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We are pleased to release the winter 2013 edition of the Answering TTP Foundation newsletter. Help raise awareness for TTP by forwarding/sharing this newsletter. Enjoy! Sincerely, Sydney Bryant Kodatsky, Executive Director Answering TTP Foundation. You're receiving this email because of your relationship with Answering TTP. Please [confirm](#) your continued interest in receiving email 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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## Newsletter

Winter 2013

Follow us 

### Heather's Story



I am 32 years old and I live in Lake Zurich, IL. I live with my husband and two boys (ages 4 and 2) and I have worked in the pharmaceutical industry for 10 years up until my last relapse, and have just started back doing consultant work for the same company I use to work for.

I was first diagnosed with TTP in April of 2002, 6 weeks before my college graduation. I was 21 years old and invincible, or so I thought.

I had a scheduled appointment to see my doctor after a car accident. About a week before my appointment, I started to get little dots all over my legs and a nose bleed that just wouldn't stop. Over the weekend, I developed large bruises on the inside of my knees.

Monday morning, I was tired, but I went to class, and then drove to my hometown to see the doctor. She asked me if there was anything knew, so I showed her my legs. She said that I needed to have a CT scan because I was bleeding and she didn't know why. I didn't feel sick, just a little tired....so I figured I might as well get this over with. I went to the hospital, registered, and started taking the gastroview.

When I was walking out of the hospital the left side of my face and all around my mouth, started to go

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#### Awareness Wristband Gift Campaign

1 Wristband for each \$25 donation



Answering TTP Foundation is arming

numb. I told my mom, she called the hospital, and they said they had never heard of that and to keep taking the gastroview and come back in two hours. We left for my little sister's softball game, but didn't quite make it there. When we pulled in the parking lot about ten minutes from the hospital, I started throwing up blood. I was slurring my words and I could not stay awake. My mom turned back around and took me back to the hospital. When we got there they said that I needed the CT scan and sent us down for one. I do not remember too much more from this night.

The doctors had told my parents that I had TTP and would be lucky if I made it through the night and that if I did they would discuss where to go from there.

About a week into treatment, I finally was aware enough for my parents and doctors to explain what was going on. I had never heard of TTP, I had never really been sick with anything. It was a lot of information to take in, but my family was there to help me through it.

I received plasmapheresis every day, but they could not get my platelets above 12,000. They increased my pheresis to twice a day and increased the volume of plasma I was receiving. After being in the hospital for two months, my doctors decided we should try Imuran and Vincristine. I started both chemotherapy drugs, with not much change. After about another month in the hospital, suddenly my numbers jumped up, I also got hit with all the other side effects of chemo (nausea, constipation, hair loss). But, my platelets went up, first to 60,000 then to 100,000 and so on. Success!

I was sent home and tapered off of the twice a day pheresis to once a day, then to every other day, until I was off completely. This experience forever changed me, at 21 I was lucky enough to realize how precious life is and how quickly it can change.

Since then, I relapse about every four years. I got sick again in 2006. Two years later I gave birth to a healthy baby boy and then his little brother joined us two years after that. I get monitored regularly and just before finding out I was pregnant with baby number two, my Adamts13 test started to drop.

Then, a month after I quit breastfeeding, I noticed a large bruise on my arm, went to get my platelets checked, and they were at 13,000. This was in November of 2011. Same treatments as before, except this time I seemed to respond quicker, only to relapse a couple of days later. I was home the month of January and most of February, receiving pheresis daily.

Next, I came down with a fever and pain all over. Back to the hospital we went, where I was diagnosed with Endocarditis, Meningitis, a 4 cm mass in my right atrium, and two large pulmonary embolisms in my left lung. Again, I was sent to Northwestern Memorial in the city, my central line was removed, I was given 4 units of FFP to bring my platelets to a safe range, and I had open heart surgery on March 9, 2012.

I stayed on the chemo the whole time, and continued taking the chemo until October of 2012. It has now been four weeks of no chemo and my platelets are still at 250,000!

donors with awareness bracelets to help get the conversation started to raise awareness for TTP to help save lives.

