

The Thyroid Trust
Annual Report
30 June 2020



Registered Charity number 1183292

Contents

Administrative details	2
Trustee Report	3
Independent Examiner's Report	9
Statement of Financial Activities	10
Balance Sheet	11
Notes to the Financial Statements	12

Administrative details

Name of charity	The Thyroid Trust (also known as Thyroid Friends Network and TTT)
Organisation type	Charitable Incorporated Organisation
Governing document	Constitution dated 27 April 2018
Registered charity number	1183292
First registered	7 May 2019
Trustees (from 27 April 2018 except where noted)	Judith Taylor (Chair) Theresa Baker Dr Andrew Clempson (resigned 25 June 2020) Deepa Gadhvana (appointed 16 July 2020) Karen George Stephen Hey (Treasurer, appointed 25 February 2020) Dr Paul Jenkins Professor Fausto Palazzo Douglas Frost (Treasurer, resigned 25 February 2020)
Director	Lorraine Williams
Registered office	15 Great College Street London SW1P 3RX
Bankers	Lloyds Bank plc
Website	www.thyroidtrust.org

The website includes biographies of the Trustees at www.thyroidtrust.org/leadership-team.html

Trustee report

The Trustees of The Thyroid Trust (the “Charity”) have pleasure in presenting their Annual Report for the year ended 30 June 2020.

Objectives and activities

The Thyroid Trust provides access to reliable information and quality peer support for people affected by thyroid disorders and undertakes awareness raising and advocacy work to address the issues of most importance to patients.

At the end of the previous period, the Trustees agreed the objectives for this financial year: to continue to deliver regular support and information events and to seek to expand our awareness raising and advocacy work, aiming to put the organisation on a more sustainable footing for the future and increasing our capacity to do more over time, by developing our volunteer team and fundraising efforts.

In any one year, one in four of the population have their thyroid function checked¹; 3% of people in the UK are being treated for the most common thyroid disorder, hypothyroidism. Yet thyroid disease is seldom talked about. Many people don’t know what their thyroid gland is or what it’s for, they may not even know they are being tested, or that they may be at risk of what can be an extremely debilitating condition.

While the majority of patients may be relatively easily treated, there is a significant minority, estimated between 5-20%, who can have a dreadful time when their thyroid goes wrong. Symptoms can include distressing cognitive impairment, as well as significant physical disability. Research is scant and treatment is inconsistent, sometimes very poor, with many patients telling us they spend years with very poor quality of life and feeling overlooked. Research published in the Lancet indicates that access to specialist treatment is particularly restricted in areas of greatest deprivation².

There is a clear need for improved access to reliable information, quality peer support and improved care, as well as general awareness raising, more research and effective advocacy for thyroid patients.

The Trustees have had regard to the Charity Commission’s guidance on public benefit.

Achievements and performance

The Thyroid Trust was conceived in July 2017 by a group of thyroid patients who had been organising information and support events in London since 2010.

¹ Royal College of Physicians, The Diagnosis and Management of Primary Hypothyroidism, as revised June 2011

² Liothyronine cost and prescriptions in England The Lancet: January, 2019 DOI: [https://doi.org/10.1016/S2213-8587\(18\)30334-6](https://doi.org/10.1016/S2213-8587(18)30334-6)

A generous grant from The Federated Foundation supported the appointment of a Director and initial running expenses. Registration with the Charity Commission was completed in May 2019.

For the financial year to June 2020 The Federated Foundation continued their support alongside other grant-givers, the National Lottery and St James' Place Charitable Foundation. We have also commenced community fundraising and individual donations.

This support has enabled us to develop a strong Trustee board and a growing Volunteer Team to work with our Director. We have continued to deliver a much-needed programme of events, advocacy and publicity activities.

Until March 2020 we continued the programme of face-to-face meetings in London, at Crown Court Church in Covent Garden, informal get-togethers at the Wellcome Collection cafe and from September 2019, supported by Transport for London, at Palestra in Southwark. Our events programme included an Introduction to Health Coaching with Barbara Babcock; Nutrition and Thyroid Disease with Professor Margaret Rayman and Dr Sarah Bath; and an Overview of the new NICE Guidelines on the Management of Thyroid Diseases with Dr Kristien Boelaert. Since the lockdown as a result of COVID-19 we have arranged a series of online meetings including Evidence and Patient Advocacy, with guest speakers, Dr Brooke Lumisci and Hannah West from Sense About Science and the MS Society; Hypothyroidism from both ends of the stethoscope, with Dr Renée Hoenderkamp; and a Special Self Care Session with Michelle Varchione to mark International Thyroid Awareness Week in May 2020.

