



**Thyroid
Federation
International**

Thyroid Patients Worldwide

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Thyroid Federation International

Established in September 1995 in Toronto, Canada

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Diana Meltzer Abramsky, CM BA (Canada) 1915-2000

Mentor & First President

Lawrence C Wood, MD FACP (USA)



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Member Organizations

The names of the organizations and their current addresses are given on page 40.

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Message from the Editors

We welcome you to the 2019 edition of our ThyroWorld newsletter, and to the beautiful city of Budapest and its rich history. We are proud to be present at the 42nd annual meeting of the European Thyroid Association.

Thyroid Federation International celebrates its 24th anniversary this month, September 2019 – from 6 founding members when the organization was created back in 1995, it has now grown to more than 30 member organizations in all parts of the world! We are particularly proud to welcome several new members from Africa (Ghana, Kenya and Nigeria).

We encourage everyone who provides evidence-based information to thyroid patients to apply for membership. We are very glad to welcome patient-led organizations, but they do not exist everywhere. Please contact our president Ashok Bhaseen during the ETA congress if you are interested.

This edition has articles about innovative therapies of benign thyroid nodules, about a new trial with a targeted therapy for metastatic thyroid cancer, about 3D modeling to help surgeons maximize orbital decompression, about the Rare Revolution magazine for rare diseases, about MCT8 deficiency, about a joint project to decrease worldwide iodine deficiency... and testimonies from many of our member organizations about their activities in different parts of the world.

Wishing all delegates an enriching stay in Budapest!

BEATE BARTÈS, PETER LAKWIJK
AND NANCY HORD PATTERSON, EDITORS



Beate Bartès



Peter Lakwijk



Nancy Hord
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ThyroWorld

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President's Message

ASHOK BHASEEN, M. PHARM, MMS,
PRESIDENT, THYROID FEDERATION INTERNATIONAL

Dear Readers,

Welcome to the twin city of Budapest, Hungary. Budapest's estimated metropolitan population is 3.3 million, comprising 33% of the total population of Hungary. To all delegates, a big welcome to the 42nd Annual meeting of the ETA. The city of Budapest was officially created on 17th November, 1873 by the merger of the Pest, Buda and Óbuda cities, eventually growing to become Greater Budapest in 1950. History can be traced to the Celtic people from the 4th century BC, prior to its conquest by the Roman Empire. The ruins of a Roman fortress from the town of Aquincum remains on the site of today's Budapest, built in AD 100, and the subsequent arrival of the Hungarian people. The Kingdom of Hungary was established in the year 1000 AD.

Thyroid Federation International is on its way to mark its 25th Anniversary. I have personally been associated with the Thyroid world since 1999 and during this time I have had the opportunity of meeting Endocrinologists all over the world. I have also met thousands of patients and heard about their experiences on how they deal with their issues and try to live normal lives. Some narratives are unforgettable, i.e. how people in the 1950's had to line up at the butcher's shop for desiccated thyroid and more recently, a young 12 year old girl, who was bullied at school because her physical abilities were impacted by Graves'. Irrespective of geographical boundaries, patients face common issues related to Thyroid.

Thyroid Federation International has come a long way in recent years. We have kept pace with our increase in spreading education and awareness to seven new countries during the 2017-2019 period. Thyroid foundations in Croatia, Greece, Nepal, Nigeria, Ghana, Kenya and Colombia are our newest TFI members. It is important that Thyroid patients have access to information on thyroid disease in their own language, hence the importance of having local patient organizations pertaining to thyroid issues. As TFI grows, our need for funds is stronger than before, as needs to invest in education and awareness efforts increase. We are thankful to Merck KGaA, IBSA, Medtronic and Horizon for their contributions and support in 2018-19.

Recognition of patient organizations and their contributions has taken a while; from the ETA meeting in Athens, Greece in 1998 to TFI's recognition at the



Ashok Bhaseen

40th ETA Annual Conference in Belgrade on their 50th Anniversary celebration associated with their ETA publication. LATS, ETA, ATA and AOTA have further strengthened their collaboration with TFI through joint declaration and endorsements on clinical practice guidelines, and Krakow's Declaration on Iodine, to name a few, during 2017-19. We look forward to working with ETA officials to further strengthen this bond for better patient outcomes.

On the Industry front we continue to witness a patient-centric approach and were glad to participate in two advisory board meetings so that we could share our own experience and patient journeys. Levothyroxine is a narrow therapeutic index product; any minor changes in the formulation can impact a lot of patients, hence we urge the Industry to work with us in advance to avoid those complications.

