



Answering T.T.P.

Thrombotic Thrombocytopenic Purpura Foundation

2018 TTP Day Participant Instructions

Thank you for participating in our 8th Annual *International Fundraiser.*

We are stronger together. We may be an ultra-rare and geographically dispersed community, but if we all make an effort in our local communities, we can raise critically needed research funds. The sum total of many is far greater than the sum total of one. As those affected by TTP, it's up to us to overcome the rarity of this disease and ensure that we're making a difference. To do so, we need to go beyond.

- We need to dive into the Answering TTP Website and create a presence to gather donations.
- We need to push beyond our comfort zone and ask our supporters for donations like we've never asked before.
- And, we need to make some noise!

Participate your way to raise funds for TTP,

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

TTP Day is designed to enable everyone to help improve the prognosis for all TTP patients. In previous years this event was mandated to be a walk. This year we are trying something new to ensure everyone feels that they can participate. You can walk any distance, for 2 hours anywhere in the world, OR NEW you can fundraise another way. This is your opportunity to be the change. Challenge yourself, organize an event or sell something. Everyone can contribute. Gather your friends, family, colleagues, neighbors and local businesses to support your efforts.

The Day: Saturday September 15, 2018 International TTP Day. It is our day. You may complete your challenge this day or host your event. You may also decide to use this day to promote your event or challenge that will be done at a later date. Those who are participating by selling something would use this as a big promotion day.

Location: Anywhere or virtual. Whatever fits your challenge, event or sale.

Cost: \$20 per individual or \$150 for Team of 10 persons. Registration fees include a complimentary participant commemoration button, and a fundraising page ready for you to customize with your initiative, story and pictures. Team registrations also have access to a team fundraising page to consolidate fundraising efforts for each team member.

Deadline: Final results of International TTP Day (this initiative) will be tallied on October 31. All donations to your event page will be tallied on this day.



Welcome to our Step-by-Step Instruction Guide

Table of Contents

- As early as possible before International TTP Day 3
- On International TTP Day: September 15, 2018..... 6
- After International TTP Day 7
- Event Close Day 7
- Event Donation Solicitation Flyer 8
- What is TTP? 8
- About Answering TTP Foundation..... 8
- Dollars at Work..... 8

As early as possible before International TTP Day

1. REGISTER AND SET UP YOUR DONATION PAGE NOW

Please visit www.TTPDay.dojiggy.com to register as an individual or as a team to begin your fundraising for better treatment and eventually a cure for TTP.



	Team of 10	Individual
Registration Fee	\$150	\$20
Mailed Item	Qty 10: TTP Day Button	Qty 1: TTP Day Button
Registration Deadline	August 16, 2018 11:59pm EST	August 16, 2018 11:59pm EST

When you register for the event, you will be asked to:

- Create a unique username and password,
- Create a personal web link, and
- Set a personal fundraising goal.

When complete, the system will prompt you with: *'Please click here to go to your personal fundraising page to personalize your webpage, send emails and track your progress.'*

You can create your personal webpage now, or log back in at a later time to complete your page set-up (we strongly encourage you to take the time now to setup your webpage). The instructions following provide more detail in setting up your personal webpage. Please consider uploading a picture; a picture says a thousand words.

Using the Platform

To ensure you have all the professional tools you need to raise funds for your walk, Answering TTP Foundation is facilitating this event using an online fundraising software company that specializes in making sites for peer to peer donation events. As a participant, you receive a fundraising page to customize to collect donations towards your individual and/or team goal. This is your place; your space to upload images, and express why you/your team is participating as well as your goals. Your friends and family can visit this page to support you through donating, but also to understand more about your interest and excitement for the 2018 International TTP Day. Make your message personal to resonate with potential donors; use words like I and me whenever possible. This is YOUR space to tell YOUR story.

Feel free to be creative with your space. We hope that it provides an opportunity for you to share important information with friends and family in a way that creates excitement for them about you and about your goals.



➤ **Participant Control Panel**

Upon registration you will be asked to create a unique username and password. With this information, you will be able to log into your Participant Control Panel (PCP). The PCP is accessed from the event registration website where you registered.

- *My Page – Customize your donation page*
- *Email – Send emails to contacts to engage supporters*
- *Instructions – Event instructions*
- *My Account - Update your personal information.*

➤ **My Page**

When you register for the event you will be asked to create a Donation Page. The page includes: a personal fundraising goal, which must be more than \$350 (you do not have to obtain your goal to participate), a statement, one or more pictures and/or video. This is where your friends and family can go to access your page and make donations.

