



Thyroid Eye Disease Charitable Trust

Charity Commission No: 1095967

Office of the Scottish Charities Regulator No: SC042278

Trustees' Report to Charity Commission and Office of the Scottish Charities Regulator 2021-22

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Trustees' Report 2021/22

The Trustees of TEDct have prepared the Annual Report and Accounts in accordance with the rules of the Charity Commission for England and Wales and the Office of the Scottish Charities Regulator.

The objective of TEDct is to inform, educate and support those who suffer from Thyroid Eye Disease, to educate and inform health professionals and to support research, development and understanding of the treatment of Thyroid Eye Disease ("TED").

Trustees

Those who served as trustees of TEDct in the financial year 2021/22 were as follows:

Miss Gill Adams	Consultant Ophthalmologist
Dr Paul Cauchi	Consultant Ophthalmologist
Prof Colin Dayan	Consultant Endocrinologist Chairman of Board of Trustees
Mrs Maureen Fletcher	Secretary to the Trustees
Prof Bijay Vaidya	Consultant Endocrinologist

Miss Gill Adams retired as a trustee during this year and Mr Jimmy Uddin has been appointed from 2022.

Committee Members

Mrs Gillian Barron	Helpline Counsellor
Ms Violet Fazal-Sanderson	Specialist Nurse in Endocrinology
Ms Rebecca Ford	Consultant Ophthalmologist, Chair of Committee
Dr Vassiliki Bravis	Consultant Endocrinologist- (left Committee in 2022)
Dr Ioana Pereni	Consultant Ophthalmologist
Ms Josian Phillips	TED patient
Mr Tony Davies	Hon. Treasurer
Ms Ioana Pereni	Consultant Ophthalmologist

THYROID EYE DISEASE CHARITABLE TRUST

Trustees' report 2021/22

The Thyroid Eye Disease Charitable Trust (TEDct) is registered with the Charity Commission for England and Wales under number 1095967 and in Scotland at the Office of the Scottish Charities' Regulator under number SC042278. TEDct aims to provide information, care and support to those affected by thyroid eye disease and to promote research into its causes and cures. It operates under a Trust Deed dated 10th December 2002.

Registered address of the charity

c/o Miss Rebecca Ford, Consultant Ophthalmologist
Bristol Eye Hospital
Lower Maudlin Street
Bristol BS1 2LX

Banking Details

Lloyds Bank plc
PO Box 1000
Andover
SP10 1RE

Charity Bank Ltd
Fosse House
182 High Street
Tonbridge
TN9 1BE

Structure, Governance and Management

TEDct was first registered in 1990 under the name Thyroid Eye Disease Association. In 2002 the organisation became a Charitable Trust with the Trust Deed dated 10th December 2002.

Trustees are appointed when there are vacancies due to retirement or resignation. It is expected that Trustees will have an active interest in thyroid eye disease either in a professional medical or surgical capacity, or as a patient or former patient with the condition or a familial interest. Trustees are nominated by existing Trustees and appointment is confirmed by a majority vote of the existing Trustees. Most Trustees have previously been members of the Committee.

Committee members are recruited from medical professionals, patients, former patients and from other sources when specific skills are required. References are always sought.

ANNUAL REPORT 2021/22

The charity is managed by a working committee which is involved in the day-to-day organisation of the charity and by the Board of Trustees which has oversight of the working committee. The Board of Trustees ensures that the activities and use of charity funds are in accordance with the purposes for which the charity was set up and in addition it ensures adherence to legal aspects including compliance with Charity Law both in England and Wales and in Scotland.

TEDct has no paid employees and all committee members and Trustees give their time on a voluntary basis. Some administration is outsourced to a paid "virtual assistant".

Membership

The total number of members on 31 March 2022 was 550 (compared with 478 on 31 March 2021). Membership has increased substantially since we were able to move to a free membership. An increasing number are joining TEDct using the website. Membership has a degree of natural turnover as people develop then recover from TED, which has a typical timecourse of two to three years active disease which may be followed by many years of chronic eye problems.

