



newsletter

AUTUMN/WINTER 2019



Thyroid Eye Disease
Charitable Trust

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Associated with the *British Thyroid Foundation*

*Introduction by
Rebecca Ford*

We're am very sorry that we haven't had a newsletter for some time. This has been due to a reduced number of active volunteers and article writers. Larene have tried to keep information flowing via Twitter @thyroideye and Facebook, but hope to be back on track with newsletters in the coming year.

News from this year includes:

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If you have any TED-related events or news you would like to see on our social media please email us at **info@TEDct.org.uk**

Thanks to Rebecca Ford for editing
& Becky Jaggs for the design

We have had to say a special goodbye to Julie MacLaren after many years as a stalwart of the committee. We will miss her greatly and extend a massive thank you to her for all her hard work, especially in keeping TEDct going even in the toughest years. We hope to see her in a special guest capacity at future Patient Information Meetings!

*Report by
Rebecca Ford*

We also said goodbye to Mike Murphy as he retires from the post of treasurer, as well as clinicians Anna Mitchell and Matt Edmunds leaving active roles on the committee due to their work and family commitments, though they will still be available in advisory roles. Thanks to all of them for all their contributions and dedication.

On a happier note we are delighted to officially welcome our new treasurer Tony Davies. Tony graduated in mathematics from Cambridge University, and spent his working career in research and management consultancy, principally in the financial services sector. He is the MD of a financial advisory firm. Working part time, he is keen to use his free time to provide assistance to charities



and voluntary organisations. He has prior experience as a charity treasurer and looks set to bring invaluable expertise in these times when managing charity finances can be a complex issue.

Collaboration with TEAMeD & new patient information leaflet

*By
Rebecca Ford*

We have continued our close collaboration with TEAMeD this year, part-funding their work in raising awareness of Thyroid Eye Disease and their campaigns to educate endocrinologists about early diagnosis of TED. You can read more about TEAMeD on the BTF website <http://www.btf-thyroid.org/projects/teamed/225-about-teamed>.

Another key project this year was updating patient information leaflets about TED. We joined forces with the British Thyroid Foundation, TEAMeD and the British Oculoplastic Surgical Society (BOPSS) to write a joint leaflet approved by all parties giving key information about the condition. We will supply this to hospitals as well as posting it on our websites. We are now starting a translation project whereby we

hope to make the leaflet available in as many languages as possible. We have started with Arabic, Polish and Urdu, with Farsi, Romanian and Mandarin in the pipeline. If any readers speak other languages with some knowledge of medical terms and would like to volunteer as translators we'd love to hear from you!

Helpline continues to support those who need to talk

Gillian Barron has taken over as helpline counsellor after the retirement of Lin Welch.

We were interested to hear at our last committee meeting that she has taken more than one hundred calls in the last few months, so this remains a critical aspect of TEDct's work and we thank Gillian and Lin for all the support they are providing for people who often just need to talk to someone that has experienced what they are going through.

Sometimes callers want advice about local services for TED, and whilst we can't recommend individual doctors, we can help patients to navigate referrals and empower themselves to seek referral to a clinic that has expertise in the condition.

*By
Rebecca Ford*

Representation at meetings

By
Rebecca Ford

We have not had as much representation at academic meetings as in recent years, due to reduced number of available volunteers. However, we have raised awareness at some key meetings in the past year.

I (Rebecca) have spoken at many meetings about thyroid eye disease, including Oculoplastics Association of India, Bombay Ophthalmological Society, Lifeline Express meetings in China, and the British Oculoplastic Association meeting, and have publicized the role of TEDct at each, leading to some interest from international partners.

At the International Thyroid Eyes Disease Society (ITEDS) meeting in Singapore in February I presented a poster about the activities of TEDct and got to meet our counterparts from a thyroid charity in the USA, which may lead to future collaboration.

TEDct Patient Information Meeting, Western Eye Hospital

London June 2019

Our latest TEDct PIM was held on 8-6-19 at the Western Eye Hospital, brilliantly organised by Vickie Lee (Consultant Ophthalmologist at the WEH) and her colleagues from Imperial College NHS Trust. The Faculty consisted of 4 Consultant Ophthalmic & Oculoplastic Surgeons, 1 Consultant Immunosuppression Specialist, 2 Endocrinology Professors and 2 Endocrinology Consultants.