TFI has worked hard on establishing May 25th as World Thyroid Day and is also celebrating its 11th anniversary of International Thyroid Awareness Week (ITAW), May 25-May 31, 2019. This year's topic was "The Many Faces of Thyroid Disease". Merck Serono has played an important role in ITAW and has supported this initiative through the past 10 years. Now, thanks to Horizon, IBSA, Medtronic and Merck KGaA, we are able to continue with this initiative. Thanks to ETA, ATA, LATS and AOTA for their partnership and all the Endocrinologists and Physicians throughout the world who gave their precious time to educate patients and helped with programs on creating awareness of thyroid-related issues. It is good to see ETA, ATA, LATS and AOTA recognize World Thyroid Day May 25th each year and also great to see them provide a platform of communication and partnership to TFI.

TFI has been participating at ETA meetings for 21 years now and looks forward to a continued collaboration for the benefit of thyroid patients.

I would like to thank all those who have contributed to the articles in Thyroworld and encourage others to contribute. We also embarked upon an electronic news bulletin; if you have any suggestions on how to improve it, please let us know. I would encourage you to sign up to receive the bulletin. We have a lot to do and miles to go before we sleep.

We look forward to meeting each one of you at the TFI booth - and have a great ETA, Budapest conference!

Tributes to June Rose-Beaty

We are sad to say goodbye to a dear friend, June Rose-Beaty, who passed away in March this year. June was one of the founders of the Ottawa, Canada Chapter of the Thyroid Foundation of Canada and later became editor of their newsletter, Thyrobulletin.

TFC was one of the 6 organizations who founded TFI in 1995. June later moved on to become the Editor of TFI's newsletter ThyroWorld, beginning with the very first edition in 1998, featuring a beautiful drawing by Emma Bernini from Italy on the cover. She continued as TFI editor until 2008.

LAZ BOUROS, PRESIDENT TFC

I first met June Rose-Beaty 31 years ago at a Public Education Program (PEP) meeting sponsored by the Ottawa Chapter. I attended the meeting to get some information on Thyroid disease and to see if I could lend a helping hand. As it turns out, it was also a recruitment night!

I was informed of all the available position and then persuaded into volunteering for the Chapter President position. In those days, June helped me a lot with my new position responsibilities and we became great friends!

She was a big supporter of the Ottawa Chapter, a natural leader and a skilled organizer. She helped in a variety of ways including introducing the speakers at our PEP meetings and recruiting new volunteers. In those days, we put on five PEP meetings a year with about 60-75 patients in attendance.

We established an Ottawa Chapter Help Line for patients. On the weekends, we provided the public with information on Thyroid disease through our shopping mall table displays.

June was an excellent communicator both in speech and in writing. Since she was also Editor of our Thyrobulletin newsletter and we often shared a ride to Kingston to attend the TFC AGMs which gave us the opportunity to exchange ideas.

A few years later, when the next Ottawa Chapter President suddenly retired, June and I shared the position until a new candidate was found.

In 2004, June received a Civic Award for her long and outstanding commitment as a volunteer to the Thyroid Foundation Ottawa Chapter!



ASHOK BHASEEN, PRESIDENT, TFI

As President of Thyroid Foundation of Canada I came to know June Rose-Beaty who was an editor for Thyroworld during 2006 to 2011 period. She was a person who had a sense of purpose, dedication and a great gift with words. Her passion was evident in my 1st meeting, despite her health. It was an honor and pleasure to know June Rose who hails from my native country of Canada. She will be missed.

On the news of her passing away these were the words that I wrote as President of TFI:

'I learnt about the passing away of June Rose-Beaty today. We at the Thyroid Federation International knew her by that name, everybody was very fond of her and remembers her contribution to the Thyroworld Publication. We are deeply sorry to hear about her passing away. I want her family to accept our heartfelt sorrow and loss and we want to let you know that globally we feel this loss to have lost June. We will dedicate a page in our upcoming Thyroworld publication in her memory and contributions.

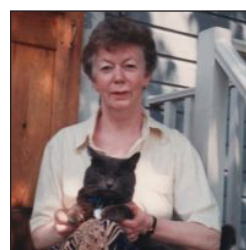
We will for always remember our dear June Rose-Beaty and her contributions to our organization. On behalf of the TFI Board and foundation, we wish the family well.'

NANCY HORD PATTERSON, FOUNDER/1ST PRESIDENT OF THE NATIONAL GRAVES' DISEASE FOUNDATION, USA

I had the pleasure of meeting June as part of the delegation of the Thyroid Foundation of Canada at the inaugural meeting of the TFI. Little did I know that I had the HONOR of meeting and knowing her!