Financial Position

TEDct remains in a healthy financial position. During the financial year 2017/18 a former member left a legacy of £374,097. In 2021/22 income was £9,165 and expenditure £27,558. The trustees decided to commit some of the legacy to developing the charity's website and learning material. The remaining monies from the legacy are largely invested, with the assistance of a firm of discretionary portfolio managers, in a medium risk portfolio avoiding tobacco, arms and munitions stocks.

Charity Activities 2021/22

TEDct continues to focus on providing support to people affected by thyroid eye disease, raising awareness and understanding of the condition among medical professionals and supporting research into TED.

Attendance at Conferences and other professional education activity.

Medical conferences continued to recover from the impact of COVID, so TEDct was represented at fewer conferences than pre-pandemic. We did initiate a new prize at the British Oculoplastic Surgical Society conference for the best research presented on TED at the meeting; the first award of this was at the June 2022 meeting. A similar award for endocrinologists is planned for the British Endocrine Society meeting, and we hope this will stimulate young researchers interest in the condition.

Work has continued on an e-learning project to educate NHS professionals about TED, due to launch in early 2023. The educational material is almost complete and the charity will fund its provision for all members of the NHS on the e-Learning for Health platform.

TEDct put a proposal for an open access textbook on TED to be developed with Springer Press. The open access model means that the charity will fund production of the book, which will be available free in an electronic format to anyone who wants a copy. This will allow high quality, up-to-date information on TED to be shared worldwide by all clinicians managing the condition.

Services provided to TEDct members and to the general public

Newsletter

Again only one newsletter was sent to members during this financial year, due to the current small number of volunteers and the impact of the pandemic. However, TEDct is gradually moving towards a digital format wherever possible and will provide articles on the new website that cover topics that might have been in newsletters in the past.

Our newsletters provide an overview of TEDct activity, informative articles on thyroid eye disease and reports on conferences attended, patients' experiences, research projects and Patient Information Meetings.

The Helpline

The Charity offers a helpline, which people affected by TED can call for support and lay advice. It is advertised on the website and in the newsletter as well as on all TEDct literature. Common reasons for calling the helpline include advice on finding a referral or specialist for TED, feelings of isolation and need to speak to someone who has experienced the disease. The Helpline lends an empathetic ear to all callers and many find it an invaluable source of information and solace. More than 150 calls were received during the financial year 2021/22. The service does not provide specific medical advice but provides general support to people who often just want to talk to someone who understands what they are experiencing, but it can also help to direct patients on how to access advice from relevant healthcare professionals in their region.

Social media

Our online Facebook patient support forum has gone from strength to strength. This now has over 500 members. The group is 'closed', such that people can join by request only, after indicating why they wish to join and agreeing to abide by the rules of the forum. Moderation is by committee members and a volunteer with prior experience in online moderation. The forum has been very successful in offering peer-to-peer support and linking people together who may not have had a chance to share experiences with others affected by this relatively rare condition. Thread topics on the forum help the charity committee to understand which topics are important to people affected by TED.

TEDct twitter and facebook has also provided a further platform to disseminate information including the COVID & TED FAQs.

Patient Information Leaflets

TEDct sends Patient Information Leaflets which contain general information on TED as well as contact details of our charity to both ophthalmology and endocrinology departments at hospitals around the country. 2666 copies of our patient information leaflet have been distributed this year. It has also been translated into 4 other languages by volunteer translators.

Panel of Medical Experts

TEDct has a panel of ophthalmologist and endocrinologists – all either trustees or committee members – who answer patients' medical enquiries. Many of the common queries have been turned into 'Frequently asked questions' on our new website.

Website

TEDct launched a brand new website in 2022, designed in collaboration with the web developer Vu Online. The TEDct website provides contact details of the organisation, information regarding medical aspects of thyroid eye disease, news on any future events including Patient Information Meetings. There are also useful links to other relevant organisations. The new website is a big improvement on our old one, and provides clearer information with more video content.

The TEDct logo was also redesigned during the website overhaul, to give us a more recognisable branding and modernise the image of the charity.