In August 2019, we held our first community fundraising event at our annual summer social, having successfully registered with the Just Giving fundraising platform and had some branded T-shirts printed. Ten of us, including a representative from Sense About Science, walked from Broadstairs to Ramsgate on the Kent coast and enjoyed a delicious lunch together overlooking Ramsgate harbour, raising over £300 in total. Everyone thoroughly enjoyed the day out and our T-shirts attracted lots of attention from interested passers-by.

During the course of the year, we added Paypal and Virgin Money Giving as additional ways for our supporters to be able to support us online. We began receiving payments from Paypal Giving Fund as a result of spontaneous support from Facebook and Ebay users.

We were included in the national 2.6 Challenge in April 2020, "to save the nation's charities" with a dedicated web page on Just Giving and set of fundraising tools which they set up for us. We communicated the challenge to all supporters via Mailchimp, Twitter and Facebook and received £270 in donations as a result.

As members of Thyroid Federation International, the umbrella body for thyroid patient organisations, we developed butterfly themed fundraising and awareness raising activities around International Thyroid Awareness Week in May 2020, which as far as we could tell had previously not been marked in the UK. Despite the COVID-19 pandemic meaning our plans to enter a team into our first mass participation fundraising event could not go ahead, a number of our supporters undertook their own individual fundraising challenges on our behalf, including solo butterfly themed running and cycling challenges, raising over £3,000 in total.

In the previous financial year we led on a project to deliver the Liothyronine Dossier, a major report for the Department of Health and Social Care, working with other patient organisations and the thyroid specialists' body, The British Thyroid Association. We have continued these positive working relationships. As a result of this work and with further input from the patient organisations which we coordinated, NHS England Regional Medicines Optimisation Committee revised their prescribing guidance for liothyronine in July 2019.

Liothyronine (T3) can be life transforming for some patients; however, some who might benefit from this treatment are still not able to access it due to many local areas still not following national guidance. This issue is an ongoing key focus of our work. We are continuing to receive frequent distressing reports of patients being denied NHS treatment, despite expressions of support at a national level and from clinicians. Finding a way to influence local healthcare providers is proving phenomenally challenging for us and our partners, all of whom are significantly lacking in resource and we are all learning together.

We held a meeting with NHS England, Healthwatch England, NHS Commissioners, Professor Chatterjee of the British Thyroid Association, Lord Borwick, Lord Hunt and Thyroid UK, which was reported in Hansard. However, follow ups to this meeting have been very much hampered by COVID-19, as NHS resources have been largely focused on the pandemic.

We worked with Elaine Smith MSP and Dr Anthony Toft to provide template letters for patients in Scotland to help influence the Scottish Parliament investigations into treatment of people with thyroid disease following the Scottish Parliament petitions committee proposing an Inquiry into thyroid care by the Health and Sports Committee.

As National Voices members, we were co-signatories to the VCSE statement to improve the debate on health published 19th Nov 2019 and participated in the National Voices campaign to highlight the needs of patients with chronic conditions during the pandemic, #OurCovidVoices

We have made a good connection with the author Michael Rosen who has been helping us reach a wider audience on Twitter. Michael has hypothyroidism and has written a book about his experiences, This is Not My Nose, now featured on our website.

We were active stakeholders in the development of the new NICE (National Institute for Health & Care Excellence) guideline, 'Thyroid disease: assessment and management', published in November 2019 and we were pleased to have many of our suggestions adopted in the new guideline. We are listed on the guideline NG145 as approved public information providers and we are now also stakeholders in the development of the new guideline for thyroid cancer.

We secured a swift correction in the British Medical Journal article which mis-stated the new guideline's position on liothyronine, T3 when it was first published online

We have produced four new films using content generated at our events about thyroid disease including a talk by high-profile thyroid expert and TTT Trustee Dr Paul Jenkins and three talks on different aspects of using evidence for patient advocacy from our event with Sense About Science and the MS Society. Our growing YouTube channel makes video content from our events and awareness messages available to a wider audience. At the end of the financial year we had one further Information video in production and three more planned for the year ahead.

Our Director was interviewed by Emma Goode of 24 Fingers for her 24 Questions video series on Facebook. From that we conceived a new series, TTT 24 Questions #TTT24Q, interviews with our team members to help stakeholders get to know the team, to help us strengthen our internal relationships and for thyroid patients to feel less alone, to be launched later in 2020.

We upgraded our website to include a search function and improved signposting, to make it easier for people to find the information they are looking for and added new information on research projects and campaigns, including new patient resources for the T3 access project and our new Information Videos, as well as more patient stories more blog articles and more Fun Stuff, like our T-shirts and lovely TTT Kindness Rocks created by volunteer, Amanda Walsh.

