

We are pleased to release the Spring 2015 edition of the Answering TTP Foundation newsletter. Help raise awareness for TTP by forwarding/sharing this newsletter. Enjoy! Sincerely, Sydney Bryant Kodatsky, Executive Director. You're receiving this email because of your relationship with Answering TTP Foundation. Please [confirm](#) your continued interest in receiving email from us. To ensure that you continue to receive emails from us, add [contact@answeringttp.org](mailto:contact@answeringttp.org) to your address book today.

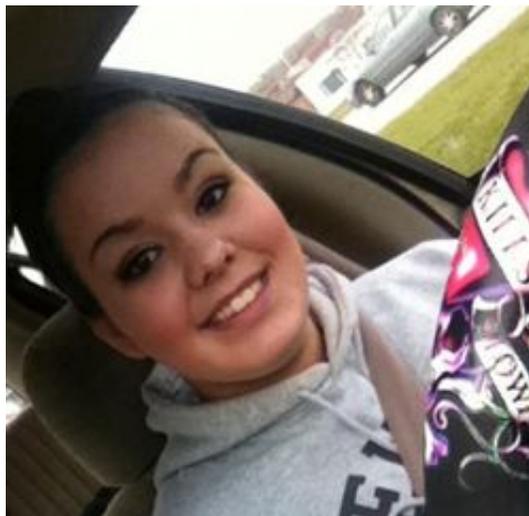
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## Stephanie's Story

My daughter Bobbi has always been very active - taekwondo, volleyball, softball and so on. Bruises were the norm for her and we didn't think twice about them.

In November 2009, she was 15 and a sophomore in high school when the symptoms began. One day, while horsing around with her brother he kicked her in the shin; within an hour she had a bruise that went from ankle to knee. The next day she was exhausted and suffering from a headache. I thought it was the flu.



Three days later, she was very lethargic, so we took her to our family doctor to find out what was going on. Fifteen tubes of blood were drawn before a possible diagnosis of the parvo virus was given. We went home and I put her to bed with fluids and thought she would come around in no time. Then it happened - the doctor called. When your phone rings at 7:00pm and it's your doctor, you know it isn't a good call. Her platelet count was low, 11,000. We were to follow up the next AM with a hematologist.

We arrived at Children's Hospital that morning and it was a whirlwind of activity. Her platelet count had dropped to 8,000 and she was critical. I remember Bobbi commenting "I hope they keep me overnight so I can order room service." Little did she know she was going to be there for more than one night.

Multiple medical professionals saw Bobbi that morning. She was admitted, a central line was inserted and plasmapheresis started immediately. I'll never forget the fear I saw in my daughter's eyes that evening and the feeling of knowing there was nothing I could do to make it better.

After a month of inpatient plasmapheresis, she was released for treatment as an outpatient for approximately two months. She was followed extensively due to her being a child and having the rare diagnosis of TTP. We were lucky we had the best of the best in our state treating our child.

In July 2014, Bobbi relapsed. She began to complain of a very bad backache and just not feeling well. Though she was worried about her dark urine, she didn't seem overly concerned, so I didn't ask her the question I always ask "Does it feel like it's back?" On Friday July 18, 2014, she sent me a text message telling me "I don't feel good". I took her straight to the emergency department. Even though we told the emergency room doctor of her history with TTP, he dismissed it and told us he thought it was a kidney stone because of the back pain. I had to insist on him doing a CBC. When the results came back her count was 10,000. She was immediately transferred to another Hospital and admitted for TTP.

Half way through this round of plasmapheresis treatment, she developed an allergy to a protein in the donor plasma. Anaphylactic shock set in and she was transferred to the ICU. The allergy and hematology teams had no answers as to why...why was there a reaction and what were we going to do? Bobbi spent a total of 5 days in the ICU receiving Benadryl 13 hours, 6 hours and 1 hour prior to her treatments, as well as prednisone and an EpiPen sat at her bedside. Thankfully, she responded to that treatment plan and required no further medical intervention for the reaction to the protein.

