

## Resource Guide

What you need to know to help  
raise awareness of cTTP



### About cTTP and the resource toolkit

Congenital Thrombotic Thrombocytopenic Purpura (cTTP), or Upshaw-Schulman syndrome, is a rare and serious condition where small blood clots form in blood vessels due to a deficiency of the A disintegrin and metalloproteinase with thrombospondin motifs 13 (ADAMTS13) enzyme, leading to low platelet counts and red blood cell destruction.<sup>1-3</sup> This condition can be life-threatening.<sup>1,2</sup> Organizations that support rare diseases play a critical role in addressing the needs of individuals and families affected by cTTP. By providing access to accurate information, resources, and supportive communities, organizations can foster connections that reduce feelings of isolation and empower affected individuals in managing this complex condition.

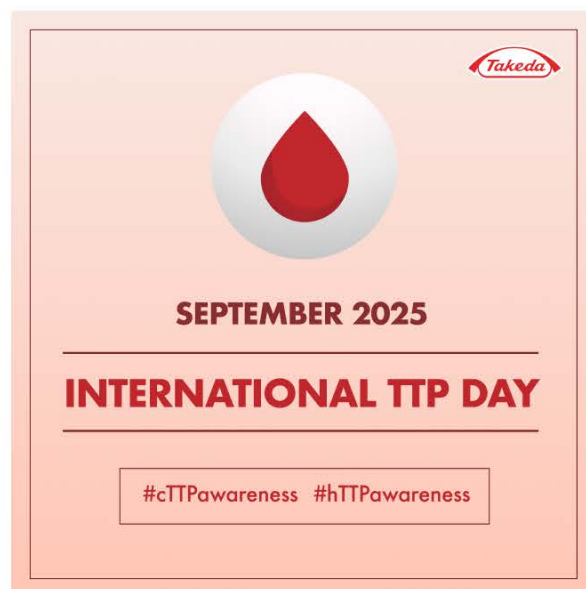
### How to use the resource toolkit

As an organization, you have the power to make a meaningful impact on the lives of those living with cTTP. By raising awareness, you can foster greater understanding and support for this rare condition. To help, we've prepared a series of ready-to-use social media posts, complete with potential hashtags to expand your reach. You can also use the image assets from our graphics pack or key facts from this guide to create your own content.

#cTTP #CongenitalThromboticThrombocytopenicPurpura #RareDisease #BloodDisorder  
#PatientAdvocacy #Healthcare #TTPAwareness #cTTPQuickFact #cTTPDiagnosis #cTTPTreatment

## Campaign materials – graphics pack









Visuals can capture attention, convey information quickly, and evoke strong emotions. Social media posts with images typically see higher engagement and are shared more frequently than text-only posts.<sup>4</sup> Our graphics pack provides a variety of powerful visuals to help elevate your social media content. Feel free to explore the resources below.



...Download these and more [here](#)

## Key Facts

Why not use these key facts to create your own posts or captions?

- |   |   |
|---|---|
|  <p>cTTP is one of two forms of a condition called Thrombotic thrombocytopenic purpura (TTP)<sup>5</sup></p> |  <p>cTTP is also known as Upshaw-Schulman syndrome<sup>5</sup></p>   |
|  <p>Around one or two persons per million are diagnosed with cTTP<sup>5</sup></p>                            |  <p>cTTP is caused by a deficiency of a blood protein called ADAMTS13<sup>5</sup></p>                          |
|  <p>There may sometimes be a delay of almost 4 years before cTTP is diagnosed<sup>3</sup></p>                |  <p>cTTP can be treated with infusion therapies to replace the missing blood protein ADAMTS13<sup>7</sup></p>  |
|  <p>cTTP flare-ups may be triggered by infections, certain drugs and pregnancy<sup>6</sup></p>               |  <p>cTTP often develops in children before they turn 10 years old but can appear in adults too<sup>5</sup></p> |



## Key Dates

Most awareness days will have a specific hashtag for you to use in your posts, which will help people find you and open the conversation with a wider audience.

First week of December 2024 - **Patient Solidarity Day** - [#patientsolidarityday](#)

September 26<sup>th</sup> 2025 - **Purple for Platelets Day<sup>SM</sup>** - [#purpleforplatelets](#)

February 21<sup>st</sup> 2025 - **National Caregivers Day** - [#nationalcaregiverday](#)

6<sup>th</sup> - 10<sup>th</sup> October 2025 - **International Plasma Awareness Week** - [#plasmaawarenessweek](#)

February 28<sup>th</sup> 2025 - **Rare Disease Day** - [#rarediseaseday](#)

October 2025 - **Thrombosis Awareness Month** - [#ThrombosisAwarenessMonth](#)

June 14<sup>th</sup> 2025 - **World Blood Donor Day** - [#worldblooddonorday](#)

October 10<sup>th</sup> 2025 - **World Mental Health Day** - [#worldmentalhealthday](#)

July 10<sup>th</sup> 2025 - **Chronic Disease Awareness Day** - [#chronicdiseaseawarenessday](#)

October 13<sup>th</sup> 2025 - **World Thrombosis Day** - [#worldthrombosisday](#)

September 2025 - **International TTP Day** - [#internationalttpday](#)

## FAQs

### What are the cTTP resources for?

Our Resources section contains key information and support related to cTTP. It houses a wealth of tools and materials to help with navigating the cTTP journey and raising awareness of the condition. You can find practical advice, sources of support, downloadable resources and much more here.

### When is the best time to post on social media?

There is no one answer to this question – it really depends on your target audience and the platform you're using. One school of thought is that the best times to post may be during work breaks (such as lunchtimes) and commuting hours.<sup>8</sup> But, this may not always hold true if a large portion of your audience are not full-time workers. It's best to experiment and find the optimal times for your specific audience. Keep in mind, that there are tools you can use to track audience engagement and adjust your posting schedule accordingly.

### Should I use hashtags in my posts?

Yes! Hashtags are a wonderful tool for increasing your post's visibility. They help your content reach a wider audience by categorizing it. However, it's important to use relevant hashtags. Resist the temptation to include too many hashtags in your post as it could look spammy. A mix of general and specific hashtags often works best.



## References

1. TTP Network. Available at: <https://www.ttpnetwork.org.uk/about-ttp>. Accessed October 2024.
2. National Heart, Lung, and Blood Institute. Platelet Disorders: Thrombotic Thrombocytopenic Purpura (TTP). Available at: [www.nhlbi.nih.gov/health/thrombotic-thrombocytopenic-purpura](http://www.nhlbi.nih.gov/health/thrombotic-thrombocytopenic-purpura). Accessed October 2024.
3. Alwan F, et al. Blood. 2019;133(15):1644–1651.
4. Dhanesh G, et al. Public Relations Review. 2022;48(2):102174.
5. Sukumar S, et al. J Clin Med. 2021;10(3):536.
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