After a welcome from WEH ophthalmologist Rajni Jain and brief update from Rebecca Ford on the activities of the charity, Vickie gave an introduction to TED and its relationship to Graves' disease and thyroid problems, with an overview of the patient journey and available treatments from diagnosis to rehabilitation. Vickie is the National Ophthalmology Lead for the TEAMeD program, which is a project supported by TEDct that promotes early diagnosis and access to good quality TED care. We heard that whilst most people have an overactive thyroid around the time of their TED, this is not always the case and

*By
Vickie Lee &
Rebecca Ford*

some people even develop TED without ever having a thyroid hormonal problem. Vickie reminded us that smoking is very bad for TED, increasing the risk of severe disease and making the condition go on for longer in its active form. She also outlined the benefits of a multidisciplinary (MDT) approach to this complex disease where ophthalmologists and endocrinologists work in the same clinic and see the patients simultaneously to ensure a holistic approach.

Vickie also highlighted the impact of the disease on people's quality of lives, which is something everyone at TEDct is concerned about. She described a study from Germany where all patients in a clinic completed a questionnaire about how TED affects their life. They found that 36% of patients were on sick leave, 28% considered themselves to be disabled by the condition, 5% had had to take early retirement and 3% had actually lost their jobs due to the disease.

Vassiliki Bravis, endocrine consultant from Imperial College and TEAMeD regional lead, told us about how the normal thyroid gland works and its roles in the body. The thyroid gland and its hormones has effects on many

different parts of the body, from fluid balance in the tissues to heart rate, bowel function, menstrual cycle, response to stress and many others. Hyperthyroidism (overactive thyroid) can disrupt any of these bodily systems, and if thyroid overactivity persists for years it can even shorten your lifespan, so it is important that patients with hyperthyroidism receive specialist care - Vassiliki reminded us that all patients with Graves' should see a specialist endocrinologist, and that whilst a good relationship with your GP is also important in keeping thyroid disease under control, patients are entitled to expert input.

We heard about how thyroid drugs are used to control the thyroid function, and about the role of other treatments like thyroidectomy and radio iodine. Carbimazole and propylthiouracil (PTU) drugs block the production of thyroid hormone, and are usually the first line of treatment for overactive thyroid (excess thyroid hormone). Doctors need to beware blocking the gland so much that people become hypothyroid, or swinging between over and underachieve states, so sometimes we use 'block and replace' where enough carbimazole is given to completely

block your own thyroid hormone production but supplement with levothyroxine (a stable amount of thyroid hormone replacement.) Uncontrolled and fluctuating thyroid hormone levels are bad for patients wellbeing, but also particularly bad for thyroid eye disease, which can get worse if hormone levels are variable. Hence 'block and replace' may be a good choice for TED patients. For those who can't manage to take the tablets due to side effects or other issues, thyroidectomy (thyroid removal surgery) can be a good option, but must be a carefully considered decision as the surgery itself can carry risks. Some patients cannot achieve remission of their disease with drugs alone, and the problem may recur once

Vassiliki described what her patients experience when their thyroid function returns to normal. Most people with hyperthyroidism lose weight, but this is a 'pathological' (ie abnormal and unsafe) type of weight loss. Patients have to be prepared that most will put on weight as things return to normal-most will put on around 4kg - so it is important to watch what you eat when your thyroid condition is first diagnosed.

Next we heard from Claire Feeney, an endocrinologist with a special interest in research into early diagnosis and imaging of TED, who described some tools clinicians use to try to detect where people are in their TED disease course. This is important, as we know that some treatments probably only work when given early, and we also want to know whether people are at a stage where TED will continue to get worse versus a stage when the disease is ‘burning out’.

We can use various scoring systems to measure the clinical activity of the disease and the severity of the disease. These are based on a combination of symptoms reported and examination of the eyes in clinic. However, these scores are only looking at what we can feel or see - this may only be looking at outward signs of the disease. Hence we may need to use imaging techniques (scans etc) to see deeper inside the orbits. CT scans are based on X-rays, and are best at imaging the bones. CT scans are very useful for looking at bone structure before bony surgeries like orbital decompression. However, MRI (magnetic based scans) are able to look at the tissues within the eye