We increased our volunteer pool from 12 to over 40 people, who have generously supported us in a variety of ways.

One volunteer with lived experience of Graves' Disease and Thyroid Eye Disease, Kelly Southcott, attended the EUGOGO Conference in Pisa, supported by the Working Group for European Cancer Patients, Thyroid Federation International and Thyroid Cancer Alliance. Her report and personal story are published on our Thyroid Friends blog

We developed a statement in response to COVID-19 and signposted to reliable sources of further information including British Thyroid Foundation, who took on board some of our suggestions for the information they produced.

We sent delegates to other professional conferences and training events including the WECAN entry level patient advocacy training in Frankfurt in July 2019 and monthly WECAN masterclass webinars, the British Thyroid Association, American Thyroid Association and European Thyroid Association Joint T3 Conference in London in December 2019 and National Voices Social Prescribing Webinar in March 2020.

As members of the international organisation, Thyroid Cancer Alliance, we attended their phone conference with members from around the world to discuss how the COVID-19 pandemic is affecting thyroid cancer patients in different countries. The call included other organisations from France, Mexico, Spain, Bulgaria, Argentina, Peru and Netherlands and The Thyroid Trust represented the UK.

The Thyroid Trust is addressing a major need for thyroid patients, providing:

- improved access to reliable information and support;
- a strong public voice;
- collective capacity for patients to be heard and taken seriously.

Deborah Cartwright, CEO of Oasis Domestic Abuse and Social-led Consultancy kindly undertook pro bono work with the leadership team and additional key stakeholders, starting with a workshop, in June 2020 and planning a stakeholder survey for later in the year, to help us to start to develop a new five-year strategy, to best understand and meet the needs of thyroid patients going forward.

Structure, governance and management

The Thyroid Trust is a Charitable Incorporated Organisation (CIO). It adopted its Constitution on 27 April 2018 and was registered with the Charities Commission on 7 May 2019. Each of the Trustees is a member of the CIO. The members of the CIO have no liability to contribute to its assets and no personal responsibility for settling its debts and liabilities.

The Trustee Board has a breadth of professional and medical experience and includes members with first-hand experience of thyroid conditions. The Trustees meet at least four times a year. Day-to-day operations of the Charity are carried out by a freelance Director who reports to the Trustees and is a thyroid patient herself. The Director co-ordinates a growing team of volunteers.

In the opinion of the Trustees there is no ultimate controlling party of the Charity.

During the year Douglas Frost and Dr Andrew Clempson resigned as Trustees. Dr Anthony Toft stood down as advisor to the Trust having now retired from his long and illustrious career in medicine. We thank them for their contributions, and in particular for their participation and guidance to the establishment of the Trust.

We welcome Deepa Gadhvana, known as Deepa Verma, and Stephen Hey who have joined the Trustees.

Financial review

The Federated Foundation has continued to provide substantial support for the Charity for the financial year to June 2020 and has indicated they may continue to support the Charity as it becomes more established, reducing their commitment as other income streams are developed.

In the year to 30 June 2020 the Charity's income was £38,432 (2019: £34,820). This included a grant of £9,980 from the National Lottery Community Fund's Awards for All scheme to support six public events held in the calendar year 2020. We received £1,000 from St James' Place Charitable Foundation to support our work to develop the volunteer team.

We have commenced public fundraising campaigns with a number of individual sponsored events including solo Butterfly Runs as part of International Thyroid Awareness Week in May 2020. However, the COVID-19 pandemic has adversely affected our community fundraising ability. We had runners signed up to take part in the London Asics 10K and the Milton Keynes marathon, but these were cancelled with other large-scale fundraising events. We have been unable to meet in person since March 2020.

Expenditure amounted to £35,178 (2019: £34,223), being primarily the cost of the Director who works on a freelance basis.

Since 30 June 2020 we have received £15,000 from the National Lottery Community Fund's Reaching Communities scheme put in place to enable us to keep going during the COVID-19 pandemic in the second half of 2020.

Reserves

At the end of June 2020, the charity held reserves of £3,851 of which £3,327 were held on a restricted fund. We have no employees or other significant fixed costs and therefore we can operate with limited reserves; however, it is the intention of the Trustees to build our reserves in order to secure an increased level of activities in future.

Preparation of the report

The report was approved and authorised for issue by the Trustees on 25 February 2021 and is signed on behalf of the Trustees by:



Trustee



Trustee

Independent Examiner's Report

Independent examiner's report to the trustees of The Thyroid Trust

I report to the trustees on my examination of the accounts of the above charity ('the charity') for the year ended 30/06/2020.

