



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 2020/21

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Trustees' Report 2020/21

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 2020/21 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

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
Dr Ioana Pereni	Consultant Ophthalmologist (from 17 October 2020)
Ms Josian Phillips	TED patient (from 16 January 2021)
Mr Tony Davies	Hon. Treasurer

THYROID EYE DISEASE CHARITABLE TRUST

Trustees' report 2020/21

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 2020/21

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 2021 was 477 (compared with 395 on 31 March 2020). Membership has increased by a significant amount due to the fact that membership is now free. An increasing number are joining TEDct using the website. There is a natural wastage of members when they recover from TED and no longer feel the need of the support given by TEDct. The course of TED can be from two or three years to many years.

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 2020/21 income was £9,472 and expenditure £6,506.29. The monies from the legacy have largely been invested, with the assistance of a firm of discretionary portfolio managers, in a medium risk portfolio avoiding tobacco, arms and munitions stocks.

Charity Activities 2020/21

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.

The COVID pandemic resulted in almost all medical conferences and seminars shutting down in 2020-21. Hence our team were unable to continue their usual work of attending conferences to raise awareness of TED. This will recommence as soon as conferences return to face-to-face format.

Work has continued on an e-learning project to educate NHS professionals about TED. However, this was also delayed by the pandemic due to pressure of clinical work on the clinicians writing the material.

Services provided to TEDct members and to the general public

Newsletter

Just one newsletter was sent to members during this financial year, due to the current small number of volunteers and the impact of the pandemic. Since the move to free membership model, newsletters are now sent by email as default, with a paper version available on request. On-line versions of the newsletter are sent to many interested clinicians and other

healthcare professionals. Many back copies of the newsletter are available to members and the public on our website.

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. Due to our increasing presence on social media, we have also started posting links to our newsletter on TEDct Facebook and Twitter this year. Recruitment of new committee members and plans for a new website mean that newsletter and news updates should be more regular next year.

TEDct also issued an extra bulletin in the form of a FAQ (frequently asked questions) sheet at the start of the pandemic, responding to commonly asked questions about how COVID may impact people with TED. Answers to the FAQs were drawn up by our expert clinicians.

The Helpline

The Helpline is advertised on the website and in the newsletter as well as on all TEDct literature. The Helpline continues to be busy with calls being answered on general TED related queries as well as a number from distressed patients and relatives who are looking for help with finding information on TED/TEDct. The Helpline lends an empathetic ear to all callers and many find it an invaluable source of information and solace. Some 107 calls were received during the financial year 2020/21. 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.

Patient Information Meetings and Webinars

COVID forced a complete change in the method of delivery of our patient information meetings. In place of face-to-face meetings we ran 4 webinars on different topics related to TED. Talks from these were recorded for our website. The webinars proved popular, with at least 30 people attending each one, and were a good way of reaching people with relevant information. They also resulted in some new individuals coming forward for volunteer roles with the charity.

Social media

A big initiative this year was the launch of our patient support group online. This is managed within Facebook groups, and now has over 400 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.

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. This year we have again collaborated with other organisations looking after patients with or at risk of thyroid eye disease (BOPSS, BTF, TEAMeD, RCOphth) to maintain a Patient Information Leaflet that is up to date and provides consistent information agreed by all these stakeholders. 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. Some of these queries, with the patients' permission, are published in the Newsletter and/or on the website in the knowledge that they will be able to help others.

Website

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 organisations. The website is updated regularly to reflect new developments in TED. A complete overhaul of the website has commenced in the financial year 2020-21, after a procurement process to appoint web developer Vu. The Trustees felt that the website is one of the most critical aspects of TEDct and that it is a good use of funds to update it to make it more user friendly and easier to update with new blog posts, news and videos.

