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We are pleased to release the Fall 2017 edition of the Answering TTP Foundation newsletter. Help raise awareness for TTP by forwarding/sharing this newsletter. Enjoy! Sincerely, Sydney Kodatsky, Chair, 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](mailto:contact@answeringttp.org) to your address book today.

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## Fall 2017 Newsletter

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### Ernie's Story

My name is Ernie Kowalski. I've been the victim of TTP a total of 4 times over the last 22 years.

1997 was my first experience with TTP, I was 43 years old. I had never heard of this disease up until this point in my life. At first I thought I had the flu, just a general unwell feeling, lethargic, tired, headaches, vision seemed to be getting blurry. We were celebrating our tenth wedding anniversary on a remote island off the coast of British Columbia. The local emergency clinic found my platelet count to be only 8. I was taken by ambulance to Victoria, British Columbia, then after a



further drop I was immediately taken by helicopter to Vancouver General hospital.

I spent the next 3 weeks in Vancouver hospital with daily plex. Once my platelets had stabilized over 100, the decision was made to medivac me to Edmonton University Hospital so we were closer to home. I was finally declared in remission and returned home in December, we had left home for our 10th anniversary in August, and I finally returned home in mid December, 4 ½ months later.

It was the summer of 1999, I experienced my second episode with TTP. I had what was called spontaneous pneumothorax (collapsed lung). While in the hospital, routine blood work was done, my wife noticed my platelet count was fewer than 100. I was medevac'd to Edmonton. I responded quickly this time and was released after a week of treatment.

The next 16 years of my life returned to normal, it took about a year to regain my strength. We continued to work, go on vacations and plan our future.

In February, 2016 while at my secondary home in Lakeland, Florida, I wasn't feeling well. I went to a local clinic. My platelet count was at 10 and other numbers were alarming as well. Due to the condition of my aortic valve which seemed to have deteriorated they were concerned about inserting the plex line. I was first given a bag of plasma, and then moved to the operating room to install the line in my neck.

During the procedure, my lungs started filling with fluid, an emergency requiring the insertion of a breathing tube had to be installed. I awoke later in ICU with a breathing tube in me and I was strapped to the bed, hands and feet. After regaining my composure and breathing without assistance the tube was removed.

I began daily plex for the next 7 days; my platelet count began to respond. I then did outpatient plex for the next 3 weeks twice a week. When I was released we immediately made arrangements to return to Canada. We were informed by our travel insurance company that they had determined I had not declared a pre-existing condition (aortic stenosis) therefore my insurance was null and void; they would not be responsible for any of the cost of my emergency in Florida. To say we were devastated is an understatement. We were forced to hire a lawyer and eventually worked out a settlement with the hospital.

After returning to Canada I had seen my cardiologist, an echo was done and the results showed my aortic valve had deteriorated to the point I needed surgery soon. Surgery was performed on May 31/2016. All went well, I spent the summer recovering.

October, 2016, we made plans to leave for Florida. We left our home in Cochrane, Alberta, November 6, 2016. It was shortly after Christmas when I noticed a drop in my weight and a general feeling of unwell. On January 1, 2017 we decided to see a doctor. We were in shock when he told us my platelet count was at 49! I phoned my hematologist in Canada, he urged me to go directly to the hospital. We booked a direct flight back to Canada. I was at the Foothills Hospital in Calgary, Alberta the next day.

The plex continued for the next 2 weeks daily, my platelet count started to respond slowly. I was finally released from the hospital on February 24, 2017. During my stay in the hospital I was given a drug called Rituximab, once a week for 4 weeks, it was explained to me by the hematologists to either prolong the time between relapses or possibly eliminate TTP from ever coming back again.

We hope and pray this is the case. I never want to go through this again.

[Ernie's full story here](#)

[Help support others affected by TTP and raise awareness by sharing your story. Learn more here.](#)

## 2017 Walk To Answer TTP Together

*Walk to Answer TTP  
Together*



*Saturday, September 16, 2017*

**We surpassed our Goal!**

**Congratulations to all those  
who participated.**

On Saturday, September 16, 2017, one hundred and fifty registered participants took part in the 7th annual Walk to Answer TTP Together. Participants walked internationally, in their local communities to help raise life-saving awareness and funds for TTP! We did it! Together we surpassed our \$30,000 fundraising goal.



