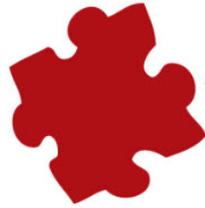


We are pleased to release the Fall 2018 edition of the Answering TTP Foundation new sletter. Help raise awareness for TTP by forwarding/sharing this new sletter. Enjoy! Sincerely, Sydney Kodatsky, Chair, Answering TTP Foundation.



Answering T.T.P.

Thrombotic Thrombocytopenic Purpura Foundation

www.AnsweringTTP.org

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In Memory of Lauren

Answering TTP Foundation would like to dedicate this newsletter in memory of Lauren Marie Chapman Ruiz. Lauren is the recipient of the Volunteer of the Year award from the Foundation for 2018 - 2019. We would like to take this opportunity to send our heartfelt condolences to her family.

Lauren was such a vibrant, kind and giving person. She was a patient who took meaningful action to support all those affected by TTP. Over seven years of service she helped design our educational and fundraising materials, helped with peer support, and patient feedback. There have not been many people who have lent their expertise to the Foundation like Lauren. We will miss her terribly.



According to her father, *Lauren passed away from TTP complications. In the 37th week of her pregnancy on Sept. 23rd she was admitted with platelet count of 6,000. She received 3 plasmapheresis exchanges which did not move her count one bit. The doctors felt that the pregnancy was impacting her immune system and they gave her platelets to allow her to deliver her daughter Samantha on Sept. 27th. She was able to hold her daughter and introduce her to her big sister Elizabeth aged almost 3.*

Obituary is listed [here](#).



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

International TTP Day Raises over \$31,000

On Saturday, September 15, 2018, the community recognized International TTP Day for the first time. To mark this international day, participants raised funds for research many different ways any where in the world.

Together we raised over \$31,000!

[Check out the pictures in our 2018 International TTP Day album.](#)

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 part of this international movement bringing small communities together to be a part of something big! *This event was previously called the Walk to Answer TTP Together. Participating by walking (as in previous years) is still a great way to take part. More information in our [detailed participant instructions here](#).*



Participants raised funds using their personal donation page their way...

- Challenge - walk, bike, yoga...
- Event - BBQ, concert, fashion show...
- Product sales - lemonade, art, bake, t-shirts...



Congratulations to the Top Fundraisers!

Kathi wins top prize for fundraising this year. Congratulations Kathi. We will mail you the LD KeyFinder like the one pictured below. We congratulate you and commend you on your overwhelmingly successful fundraising campaign in honour of your daughter, Kaitlyn who passed from TTP on April 25, 2017. Thank you for helping fund hope for others who battle TTP.

Top 3 Fundraising Individuals

1. [Kathi Nees](#) raises \$7,227
2. [Bruce Morton](#) raises \$6,325
3. [Mina Rajan](#) raises \$4,430

Top Fundraising Team

- [TTP Team Toronto](#) raises \$7,281



Kathi's daughter, Kaitlyn
[Story here.](#)

Top Fundraiser Prize



The LD KeyFinder generously donated by [LDL Designer Fashion Inc.](#) is the prize for top International TTP Fundraising Individual this year.

Save the Date - September 21, 2019 - International TTP Day

For more information please review the [participant instructions](#). Also, check out the [Tips and Tricks](#) document to help you plan.

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

2018 Research Winner

Answering TTP Foundation had committed over \$1.8 Million to research grants through 2020.

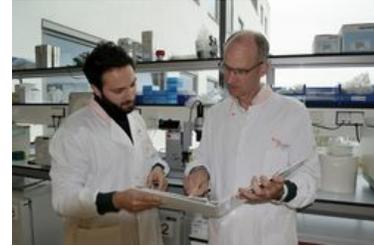
The 2018 research competition attracted more research proposals than ever before. The decision to

fund was not easy, nor taken lightly. Three experts in TTP provided detailed reviews of all seven proposals submitted. The winner was selected based on scientific merit. Thank you to all those who contributed to this important process.

The Foundation understands the need for biomedical, clinical and population health research and accepts research proposals internationally every year on April 1. To find out more about our research grant program and for contact information please visit our [For Professionals](#) page.

2018 Research Proposal Winner Profiling of T cells in patients with acquired TTP

Prof. Dr. J. Voorberg
Department of Plasma Proteins
Sanquin Research and University of Amsterdam, The Netherlands



Research Aims of this Study:

"The overall goal of the current study is to obtain more insight into events that trigger the development of auto-antibodies in previously healthy individuals. We also would like to study what causes relapses in patients with acquired TTP."

How did Dr. J. Voorberg become interested in TTP research:

"I became interested in TTP research shortly after the identification of ADAMTS13 in 2001. Since then I have been working on the characterizing of auto-antibodies that develop in patients with acquired TTP. Thanks to our clinical collaborators and the active participation of many patients we have been able to identify the binding sites for auto-antibodies on ADAMTS13."

How Dr. J. Voorberg believes this research will impact individuals living with or impacted by TTP:

"We believe that a better understanding of the triggers that induce acquired TTP will help to develop novel approaches for treatment or prevention of relapses in patients with acquired TTP. The research sponsored by Answering TTP will focus on the characterization of T cells recognizing ADAMTS13. We hope that by studying ADAMTS13 specific T cells we will be able to identify triggering events for acquired TTP."

