

We are pleased to release the Spring 2018 edition of the Answering TTP Foundation new sletter. Help raise awareness for TTP by forwarding/sharing this new sletter. Enjoy! Sincerely, Sydney Kodatsky, Chair, Answering TTP Foundation.



Answering T.T.P.

Thrombotic Thrombocytopenic Purpura Foundation

www.AnsweringTTP.org

In This Issue

- Kaitlyn's Story
- International TTP Day - Register Now!
- Featured News
- 2018 Chance for Change Game Night Results
- Research Outcomes

Kaitlyn's Story (2018 International TTP Day Story)

In July of 2015, my daughter Kaitlyn was diagnosed with TTP. We had noticed several small bruises all over her legs and arms during her daughter's pool party. Kaitlyn scheduled a doctor's appointment the following day, but was unable to make her appointment since she felt too sick to drive. The following day she was feeling worse, she had always had migraine headaches and just believed it was another severe migraine. I told her we should go to the ER and get her rehydrated since she had been sick for two days.

We were lucky that the doctors at Mid Coast Hospital in Brunswick were able to do a preliminary diagnosis of TTP within one hour, and immediately consulted with a haematologist at a neighbouring hospital. Kaitlyn's platelet count was down to 7000, and that's when we began plasmapheresis. I didn't realize the severity of the disease until the doctor informed me she could bleed out; I had no idea that my daughter could die from this disease! Thankfully, my sister who is a nurse came to be with us at that time.

Despite the plasmapheresis treatments, Kaitlyn's platelet levels kept dropping and she began to feel discouraged. Test results later disclosed that Kaitlyn had had a couple of strokes, damaging her brain. After 16 days of plasmapheresis Kaitlyn was discharged with a bagful of medications. Follow-ups with the haematologist concluded she was fine, but Kaitlyn was reminded to go to the hospital if she ever noticed the same symptoms as the ones before.

I lost my daughter on April 25, 2017 after she drove her daughter to school and came home to lie down. Once I got home with her daughter I decided to bring her to the hospital as she was still sleeping on the couch. We arrived to the hospital at 4:30 pm, and it was discovered the TTP was no longer in remission. Phone calls were made but no treatment was done. I lost Kaitlyn at 9:25 after she said "help me" two times. She was pronounced dead at 10:30 pm; cause of death was an ischemic stroke.



Kaitlyn's full story.

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

International TTP Day - Register Now!

Answering TTP Foundation's International TTP Day brings local TTP communities together on a global scale to raise funds to support research, education and support. Participants use their custom fundraising page to collect funds for their event. Registrants either walk or fundraise another way to be a part of this international movement bringing small communities together to be part of something big! Customizable donation webpage for TTP fundraising provided. Registration ends August 16.

International TTP Day

Raising Funds for Research



NEW Participate Your Way

Challenge Yourself walk, bike, yoga... Organize an Event BBQ, concert, fashion show... Sell Something lemonade, art, t-shirts...

Participating by walking (as in previous years) is still a great way to take part.

Click Here To
**Participate
Your Way**

\$20 each or \$150 for Team of 10 persons
Challenge Yourself | Organize an Event | Sell Something

Please download the [participant instructions](#) and read carefully. Also, check out the [Tips and Tricks](#) document to help you plan your best walk ever! Share the [walk poster](#) electronically or print and hand out to help raise awareness.

Connect with other participants. To be connected with other participants in your area, please email Events@AnsweringTTP.org by September 10, 2018. You must have already registered for the event to be connected.

Featured News

Register for the Working Group Info Session

Answering TTP Foundation is looking to form a virtual working group to initiate and carry out a communication campaign. This campaign will be focused on sharing information about newer treatment practices with TTP treatment centers across Canada. [Register for the information video call here by May 31, 2018.](#)

This pilot will be focused on communicating with Canadian treatment centers. Upon completion, this initiative will be evaluated for effectiveness in other geographic regions. You don't need to be in Canada to take part. Meetings will be held via [ZOOM video conferencing](#). You will need access to PC, Mac, Linux, iOS, iPhone or Android with internet connection, a camera and a microphone.