She was quiet, listened patiently and when the rest of us were finished with all our random discussion, June would expertly explain to us how things were, and how they needed to be managed!

She was a wonderful strength to the TFI.



(continued on page 5)

Tribute to June Rose-Beaty (continued from page 4)

YVONNE ANDERSSON LAKWIJK (SWEDEN), PAST PRESIDENT OF TFI

A very dear friend, June Rose-Beaty, has left us!

In writing this memory of June, I miss her already in the first sentence, because in past times when I wrote an article for ThyroWorld, I could always rely on June to correct it and to add that extra touch to it in the way that only June could do. Now I have to manage myself.

I met June and her husband Stuart for the first time at the annual meeting of Thyroid Federation International (TFI) 1998 in conjunction with the TED and ETA conference in Greece. June was there as the editor of ThyroWorld, the newsletter of TFI. Her personality was warm, caring, honest and with a huge devotion for the written word. Of course she showed great engagement in voluntary work for the benefit of thyroid patients. As well as her professional skills she was a social person who was pleasant to join for dinner; a lot of talking and many laughs which resulted in lovely memories. The two of them were a lovely couple, so supporting and encouraging to each other.

June presented a perfect newsletter every year and in those days we had both a spring and a fall issue. She was easy to work with and had a good eye for getting a nice mix of articles.

In 2002, the TFI annual meeting was in Gothenburg as well as the ETA conference. It was a lovely meeting with many steps forward for the co-operation between the ETA and TFI and the city presenting itself in beautiful Swedish summer weather. This, her husband Stuart made use of and painted the most beautiful variations of different venues in Gothenburg. He was the artist of the colours, she the artist of the words, what a talented couple they were.



Gothenburg Harbor. (painting by Stuart Beaty)

From the year after June came to share the responsibility for the editorial work with the new secretary of TFI, Beate Bartès, the Parkinson's disease

which she had struggled with made it more difficult for her to do the practical writing, which was a great sorrow to her.

Unfortunately we didn't have such frequent contact in the last years, but when I heard that she had passed away, I was struck with the loss of a very dear friend.

June will always have a place in my heart, as well as her dear husband, Stuart.



Canadian Contingent in Kyoto 2000

L-R: Stuart Beaty, June Rose-Beaty, Katherine Keen, Emily Keen, and TFC President, Arliss Beardmore

KATHERINE KEEN, TFI ADMINISTRATIVE COORDINATOR

My best memories of June were in Kyoto, Japan with TFI representatives from different countries around the world. June came with her husband Stuart and I brought my teen-aged daughter with me. What an experience it was! Dr. Fumito Akasu was a wonderful host, the Imperial Prince and his wife attended the Congress reception, we watched a historic parade with costumes through the ages, and we had a day trip to Nara where we met Dr. Hashimoto's son.



Painting by Stuart Beaty.

TFI AGM and ETA Congress 2018

Newcastle, Great-Britain

BEATE BARTÈS, SECRETARY, THYROID FEDERATION INTERNATIONAL

As every year, TFI held its Annual General Meeting in the days before the 41st ETA congress. In 2018, it was in Newcastle, Great-Britain. The TFI members were from Australia, Bulgaria, Denmark, Finland, France, Germany, India, Italy, Netherlands, Norway, the Philippines, Spain, and USA.

We spent two very busy days, discussing on TFI's past and future projects and challenges. Each member presented the national activities of his organization.

The annual TFI meeting provides a platform where patient organizations from all over the world can share their experience, talk about their challenges and opportunities, learn from each other and encourage each other.

During the ETA congress, TFI had a booth, which had a lot of visitors, and attended many interesting lectures. The congress is always a great opportunity to meet leading thyroid specialists from all over the world, to present our umbrella organization to those who don't know it yet, and to encourage doctors to create and assist patient groups in countries which don't have such a group yet.



TFI AGM 2018 – Newcastle, UK

Front row: Téo San Louis (*Philippines*), Julie Lund (*Denmark*), Ashok Bhaseen (*India*), Linda Henderson (*Italy*).

2nd row: Beverley Garside (*Australia*), Ulla Slama (*Finland*), Maria Silyanovska (*Bulgaria*), Beate Bartès (*France*), Marika Porrey (*Netherlands*).

3rd row: Carmen Villar (*Spain*), Harald Rimmele (*Germany*), Peter Lakwijk (*Sweden*), Yvonne Andersson-Lakwijk (*Sweden*), Jo Inge Kaastad (*Norway*), Nancy Patterson (*USA*).