From the **My Page** tab:

- **Settings:** Enter or edit your Personal Web Link. This is a combination of numbers and letters only and becomes part of your unique web address. Friends and family will click on your unique web address to see your personal fundraising page and donate to your cause. Enter the dollar amount you wish to set as your personal fundraising goal. Your personal thermometer will rise as you reach this goal, so be sure to make a reasonable goal that you can achieve.
- **Statement:** Enter the text for your personal fundraising page statement here. This is your plea for support, so make it compelling. We hope that this space provides an opportunity for you to share important information in a way that creates excitement about your cause and goals.
- **Pictures:** You may upload any combination of four pictures and videos which will appear on your website. Images will be resized to 415x300. All standard image formats are supported. After saving changes, click on View your personal webpage to review.
- **Videos:** browse your computer to upload video to appear on your donation page
- You may upload any combination of four pictures and videos which will appear on your website. All video uploads must first be posted to YouTube. Then provide the YouTube Video ID for the video here. The video ID is the 11 character unique identifier for the video. If your video URL is: <http://www.youtube.com/watch?v=jebJ9itYTJE>, then the video ID is jebJ9itYTJE. After saving changes, click on View your personal webpage to review.
- **Donations:** The Donation Report is designed for you to review your donations. The thermometer will reflect how close you are in meeting your overall fundraising goal. Offline donations via cheque are no longer accepted. Select a donation from the Donation Report and you can send an email thank you to the donor. While the system will send an auto-generated thank you to each donor, it is always nice to receive a more personalized reply. To send a personalized thank you note to a donor or group of donors, check the donor and click on the 'Email Thanks' button.
- **Thank You Message:** This is the area where you can customize the system's thank you message to your donors. Enter the content you want to include in your donors' receipts and hit Save.



➤ **Email**

This section is where you will write and send a personalized email message to your friends, family and co-workers telling them about your cause. Your heartfelt appeal in asking them to make a pledge can have a real impact in meeting your fundraising goal.

By clicking on Import from my address book, you can import your address book from your Yahoo, Gmail, Hotmail, AOL, Plaxo, or Outlook account. Alternately, enter the email addresses for those that you wish to send your personal website. Enter one email address per line, using this method.

Enter your Subject and customize your message in the next two fields and hit Send.

➤ **My Account**

Update Profile

In this area you can easily change your profile or contact information, including your mailing address, Email address and phone numbers. Keep this information current so that your event administrator can stay in contact with you throughout your event. You may also update your account username and password here. Click on Save when you're finished updating your information.

Sharing

Your personal fundraising page includes social media sharing tools in the footer. You can share your personal fundraising page or other website pages with friends and family using your favorite social media tools, as outlined here.

In addition, four fundraising widgets are available. To add a personalized fundraising widget to any website or blog on the internet, just copy and paste the sample HTML code provided into your web page editor.

Functions for Team Captains

Team captains will have the ability to configure a team fundraising page and manage team donations from their PCP. Only team captains (and not team members) will see a tab for Team Page. Here is where the team fundraising page is configured. This team fundraising page includes team pictures or videos, a team mission statement, and thermometer which is different from the captain settings.

From the Email tab, there is a submenu for Team. Here captains can email potential donors on behalf of the team. These functions work in the same way as described above for personal settings.

Good luck with your fundraising efforts!



2. GATHER DONATIONS

Now that you are registered and have built your or your team donation page it is time to start gathering donations. Email friends, family, colleagues and local businesses with a link to your web page. Ask neighbors and people in your community. Let people see your excitement. People love to support causes, especially when they can see how much it means to you.

For many fundraisers, it can be difficult to ask personal friends, family members and acquaintances for financial support. Start with those you know will be willing to support you and use this to build momentum. It's always easier to hear a "no" after you have heard "yes" a few times.

Here is a list of common members of our community to consider asking.

- Family (parents, grandparents, siblings, aunts and uncles, cousins)
- Neighbors
- Family friends
- Close friends of your extended family (i.e. Grandma's best friend)
- Bosses and co-workers
- Businesses with whom you do frequent business
- Hair stylist
- Etc.

RESOURCES AND HELP

Good luck with your fundraising efforts! Contact Events@AnsweringTTP.org with questions.

On International TTP Day: September 15, 2018

Celebrate your participation in this international event

What you do on event day depends on the type of event you have decided on. If you registered as part of a team, ensure to arrange pickup of your button from your team captain in time for the event.