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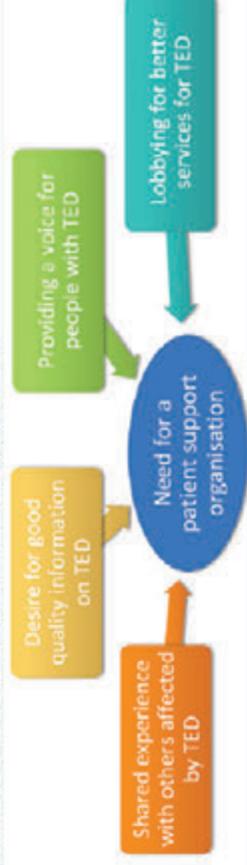
This is the poster presented by Rebecca Ford on behalf of TEDct to publicise the charity at the International Thyroid Eye Disease Society conference in Singapore in February 2019

THYROID EYE DISEASE CHARITABLE TRUST: THREE DECADES OF SUPPORTING PEOPLE WITH TED

Rebecca Ford, TEDct Committee Chair, on behalf of TEDct

Why is there a need for the Thyroid Eye Disease Charitable Trust, a patient support organisation for

- TED is an uncommon condition: affected people may desire connection and shared experience with others similarly impacted
- TED, with its physical, emotional and functional consequences, has significant psychological and social impact that healthcare professionals may be unable or un-resourced to help with.



Goals of the Thyroid Eye Disease Charitable Trust (TEDct)

- TEDct was founded in the UK in 1990 by patients for patients, with healthcare professionals invited onto its committee.
- The founders recognised the need for better information, education and support for those affected by TED.
- Membership is free for all affected by TED and for healthcare professionals.
- Goals have evolved to be:



What is TEDct doing to achieve these goals?

Patient information: Up-to-date information about TED is provided in written and video format on the website www.tedct.org.uk. TEDct has supplied patient information leaflets to UK hospitals since it was founded in 1990. Future projects may include translation of materials for access by non-English speakers.

Patient support: The TEDct telephone helpline receives around 120 calls per year with common themes raised being a need to talk to someone else who has been through the disease, difficulty accessing appropriate care, anxiety about treatments and work-related problems. Quarterly newsletters keep people updated on developments in TED, and help them to share stories of their experiences. TEDct also runs patient information meetings twice yearly around the UK where patients can meet, hear talks from healthcare professionals and take part in discussion forums.

Education and awareness for healthcare professionals: TEDct representatives attend ophthalmology, endocrine and nursing conferences to spread awareness of TED. The charity provides grants for professionals to attend educational events related to TED. This year TEDct is funding development of an e-learning module about TED aimed primarily at ophthalmologists, and will continue to partner with the TEAMed initiative to promote early diagnosis of TED.

Research promotion: TEDct partners with Fight for Sight to provide a research grant for TED research annually, as well as small meeting attendance grants and prizes for TEDct research at UK meetings.

Improving services for TED: TEDct has been involved in a number of initiatives aiming to improve equity of access to specialist TED care. The charity may have an increasing future role in providing a voice for patients in the UK as some aspects of treatment for TED, such as some reconstructive surgery, become defunded on the UK National Health Service.

TEDct
Thyroid Eye Disease
Charitable Trust

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Charity No 1096697 England & Wales, SC042278 Scotland



*Continuing
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sockets in more detail, looking at the muscles and fat around and behind the eye. Claire is researching a type of MRI called diffusion weighted imaging (DWI), which might be able to provide a measurement of how active the inflammation is around the eye. This may be useful especially for patients with relatively mild visible inflammation, as it can be difficult to know whether such people would benefit from early treatment or whether they are not defined to develop severe enough disease to make treatment worth the risks or side effects.

This led nicely on to Rashmi Akishar, an ophthalmologist who is an expert in immunosuppressive drug treatments. She described how we can try to modify the immune system to combat the autoimmune malfunctions that are at the root of TED & Graves. Immunosuppressive drugs need to be used during the active inflammatory stage of the disease - they 'put out the fire' of active disease, aiming to stop the disease progress, so that recovery can then commence and patients can safely have rehabilitative surgery if needed. There are many drugs that can be used to suppress the

immune system. We know that TED's active phase usually lasts 1-3 years. Therefore if we use 'second line' treatments (used after or instead of steroid treatments) we hope to dampen the inflammation during this period. One such drug is Cellcept (mycophenolate), which is used by quite a few TED specialists. Radiotherapy can also be used as an alternative - the effects of radiotherapy to the orbits can be unpredictable (it doesn't work for everyone) but it seems to be most effective for people with muscle enlargement and 'restrictive symptoms, such as double vision.

Rashmi mentioned the newer possible treatments (monoclonal antibodies), such as rituximab and teprotumumab, that show great promise in controlling the disease. At present there are barriers to funding of these drugs in the UK, but we hope that they will become more affordable and widely used in future. She finished by reminding us of some of the celebrities who have been affected by TED, but also that all of our TED patients are stars when they help us to advance our understanding and treatment of disease.