5th International Thyroid Eye Disease Society (TEDS) Symposium

NANCY HORD PATTERSON, PH.D.
FOUNDER, GRAVES' DISEASE & THYROID FOUNDATION

Singapore, February 2019

The theme: Current perspectives in the management of Thyroid Eye Disease ~ East meets West ~

While I have had the privilege of attending a number of international meetings as an exhibitor for either the Graves' Foundation and/or the Thyroid Federation International, it has usually been just that: as an exhibitor. I usually get time to sit in on a few sessions, but this is the first time I have actually attended the entire physician presentations. Their presentations range from 5 minutes to 25 minutes, and they go like clockwork. Since this entire symposium was about TED, I understood most, or at least much, of what was presented. A great deal of the focus, from all the countries, was the new biologic research that is being

done. The big question was: "Will the medical research make surgery redundant?"

Our Medical and Scientific Officer, Dr. Terry Smith, was one of the three Keynote speakers. To say that he is well-known and respected around the world is an understatement. He is the principal investigator of the new drug, Teprotumumab, an immune-modulatory treatment for TED in the early stages. His message was clear: Things are changing significantly. The first speaker was Dr. Peter Dolman, from Canada. His first topic was regarding the Quality of Life (QOL) in patients with TED. I had hoped for much more on this subject, but it was a physician, not a patient, symposium. Several physicians spoke with me over the period of the meeting, and expressed a need to hear more about QOL, and how to insure it for patients. Dr. Robert Goldberg, also a GDATF supporter, spoke about "Fibrosis: The Villain in TED".

(continued on page 7)

5th TEDS Symposium (continued from page 6)

The faculty was amazing, and absolutely world-wide. North and South America (USA, Brazil & Canada); Europe (UK, Italy, the Netherlands, France, Spain & Belgium,); Asia-Pacific (Japan, Taiwan; South Korea, Hong Kong, China, India); and Singapore. The entire event was presented in English. The closing presenter on that day was by Dr. Raymond Douglas, the co-principal investigator for Teprotumumab, and also an active member of the GDATF Medical Advisory board. His speech was “The path from theory to reality” and addressed the challenges, pathways and progress over the past three decades for all physicians who have dedicated their practices to treating and improving TED for their patients.

There were several attendees from the USA, and they found me in the audience and we talked about the support groups they help lead, and the work they are doing for patients. I got to spend time with the folks from Horizon Pharma, which was a delight.

There was a little time to explore the city of Singapore. It was amazing. It is known to be the cleanest and safest city in the world. If you have time, type in “Singapore” into your search engine and just take a look around.



Nancy Patterson with Gail Moore, at the Botanical Gardens in Singapore.

TFI – Echoes from the Conferences

BY PETER LAKWIJK, TFI BOARD

As a representative of Thyroid Federation International, there are many different meetings to attend. This year I went to four meetings.

Thyroid, Autoimmunity and the Eyes, Mainz, Germany

On the TFI Board, I am responsible for rare thyroid diseases, and in that role I was invited by Dr. George Kahaly to attend a patient information meeting about thyroid, autoimmunity and the eyes. As well as TFI, other European patient organizations for autoimmune diseases, celiac and intestinal diseases were invited to this meeting.

In patients with autoimmune thyroid disease, other autoimmune diseases may occur, especially celiac disease. The presence of several autoimmune diseases in the same person can lead to severe mental stress. In addition, nutrition plays an important role in many autoimmune diseases.

For this reason, a close clinical and scientific collaboration has been established between the eye clinic and the department for internal medicine clinic of the Johannes Gutenberg University, with a special consultancy for celiac disease and small intestinal diseases.

First Patient Conference on Thyroid Diseases for Central and Eastern Europe, Sofia, Bulgaria

VIOM, our member organization in Bulgaria, organized the First Patient Conference on Thyroid Diseases for Central and Eastern Europe. They invited representatives of TFI and of the Thyroid Cancer Alliance to speak about how to start new patient organizations and about the benefits of international cooperation between patient organizations. We underlined the importance of closely working together with the doctors and we showed the efforts and results of the collaboration of Thyroid Federation International with the doctors.

The first day we had a meeting with patient organizations from different countries, and on the second day there was a patient meeting with approximately 100 attendees. There were lectures given by patients and doctors about their experience with thyroid diseases.