Challenge Participants

Those participating in a challenge (walk, bike, yoga...) would use this day to complete their challenge. In past years this is the day that everyone would walk in their local communities for two hours at any time of day along any route. This is still a great option to participate!

You may complete your challenge individually, with your team, or in small groups. Please wear the buttons provided, and add red spirit items like red bandanas, hats, and/or t-shirts. If you are feeling super confident add some noise to your walk with red horns or bells to draw more attention from passersby.

You've worked hard to gather your donations! Now, honor all that have supported you by having the best challenge possible. The following will help boost your energy, and keep unwanted accidents from happening.

- Eat a good breakfast – You'll need fuel to keep your energy going.



- Wear comfortable and supportive shoes – Don't wait until event day to break in a new pair. Make sure your shoes will not cause blisters, or cause pain post-event.
- Protect yourself from the sun – please wear and bring sunscreen. We also recommend wearing a hat, or visor, and using sun glasses to protect your eyes.
- Stay hydrated – Make sure to drink plenty of water, or alternative sports drink, to avoid dehydration and headaches.
- Don't push – Set a goal that is reasonable and safe for you.
- Bring your smile – We want you to have fun, and look good on camera! Take lots of pictures to share with the community on your walk.

Organizers of an Event:

Those who have organized an event may have chosen September 15, 2018 to host the event for their friends, family, and/or co-workers etc. If this is not a practical day to host your fundraising event, choose another day and use this day as an excuse to communicate (publicize) your event with guests and supporters.

Selling Something:

Those who are selling a product or service to donate the proceeds would use this day to publicize their offering to potential purchasers and donors. As the official International TTP Day, participants would solicit purchases as a way to commemorate the day.

✿ After International TTP Day

When you have completed your challenge, event or sale of product/service it is time to feel proud. Those organizing an event may choose to host the event later than International TTP Day. Likewise, those selling a product or service may continue to sell product after International TTP Day.

Congratulations! You have successfully completed your goal, and you have raised a lot of money for TTP research and patient support. Now it is time to,

1. Update your website with news and information from your experience and thank your donors. Include some of the pictures you snapped.
 - Post some pictures with descriptions to Answering TTP Foundation's Facebook page at www.facebook.com/AnsweringTTPFoundation
 - Submit your photos and video to Events@AnsweringTTP.org
 - Send one last email to all your supporters with a link to your website and a thank you for their support.
2. Take a moment to feel proud! Your efforts made a difference.

✿ Event Close Day

Final results of International TTP Day (this initiative) will be tallied on October 31. All donations to your event page will be tallied on this day. Ensure to have all your money in to count towards our final standings.

Thank you for all your hard work, today, and throughout the past several months!

Event Donation Solicitation Flyer

Last page. Please print and distribute. Add your personal donation page to drive traffic directly to support your efforts.

What is TTP?

A TTP, Thrombotic Thrombocytopenic Purpura, diagnosis is scary and complex. Many patients have never heard of this 3 letter acronym before, nor have they any idea as to its ramifications. TTP is characterized by small blood clots that form throughout the body which lead to complications including stroke, heart attack, kidney failure and cognitive dysfunction.

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.

About Answering TTP Foundation

Answering TTP Foundation was formed by a local Toronto patient (with much help from friends and family) in 2009 to raise funds for Thrombotic Thrombocytopenic Purpura (TTP) research at her local hospital. Since that time Answering TTP Foundation has incorporated and gained charitable status in Canada in order to more effectively pool funds for effective research, and to support the TTP community. Answering TTP Foundation is a recognized Canadian charity run by volunteers both in Canada and internationally.

Dollars at Work

Answering TTP Foundation serves the TTP community to improve the prognosis for all TTP patients. Answering TTP Foundation understands the need for biomedical, clinical and population health research. The Foundation considers international research proposals, and has granted over \$1.6 million toward TTP research through 2019.

Whenever possible we endeavor to extend our programming internationally to engage the geographically dispersed TTP community. Our platform delivers:

- Fundraising support and guidance to raise funds and direct those funds towards effective TTP research to ultimately find a cure

International TTP Day
Raising Funds for Research



- A consolidated information platform to disseminate information to the geographically dispersed community via www.AnsweringTTP.org
- TTP education materials to educate the public and the medical community to speed diagnosis and save lives
- Patient support to alleviate the feeling of isolation that accompanies the diagnosis of a rare disorder via our new patient brochure and conference calls/online sharing tools
- A unified voice to ensure access to the safest and most effective treatments for TTP patients

Please visit our website for more information AnsweringTTP.org and email Events@AnsweringTTP.org if you have any questions.