Research Grants

No grants or awards were made during the year. The Trust plans to re-advertise our research grant jointly with Fight for Sight next year, pandemic allowing. During the previous period, TEDct met half the cost of providing Open Access to an academic paper "A Survey of Current Practices by the British Oculoplastic Surgery Society and Recommendations for providing a sustainable multidisciplinary approach to Thyroid Eye Disease in the United Kingdom". TEDct also sponsored a prize at the Society for Endocrinology meeting in December 2019, to encourage research into thyroid eye disease. The first SfE prize was awarded to Mohammed Alshahrani for his project 'The proto-oncogene PBF mediates Src modulation of radioiodine uptake'. Reports are awaited from three projects previously provided with financial support by TEDct and Fight For Sight, but the pandemic has 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. The bursary was not awarded during the pandemic but we will 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). Our patient representative post is currently vacant. Until staff were furloughed in 2020 because of the pandemic, TEDct shared with the British Thyroid Foundation the cost of administration services for the TEAMeD project, which employs two part-time administrative staff. The booklet “Your guide to Thyroid Eye Disease” is also jointly funded by the two organisations. We hope that TEAMeD will restart its activities after the pandemic.

Personnel

There were no changes during the year to the Board of Trustees. During the year, Dr Ioana Pereni (an ophthalmologist) and Ms Josian Phillips (a TED patient) joined the Committee.

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. 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.

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.

It was not possible to hold live Trustees or Committee meetings during the pandemic, but both groups continued to function effectively by means of Zoom meetings.

THYROID EYE DISEASE CHARITABLE TRUST

RECEIPTS AND PAYMENTS ACCOUNT FOR THE YEAR ENDED 31 MARCH 2021

	2020/21	2019/20
Receipts:		
Membership subscriptions, webinars and donations (see note 1)	£2,246.03	£1,688.36
Bank interest (see note 2)	£400.17	£512.67
Investment income	£6,826.00	£5,791.96
TOTAL RECEIPTS	£9,472.20	£7,992.99
Payments:		
TEAMeD UK (see note 3) and British Thyroid Foundation	£82.58	£7,278.02
Grants and Awards (see note 4)	£0.00	£1,700.00
Trustees' and Committee members' expenses (see note 5)	£0.00	£1,265.28
Stationery, postage, telephone	£515.48	£1,642.48
Insurance	£420.10	£415.69
IT	£439.12	£242.67
Bank charges and subscription processing fees	£39.00	£0.00
Administrative support (see note 6)	£1,414.47	£1,110.50
Investment management fees and commissions (see notes 7 & 8)	£3,595.54	£3,013.61
TOTAL EXPENDITURE	£6,506.29	£16,668.25
SURPLUS/(DEFICIT) OF RECEIPTS OVER PAYMENTS	£2,965.91	(£8,675.26)

STATEMENT OF ASSETS AND LIABILITIES AS AT 31 MARCH 2021

	2020/21	2019/20
Assets:		
Investment Portfolio with Rowan Dartington (see note 7)	£326,292.00	£264,809.00
Bank balance (Charity Bank)	£68,888.91	£68,488.74
Bank balance (Lloyds Bank)	£2,835.01	£3,499.73
TOTAL ASSETS	£398,015.92	£336,797.47

SOURCE OF FUNDS

Funds brought forward	£336,797.47	£382,568.66
Bequest from Mrs Valerie Stevens (see note 9)	£0.00	£129.42
Surplus/(deficit) for the year	£2,965.91	(£8,675.26)
Investment gain/(loss) (Rowan Dartington)	£58,252.54	(£37,233.35)
Funds carried forward	£398,015.92	£336,797.47

NOTES TO THE FINANCIAL STATEMENTS

1. Income of the charity is gained from membership subscriptions, webinar fees, donations, and occasional fundraising activities. Consequent upon a substantial legacy being received in 2018 and the investment income arising from that, 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. During the previous period the charity made the following grants and awards:
 - jointly with others, contributed £1,500 towards the cost of open access for a paper on a multidisciplinary approach to TED;
 - awarded, at a Society for Endocrinology meeting, a prize of £200 for research into TED.
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 2021.
8. The investment management fees and commissions charged by Rowan Dartington have been treated as an expense.
9. A substantial legacy from Mrs Valerie Stevens was 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.

**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 2021 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: 24/8/21