IMPACT REPORT

ttpnetwork

2025–2026

Supporting people
Connecting our community
Making a difference

A year of helping people affected by TTP to understand their condition, find support and feel less alone.

OUR MISSION

Supporting patients and families affected by Thrombotic Thrombocytopenic Purpura

Our mission is to improve outcomes and quality of life for patients and families living with TTP, through support, education and advocacy, ensuring that no one facing TTP will feel alone.

Because nobody facing TTP should have to face it alone.



WHAT YOUR SUPPORT MADE POSSIBLE

TTPNetwork exists to make sure that patients and families have somewhere trusted to turn. During 2025-26, we continued to provide information, support, connection and advocacy to people affected by TTP in the UK and beyond.

Keeping our website accurate, accessible, and up to date.

Maintaining our online community and buddy scheme.

Patient events, webinars, newsletters and opportunities to meet others living with TTP.

Sharing updates and helping patients understand developments that may affect them.

Producing and reprinting essential information and Patient Alert Cards.

Ensuring the patient voice is heard and represented.

91%

of survey respondents rated finding information from TTPNetwork as easy or very easy.

When you're diagnosed with TTP, good information matters. Being diagnosed with a rare and potentially life-threatening condition can leave patients and families with questions they never expected to have.

- What is TTP?
- What does my treatment mean?
- Can I travel?
- Can I work?
- What should I tell my family?
- What happens next?

TTPNetwork helps people find clear, reliable information when they need it. Our resources are designed to help people understand TTP and explain it to the people around them — including family members, employers and schools.

WHAT PATIENTS TOLD US

"As a new diagnosis... I feel like you can be safe in the knowledge that the information is up to date and correct. It cuts out the risk of googling and getting bad information."

"The website is easy to read and to get information."

"Up to date information."

DURING THE YEAR WE

- Kept information on our website updated
- Improved accessibility and usability
- Provided information about TTP, treatment and research
- Shared practical guidance about travel and employment
- Produced a new patient leaflets and reprinted our suite of patient information leaflets
- Continued providing Patient Alert Cards.

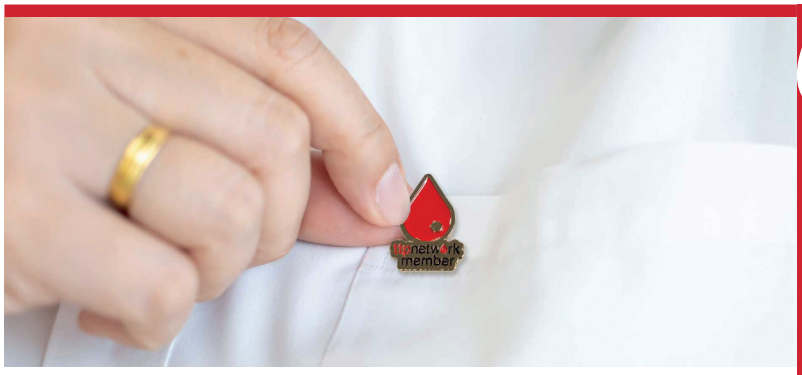
WHY THIS MATTERS

For someone living with a rare disease, finding trustworthy information can reduce uncertainty, build confidence and help them feel more in control.

Education is at the heart of our mission.

83%

of survey respondents said engaging with TTPNetwork had increased their confidence in understanding and managing TTP.



Sometimes the most important thing is knowing someone understands.

Living with TTP can feel isolating. Friends and family may care deeply, but they cannot always understand what it is like to live with a rare condition — or the fear and uncertainty that can come with it.

That's why connection matters.

WHAT PATIENTS TOLD US

"Being signposted to the Facebook page by the hospital made me feel less alone."

"Without access to this I would be somewhat lost."

"It has been a hugely positive influence in the way I've learned to live with TTP."

DURING 2025–26, TTPNETWORK CONTINUED TO PROVIDE:

PEER SUPPORT

Our Facebook community provides a place for people affected by TTP to connect, ask questions, share experiences and support one another.