Ahmad Aziz, another ophthalmologist, provided a clearly illustrated (but thankfully bloodless) explanation about orbital, squint and eyelid surgery in TED. These are usually used when the active phase is over. Orbital decompression can be used to reduce proptosis (bulging of the eye) and tension within the eye socket, by making extra room in the eye socket by removing parts of the bony walls of the socket. Like any surgery, there is some degree of risk involved, and patients need to understand the potential (usually small) risks of infection, double vision, visible scars and damage to the vision before deciding to undergo the surgery. Occasionally decompression needs to be done urgently if the optic nerve is compressed and vision is under threat, but this is quite rare.

For patients who have double vision, surgery to the eye movement muscles may be recommended. It is often not possible to give patients single (stereo) vision when looking at all directions, as TED can affect any or all of the eye movement muscles to differing degrees. Ahmad explained that the aim of squint (strabismus) surgery is usually to give patients single vision in the directions

most usually used, ie looking straight ahead & looking down, and that patients may have to accept the compromise of ongoing double vision when looking upwards. The last step in surgical rehabilitation of TED is usually lid surgery - many patients can benefit from upper lid blepharoplasty, to debulk excess tissue in the upper lids, and some need lid lowering, to reduce the upper lid retraction that gives the 'wide eyed' or 'starey' look in some TED cases. There are challenges in some regions of the UK in getting funding for eyelid surgery even when the cause is TED, and this is something about which TEDct are trying to raise awareness and provide advocacy to fundholding bodies to demonstrate that the benefits to patients' lives can be large enough to make surgery good value for money to the NHS.

These thoughts about patient benefit lead on to Tessa Fayers, an ophthalmologist from the Western Eye Hospital, talking about quality of life in thyroid eye disease and how we can measure it. QOL can encompass different things for different people, such as happiness, energy levels, mental health, appearance, ability to do jobs or hobbies,

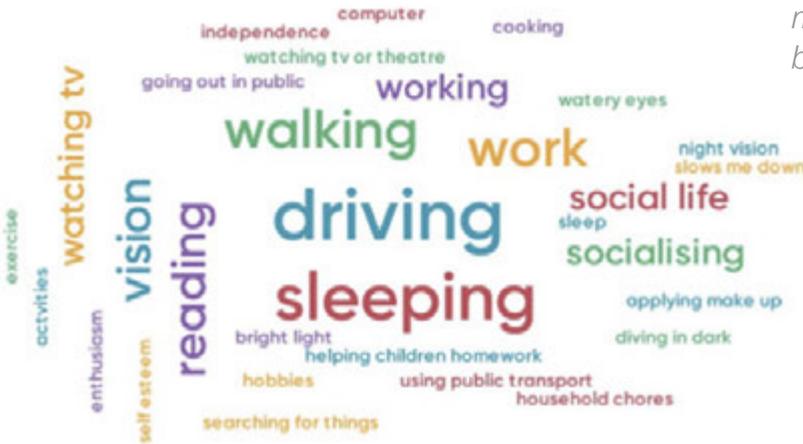
emotional relationships and sexual function etc. Measuring QOL can help us to compare the effects of different treatments - does the treatment improve people's quality of life? Researchers have developed many questionnaires to try to assess people's QOL in different medical conditions. Some of these are for eye conditions and some for general health, but many don't relate well to thyroid eye disease. A Dutch questionnaire, GO-QOL, has been around for some time, but it is quite long and not all questions are totally relevant to UK patients.

Tessa developed a questionnaire during her fellowship training in Canada with TED expert Peter Dolman. They tried to make a simple, reliable questionnaire that reflects patients' QOL and detects QOL improvements (or deteriorations) after various treatments and intervention. They tested their questionnaire with the help of 100 patients and compared it with other measures of QOL and TED disease activity. They managed to make a useful questionnaire that can help clinicians to understand more about what the patients are feeling. Interestingly, QOL did not always correlate with disease activity or

severity as measured by the clinical scales.

After a delicious lunch, Professor Meeran and Dr Feeney led a graphical interactive session. This was one of the highlights of the day, and something we have not tried before at a PIM. Attendees participated in activities like formulating word clouds about how TED affects them (see picture below).