On August 10th, 2014, two days before her 20th birthday, Bobbi went home. It's been a whirlwind of central lines, plasmapheresis and medications with no real answers. Given her very young age and the rarity of the condition, she has a team of eight medical professionals treating her. The whys are too many to count and the sleepless nights are draining at the very least.

*~ Stephanie Radonski*

[\*\*READ STEPHANIE'S FULL STORY HERE\*\*](#)

## SUBMIT YOUR PATIENT / SUPPORTER STORY!



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

Are you looking to take the first step to get involved with the Answering TTP Foundation?

Why not start by sharing the story of your personal experience with TTP as a patient or, if you are a supporter, the experience of a loved one you stood by as they went through or are going through TTP.

Sharing stories will help to strengthen the voice of the TTP community while raising life-saving awareness! Your submitted story will be published on our website to help others facing similar challenges as well as adding a face to this rare blood disorder.

[LEARN MORE](#)

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## THE CAG RITUXIMAB STUDY

**A note from Dr. Gail Rock, MD PhD FRCP  
Chair, Canadian Apheresis Group**

*The Canadian Apheresis Group has recently completed the write up of the study in which we used the drug Rituximab in 20 patients with refractory TTP and 20 with relapsing disease. The paper is now in press with the British Journal of Hematology and is entitled "A Phase-II sequential case-series study of all patients presenting to four plasma exchange centres with presumed relapsed/refractory TTP treated with Rituximab". Discussions following completion of the study have raised several important questions including the potential for relapse following Rituximab therapy and the long term outcome of patients who have received this drug, which acts by killing the B cells that produce antibodies.*

*We have therefore initiated a long-term follow up on all of these 40 patients. To date, we have information on the 12 patients that were entered from London, Ontario. We are also hoping to get information from the other centres from which there were 13 patients at the Toronto Hospital, 7 patients in Hamilton and 5 in Vancouver.*

At this time I would like to appeal to any patients at these last three centres who were in the study to return to your treatment centre and provide information on the general state of your health and whether or not you have subsequently had a TTP relapse.

*This information will be very helpful to us in planning future therapy and/or the need for other studies. In TTP, as in most apheresis procedures, once a patient has completed apheresis therapy they are often lost to follow-up by the apheresis unit. Only by receiving this feedback will we be able to plan for the future. Therefore, if you were in the study or know anyone who was, we would appreciate it if you would provide the needed information or encourage other patients in this follow up exercise. Your help in this is greatly appreciated.*

[LEARN MORE ABOUT THE CAG](#)

## DID YOU KNOW?

On January 28, 2015, [Canadian Blood Services](#) introduced a new [Solvent Detergent Plasma \(SDP\)](#) Request Form for Canadian Hospitals. We are hopeful that this will mean an ease of access to this product for patients in Canada!

[LEARN MORE ABOUT SDP](#)

## MARCH 28, 2015 A GAME NIGHT TO REMEMBER

The 6th Annual Chance for Change Game Night has come and gone. This year the Chance for Change Game Night volunteer committee looked outside the box to deliver an exciting new "Carnival" theme for Chance for Change. From a stilt walker and juggler, to midway style gaming, prizes and carnival foods, this Game Night truly felt like an evening spent under the "Big Top".

We would like to congratulate and thank the hardworking volunteer committee for all their extraordinary efforts this year! You outdid yourselves raising \$140,00 in life-changing funds for the TTP community! We can't wait to see what you cook up for next year's event!



Chance for Change - 2015 - Benefitting  
Answering TTP Foundation

### A Note from Chance for Change Game Night's fearless Chair, Tammy.

*"I'm not really sure if my favorite time of the year is leading up to the [Chance for Change Game Night](#), or just after the event has happened. Both are equally rewarding because of the time I spend with the talented and dedicated team of [volunteers](#) that give their time to prepare and execute the event, as well as the sense of accomplishment we feel once the event is behind us and the results are in.*

