

2013 Community Survey

Prepared by



National Patient Advisory Board

Task Group

Sherri Sullivan

Advocacy Director & Chair National Patient Advisory Board

Gergana Sandeva

National Patient Advisory Board

Sydney Kodatsky

Executive Director

Admin Contact

Marie Dimech

Administrative Assistant

Answering TTP Foundation

22 Prince George Dr.

Toronto, ON M9A 1Y1

Direct 647-260-3502

Marie@AnsweringTTP.org

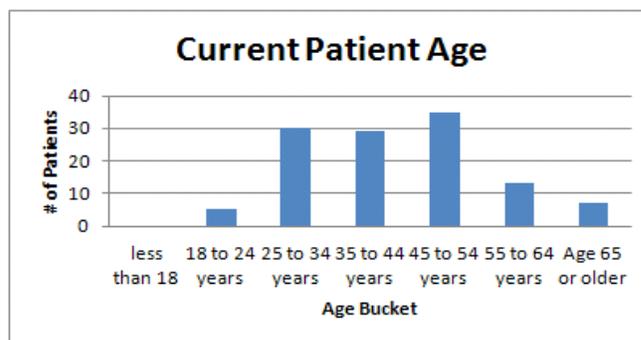
*This information was not prepared by professionals.
It is for informational purposes only.*

2013 TTP Community Survey

The Answering TTP Foundation was pleased to create an online anonymous survey to compile feedback from as many TTP patients as possible to provide insight regarding their personal experiences. This feedback is useful to the Foundation in a number of capacities, not limited to: identifying gaps in patient support and education, advocacy requirements and ideas for potential research opportunities.

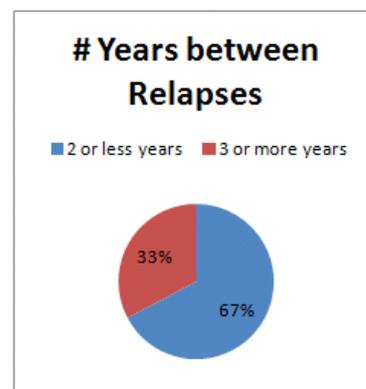
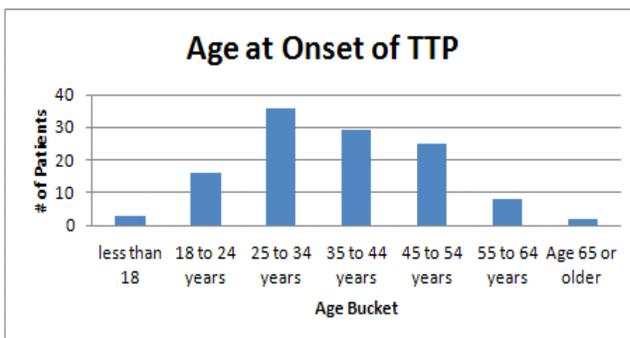
Respondent Profile:

- 122 respondents, from around the world, who completed the online survey.
- The median age of the TTP patients that completed the survey was 43 years old.
- The majority of respondents represented patients from the US (51%), followed by Canada (30%) and the UK (11%). Responses were also received from the Netherlands, Australia, Sweden, New Zealand, Norway, Portugal and Italy.



Diagnosis and relapse:

- The median age of TTP diagnosis amongst respondents was 35 years old.
- 35% of respondents perceived that diagnosis occurred less than 1 week after they experienced their first symptoms of TTP. 62% of respondents cited less than 2 weeks between their first TTP symptom and the TTP diagnosis. Whereas, 9% of respondents cited more than 3 months duration between first TTP symptom and their diagnosis.
- 48% of those who responded to the survey had experienced at least 1 TTP relapse. A relapse is defined as full remission (blood levels normalized, and weaned from applicable medications used to treat a TTP crisis) followed by the occurrence of another acute TTP episode. Whereas a "flare" is a worsening of the disease state when remission has not yet been achieved.
- 46% of relapses were reported to occur 2 years or less from the previous TTP episode. This follows the generally accepted notion that the further a patient is from their last episode, the less likely they are to relapse.



Answering TTP Foundation ■ www.AnsweringTTP.org ■ Contact@AnsweringTTP.org

22 Prince George Dr., Toronto, ON M9A 1Y1 ■ 416 792 4656

This report is for informational purposes only.

- A respondent suggested raising awareness “targeted at the laboratory personnel in the hematology department. We need to target their journals and school textbooks. Not just the general public” to help speed diagnosis to save lives.
- One patient expressed their frustration with delayed diagnosis upon relapse: “emergency nurses did not realize the seriousness of the disorder when I went for my 2nd relapse. Also lab techs sent back my blood claiming it was not taken correctly because the platelet counts were so low and they drew blood a second time. This happened on the 3 relapses.”

Treatment:

In order to capture the exposure to blood product experienced by each TTP patient, respondents were asked to detail the number of plasma units used in treatment they had undergone for each TTP crisis. 71 patients were able to recall the total number of plasma units used for their treatment.