**DONATE NOW**  
[www.AnsweringTTP.org](http://www.AnsweringTTP.org)

## **How You Can Help**

- Join our the Community**
- Share your Experience**
- Donate**
- Fundraise**
- Participate in Support Groups**
- Raise awareness for Blood Donation**
- Volunteer Opportunities**



## **Share Your Story**

As patients and supporters, we encourage you to share your stories with us. We will publish your submissions online and/or in our newsletters and educational materials to raise awareness and help others facing similar challenges.

For instructions and tips visit our [website](#).

## **Events Snapshot**

**February:**

**- Chance for Change Game Night** raised \$150,000!

**- Rare Disease Day Blood Drive**

**- Roadshow Montreal**

**- Rare Blood Disorders Education Day**

**Spring:**

**Conference Call Enabled Support Group**

**Ongoing:**

**- Support Programs**

**- TTP Denim Days**

## **Rare Disease Day TTP Blood Drive**

Donate on or close to  
Thursday February 28, 2013  
Anywhere in the World!

My family has been right beside me learning about the disease and what we can do to beat it! My husband has had to endure taking care of the kids, working, and getting to the hospital to see me, but we have survived. I am thankful to be here to see my boys every day!

I get so nervous whenever I have bloodwork done. Those are the worst five minutes of my day until they bring out the results. For now everything is good. I know that I will probably relapse in a couple of years, but I try not to let that dictate my life.

I am so lucky to have the support of my loved ones. I think that is what got me through every day in the hospital. I will not let TTP rule my life! To all the other TTP survivors out there....stay strong, stay positive, and don't ever hesitate to get help when you notice something is wrong.

High platelets to you all!!

*Heather Van Daele*

[More Patient Stories \(click here\)](#)

## Rare Blood Disorders Education Day

Answering TTP Foundation is a member of the Network of Rare Blood Disorder Organizations (NRBDO). This coalition of blood recipient groups shares ideas and works to further common goals on key issues. More information [here](#).

On Saturday March 9, 2013, the Alberta NRBDO chapter will be hosting an education day. The morning will focus on Comprehensive Care issues common to all rare disorder patient groups. Comprehensive care is an approach to treat the whole patient, not just one disease or symptom at a time. The afternoon will consist of disease specific break-out sessions. This is a great opportunity for TTP patients to learn and connect with peers from other rare blood disorder groups. [Click here for registration form](#). [Click here for event poster](#).

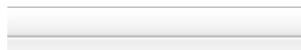
Details: Saturday March 9, 2013 from 8am - 4:30pm in the Allard Family Lecture Theatre, Katz Group Centre for Pharmacy and Health Research, 87 Ave & 114 St. (University of Alberta), Edmonton, AB.

For more information about Support Group and Information Sessions, including how the Foundation can help you to organize a local session, please visit [www.AnsweringTTP.org](http://www.AnsweringTTP.org). Register for the [Answering TTP Community](#) for event notifications.



Blood donation saves lives and participating as part of the Answering TTP Team helps raise awareness for TTP to save even more lives. Each TTP crisis is a medical emergency and early diagnosis is key to mitigating the risk of irreversible complications, or death.

[CLICK FOR DETAILS](#)



*Walk to Answer TTP  
Together*



2013

Save the date

September 21, 2013

JOIN THE COMMITTEE

Awareness Coordinator  
Participant Coordinator  
Sponsorship Coordinator  
Purchasing Coordinator  
Website Developer  
Creative Lead

This is a virtual committee working across borders to engage the international Answering TTP Community to walk together!

[Register for the first team planning call here!](#)

## Chance for Change



# Bigger and Better Than Ever

Cold winter temperatures? So what? They were no match for the biggest Chance for Change night ever, which boasted authentic Vegas Gaming, a massive silent auction, delicious food and drink, not to mention a celebrity host! - as over 250 guests descended on the Toronto landmark The Old Mill on February 2nd, 2013.



Now in its fourth year, Chance for Change is a night of casino-style gaming and both live and silent auctions with all proceeds benefiting TTP research. Guests played blackjack, craps, roulette, and poker, while professional dealers were on hand to give the night a Vegas feel - and to help novice players get started.



Winners at the gaming tables traded their chips for raffle tickets, which gave them a big advantage when it came to winning fabulous raffle prizes.

The top Grand Raffle prize was a "VIP Indulgence Experience" at Caesar's Palace in Las Vegas. For those who preferred a northern getaway, a week-long trip to Lake Joseph, the most exclusive and fashionable cottage spot in Ontario's Muskoka region, was the second-place prize! A Beaver Valley home upgrade, tutored wine and appetizer tasting, and a 32" LED TV rounded out the Grand Raffle prizes.