**We raised over \$40,000!**



2017 Walk to Answer TTP Together

[Check out the pictures in our 2017 Chance for Change album.](#)

**WINNERS**

### TOP FUNDRAISING TEAMS

Rank	Team Name	Amount
#1	<b>Bruce Fights TTP</b>	\$8,339.00
#2	<b>Toronto Walkers</b>	\$6,980.00
#3	<b>Walking for Trevor</b>	\$5,370.00

### TOP FUNDRAISING INDIVIDUALS

Rank	Name	Amount
#1	<b>Mina Rajan</b>	\$4,005.00
#2	<b>Tamar Pilavdjian</b>	\$3,550.00
#3	<b>Tony Hooper</b>	\$3,230.00

### SPIRIT AWARD

**Cindy's Crew**

The #1 place finish in each category will be provided a TTP LDL Designer Fashion Key Finder to commemorate their win. Congratulations to Bruce, Mina and Team Cindy. You inspire us all.



TTP LDL Designer Fashion Key Finder

**Presentation Video: Entrepreneurial Innovation Bootcamp in Rare Diseases, Belgium**



2017 Leuven Bootcamp Presentation

On October 23, 2017 Sydney Kodatsky (Chair, Answering TTP Foundation) virtually presented to the Entrepreneurial innovation Bootcamp in Rare Diseases hosted in Leuven, Belgium. One of the organizers included TTP researcher [Prof. Dr. Karen Vanhoorelbeke](#). Organizers asked Sydney to share her personal TTP story and her experience starting Answering TTP Foundation.

Sydney's presentation was well received. *"I got a lot of positive reactions from the audience. They experienced your testimony as really impressive. Some people even stated that it made them look differently to the way they approach their research:). I guess that is one of the things we hoped to reach! Your testimony wakes up people and makes them tackle the different issues in rare diseases from a different point of view. Thanks a lot of sharing your story with us."* --- Prof. Dr. Karen Vanhoorelbeke.

The target audience of this event was not limited to life scientists from academia / industry but also included C-level executives and policy makers from Belgium and abroad dealing with orphan disease drugs.

## Featured News

### Virtual Support Group

Answering TTP Foundation is excited to pilot a new virtual peer support group series moderated by a professional social worker. These themed sessions enable participants to learn about a session topic and share their experiences in a meaningful and collaborative environment.

The fall session is underway. We hope to start another group in January. This is a first-come first-served initiative. Fill out the [registration form](#) to indicate your interest in joining an upcoming group.

Participation is capped (8-10 persons) to facilitate meaningful conversation. Participation is open to the international TTP Community. The session will be held in English. All participants will be required to accept the [Virtual Support Group Guidelines and Waiver available here](#). More information, and registration form [here](#).



## Ohio TTP & aHUS Support Group Meeting

The Ohio State University TTP/aHUS face-to-face meeting was made available to non-local participants to join virtually. On Tuesday October 10th, Dr. Cataland welcomed special guest Dr. James N. George, of the University of Oklahoma Health Sciences Center. Face-to-face and virtual participants from around the world asked many important and relevant questions about such hot topics as; the role of the ADAMTS13 enzyme, ongoing cognitive issues and coping strategies, the safety of pregnancy, the difference between TTP and aHUS and the role of a new and exciting drug called caplacizumab.

Dr. George commented on the importance of support groups particularly for such rare diseases as TTP. Those suffering from more common conditions are more easily supported by their communities - "When you tell your neighbour that you have TTP, the best you can hope for is a blank stare." How true! Dr. George reminded patients of the Foundation's physican connect program to discuss complex TTP cases.



Did you miss the original webcast? Links to the recorded session [here](#).

