

## **Report and Financial Statements for the period 9/7/21 – 31/3/2022**

For: TTPNetwork

Charitable Incorporated Organisation

Registered Charity No. 1195109

### **Registered Address**

61 Bridge Street

Kington

Herefordshire

HR5 3DJ

### **Trustees**

Joseph Wildy

Catherine Howell

Saida Ladha



– Redacted on public copy

### **About**

TTPNetwork was established as a not for profit organisation in 1998 and provides 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 client group.

TTP is an autoimmune condition that affects between one and four people per million in the UK. Without prompt treatment TTP has a mortality rate of 80%. Optimal treatment currently includes donor blood products and specialist drugs which target the immune system.

TTP occurs in both men and women, children and adults.

### **Structure & Management**

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 other trustees.

TTPNetwork is also supported by a patient volunteer who helps moderate the private Facebook Group and helps coordinate the patient buddy scheme. The patient volunteers have signed a confidentiality agreement and are familiar with the charities data protection and safeguarding policies. The TTPNetwork bookkeeping is managed by an accountant who is also a patient volunteer.

TTPNetwork has not yet embarked on recruiting new trustees.

## **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.

By:- the provision of information, advice, support, representation and advocacy.

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

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, 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 first eight months of our operation as a charity (but having operated as a not for profit in the preceding 23 years), we saw activity that was consistent with previous years. This included:

10 New Patient enquiries via email

5 new patient family enquiries

And 4 enquiries from nursing or medical staff.

The enquiries centred around patients seeking to find someone who understood their diagnoses and to feel less alone. We provided information about our website, our Facebook group and our Buddy scheme.

We also supported in excess of 20 patients to take part in research studies looking at the quality of life of patients living with either Acquired TTP or Congenital TTP.

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

We have shared 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 worked with NHS England to help them commission 9 regional specialist centres for the treatment of TTP. Two trustees sat on the working group and represented the patient voice in the development of the specification for the centres (prior to registration as a charity) and in the past year they have sat on the commissioning panel.

We have been involved in the development of a specific phone application for patients with TTP. This work is being led by the Haematology staff at the Queen Elizabeth Hospital in Birmingham.

Our private Facebook group is the most popular method of communication for our patients and their families. Our group is made up of 85% women, with ages ranging from 18 to over 65 years and the highest number of patients in the 33 to 44 years age group.

Most of our patients are in the UK, however and our Facebook group also reaches patients and families in the USA, and 43 other countries including Israel, India, Canada, New Zealand, Australia and many countries in Europe.

Through this group we have been able to share important, and factual information about COVID and the COVID Vaccines to patients who have been concerned about their own health in the pandemic. This has provided much needed reassurance.

Our Buddy scheme has been less active in the past year and there were no new buddy pairings during the reporting period.

Of our service patients have said:

*"The practical advice has been incredibly helpful. It made things a lot less stressful. Connecting with other people so you know you're not alone is very valuable."*

*"TTP network is my main source of information and knowledge about what to expect and what resources and support is available."*

## **Financial Report**

Please see the attached documents for our financial return.

## **Profit & Loss Statement**

**09/07/2021 to 31/3/2022**

### **INCOME**

Donations Received	£	322.83
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### **Earned Income**

Consultancy Income	£	2,495.00
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Sales Income	£	786.80
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Other Income	£	-
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<b>Total INCOME</b>	<b>£</b>	<b>3,604.63</b>
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### **EXPENSES**

Donations Made	£	-
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### **COGS Expenses**

Printing Material	£	-
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Direct Material	£	-
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Merchant Fees	£	38.91
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Postage Costs	£	22.97
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### **Operating Expenses**

Professional Fees	£	50.00
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Internet & Website	£	158.74
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Stationery & Supplies	£	-
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Travel	£	40.80
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<b>Total EXPENSES</b>	<b>£</b>	<b>311.42</b>
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<b>Profit / (Loss)</b>
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<b>£ 3,293.21</b>
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## NOTES

donations into TTP Network

Opinion Health, NHS Blood, Safoni  
shop receipts  
bank interest received

donations to UCLH

buy printed leaflets (sold through shop)  
buy badges (sold through shop)  
Stripe fees (£0.20 + 1.4% per transaction)  
buy P&P (to post items sold through shop)

Fundraising Regulator  
GoDaddy + Docusign  
notebooks, books  
train tickets