Throughout the evening, guests bid on over 400 silent auction prizes. From jewelry to entertainment to electronics, there was no shortage of prizes to appeal to every taste - and every single prize was donated for the cause.

The event was anchored by celebrity host Elaine Lui of CTV's eTalk and laineygossip.com. Lui, hosting Chance for Change for the second time, ushered guests through the evening with energy, warmth and a healthy dose of humour.



And to bring home the reason why Chance for Change events were created in the first place, two TTP patients spoke movingly about their experience with the disease, and brought an emotional resonance to the evening. From a medical perspective, TTP specialist Dr. Donald Arnold spoke about the disease and the Answering TTP Foundation's important work in the search for a cure.



When the gaming was done, auction items won and raffle prizes collected, over **\$150,000 - a new record for the Chance for Change series - had been raised.** Every dollar will go to TTP research, education and patient support. This means a brighter future for patients and their loved ones.

The Answering TTP Foundation and the Chance for Change Committee would like to thank everyone who attended the event, and can't wait to see you - and all your friends - out to change things for TTP patients again next year!

Click to view more pictures and the event video [here](#).



## Rare Disease Day TTP Blood Drive

International Event  
Join the team to save lives!

Register to give blood at your local blood donor clinic on (or around) Rare Disease Day, February 28, 2013.

Blood donation saves lives and participating as part of the Answering TTP Team helps raise awareness for TTP to SAVE EVEN MORE LIVES. Each TTP crisis is a medical emergency and early diagnosis is key to mitigating the risk of irreversible complications, or death.

Participation details at  
[www.AnsweringTTP.org](http://www.AnsweringTTP.org)  
or call 416 792 4656 or toll free 1-888-506-5458

Five years after successfully battling Breast Cancer, Pam Smith suddenly forgot how to get out of the car and started slurring her words. She was 63 years young. Her husband rushed her to the nearest hospital in Charlottetown, PEI where she was diagnosed with TTP.

Pam was transferred to Halifax, NS by ambulance to receive treatment for TTP called plasma exchange; her entire blood volume was exchanged through a machine to replace the plasma portion of her blood with that of donated blood plasma day after day.

Pam has been through the TTP treatment regime 3 times thus far and has required about 500 blood donations. She, her husband, her 5 children, 14 grandchildren, 5 great-grandchildren and the rest of her family, are thankful for all those selfless strangers that donate blood.

She does not know when TTP may reoccur, but knowing that there are blood donors like you gives her a fighting chance against this rare and devastating disease.

[Click here for Pam's full story.](#)



Pam Smith

**Help to raise 180 blood donations in 2013!**

Please pass this notice to friends, family and co-workers.

[Print-friendly flyer here.](#)

Our donation team contributed 90 blood donations in 2012! Congratulations to all team members and all those who have actively recruited family and supporters to the team.

Ninety blood donations is a great start for this program. What is even more exciting is the number of first time donors that come out as part of the team, and continue to give regularly. Did you know that young donors who are successful in giving 3 times are very likely to become regular donors? As the average age of blood donors increases, recruiting new young donors is becoming increasingly important.

TTP patients are encouraged to recruit their family and friends. Existing team members are asked to consider bringing a friend or co-worker the next time they donate. Still not convinced? Giving blood is the best excuse to refuel with cookies!

More information about the success of our 2012 blood donation team on [our blog \(click here\)](#).

## Awareness Campaign

TTP awareness wristbands are being given to donors while supplies last.

Answering TTP Foundation is arming donors with awareness bracelets to help get the conversation started to raise awareness for TTP to help save lives.

THIS IS A LIMITED TIME INITIATIVE. For every \$25 donated, 1 awareness wristband gift will be mailed. Donate \$25 to receive 1 wristband gift; \$50 to receive 2 wristband gifts; \$75 to receive 3 wristband gifts etc

[DONATE TODAY \(click here\)](#).



TTP Awareness Wristband

## Research and Education Initiatives

Answering TTP Foundation raises funds, not tied to one institution, for effective TTP research. We recognize the need for biomedical, clinical and population health research. We promote international collaboration to speed research for our small and geographically dispersed patient population. Answering TTP Foundation will consider research proposals that demonstrate a direct link to TTP. Visit our [website \(click here\)](#) for more details.

