



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

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

<p style="text-align: center;">TTP Network Independent Examination of 2023/24 Accounts</p>
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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