*Our team took a risk this year by promoting a fun casual atmosphere of carnival style games. By doing so, we found the perfect mix of elegantly dressed guests wildly shooting baskets against their opponents, dropping tokens in our Plinko game, shooting darts and throwing their rings for a chance to win prizes. We added a Scavenger Hunt this year, which allowed our guests to get into the spirit of the evening from the moment they walked in the doors.*

*We were able to learn a bit more about TTP from a patient's perspective, and were given a snapshot into the world of research where the majority of the funds raised through this event are targeted. Together, and with the generous support of our sponsors, donors and even guests, we raised **\$140,000** this year, bringing our Chance for Change Fundraising event total to **\$700,000** in just 6 short years.*

*On behalf of the [Chance for Change Game Night Committee](#), a heartfelt thank you to those of you that supported and attended the event this year. Also, thank you to those who took the time to complete our event feedback survey, which gives us the insight to continually improve the event. The winner of the survey prize draw is Tony Hooper! Congratulations! Tony won a beautiful TTP LD Key Finder!*



The TTP LD Key Finder

[Find out more about the TTP LD Key Finder and how you can get one HERE!](#)

**A Teaser of the 2015 Chance for Change Feedback Results:**

- 100% of those surveyed said that they would consider recommending the event to friends next year!
- 95% of those surveyed said they were impressed by our Carnival games.

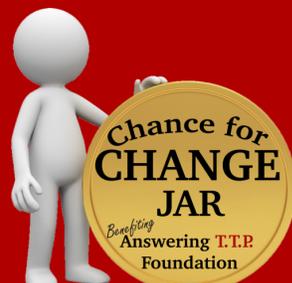
We're proud to support Answering TTP, and invite you to join our team as we plan new initiatives for 2015. The first of which kicked off at the event with our guests taking a Chance for Change jar home. Learn more about this new campaign [HERE](#).

I'm grateful that I had the opportunity to work with the committee again this year and I marvel at the dedication and commitment of the team. Giving time to a charity is one of the most important and simple gifts any of us can give, and yet the benefits of the gift are far beyond what any of us can imagine. "The smallest good deed is worth a thousand grand intentions". We'll all look forward to seeing you again at our next [Chance for Change Game Night!](#)"

~Tammy



**[LEARN MORE ABOUT AND SEE PHOTOS FROM THE EVENT](#)**

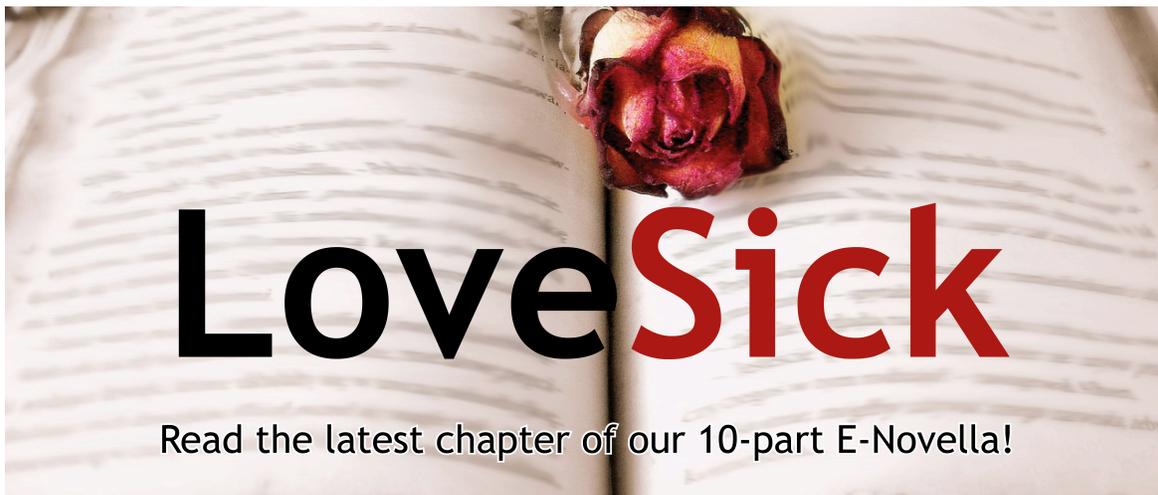


**MAKE YOUR CHANGE COUNT!  
START YOURS TODAY!**

[Learn More](#)

**HAVE YOU BEEN READING LOVE SICK?**

On February 12, 2015, Answering TTP Foundation launched a NEW and EXCITING awareness initiative with the help of a dedicated volunteer writer, Laura Santana.