Name the 3 daily activities that have been most affected by this disease



We then heard from two local patients, Jennifer and Aldith, who spoke movingly about their experiences of thyroid eye disease. We would like to thank them very much for their participation and answering questions from attendees - it was also good to hear from two people who have managed to 'survive' the disease with such positive attitudes!

We ended with a question and answer panel discussion. Topics that came up included driving and TED - London orthoptist Jamie Spofforth, and expert in caring for people with double vision, reminded us that legally people must inform the DVLA if they develop double vision. However, rehabilitation of ability to drive may be achieved by Fresnel prisms attached to glasses in the short term, or by permanent prisms in glasses or squint surgery in the longer term. Some people may prefer to patch one eye - it is legal to drive a private car with one eye covered, but only once you have acclimatised to getting about with only one eye, so this may not apply to many people with TED. Another topic was difficulty in sleeping during steroid treatment. We agreed that there are not any 'miracle' solutions; most people find they are only affected for a day or two after intravenous infusions, in which case it might be appropriate to speak to the GP about short term use of sleeping tablets. People who had been through steroid treatment felt it is important to keep sight of the fact that it doesn't last for ever, and someone joked that lack of sleep enabled her to have the

energy to clean the house!

We also discussed tips for coping with eyes that don't close while sleeping ('lagophthalmos'). Ointment at night is the mainstay of treatment. Trying to tape lids shut often doesn't work, especially over bulging eyes (proptosis), but some people have relief by taping clingfilm over the eye to stop ointment evaporating - a top tip was to clean skin with makeup remover first to remove oils. The last query was wondering why puffiness and diplopia tend to be worse in the morning. The panel felt that this is the effects of gravity and lack of overnight movement allowing fluid (oedema) to pool in the eye socket tissues overnight. We also noted that all inflammatory conditions tend to be worse in the mornings, possibly due to the day-night cycle of secretion of natural hormones such as cortisol.

The day ended on a really high note with a lot of positive feedback. Maureen Fletcher, TEDct trustee and prior long-serving committee member, described the meeting as 'one of the best I have attended over a period of around fifteen years. All aspects were arranged and executed to an

extremely high standard' which is high praise indeed as she has been instrumental in many previous meetings.

Another attendee wrote: 'My husband and I would like to thank everyone involved with today's seminar. For the time and information given, to give us all more understanding of our health issues in more depth. Giving us confidence to move forward ourselves to ask more from our treatment where possible. Thank you also for the hospitality and friendliness given and felt in the room. For me I now have contacts to progress without fear my eye problems.'

The TEDct team would like to thank Vickie, Tessa, Rajni, Vassiliki and all their colleagues who contributed to organising this great day in London. The Western Eye / Imperial College team are active researchers and would love any patients in the London area who are interested in participating in TED research projects to contact them **tedresearch@nhs.net**.

The next PIM will be in Cardiff at University Hospital Wales, at 2pm on Saturday 30th November 2019. Please contact us for more information and directions to the venue: **info@TEDct.org.uk**

Here's the
flyer about our
next patient
information
meeting:



Thyroid Eye Disease Patient Information Meeting

TEDct are holding a patient information meeting
in Wales on:

Saturday 30th November 2019
2pm

Venue: C2 Link Corridor Reading Room No 257,
University Hospital of Wales, Cardiff
Please email tedct.org.uk for full directions

- Talks by specialist ophthalmologists & endocrinologists
- Opportunity to meet others affected by TED
- Light refreshments provided
- Admission free, open to all, friends & relatives welcome

For further information, full program &
directions to venue please contact :

T: 07469921782

E: info@tedct.org.uk

www.tedct.org.uk



Registered charity in
England & Wales 1095967
and Scotland SC042278



GIG
CYMRU
NHS
WALES

some useful contacts

British Thyroid Foundation (BTF)

Suite 12, One Sceptre House Hornbeam Square
North Hornbeam Park Harrogate HG2 8PB
01423 810093 www.btf-thyroid.org

British Thyroid Association (BTA)

www.british-thyroid-association.org

Helpline

Gillian Barron is the helpline TEDct helpline volunteer with personal experience of the condition. You can speak to her directly on **0746 992 1782** or leave a message and she will ring you back.

Getting social

Follow us on Twitter **@thyroideye**

Find us on Facebook

TEDct: Thyroid Eye Disease Charitable Trust



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TEDct aims to provide information, care & support to those affected by thyroid eye disease. An optional annual membership is £12 / overseas £20. If you would like to make a donation, please state if you are a UK taxpayer as TEDct can reclaim 25p in the pound from HMRC.