The Thyroid Trust Annual Report 30 June 2022



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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 Judith Taylor (Chair)

Theresa Baker Karen George

Stephen Hey (Treasurer)

Dr Paul Jenkins

Wendy Sharpe (appointed 6 July 2022)

Deepa Gadhvana (resigned 14 May 2022)

Professor Fausto Palazzo (resigned 18 June 2022)

Registered office 15 Great College Street

London SW1P 3RX

Bankers Lloyds Bank plc

Website <u>www.thyroidtrust.org</u>

The website includes biographies of the Trustees at https://www.thyroidtrust.org/trustees

Trustee report

The Trustees of The Thyroid Trust (the "Charity") have pleasure in presenting their Annual Report for the year ended 30 June 2022.

Objectives and activities

The Thyroid Trust seeks to make life better for people affected by thyroid disease by:

- improving access to quality peer support and reliable information;
- raising the profile and understanding of thyroid conditions;
- providing a platform for patients to communicate about the issues that matter to them;
- advocating for better care and treatment options.

The priorities of the Trustees for the current financial year have been to continue to deliver regular support and information events, to expand our awareness raising and advocacy work, to put the organisation on a more sustainable footing for the future and to develop our volunteer team and fundraising efforts, while working with the challenges and constraints of the pandemic.

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

Achievements and performance

Events

We have been able to continue our programme of events despite the restrictions necessitated by the COVID-19 pandemic: -

- In July and September 2021 Simon Pearce gave a two-part talk, 'Getting the best treatment for hypothyroidism'. Simon is Professor of Endocrinology at the Translational & Clinical Research Institute, Faculty of Medical Sciences at Newcastle University. He is editor of the European Thyroid Association Journal and President of the British Thyroid Association. This talk was his exploration of the complex evidence concerning wellbeing, hypothyroidism and thyroid hormone replacement
- In August our Trustee, Karen George, led a Thyroid Café event, 'Let the sun shine in'. Karen has lived experience of Graves disease
- In September we held a Thyroid Cancer Café event facilitated by our Trustee, Judith Taylor, a two-time thyroid cancer survivor
- In February 2022 we held our first post-lockdown meeting in person, held in central London; a Patient Voices event and an opportunity to catch-up with thyroid friends

- In March we joined Billy Kenber for a discussion of his new book, 'Sick Money: The Truth About the Global Pharmaceutical Industry'. Billy is an award-winning investigative journalist who, in 2016, broke the story in The Times that the specialist thyroid treatment, liothyronine, an old generic medicine, had increased in price by 6000% in the preceding tenyear period. In his book Sick Money: The Truth About the Global Pharmaceutical Industry, Billy explores the idea that medicines have become financial assets for drug companies and says that the way drugs are priced and who gets access to them can be driven by the returns for shareholders. The discussion was chaired by leading endocrinologist, Dr Mark Vanderpump
- In May we held a Patient Voices support meeting with guest speaker, Kamal Mandalia.
 Kamal had been diagnosed with Papillary Thyroid Cancer; he spoke about his own experience and the important role patients can play in helping educate healthcare providers, by sharing their stories, so that clinicians and policy decision makers may better understand patient needs and accurately incorporate the patient voice into their services
- In May Karen George led a Thyroid Café discussion on hyperthyroidism and Graves disease
- To mark World Thyroid Day in May, a group of supporters joined our Director, Lorraine Williams, for an afternoon at the seaside with a walk and picnic on the beach in the Kent coastal town of Broadstairs
- In May, Anthony R Salandy, editor of Fahmidan Journal, led a Thyroid Café event to talk about poetry inspired by our thyroid conditions.

Most of these events have taken place via Zoom. Where possible we have recorded the events and uploaded them to our YouTube channel. The YouTube channel includes a series of films including a talk by Dr Paul Jenkins, a high-profile expert and one of our Trustees, and three talks on aspects of the use of evidence for patient advocacy from our event with Sense About Science and the MS Society.

Our online Thyroid Café events are moderated peer support events that allow participants the opportunity to chat informally and share their experiences.

Since our financial year-end we have arranged events including a round-table discussion of thyroid champions, facilitated by Lord Hunt of Kings Heath; further Thyroid Poetry Café events and a Patient Voices event at Crown Court church in central London.