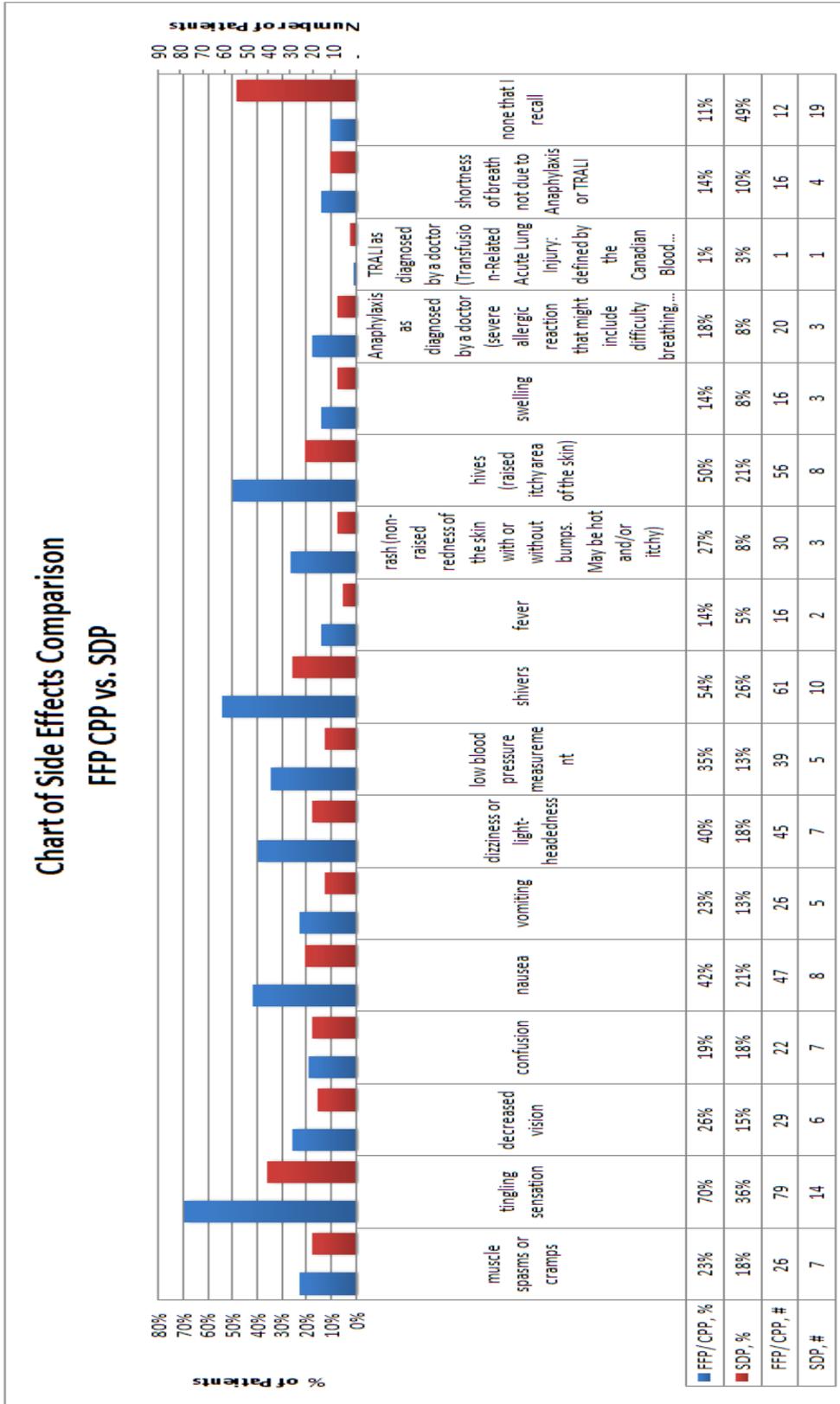
	TOTAL
Count of Patients	71
Max # of units	3160
Min # of units	11
Average # of units	358

One respondent indicated exposure to over 3,000 units of plasma product. The average was 358 units required for TTP treatment since diagnosis.

In order to compare the side effects and long-term effects of FFP/CPD vs. SDP, respondents were asked to select all side effects that they had experienced. The data suggests that those respondents that were given SDP as a replacement product had less side effects than FFP/CPD. However, the information collected may not be statistically significant due to the relatively small number of respondents receiving SDP. See chart on next page for details.

Other Comments Regarding Plasmapheresis with FFP/CPD

- “During initial treatment I stopped breathing and my heart stopped beating, I flat lined and ‘code blue’ was announced in the ICU, however I was having my plasma exchange and they were giving me whole blood in an IV in my arm at the same time.”
- “I’ve had 3 cardiac arrest due to FFP”
- “Had severe allergic reaction, swelled up and lost consciousness.”
- “I think that patients should be informed about the potential reactions to plasma exchange. When it happens suddenly it’s so confusing and adds fear and anxiety to future treatments.”



Long term side effects of TTP

When asked if respondents had anything else that they wanted to share with investigators, they often cited frustrating long term side effects of TTP including:

- Fibromyalgia
- bones ache and cramps
- tendonitis
- arthritis
- headaches & migraines
- memory loss
- brain fog/ acuity
- tiredness
- vision problems
- neuropathy

Conclusions

The findings from this survey emphasize the opportunity that each member of the TTP community has to help unlock answers to this rare and dangerous disorder. Insights from this survey help gain insight into potential areas of research and opportunities for effective support initiatives.