## Positive topline results from the Phase III HERCULES study with caplacizumab

October 2, 2017 ABLYNX "*announced positive topline results from the Phase III HERCULES study with caplacizumab, the Company's anti-von Willebrand factor (vWF) Nanobody® being developed for the treatment of acquired thrombotic thrombocytopenic purpura (aTTP).*"

[Read full press release](#)

## Pam shares her story



Walk to Answer TTP participant continues her awareness and fundraising for TTP. On September 22 Pam hosted a blood drive in Charlottetown. Pam has been participating in the annual Walk to Answer TTP Together since 2012. Thank you for your dedication to the cause Pam. Your efforts keep the conversation about TTP alive. Pam's story is available [here](#). Local news coverage available at [theguardian.pe.ca](http://theguardian.pe.ca).

## aTTP Study Recruiting



A healthcare research firm is currently conducting a research project with patients who have been diagnosed with acquired thrombotic thrombocytopenic purpura (aTTP) and live in the Continental US. This research will focus on understanding your experience with aTTP as well as evaluating a questionnaire designed for use in patients with aTTP. This research may help improve how the patients' experience is accounted for in clinical trials for new treatments.

For more information and for participation instructions click [here](#).

*NB: Mention of any treatment products associated with this study are provided for information only and their inclusion is not an endorsement of a particular product or company by Answering TTP Foundation.*

## Save The Date

Saturday April 21, 2018.

The 8th Annual Chance for Change Game Night marked a momentous milestone.

Mark your calendars for next year's anticipated event. We aim to entertain and amaze.



2017 Chance for Change Event Video

The event is the Foundation's life-blood fundraiser, bringing in over 85% of all the donated funds towards our charitable programs. This event would still be a small fundraiser in Sydney's basement if it wasn't for our talented and dedicated committee of volunteers comprised of Sydney's friends and family, all of whom have contributed to the success of the event in an effort to provide hope to the Bryant family. They're inspired by Sydney's commitment to fund research in an effort to find a cure for TTP.

Our sponsorship has grown to include 31 very generous businesses contributing sponsorship funds that have a huge impact on the Foundation's ability to support research grants. Many of these businesses have supported Chance for Change for a number of years, for which we are very grateful.

Our guests compliment our committee year over year on the quality of contributions and we take pride in being able to offer items that are 100% donated to ensure the Foundation benefits from your auction bids.

Your enthusiasm for Chance for Change Game Night inspires our committee, and all the

volunteers of the Foundation, to continue our hard work all year long. We can't wait to offer our guests even more to enjoy on April 21, 2018.

[CHECK OUT 2017 EVENT PHOTOS HERE](#)

## How You Can Help

Join our Community

Share your Experience

Donate

Fundraise



Submit your story officially to receive our TTP Awareness Hat. Limited supply available.

### Submit Your Patient / Supporter Story!

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.](#)



### Helping Hands

Volunteers are needed to help stuff and stamp charitable receipts in February 2018. Email [Contact@AnsweringTTP.org](mailto:Contact@AnsweringTTP.org) for more information and to help out. Many hands make lighter work. This event will take place in west Toronto, Canada. This event qualifies for high school students looking to meet their charitable volunteering requirement.

## 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](mailto:Contact@AnsweringTTP.org) providing your contact details (name, hospital/office name of where you practice, and preferred method of



contact.) We will then connect you with an appropriate member of the Medical Advisory Network.

## Patient Education Materials



### Patient & Supporter Information Brochure Patient Resource

Available for download in English, French, Italian, Simplified Chinese, Russian, Portuguese, Punjabi, German and Spanish from [www.AnsweringTTP.org](http://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](http://www.AnsweringTTP.org) to everyone.

## Attention Doctors

Please download and circulate our educational materials to your patients. More information on our physician and researcher programs [here](#).

## About TTP and The Foundation

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:

- supplying [fundraising support and guidance](#) to raise funds for effective TTP research to ultimately find a cure;
- 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; and
- developing TTP education materials and distribution initiatives to educate the public and the medical community to speed diagnosis and save lives.

We need [your help](#) to improve the prognosis for TTP patients. Help us find the answer to TTP.

Answering TTP Foundation | [Contact@answeringttp.org](mailto:Contact@answeringttp.org) | [www.AnsweringTTP.org](http://www.AnsweringTTP.org)

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