Comments from Dr. J. Voorberg to donors:

"We feel very privileged to receive support from the Answering TTP Foundation. We would like to thank the many donors of the Foundation for their generous support and their commitment to promote research on acquired TTP. We are very committed to work together with the Foundation, patients and clinicians to find a cure to this disease."

Featured News

Researcher's Work is Published



Dr. Long Zheng
More information about
research grant funding to Dr.
Long Zheng [here](#).

Answering TTP Foundation provided research grant funding to support Dr. Long Zheng which has resulted in two research papers on TTP. Together we are furthering the understanding and coming closer to a targeted treatment for TTP. Congratulations Dr. Long Zheng! And congratulations to all supporters of the Answering TTP Foundation.

The first, "[Clinical factors and biomarkers predicting outcome in patients with immune-mediated thrombotic thrombocytopenic purpura](#)" was featured in *Haematologica*, the journal of the European Haematology Association, online on August 23, 2018.

The second, "[Transfusion of Platelets Loaded With Recombinant ADAMTS13 is Efficacious for Inhibiting Arterial Thrombosis in Mice and in Human](#)" was published in the journal *Arteriosclerosis, Thrombosis, and Vascular Biology (ATVB)*, on September 13, 2018.

New Drug Approved by European Commission

The European Commission has granted marketing authorization for caplacizumab for the treatment of adults experiencing an episode of aTTP on August 31, 2018.

According to The [European Medicines Agency](#), "*Caplacizumab, the active substance in Cablivi, is a nanobody (a small antibody) which has been designed to attach to von Willebrand factor in a way that stops it acting on platelets. This reduces platelets sticking together and forming clots in blood vessels and, as a result, platelet levels in the blood rise because they are no longer taken up to form clots. The European Medicines Agency decided that Cablivi's benefits are greater than its risks and it can be authorised for use in the EU. The Agency considered that, in patients with aTTP, Cablivi combined with plasma exchange and immunosuppression can reduce the time it takes for platelet counts to return to the normal range, which is associated with shorter duration of plasma exchange treatment and shorter stay in intensive care facility. The most important side effect of treatment is bleeding but it is considered manageable. The company is expected to provide results of a study on Cablivi's safety and effectiveness over a longer period.*

Moreover, according to [Hematology News](#), it has been reported that "*the drug has been accepted for priority review in the United States and the Food and Drug Administration is expected to make a decision by February 6, 2019.*"

Fall 2018 Ohio TTP & aHUS Support Group Meeting



Dr. S. Cataland

[Click to play archived video recorded session.](#)

The Ohio State University TTP/aHUS face-to-face meeting was made available to non-local participants to join virtually. On Wednesday November 7th, Dr. Cataland presented a great layman explanation about the role of the ADAMTS13 enzyme in TTP. In addition, he thoughtfully answered questions from both the face-to-face and virtual audiences about TTP triggers, treatments, side effects and more. On an exciting note, he explained the role of a new drug called [caplacizumab](#).

The audience was invited to learn more about participating in research by contacting [them](#) or their local [Consortium location](#).

Missed it the first time. Listen to the recording at http://go.osu.edu/ttp_ahus_support.



Join the TTP Community

Receive the quarterly newsletter, updates, notices (like the one sent about the Ohio meeting detailed above) and surveys.

[Register for free today. Click here.](#)

2019 Chance for Change - SAVE THE DATE



10th ANNIVERSARY CELEBRATION

Fabulous Prizes, Entertainment & Dinner benefiting TTP
Saturday, April 27, 2019 at Famous People Players, 343 Evans Ave., Toronto

We will again be hosting our acclaimed fundraising event at Famous People Players in Toronto! The event will have amazing prizes you can't live without, a new show that is sure to be as thrilling as last

year, and a delicious full course chef inspired dinner! All for a great, underfunded cause.

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...socializing, show, dinner.*

NEW - Pricing for children 12 and under. This is a family friendly event sure to impress all ages.

**Purchase
Donate**
Click Here

**Support
Opportunities**
Click Here



Benefiting
Answering T.T.P.
Thrombotic Thrombocytopenic Purpura Foundation

Chance for Change

An evening of fun, fabulous prizes and entertainment benefiting T.T.P.
Saturday April 27, 2019 at Famous People Players. 10th Anniversary Celebration. Don't miss out!
343 Evans Ave., Toronto. Doors open at 6pm.
Dinner and drinks included. Smart casual attire.
Early bird admission \$200 each before March 31, after \$235 each. Children 12 and under \$75 each.
70% of admission price was eligible for a tax receipt in 2018.

Purchase Admission Today! at www.AnsweringTTP.org
Sponsorship & donation opportunities also available.

Answering TTP Foundation | 22 Prince George Dr. | Toronto, ON | M9A 1Y1 | Contact@AnsweringTTP.org | Charitable Registration # 84600 4802 RR0001

[Check out the 2018 event photo album here.](#)

Upcoming Events

- [Giving Tuesday](#) is November 27th
- [Helping Hands](#) are needed February 9th
- [Chance for Change](#) is April 27th
- [International TTP Day](#) is September 21st

Visit our Website

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