Research Grants

No grants or awards were made during the year. This was because no suitable applications were received; it appears that TED research has slowed due to COVID. The Trust plans to re-advertise our research grant jointly with Fight for Sight next year, pandemic allowing. Reports are still awaited from three projects previously provided with financial support by TEDct and Fight For Sight, but the pandemic slowed all research.

TEDct Nurse/Health Professional Bursary Scheme

TEDct offers a bursary of up to £500 to support education (course fees) or for travel/accommodation expenses or a combination of these. This bursary is aimed at nurses and other health professionals. In exceptional circumstances and with reference to the trustees, funding exceeding £500 will be considered. This was not awarded during the pandemic but we will continue to advertise it as face-to-face meetings recommence.

Improving quality of care for patients with TED

As in previous years, TEDct has played an active role in national initiatives to raise awareness of TED and improve the quality of the care for patients with TED. The Chairman of TEDct, Dr Colin Dayan, is our representative on the Thyroid Eye Disease Amsterdam Declaration Implementation Group UK (TEAMeD UK). TEDct provided funding to the TEAMeD initiative prior to the pandemic and will continue to do so as TEAMeD activities recommence post-pandemic.

Personnel

Miss Gill Adams announced her retirement from the Board of Trustees in 2021/22 after many years of service on both the committee and the Trustees, and will be replaced next year by Mr Jimmy Uddin. Mrs Jeannie Mackenzie joined the committee for part of the year but was unfortunately unable to continue into 2022/23.



**Colin Dayan MA MBBS PhD FRCP
Chairman of TEDct Trustees**



**Rebecca Ford BMBCh MA MRCP MRCSEd FROphth
Chairman TEDct Committee**

THYROID EYE DISEASE CHARITABLE TRUST

FUTURE POLICY STATEMENT

Membership Subscriptions

Since the overall financial position of the Charity has improved due to a substantial legacy being received, TEDct is now free to join. As hoped, free membership has encouraged patients to join the organisation more readily.

Independent Financial Advice

The Trustees and Committee benefit from independent financial advice. The majority of the legacy funds are invested in a diversified portfolio. The investment mandate precludes investment in the tobacco industry (due to the deleterious effects of smoking on thyroid eye disease) and in arms and munitions.

Social Media

TEDct has *Twitter* and *Facebook* accounts, and a forthcoming *Linkedin* account. We hope that these forms of improved communication will enable the work of the charity to be more widely accessed by all interested parties. Posting or streaming videos from our patient information events should enable these to be seen by people affected by TED who cannot travel to the meetings.

THE EFFECTS OF THE COVID-19 PANDEMIC

During the pandemic it was not possible to hold Patient Information Meetings. Instead, however, TEDct organised a series of webinars on specific topics. The webinars proved popular so we plan to continue a mixture of face-to-face meetings and webinars.

It was possible to produce only one Newsletter during the year.

The Helpline was unaffected by the pandemic.

Staff of TEAMeD were furloughed by the British Thyroid Foundation on 31 March 2020. Ceasing to contribute to their salary costs had a positive impact on TEDct's finances, but we will likely recommence funding them in the 2022/23 financial year.

The move to holding meetings on the Zoom platform has been welcomed by Trustees and committee members, who have elected to continue most meetings in this format.

THYROID EYE DISEASE CHARITABLE TRUST

RECEIPTS AND PAYMENTS ACCOUNT FOR THE YEAR ENDED 31 MARCH 2022

	2021/22	2020/21
Receipts:		
Membership subscriptions, webinars and donations (see note 1)	£2,303.55	£2,246.03
Bank interest (see note 2)	£199.11	£400.17
Investment income	£6,662.00	£6,826.00
TOTAL RECEIPTS	£9,164.66	£9,472.20
Payments:		
TEAMeD UK (see note 3) and British Thyroid Foundation	£221.00	£82.58
Grants and Awards (see note 4)	£0.00	£0.00
Fee to Royal College of Ophthalmologists for development of 4 e-learning modules	£12,000.00	£0.00
Trustees' and Committee members' expenses (see note 5)	£0.00	£0.00
Stationery, postage, telephone	£519.55	£515.48
Insurance (see note 9)	£0.00	£420.10
Website development	£9,970.00	£0.00
IT	£199.08	£439.12
Bank charges and subscription processing fees	£0.00	£39.00
Administrative support (see note 6)	£847.87	£1,414.47
Investment management fees and commissions (see notes 7 & 8)	£4,050.91	£3,595.54
TOTAL EXPENDITURE	£27,558.41	£6,506.29
SURPLUS/(DEFICIT) OF RECEIPTS OVER PAYMENTS	(£18,393.75)	£2,965.91

