

## **Report and Financial Statements for the period 01/04/22 – 31/3/2023**

For: TTPNetwork

Charitable Incorporated Organisation

Registered Charity No. 1195109

### **Registered Address**

61 Bridge Street

Kington

Herefordshire

HR5 3DJ

### **Trustees**

Joseph Wildy

Catherine Howell OBE

Saida Ladha



– Redacted on public copy

### **About**

TTPNetwork was established as a not-for-profit organisation in 1998. Its main function is to provide support, advocacy and information for patients diagnosed with the very rare blood disorder; Thrombotic Thrombocytopenic Purpura (TTP).

Families of patients, and healthcare professionals working with TTP patients are also among the charities charity's key stakeholder group.

TTP is an autoimmune condition that is believed to affect between four and six people per million in the U.K. Without prompt treatment TTP has a mortality rate of 80%. Optimal treatment currently includes replacement of the patient's plasma with donor products and specialist drugs which target the immune system.

TTP occurs in both men and women and more infrequently in children.

### **Structure & Management**

TTPNetwork is not part of a wider group structure.  
TTPNetwork is led and managed by volunteers.

The founding trustee takes the lead to deliver and manage day to day operations on a voluntary basis and is supported to do this by the 3 other trustees and a small group of patient volunteers.  
The patient volunteers support the charity with coordinating a Buddy scheme, book-keeping and accounts.

All volunteers have signed a confidentiality agreement and are familiar with the charity's data protection and safeguarding policies.

There were no permanently employed or individuals on fixed term contracts working for TTPNetwork during the reporting period.

TTPNetwork has not recruited any new trustees during the reporting period.

## **Activities and Objectives**

Our activities, as stated in our Governance document are:

To relieve the needs of those experiencing or affected by Thrombotic Thrombocytopenic Purpura (TTP) in the UK and the Republic of Ireland with an international reach.

To improve equity of access to treatments, preserve and improve the quality of life and promote best practice and advancement of education in TTP.

We achieve this by:- the provision of information, advice, support, representation and advocacy.

Our Charitable Objects are:

To relieve the needs of persons experiencing or affected by Thrombotic Thrombocytopenic Purpura (TTP) in the United Kingdom and the Republic of Ireland with an international reach. In particular but not exclusively,

We achieve this by: -

- The provision of Information, advice, support, representation and advocacy in the interest of social welfare, to improve equity of access to treatments, preserve life and to improve the quality of life;
- Promoting best practice and the advancement of education of TTP in relation to the cause, diagnoses, prevention, alleviation, treatments and cure by raising awareness and providing information to the public and healthcare professionals nationally, and internationally;
- Representing the patient voice and strengthen patient advocacy on UK and international government and non-government departmental bodies and in consultations;
- Promoting public support and providing assistance for the carrying out of research by making grants for the benefit of patients with TTP;
- Generating income through fundraising activities for the purpose of improving patient care;
- Engaging in nonpartisan political activity provided that the trustees are satisfied that the proposed activities will further the purposes of the charity to an extent justified by the resources committed and the activity is not the dominant means by which the charity carries out its objects; and
- Interfacing with other Charitable organisations and corporate partners to collaborate for the benefit of patients and their families.

### **Achievements & Performance**

In the year 2022-2023 our engagement activity has increased with us receiving 27 new patient or family enquiries. Our enquiries from Health Care Professionals via email began to increase towards the end of the reporting period due to the commissioning of the new specialist TTP centres and the work the team undertook to raise awareness of those centres.

As in previous years, the enquiries received have centred around patients seeking to find someone who understood their diagnosis and to feel less alone. We provided information about our website, our Facebook group and our Buddy scheme.

We continued to assist the Royal Liverpool University Hospital to recruit patients and hospitals to their ConNeCT research which is looking at the neurological complications of TTP.

In November we supported University College London Hospital to deliver a successful patient day that was attended by over 100 patients and family members.

We have continued to share and publicise information for patients and their families about the benefits of taking part in the national TTP Registry. This is a register and long-term study of all TTP patients (where consented) and has helped clinicians to focus and improve therapies for this rare blood disorder.

We have attended the National Group meetings of the TTP Specialist Centres, to update them on our work and to hear about the progress of the new specialist centres, which has enabled us to feed back to patients about the care they can expect to receive at these centres.

We continue to work in collaboration with others on a new phone app and we organised for a cohort of patients to join a focus group with the app developers.

Our private Facebook group remains the most popular method of communication for our patients and their families. Our group is made up of 83% women, with ages ranging from 18 to over 65 years and the highest number of patients remains in the 33 to 44 years age group.

Most of our patients are in the UK, however our Facebook group also reaches patients and families in the USA, and 43 other countries including Singapore, Jordan, Australia, and many countries in Europe.

Through this group we have been able to share important, and factual information about developments in therapies to treat TTP and also news about the specialist treatment centres which launched in 2022.

Our Buddy scheme has started to pick up traction and there were several new buddy pairings during the reporting period.

Of our service patients have said:

“Thank you so much to everyone who is involved in the network - it made a HUGE positive difference to me at the scariest time of my life!”

“When I had my TTP episode, it was a really good source of information for me and my family.”

**Financial Report**

Please see the attached document for our financial return.

# TTPNetwork

## Profit and Loss

April 2022 - March 2023

	TOTAL	
	APR 2022 - MAR 2023	APR 2021 - MAR 2022 (PY)
Income	<b>£25,274.89</b>	<b>£3,604.63</b>
Cost of Sales	<b>£1,166.69</b>	<b>£61.88</b>
TOTAL	<b>£24,108.20</b>	<b>£3,542.75</b>
Expenditures	<b>£2,470.93</b>	<b>£249.54</b>
NET OPERATING INCOME	<b>£21,637.27</b>	<b>£3,293.21</b>
Other Expenditures	<b>£0.00</b>	<b>£0.00</b>
NET OTHER INCOME	<b>£0.00</b>	<b>£0.00</b>
NET INCOME/(EXPENDITURE)	<b>£21,637.27</b>	<b>£3,293.21</b>

Rebecca Davies, ACMA, CGMA  
72 Queensway, Didcot, Oxfordshire, OX11 8LU  
07736 043975

Date: 8<sup>th</sup> February 2024

I can confirm that I have conducted an independent examination of the financial accounts for TTPNETWORK (Charity Number 1195109) for the year ending 31 March 2023

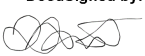
My examination included a review of the accounting records kept by TTPNETWORK and a comparison to the accounts presented with those records. It also included consideration of any unusual items and disclosures in the accounts and I sought explanations from the Treasurer concerning such matters. The procedures undertaken do not provide all the evidence that would be required for a full audit and consequently I do not express an audit opinion on the view given by the accounts.

#### **Independent examiners statement**

In connection with my examination, I can confirm that no matter has come to my attention:

- a) which gives me cause to believe that, in any material respect, the general requirements to keep accounting records in accordance with UK accounting principles have not been met.
- b) which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Signed

DocuSigned by:  
  
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09-Feb-24

Rebecca Davies