Love Sick is a 10-chapter e-novella being posted on Wattpad.com. It is the story of Maria, a young woman, who marries her college sweetheart. When they get pregnant with their first child, Maria is excited and doesn't think life can get any better. Unfortunately, her health begins to take an unexpected and scary turn while pregnant. Her doctors are left baffled and unable to diagnose her. Leaving her and her baby's lives hanging in the balance.

This informative, entertainment piece is loosely based on a real TTP experience and is helping to raise life-saving awareness outside of those who have been personally touched by TTP.

[READ LOVE SICK TODAY](#)

## TELL US WHAT YOU THINK!

Please help us improve our future newsletters by answering a few questions. Follow the link below to provide your feedback!

[Answering TTP Foundation Newsletters Feedback](#)

## WE MADE THE NEWS!

# Improving The Prognosis For TTP Patients

**PATIENT PERSPECTIVE** Living with the rare blood disorder TTP can be challenging, but is made easier through effective treatment and ongoing support.

0 SHARES // SHARE THIS PAGE



| Every year, Sydney walks with her team to raise awareness and funds for TTP.

Answering TTP Foundation participated in [Mediaplanet Canada's Rare Diseases Campaign!](#) The campaign was distributed through the National Post on March 28, 2015.

[READ THE ARTICLE ONLINE HERE](#)

## TTP DINNER SYMPOSIUM

**WHO SHOULD ATTEND:** TTP physicians, nurses and researchers

**WHEN:** June 23, 2015 | 6:30 - 9pm

**WHERE:** Toronto, ON, CA.

**WHY:** The TTP Dinner Symposium will provide a unique opportunity to share best treatment practices and to learn about TTP research being done around the world, while paving the way for collaboration opportunities in the future. The format of this symposium will integrate a formal research presentation with an engaging discussion regarding long-term prognosis and complex care.

[LEARN MORE & REGISTER HERE TODAY!](#)



## EVENTS SNAPSHOT

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

*Tuesday, June 23, 2015*  
**TTP Dinner Symposium**



TTP physicians, nurses and researchers are invited to register for our upcoming TTP Dinner Symposium. Discussion Focus: Current and Future TTP Research & Best Treatment Practices.

**LEARN MORE & REGISTER**

*Saturday, September 19, 2015*  
**5th Annual Walk to Answer TTP Together**

*Saturday, November 7, 2015*  
**Patient Education Day**



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

**LEARN MORE & REGISTER**

*You Pick The Date!*  
**You Pick The Event!**



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

[LEARN MORE](#)

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

[LEARN MORE](#)

## OUR BOARD OF DIRECTORS ANNOUNCEMENT

A note from **Sydney Kodatsky**, Founder and Executive Director



Alexis Levine

"April 1, 2015 marked the end of our first Chair of the Board, **Alexis Levine's**, term. I've known Alexis since high school and I will be forever thankful to him for all he has done to structure the Foundation. During one of his visits to the hospital during my 2nd TTP crisis in 2009, he convinced me that I should file the papers to incorporate the Foundation because no charity existed to raise money for TTP research, education and support. So we did. Forming a health charity was much more challenging than I had ever imagined, but he was always there to help guide us to the best outcome. Thanks to Alexis we have a solid governance framework. I am delighted that he has agreed to stay on the Board and head our succession planning committee."



Sherri Sullivan

"I am very pleased to announce that **Sherri Sullivan** has agreed to be our incoming Board Chair. As one of the first three Board members, Sherri was right there with Alexis and me as we built the Foundation; she has played an instrumental role in our advocacy and patient support efforts. She is a strong leader who will help steer the Foundation into the future."

[LEARN MORE ABOUT OUR BOARD MEMBERS](#)



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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