, 2012, SDP may be considered as an alternative to standard plasma for certain patients: who require a high volume of transfusions annually because they have:

- TTP (both congenital and acquired forms); or,
- HUS with associated factor H deficiency; or,
- clotting factor deficiencies for which specific licensed concentrates may not be readily available (e.g., factor V, factor XI, factor XIII),

and who:

- have experienced an allergic reaction to frozen plasma; or
- have a pre-existing lung disorder; or
- need frozen plasma, but a blood group-compatible product is not available in a timely manner.

(Source: The Canadian Agency for Drugs and Technologies in Health (CADTH) published the following



Solvent Detergent Plasma (SDP)



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

Additional information available at
www.AnsweringTTP.org

LOCAL 416.792.4656 | TOLL FREE 1.888.506.5458
www.AnsweringTTP.org
Contact@AnsweringTTP.org

recommendation in May 2011.)

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.

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.

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.

Patient Brochure

Patient Resource

Available in Print in English and French (NEW). Available for download in English, 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 Foundation, 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.



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 Danielle'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, as well as 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 ever heard of Thrombotic Thrombocytopenic Purpura before and never imagined needing massive amounts of donated blood product. Because TTP causes small blood clots that form throughout the body, you may live with irreversible damage to your heart, brain, and/or kidneys for the rest of your life. Some patients do 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.

April 12, 2014 - SAVE THE DATE



Chance for Change

Our annual [Chance for Change Game Night](#) will take place at the Old Mill Inn in Toronto, On [Saturday, April 12, 2014](#). It's a night you don't want to miss, full of professional style gaming, silent and live auctions, as well as great raffle prizes! The [2013 Chance for Change Game Night](#) raised an astounding \$150,000 - let's make this year's event even better!



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.

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 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.

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