Advocacy

In July 2021 NHS England wrote to the Thyroid Trust to confirm that they expect local health authorities to allow prescribing of liothyronine (T3) in line with the national guidance, including cases where levothyroxine alone has failed to resolve symptoms of hypothyroidism. They reassured us that they are now writing to all local Clinical Commissioning Groups (CCGs) to reinforce this expectation.

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However, in June 2022, with our partners in other patient groups and the thyroid specialists' body, The British Thyroid Association, we issued a new T3 Prescribing Report. The report revealed that 58% of CCGs in England are not following national guidance for liothyronine and that patients in these areas are frequently being denied treatment with this specialist thyroid hormone, which some require in order to be well. The report called on NHS England and the Department of Health to ensure that this inequitable situation is brought to a close and consistency is applied across the NHS.

Our Thyroid Champions, Lord Hunt and Lord Borwick, led a series of questions in the House of Lords in July 2022 on the subject of prescription practice, backed up by Baroness Wheeler, Lord McFall, Baroness Brinton and Baroness Masham. The Minister, Baron Kamall, answered sympathetically, having previously been briefed by representatives from The Thyroid Trust and Thyroid UK.

In July 2021 the original sole UK licence holder of liothyronine, Advanz Pharma, and their backers were fined by the Competition and Markets Authority for excessive pricing of the drug to the NHS.

Author and poet Michael Rosen has continued his support with us. In 2020 he was hospitalised and spent 47 days in intensive care with Covid19, the basis of his best-selling book, 'Many Different Kinds of Love, a story of life and death and the NHS'. Michael has hypothyroidism and his book, 'This is Not My Nose', describes his experiences.

Our website had 14,790 unique visits in the year. The charity now has 1,984 followers on Facebook, 755 followers on Instagram and 5,641 followers on Twitter, all continuing to rise. According to Brand24, the #TalkThyroid hashtag got a Twitter reach of 11.9k during International Thyroid Awareness Week 2022.

Media coverage has included: -

- Extensive coverage of the fine issued by the Competition and Markets Authority, particularly
 including the BBC, The Times and the Daily Telegraph for which we were asked for input and
 quotes
- UK Health Radio Triangle Magazine reporting by Billy Kenber
- Triangle Magazine covered the appointment of Michael Rosen as Thyroid Champion and referenced his 24 Questions on YouTube
- BBC Radio Kent covered International Thyroid Awareness Week. Presenter Pat Marsh spoke with our Director Lorraine on the show for 13 minutes including her Seaside Butterfly Trek in Thanet
- The Times and Daily Express coverage of the issue of our T3 Prescribing Report.

Volunteer activity

We are grateful for our team of volunteers who have continued to work alongside our Director and Trustees, both to participate in our advocacy work and to help in the administration of our charity. We are committed to offering volunteering opportunities to patients, friends, family and interested professionals to empower them to help address the issues of most importance to them and advance our charitable objectives. We have increased our volunteer pool to over 40 people, who have generously supported us in a variety of ways including:

social media posts;

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- a variety of blog posts on our website;
- development of our videos on the website and YouTube channel
- supporting us to deliver our event programme
- taking part in interviews with the media
- helping produce and disseminate reports
- sending out badges and T-shirts to our growing supporter base
- fundraising
- participating in International Thyroid Awareness Week
- assisting with strategy development and providing expert guidance and advice

For the past year we have held monthly online sessions with our volunteers to improve engagement and, based on feedback received, are in the process of developing volunteer role descriptions. We are also planning to develop an area of our website with resources to support our volunteers.

We have successfully migrated to JustGiving as a platform for online donations.

We are beneficiaries from two schemes which provide us with a modest commission whenever one of our supporters buys on their platforms; Amazon Smile and EasyFundraising and we receive further donations from Paypal Money Giving from supporters who choose to fundraise for us on Facebook or Ebay.

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 have been carried out by a freelance Director who has lived experience of thyroid disease and reported to the Trustees and.

Wendy Sharpe joined as Trustee in July 2022. Wendy is a former scientific editor who has worked at The Lancet, The Lancet Global Health, Medical Journal of Australia and for the World Health Organization. She is currently undertaking an MSc at the London School of Hygiene and Tropical Medicine. She first encountered the work of The Thyroid Trust as a patient with Graves' disease. Wendy joined the Board of Trustees in July 2022.

Deepa Gadhvana, known as Deepa Verma, resigned as Trustee on 14 May 2022. Professor Fausto Palazzo resigned as Trustee on 18 June 2022. We thank Deepa and Fausto for their valuable contributions to the work of the Charity.