- Patient Order Set: Answering TTP Foundation has engaged professionals to develop a Thrombotic Thrombocytopenic Purpura standard order set with direction and guidance from a team of international hematologists with a special interest in the management of TTP. The order set will be shared to speed diagnosis and provide information about treatment options for TTP.
- TTP Medical Research Collaboration: The Foundation is working on opportunities to bring together TTP experts to help outline a strategy for effective TTP research. The Foundation is planning to host a session at the upcoming Canadian Apheresis Group conference in Winnipeg, MB. For more details email [Contact@AnsweringTTP.org](mailto:Contact@AnsweringTTP.org).
- TTP Patient Registry Opportunity: The project will provide a foundation to achieve better understanding and potential treatment strategies through an accurate and detailed registry.



## Quebec Roadshow

Montreal Sunday March 3, 2013  
Sheraton Montreal Airport Hotel, 555 Boulevard McMillian, Dorval

The Roadshow initiative grows the Answering TTP Community support network and raise awareness for TTP.

Come out to learn more about our TTP patient group and our dedication to improve TTP prognosis with your help. Snacks & refreshments will be provided.

Registration is free of charge, but required for planning purposes.

[Click here to register TODAY.](#)

We are looking to you to participate when we visit your local area. Come out to learn more about our TTP patient group and our dedication to improve TTP prognosis with your help.

Visit the [BLOG \(click here\)](#) for details regarding past Roadshow events.

Media inquiries should be submitted to [Contact@AnsweringTTP.org](mailto:Contact@AnsweringTTP.org) or call 416 792 4656.

## Patient Voice

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. The survey was designed by volunteers and the results are only intended for informational purposes.

One hundred and twenty-two complete responses were compiled representing TTP 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.

The median age of TTP diagnosis amongst respondents was identified to be 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. 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. 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."* For the purposes of this survey, 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.

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. 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 different replacement fluids used for Plasmapheresis treatment for TTP, respondents were asked to select all side effects that they had experienced with Fresh Frozen Plasma (FFP) or Cryosupernatant (CPP) vs. Solvent-Detergent Plasma (SDP). Conclusions utilizing data from this survey may not be statistically significant due to the relatively small number of respondents receiving SDP. The data suggests that those respondents that were given SDP as a replacement product had less side effects than FFP/CPP.

### Other Comments Regarding Plasmapheresis with FFP/CPP

- *"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."*

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

[Click here to view the final public report for informational purposes only.](#)

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 understanding of potential areas of research and opportunities for effective support initiatives.

Please ensure that you are registered with the Answering TTP Community so that you may participate and be heard. [Click here to join the Answering TTP Community today!](#)



## Ongoing Support

Every person touched by TTP provides further insight into this complex disorder and Answering TTP Foundation's support programs are consistently growing to reach more patients. Sign up for the [Answering TTP Community](#) to ensure you receive invitations to participate. Other support initiatives include:

**Patient Connect:** Both newly diagnosed TTP patients and more seasoned TTP patients are encouraged to [click here to register](#) for this new program designed to connect patients to provide peer support. Help break down geographic boundaries to share your experience to help others.

**Local Support Groups:** These groups are currently running in Vancouver, Calgary, Toronto and Saint John. The Quebec Roadshow promises to connect the Answering TTP Community with Quebec centres to begin additional sessions. For information about organizing a session in your community visit [www.AnsweringTTP.org](http://www.AnsweringTTP.org).

**New TTP Patient Brochure:** This informational source outlines TTP in easy-to-understand terms, and informs patients that Answering TTP Foundation is here to support them. The brochure has been translated into French, Spanish and German and is available for download in these languages from [www.AnsweringTTP.org](http://www.AnsweringTTP.org)

**Facebook:** The [Answering TTP Facebook page \(click here\)](#) is an online support forum to enable the Foundation to connect with TTP patients around the world and raise awareness for TTP within the social media space. On this site, we discuss current topics and answer questions from the patient perspective. Posts can be circulated to your Facebook friends by simply clicking on the "Like", "Comment" or "Share" buttons.

**Website:** [www.AnsweringTTP.org](http://www.AnsweringTTP.org) was created to be a resource for the TTP community, and a place to raise awareness for TTP. Patient stories listed on the site help personalize the complex condition to help other TTP patients. Stories also garner interest and support from the public to raise awareness. Also, links to other educational resources are listed.

