

# TTPNETWORK

England & Wales · Charity number 1195109

## Details

---

**Status** Registered

**Legal form** CIO

**Registered** 2021-07-09

**Register** [View on the Charity Commission register](#)

## Contact

---

**Address** 61 Bridge Street  
Kington  
HR5 3DJ

**Phone** 0740 393 2525

**Email** [info@ttpnetwork.org.uk](mailto:info@ttpnetwork.org.uk)

**Website** [www.ttpnetwork.org.uk](http://www.ttpnetwork.org.uk)

## Activities

---

**Objects:** THE OBJECTS OF THE CIO 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; ANDINTERFACING WITH OTHER CHARITABLE ORGANISATIONS AND CORPORATE PARTNERS TO COLLABORATE FOR THE BENEFIT OF PATIENTS AND THEIR FAMILIES.NOTHING IN THIS CONSTITUTION SHALL AUTHORISE AN APPLICATION OF THE PROPERTY OF THE CIO FOR THE PURPOSES WHICH ARE NOT CHARITABLE IN ACCORDANCE WITH [SECTION7 OF THE CHARITIES AND TRUSTEE INVESTMENT (SCOTLAND)ACT 2005] AND [SECTION 2 OF THE CHARITIES ACT (NORTHERN IRELAND) 2008].

**Activities:** 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.

## Classification

---

- **How:** Provides Advocacy/advice/information
- **What:** General Charitable Purposes, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities, Other Defined Groups, The General Public/mankind

## Geography

---

- Ireland
- Throughout England And Wales

## Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£59,164	£25,464	-	-
2024-03-31	£44,769	£24,232	-	-
2023-03-31	£25,274	£2,470	-	-
2022-03-31	£3,605	£311	-	-

## Trustees

Name	Role	Appointed
Catherine Anne Howell OBE		2021-02-18
Julie Hallam		2024-08-21
Karen Jean Heath		2026-01-27
Kirandeep Kaur Grewal		2024-08-21
Paola Simoneschi		2026-04-01
Saida Banu Ladha		2021-02-18

**TTPNETWORK**

England & Wales - Charity number 1195109

---

# Accounts

---



# Trustees' Annual Report

---

For the year ended 31 March 2025

Charity Name: TTPNetwork

Charity Number: 1195109

Legal Structure: Charitable Incorporated Organisation (CIO)

Principal Address: 61 Bridge Street, Kington, Herefordshire, HR5 3DJ

## 1. Objectives and Activities

### a. Charitable Objectives

The charity's 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.



## b. Mission Statement & Vision

**Mission Statement:** To improve outcomes and quality of life for patients and families affected by TTP through support, education, and advocacy.

**Vision:** No patient or person affected by TTP will feel alone

## c. Main Activities

In the year ending 31 March 2025, the charity provided a range of leaflets for patients, their families and employers to help with understanding TTP. The TTPNetwork website was regularly updated with resources and information and the Charity proactively engaged with healthcare professionals at the 11 specialist centres in England.

## 2. Achievements and Performance

- Published a blog and downloadable information about diet and nutrition when diagnosed with TTP.
- Produced further translations of the TTPNetwork patient letter which provides medical information and contact details in case of an emergency when travelling abroad. This is now available in 25 languages.
- Supported 2 patients who had not been receiving regular check ups to connect with a specialist TTP centre.
- Recruited the Charity's first paid employee.
- Maintained and moderated a closed Facebook group with 1220 members
- Provided one-on-one support and signposting for patients and their families (excluding medical advice)

## 3. Financial Review

### a. Overview

The total income for the year was £59,164, mainly from grants and donations. Expenditure totaled £25,464, with the main costs being salary.

### b. Reserves Policy

The trustees aim to maintain unrestricted reserves of at least three months' core expenditure.



### **c. Risk**

A risk register is maintained and reviewed by the Board of Trustees at their quarterly meetings.

### **d. Fundraising**

The charity does not use professional fundraisers. All fundraising is carried out by trustees and volunteers, with full compliance to the Code of Fundraising Practice.

## **4. Structure, Governance and Management**

The charity is governed by its constitution dated 30th June 2021. It is a Charitable Incorporated Organisation registered with the Charity Commission on 9th July 2021.