Responsibilities and basis of report

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

I report in respect of my examination of the charity'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 Commission 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 which gives me cause to believe that in any material respect:

1. accounting records were not kept in accordance with section 130 of the Charities Act; or
2. the accounts did not accord with the accounting records; or
3. the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

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.

Signed:



Date: 28/03/2021

Name: Priscilla Asirifi ACMA

Relevant professional qualification(s): CIMA

Address: 8 Sandown Street, Gorton, Manchester

Statement of Financial Activities

Statement of financial activities (incorporating an income and expenditure account)
For the year ended 30 June 2020
Registered charity number 1183292

		2020			2019
		Unrestricted £	Restricted £	Total £	Unrestricted £
	Notes				
Total income from donations	2	<u>27,452</u>	<u>10,980</u>	<u>38,432</u>	<u>34,820</u>
Expenditure on:					
Raising funds		204	-	204	2
Charitable activities					
Support for people affected by thyroid disease		27,321	7,653	34,974	34,221
Total expenditure	3	<u>27,525</u>	<u>7,653</u>	<u>35,178</u>	<u>34,223</u>
Net income for the year		(73)	3,327	3,254	597
Reconciliation of funds:					
Total funds brought forward		<u>597</u>	<u>-</u>	<u>597</u>	<u>-</u>
Total funds carried forward		<u>524</u>	<u>3,327</u>	<u>3,851</u>	<u>597</u>

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in Note 6 to the financial statements.

Balance sheet

Balance sheet
As at 30 June 2020
Registered charity number 1183292

	Notes	2020 £	2019 £
Current assets			
Debtors	4	566	1,181
Cash at bank and in hand		17,492	597
		<hr/>	<hr/>
		18,058	1,778
Liabilities:			
Creditors: amounts falling due within one year	5	(14,207)	(1,181)
		<hr/>	<hr/>
Net assets		3,851	597
		<hr/> <hr/>	<hr/> <hr/>
The funds of the charity	6		
Unrestricted income funds		524	597
Restricted income funds		3,327	-
		<hr/>	<hr/>
Total funds carried forward		3,851	597
		<hr/> <hr/>	<hr/> <hr/>

Approved by the Trustees on 25 February 2021 and signed on their behalf by:-



Trustee



Trustee

Notes to the Financial Statements

1 Accounting policies

Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) - (Charities SORP FRS 102) and the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (March 2018).

The Charity meets the definition of a public benefit entity under FRS 102.

Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy or note.

Income

Income is recognised when the Charity has entitlement to the funds, any performance conditions attached to the income have been met, it is probable that the income will be received and that the amount can be measured reliably. Volunteer time donated is not recognised as income.

Expenditure

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Funds

Unrestricted funds are donations and other incoming resources received or generated for the charitable purposes of the Charity without restriction.

Debtors

Trade and other debtors include amounts where a funder has committed to settle obligations to a third party on behalf of the Charity.

Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

Creditors and provisions

Creditors and provisions are recognised where the Charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably.

		2020	2019
		£	£
2	Income		
	The Federated Foundation	20,000	34,221
	National Lottery Community Fund Awards for All	9,980	-
	St James' Place Charitable Foundation	1,000	-
	Other donors and community fundraising	7,452	599
		<u>38,432</u>	<u>34,820</u>
3	Expenditure		
	Freelance staff costs	32,141	32,097
	Office, travel and other costs	2,833	2,124
	Fundraising costs	204	2
		<u>35,178</u>	<u>34,223</u>

The Charity has no employees and no employee costs (2019 - none).

		2020 £	2019 £		
4	Debtors				
	Amounts committed by donors	-	1,181		
	Other debtors	566	-		
		<u>566</u>	<u>1,181</u>		
5	Creditors				
	Amounts due to freelance staff	<u>14,207</u>	<u>1,181</u>		
6	Funds				
		At 1 July 2019 £	Income £	Expenditure £	At 30 June 2020 £
	Restricted funds				
	National Lottery Community Fund, Awards for All	-	9,980	(6,653)	3,327
	St James' Place Charitable Foundation	-	1,000	(1,000)	-
		<u>-</u>	<u>10,980</u>	<u>(7,653)</u>	<u>3,327</u>
	Unrestricted funds	597	27,452	(27,525)	524
		<u>597</u>	<u>38,432</u>	<u>(35,178)</u>	<u>3,851</u>

During the year £9,980 was received under the National Lottery Community Fund Awards for All scheme to promote our public event programme in 2020.

During the year £1,000 was received from St James' Place Charitable Foundation to support the development of the volunteer team.

7 Trustees

No Trustee received remuneration during the year (2019: nil). No Trustee was reimbursed for expenses incurred on the Charity's behalf in the year (2019: none).