STATEMENT OF ASSETS AND LIABILITIES AS AT 31 MARCH 2022

	2021/22	2020/21
Assets:		
Investment Portfolio with Rowan Dartington (see note 7)	£339,350.03	£326,292.00
Bank balance (Charity Bank)	£44,088.02	£68,888.91
Bank balance (Lloyds Bank)	£6,631.06	£2,835.01
TOTAL ASSETS	£390,069.11	£398,015.92
SOURCE OF FUNDS		
Funds brought forward	£398,015.92	£336,797.47
Surplus/(deficit) for the year	(£18,393.75)	£2,965.91
Investment gain (Rowan Dartington)	£10,446.94	£58,252.54
Funds carried forward	£390,069.11	£398,015.92

NOTES TO THE FINANCIAL STATEMENTS

1. Income of the charity is gained from membership subscriptions, webinar fees, donations, and occasional fundraising activities. A substantial legacy from Mrs Valerie Stevens was also received during the financial year 2017/18. There are no restrictions on its use. The Trustees decided that the legacy should largely be invested, to provide an income of around £5,000 per annum. Consequent upon that legacy being received and the investment income arising from it, the Trustees decided to offer free membership in future. Some members, however, have continued to pay subscriptions.
2. A portion of the charity's cash reserves has been deposited with Charity Bank, so as to earn some interest and to provide the charity with some protection under the Financial Services Compensation Scheme.
3. In 2015 the Thyroid Eye Disease Amsterdam Declaration Implementation Group ("TEAMeD") produced guidelines for the management of patients with thyroid eye disease. The Group runs projects to improve the patient experience for people with the disease. Until March 2020 the charity made a financial contribution to the work of TEAMeD.
4. There were no grants or awards during the year, or during the previous period.
5. The charity's Trustees and committee members are volunteers but are permitted to claim for expenses incurred, such as for travel to meetings or hire of venues for events.
6. The charity has no employees, but has engaged a self-employed part-time provider of administrative support.
7. A firm of discretionary portfolio managers, Rowan Dartington, has been engaged to manage the charity's investment funds in a diversified portfolio which precludes investment in the tobacco industry, or in arms and munitions. The figure shown in the balance sheet is the market valuation as at 31st March 2022.
8. The investment management fees and commissions charged by Rowan Dartington have been treated as an expense.
9. During the period, there were no events, and hence public liability insurance was not necessary.

**Independent Examiner's report to the trustees of the Thyroid Eye Disease Charitable Trust –
Charity Commission No. 1095967 and Office of the Scottish Charity Register No. SC042278**

I report on the accounts of the charity for the year ended 31 March 2022 which are set out on pages 8 and 9.

Responsibilities of trustees and examiner

The Charity's trustees are responsible for the preparation of the accounts. The trustees consider that an audit is not required this year under the regulations of the Charity Commission for England and Wales and the Office of the Charities' Regulator in Scotland. An independent examination is required.

As independent examiner I am responsible for examining the accounts following the regulations of the Charity Commission and the OSCR and for bringing any anomalies, irregularities or other particular matters that I have found to the attention of the trustees and to the regulatory bodies.

Basis of independent examiner's report

My examination was carried out in accordance with the regulations of the Charity Commission and the OSCR. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items and, if found, an explanation from the trustees would be sought.

Independent examiner's statement

In connection with my examination, no matter has come to my attention. I have no cause to believe that accounting records do not comply with the regulations and rules of the Charity Commission and OSCR. The records, in my opinion, provide a statement of the income and expenditure of the charity in a manner which can be readily understood.

Signature:.....

Name: Roland J Adamson

Relevant professional qualification or body: FCA

Date: 10/11/22