Answering TTP Foundation is committed to supporting those touched by TTP. We are growing our sustainable initiatives through our Roadshow connections and medical community relationships.



## Request for Applications

Are you thinking of volunteering your time to a worthy cause? Do you want to really make a difference? We encourage you to get involved.

Our organization is in a grassroots growth phase that will provide you with great opportunity. Whether you are new to the workforce and are looking for experience towards your resume, or you are a seasoned professional looking to lend your skills to a worthy cause. Opportunities

include operating and committee volunteer positions.

### **Operating Volunteer Positions:**

Submit your application today. [Visit our website for details. Click here.](#)

- Outreach Coordinator
- Communications Specialist
- Volunteer Coordinator
- Walk Team Chair
- Sponsorship Coordinator
- Local Support Group Coordinator

### **Committee Volunteer Positions** for the 2013 Walk to Answering TTP Together:

To join or find out more about these committee volunteer positions, [register NOW for the first planning call by clicking here.](#)

- Awareness Coordinator
- Participant Coordinator
- Sponsorship Coordinator
- Purchasing Coordinator
- Website Developer
- Creative Lead

More information about volunteer opportunities on our [website](#).

### **Why Answering TTP Foundation?**

TTP can affect anyone at any stage of life. One day you are a healthy individual; the next you are in a hospital bed fighting for your life. You have never heard of Thrombotic Thrombocytopenic Purpura before and never imagined needing massive amounts of donated blood product. You, nor anyone you know, has ever heard of this diagnosis. Because TTP causes small blood clots to form throughout the body, you may live with irreversible damage to your heart, brain, and/or kidneys for the rest of your life. 20% of patients will not recover. And if you do recover, you may relapse. You don't know when or how to mitigate the risks. Little is known about TTP. This diagnosis makes you one of 3 in 1 million per year.

Answering TTP was formed in 2009 to raise funds for TTP research and care at St. Michael's Hospital in Toronto. Since that time, our purely volunteer Answering TTP Foundation has incorporated nationally and gained charitable status. We volunteer to represent one strong common voice of action for our patient group, and to most effectively raise funds to support research initiatives not tied to one hospital. The Foundation provides a platform for the TTP community to further common goals including: access to new drugs and safer treatment options, TTP education, patient support, and furthering TTP research to ease treatment and ultimately find a cure.

Visit our website, Facebook page and blog for additional information about our organization.

## **Patient Brochure**

Patient Resource

**NEW** - available for download in French, Spanish and German from [www.AnsweringTTP.org](http://www.AnsweringTTP.org)

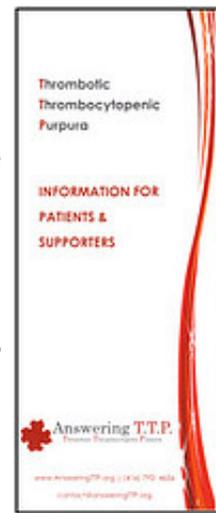
The TTP Patient Informational Brochure is designed to help new patients and families understand a TTP diagnosis and direct them to Answering TTP for further support.

The brochure includes an overview of the disorder, a patient story and information about Answering TTP in an effort to relieve some of the anxiety felt by new patients.

The brochure is available to new Canadian patients from their doctor.

## Attention Doctors

If you would like to order copies of the brochure, at no cost, please [register with us](#). We would be more than happy to ensure that you receive copies of this educational piece to distribute to TTP patients.



## Connect Online

We are raising awareness for TTP through social media. Follow [the blog](#) and connect via [Facebook](#).

Visit our blog

Like us on Facebook 

Share posts with your network to help raise awareness.



A diagnosis of TTP, Thrombotic Thrombocytopenic Purpura, is scary and complex. Many patients have never heard of this 3 letter acronym before, nor have they 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 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 provides the Canadian national TTP community with a supported platform to further common goals including:

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

We need your help to improve the prognosis for TTP patients. Help us find the answer to TTP.

**Answering TTP Foundation**

**www.AnsweringTTP.org**

22 Prince George Dr.

Toronto, ON M9A 1Y1

416 792 4656 | toll free. 1-888 506 5458

**Contact@AnsweringTTP.org**

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