Lee Mathers joined us as Operations Manager in summer 2021. Lee provides the charity with administrative and operational support, including management of our events, and co-ordinates a growing team of volunteers.

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Lorraine Williams stood down as Director of the charity at the end of June 2022. Having previously set up a support group of thyroid patients in London, she accepted the position as our first Director in 2017. Lorraine has been the driving force in building the charity to become a leading, credible voice for people affected by thyroid disease. She remains committed to the objectives of the charity and is still a warm supporter of our work.

We are currently recruiting for the vacant position of Director.

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

Financial review

In the year to 30 June 2022 the Charity's income was £41,833 (2021: £32,121). We continued to receive generous support from the Federated Foundation who granted £10,000 this year. We received £9,900 from National Lottery's Awards for All scheme in May to support our activities for the year ahead, including our events programme. One of our former supporters has left us a generous legacy of £8,800. Garfield Weston Foundation has provided £5,000. Community fundraising and individual donations amounted to £8,133 with some very generous gifts despite restrictions on our activities.

Expenditure amounted to £16,600 (2021: £34,557), being primarily the cost of the Director and freelance staff.

Reserves

At the end of June 2022, the charity held reserves of £26,648. This includes £8,800 classed as a restricted reserve, being part of the grant from National Lottery's Awards of All scheme which will be released in the year ahead. We have no employees or other significant fixed costs and have operated in the past with limited reserves. It is the intention of the Trustees to hold some 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 15 September 2022 and is signed on behalf of the Trustees by:

D.

Trustee

K Georg

Trustee

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 Trust") for the year ended 30/06/2022.

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 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 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:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- 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.

Date: 23/12/2022

Signed:



Name: Priscilla Asirifi ACMA

Relevant professional qualification(s) or body: 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 2022 Registered charity number 1183292

		2022			2021
		Unrestricted	Restricted	Total	
		£	£	£	£
	Notes				
Total income from donations	2	31,933	9,900	41,833	32,121
Expenditure on:					
Raising funds		128	-	128	29
Charitable activities Support for people affected by		15,372	1,100	16,472	34,528
thyroid disease		13,372	1,100	10, 172	31,320
Total expenditure	3	15,500	1,100	16,600	34,557
Net income for the year Reconciliation of funds:		16,433	8,800	25,233	(2,436)
Total funds brought forward		1,415	_	1,415	3,851
rotar ranas brougnt forward					
Total funds carried forward		17,848	8,800	26,648	1,415

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 2022 Registered charity number 1183292

	Notes	2022 £	2021 £
	Notes	-	_
Current assets			
Debtors	4	_	347
Cash at bank and in hand		29,311	9,164
		29,311	9,511
Liabilities:			
Creditors: amounts falling due within one year	5	(2,663)	(8,096)
Net assets		26,648	1,415
The funds of the charity	6		
Unrestricted income funds		17,848	1,415
Restricted income funds		8,800	
Total funds carried forward		26,648	1,415

Approved by the Trustees on 15 September 2022 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.

		2022 £	2021 £
2	Income		
	The Federated Foundation	10,000	10,000
	National Lottery Community Fund Awards for All	9,900	-
	Legacy received	8,800	-
	The Garfield Weston Foundation	5,000	-
	National Lottery Reaching Communities	-	15,000
	Albert Hunt Trust	-	1,000
	Other donors and community fundraising	8,133	6,121
		41,833	32,121
3	Expenditure		
	Freelance staff costs	15,639	33,515
	Office, travel and other costs	833	1,013
	Fundraising costs	128	29
		16,600	34,557

The Charity has no employees and no employee costs (2021 - none).

				2022 £	2021 £
4	Debtors			_	-
	Balances due from fundraising plat	forms			347
5	Creditors				
	Amounts due to freelance staff			2,663	8,096
6	Funds				
		At 1 July 2021	Income	Expenditure	At 30 June 2022
		£	£	£	£
	Restricted funds National Lottery Community Fund, Awards for All	-	9,900	(1,100)	8,800
	Unrestricted funds	1,415	31,933	(15,500)	17,848
		1,415	41,833	(16,600)	26,648

The restricted fund at 30 June 2022 represents part of the amount received from the National Lottery Awards for All scheme in May to promote our activities for the year ahead.

7 Trustees

No Trustee received remuneration during the year (2021: nil). No Trustee was reimbursed for expenses incurred on the Charity's behalf in the year (2021: none).