Our Condolences

Our heartfelt condolences to the family of the late Max Marin who died 10 days after being diagnosed with TTP. Max lived in Calgary, Alberta. He was a 45-year-old father, husband and well-known MMA trainer. Reports indicate that the TTP diagnosis was missed by the health clinic he visited initially. Only when his health deteriorated, and his family took him to the main hospital, was he diagnosed with TTP.

- [Global News Coverage](#)
- [CTV News Coverage](#)

Family Fundraises in Honour of Kelly

Kelly Ketcham passed from TTP one year ago. Kelly had three young, beautiful girls. She left behind loving family and friends that miss her more than words can say. Her family organized a t-shirt fundraiser in Kelly's honour to benefit Answering TTP Foundation. More details on the event page at <https://www.customink.com/fundraising/answeringttp?side=front&type=1&zoom=false>.



2018 Chance for Change Game Night Results

The 9th Annual Chance for Change raised \$200,000 on April 21, 2018. Guests were thrilled by our new venue, our wide selection of silent auction items, the fun games, exciting raffles, stunning entertainment and delicious food.

Listen to the feedback from our guests ----

- *I thought this was the best event yet.*
- *The show was stunning!*
- *Wonderful meal, great auction items. Nice to sit and chat with friends!*
- *Whole evening was well balanced...auction, socializing, show, dinner.*



Excerpt from the Chair's evening message to guests ---

"We have built a Foundation that funds TTP research. We have provided funds otherwise not available to researchers. In particular we have helped,

- *Dr. Cataland in Ohio to identify markers for TTP relapse*
- *Dr. Vanhoorelbeke in Belgium to confirm her phase I theory for a new treatment*

We currently fund,

- *Dr. Hovinga in Bern, Switzerland in her quest to find a specific treatment for TTP.*
- *Dr. Chung in Seattle, WA to improve the ability to diagnose and monitor the disease in order to intervene earlier to save lives.*
- *Dr. Thomas in London, UK in her quest to ease treatment and the treatment side effects.*

And recently we have started funding Dr. Huang, in Canada, who is addressing the #1 TTP side effect reported by patients --- memory and heart issues.

Together we are changing the outcome for patients. This event is driving research forward and is

making a real difference for patients.

In addition to research, the Foundation provides education and support to this geographically dispersed and isolated ultra-rare community. In fact we have started virtual peer support program moderated by a professional social worker. The sessions use video conferencing software to facilitate a meaningful, healing and collaborative space for patients to connect and learn from one another. The response from all participants has been overwhelmingly positive. Each participant has praised the Foundation for this new and innovative opportunity."

[Check out the event photo album here.](#)

Congratulations to the Chance for Change feedback survey draw winner. Enjoy your key finder specially made for Answering TTP Foundation (pictured below). Thank you to all who provided feedback.



Research Outcomes

The Answering TTP Foundation's Board of Directors has received impact statements from two Principal Investigators that have completed their Foundation funded grants. The results are encouraging. A patient-led organization plays a vital role in the quest to conquer TTP. Congratulations to our researchers and to all those who support the Foundation.



2013: Dr. Spero Cataland [*The Relationship of Complement Activation to Clinical Outcomes in Patients with Acquired Thrombotic Thrombocytopenic Purpura Mediated by Severe ADAMTS13 Deficiency*](#)



2015: Dr. Karen Vanhoorelbeke [*The Role of Plasmin in Thrombotic Thrombocytopenic Purpura \(TTP\)*](#)

More information about these research grant outcomes has been uploaded to each grant information page,

[Visit our Website](#)

Answering TTP Foundation | Contact@answeringttp.org | www.AnsweringTTP.org

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 are receiving this email in compliance with Canada's new anti-spam laws. While the anti-spam legislation does not apply to most communications by [Answering TTP Foundation](#) as a registered charity, we would like to obtain your consent to continue to send you important information from us, such as our newsletter containing news, updates and donation requests. You may withdraw your consent at any time by simply [clicking here to unsubscribe](#). We respect your right to receive only those emails you expressly consent to in writing. We also undertake not to share your information with anyone as per our [Privacy Policy](#). If you have any questions, please contact us for more details at Contact@answeringttp.org.

STAY CONNECTED