### **Trustee Recruitment and Appointment**

Trustees are appointed in accordance with the constitution. New trustees are recruited based on the needs of the charity and provided with an induction pack and signposted to relevant online training.

Trustees who served during the year:

Kiran Grewal (Joined September 2024)

Julie Hallam (Joined September 2024)

Catherine Howell OBE

Saida Ladha

Steven Lane (Resigned August 2024)

Jo McIntyre (Resigned May 2024)

### **Trustee Meetings**

The board met four times during the year.

## **5. Public Benefit Statement**

The trustees confirm that they have complied with the duty in section 17(5) of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission.

# TTPNetwork

## Profit and Loss

April 2024 - March 2025

	TOTAL	
	APR 2024 - MAR 2025	APR 2023 - MAR 2024 (PY)
Income	<b>£59,164.15</b>	<b>£44,758.93</b>
Cost of Sales	<b>£1,164.56</b>	<b>£1,314.07</b>
TOTAL	<b>£57,999.59</b>	<b>£43,444.86</b>
Expenditures	<b>£25,464.45</b>	<b>£24,231.66</b>
NET OPERATING INCOME	<b>£32,535.14</b>	<b>£19,213.20</b>
Other Expenditures	<b>£ -8.25</b>	<b>£0.00</b>
NET OTHER INCOME	<b>£8.25</b>	<b>£0.00</b>
NET INCOME/(EXPENDITURE)	<b>£32,543.39</b>	<b>£19,213.20</b>

**TTPNetwork**  
**Independent Examination of 2024/25 Accounts**

I report to the Trustees on my examination of the accounts of the TTPNetwork (Charity Number 1195109) for the year ended 31 March 2025.

**Responsibilities and basis of report**

As the charity trustees of the TTPNetwork you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in my respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable directions given by the Charity Commissioner under section 145(5)(b) of the Act.

**Independent examiner's statement**

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. Accounting records were not kept in respect of the TTPNetwork as required by section 30 of the Act; or
2. The accounts do not accord with those records.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Dr Bernard Crotty CPFA  
1 Bryn Coed, Radyr, Cardiff, CF15 8RH.  
7 October 2025

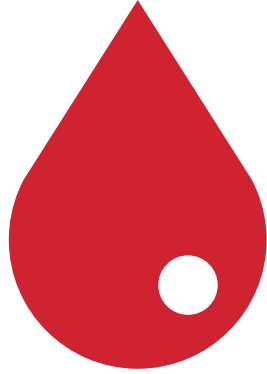
**TTPNETWORK**

England & Wales - Charity number 1195109

---

# Accounts

---



ttpnetwork

Annual Report

# Report and Financial Statements for the period 01/04/23– 31/3/2024

## For: TTPNetwork

Charitable Incorporated Organisation

Registered Charity No. 1195109

## Registered Address

61 Bridge Street

Kington

Herefordshire

HR5 3DJ

## Trustees

Joseph Wildy (resigned Aug 23)

Catherine Howell OBE

Saida Ladha

Steve Lane (joined May 23)

██████████ *redacted*

## About TTPNetwork

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 charity's key stakeholder group.

TTP is an autoimmune condition that is believed to affect between six and ten 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 blood products and specialist drugs which target the immune system.

TTP occurs in both men and women and more infrequently in children. TTP is described as idiopathic or in the case of the subtype, congenital TTP (cTTP).

## Structure and 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 the day to day operations on a voluntary basis and is supported to do this by the other trustees and a small group of patient volunteers.

The patient volunteers support the charity by coordinating a Buddy scheme, book-keeping and accounts and administration tasks such as proof reading and collaboration of ideas.

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 recruited one new trustee 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 Objectives 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 and Performance

In the year 2023-2024, our engagement activity has increased with us receiving 32 new patient /family enquiries. Enquiries from healthcare professionals via email have continued to increase as we build strong relationships with each of the 9 (over 11 sites) specialist TTP Centres in England; we received 15 new contacts from healthcare professionals.