BUDDY SUPPORT

Our buddy scheme connects people with others who have their own experience of TTP.

EMAIL SUPPORT

Patients and families can contact us when they need information, reassurance or simply someone who understands.

NEWSLETTERS & UPDATES

Keeping our community connected to news about TTP, treatment, research and TTPNetwork activities.

94%

of survey respondents felt TTPNetwork understands the impact of TTP on patients.



There is something special about meeting someone who really gets it.

Online support is incredibly valuable, but there is also something powerful about sitting in a room with other people who understand TTP.

WHAT PATIENTS TOLD US

"The patient event in May was life changing for me to be in the same room as others in the same position as me."

"I value the fact that the TTPNetwork exists so there is a trusted place to go for advice & support."

"It's there and that helps."

WE CONTINUED TO HELP PATIENTS AND FAMILIES CONNECT THROUGH:

PATIENT EVENTS

Bringing together patients, families, healthcare professionals and others who understand TTP.

WEBINARS

Making specialist knowledge and information accessible to patients and families wherever they live.

FOCUS GROUPS AND ONLINE MEETINGS

Giving patients opportunities to share their experiences and help shape our work.

RESEARCH AND TREATMENT UPDATES

Helping our community stay informed about developments in TTP.

85%

of survey respondents felt TTPNetwork understands the impact of TTP on families and carers.



From a Patient Alert Card to a conversation with an employer — small things can make a big difference.

Our resources are designed around the real-life challenges of living with TTP.

WHAT PATIENTS TOLD US

"The TTP alert card has been a life saver."

"Provided risk assessment information for me to return to work."

"Resources for employers and travel have really helped."

"I got a leaflet from the UK which guided me to you."

DURING THE YEAR PATIENTS USED OUR

PATIENT ALERT CARD

Helping patients communicate important information about their condition when they need urgent or unfamiliar healthcare.

PATIENT LEAFLETS

Providing clear information that patients can keep, share and return to when they need it.

EMPLOYMENT RESOURCES

Helping patients communicate with employers and navigate returning to work.

TRAVEL INFORMATION

Helping people understand and plan for travelling with TTP.

TTP INFORMATION FOR FAMILIES

Helping loved ones understand a condition that can be difficult to explain.

OUR AIM

Our aim is not simply to provide information.

It is to give people practical tools that can help them live their lives with greater confidence.

WHAT YOU TOLD US YOU VALUE

TRUSTED, ACCESSIBLE INFORMATION

PEER SUPPORT

PATIENT EVENTS

RESEARCH AND TREATMENT UPDATES

THE PATIENT ALERT CARD

BUDDY SCHEME

QUICK RESPONSES TO QUESTIONS

ADVOCACY

YOU ALSO TOLD US WHAT WE COULD DO BETTER

We heard that there is more we can do to:



Improve accessibility for people with additional needs, including people with SEND or autism.



Strengthen communication with local hospitals so that healthcare professionals have access to appropriate TTP information.



Continue making sure every newly diagnosed patient knows TTPNetwork exists.

Your feedback doesn't just tell us what we've done well, it helps us decide what we do next.



LOOKING AHEAD

TTP doesn't stop being part of someone's life when they leave hospital. For many people, there are ongoing questions about treatment, monitoring, work, travel, family life, research, relapse and the future. That's why TTPNetwork needs to be there — not just at diagnosis, but throughout the TTP journey.

OUR MISSION REMAINS CLEAR

To improve outcomes and quality of life for patients and families living with TTP, through support, education and advocacy — ensuring that no one facing TTP will feel alone.

THANK YOU

To everyone who donated, fundraised, volunteered, provided a grant, shared our work, attended an event, answered a survey, supported another patient or simply told someone about TTPNetwork - thank you. You are helping us make sure that when someone hears the words "You have TTP", they don't have to face what comes next alone.

TTPNetwork is a Charitable Incorporated Organisation. Registered Charity Number 1195109

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