As in previous years, enquiries have centred around patients seeking to find someone who understands their diagnosis and to feel less alone. We provided information about our website, our Facebook group and our Buddy scheme. Of the 32 new enquiries, we identified 2 patients who had not been receiving regular follow up, and put them in touch with a specialist centre.

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 and Clinical Nurse Specialists for TTP. During these meetings we have updated them on our work and learnt about the progress of the new specialist centres in England which has enabled us to feed back to patients about the care they can expect to receive at these centres.

In May 2023 we celebrated 25 years of being a not-for-profit organisation and held a patient event in Birmingham. We invited patients, their families or close friends and healthcare professionals including Haematologists, Clinical Nurse Specialists and Psychologists.

100 delegates were in attendance and for the majority, this was the first time they had been to a TTP specific event.

The event was sponsored by the following companies: Sanofi, Takeda and Octapharma. We had presentations from those with lived experience of TTP and from haematologists and researchers. We had a shop at the meeting where we were able to generate a small income from our merchandise.

The feedback from the patient day was overwhelmingly positive in terms of the range of speakers, the location, and the topics covered. We received many very positive comments including:

*Networking with other patients- first time I've ever met anyone else! As a TTP patient, I learned a lot that I did not know.*

*It was fantastic, wish I had found the support group earlier, diagnosed 2000.*

*Enjoyable day and informative to all parties, including family members.*

*Every presentation was really engaging.*

*My husband got a lot from the event. I was diagnosed in Jan 2009 and I feel he now understands TTP a lot more, especially the side effects.*

During the year we received funding from Takeda to build a new website and to update our administration and IT systems.

We now have an interactive and informative website which from an administrative perspective is easy to update and very easy for visitors to navigate. We have had positive feedback from users about the website.

In the first quarter of 2024 we reached 1,000 members in our private Facebook group. Through this group we continue to share important, factual information about developments in therapies to treat TTP. We also correspond with our audience via email.

Our Buddy scheme continues to be a resource for patients and families and our Buddy volunteer now manages this scheme via our new contact management system which helps keep records safe and eases the administrative burden.

## Financial Report

Please see the attached documents for our financial return.



ttpnetwork

[www.ttpnetwork.org.uk](http://www.ttpnetwork.org.uk)

Est. 1998

Registered Charity 1195109

# TTPNetwork

## Profit and Loss

April 2023 - March 2024

	TOTAL
Income	£44,768.93
Cost of Sales	£1,314.42
TOTAL	£43,454.51
Expenditures	£24,231.66
NET OPERATING INCOME	£19,222.85
Other Expenditures	£0.00
NET OTHER INCOME	£0.00
NET INCOME/(EXPENDITURE)	£19,222.85

**TTP Network  
Independent Examination of 2023/24 Accounts**

I report to the Trustees on my examination of the accounts of the TTPNetwork (Charity Number 1195109) for the year ended 31 March 2024.

**Responsibilities and basis of report**

As the charity trustees of the TTPNetwork you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in my respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable directions given by the Charity Commissioner under section 145(5)(b) of the Act.

**Independent examiner's statement**

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. Accounting records were not kept in respect of the TTPNetwork as required by section 30 of the Act; or
2. The accounts do not accord with those records.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Dr Bernard Crotty CPFA  
1 Bryn Coed, Radyr, Cardiff, CF15 8RH.  
25 October 2024

**TTPNETWORK**

England & Wales - Charity number 1195109

---

# Accounts

---

## **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:  
  
E1ADC417EA6F480...

09-Feb-24

Rebecca Davies

**TTPNETWORK**

England & Wales - Charity number 1195109

---

# Accounts

---

## **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

### **Earned Income**

Consultancy Income £ 2,495.00

Sales Income £ 786.80

Other Income £ -

**Total INCOME** £ **3,604.63**

### **EXPENSES**

Donations Made £ -

### **COGS Expenses**

Printing Material £ -

Direct Material £ -

Merchant Fees £ 38.91

Postage Costs £ 22.97

### **Operating Expenses**

Professional Fees £ 50.00

Internet & Website £ 158.74

Stationery & Supplies £ -

Travel £ 40.80

**Total EXPENSES** £ **311.42**

**Profit / (Loss)** £ **3,293.21**

## 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