EUsalt Annual Meeting, Rotterdam, the Netherlands

As part of the project “Mother and Baby, No Iodine Deficiency”, we connected to the European salt industry. We were invited to give a presentation about TFI and the project during their annual meeting. There was a lot of

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TFI – Echoes from the Conferences

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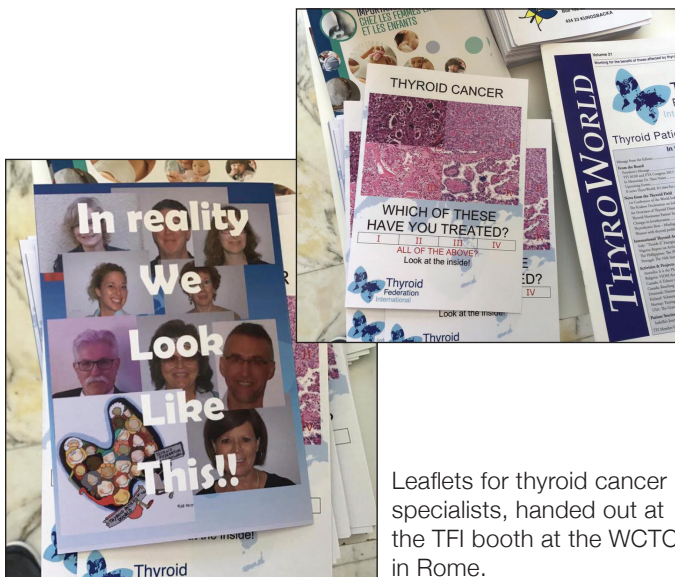
interest and many positive reactions from salt companies from Europe, Asia and Africa.

World Congress on Thyroid Cancer. Rome, Italy

There have been several World Congresses on Thyroid Cancer, in Toronto and Boston, but this was the first one held in Europe. TFI represented the patients with a booth in the exhibition hall. Many doctors that we already know came by to say hello, but a number of doctors that didn't know us yet also came to our booth. Once again we succeeded in extending our network of thyroid doctors and added contacts for our members and sources for thyroid patients in different countries.



TFI representatives at the WCTC: Harald Rimmel, Beate Bartès, Peter Lakwijk.



Leaflets for thyroid cancer specialists, handed out at the TFI booth at the WCTC in Rome.



Upcoming Events

September 7-10, 2019

42nd Annual Meeting of the ETA
Budapest, Hungary
www.eta2019.com



Oct. 30 to Nov. 3, 2019

89th meeting of the ATA
Chicago, Ill., USA
www.thyroid.org



September 8-13, 2020

16th International Thyroid Congress
Xi'an, China



Annual Awareness Events

May 25

World Thyroid Day



May 25 to 31

International Thyroid Awareness Week
www.thyroidweek.com



June 1

International Hypoparathyroidism Awareness Day



September

Thyroid Cancer Awareness Month



Thank You!

Thank you to everybody who made this issue possible, most particularly Katherine Keen, who corrected the language of all non-native speakers among our authors, and Lynda Wegner who diligently took care of the layout.

Innovative Therapy of Benign Thyroid Nodules

DOMINIQUE VAN DOORNE, MD, ROME, ITALY



Benign thyroid nodules are very frequent and widespread in the general population. A correct intake of iodine with the diet and with the daily use of a pinch of iodized salt is leading to a slow and progressive reduction in the frequency of thyroid nodules in Italy.

Many patients find they have thyroid nodules by accident, during imaging tests. The diagnosis of a thyroid nodule involves a diagnostic-therapeutic pathway that tries to answer more questions:

Is it a benign or malignant nodule? The answer, in case there is this suspicion, is given by fine needle biopsy;

Is it a nodule that produces too many thyroid hormones (so-called hyper-functioning nodule)? The answer is given by the dosage of thyroid hormones in the blood test;

Is it a nodule that progressively increases in volume? 90% of benign nodules can be “observed” over time, making only periodic checks on ultrasound and thyroid function (every 1-3 years depending on the case). However, 10% of the nodules tend to grow over time, reaching such dimensions as to give symptoms of compression of neighboring structures. The most frequent symptoms are a sense of compression, respiratory disorder (dyspnea), voice disorder (dysphonia), discomfort during swallowing (dysphagia). Other times the benign bulky nodules manifest themselves with a swelling in the lower part of the neck, visible to the naked eye, which creates an aesthetic problem.

In Italy, in 2017, approximately 26,000 surgical procedures were performed for removal of symptomatic benign thyroid nodules. In most of the operations, all the thyroid (total thyroidectomy) was removed due to the presence of nodules in the two thyroid lobes; in a smaller number of cases only half a thyroid (hemithyroidectomy or lobectomy) was removed due to the presence of one or more nodules in a single thyroid lobe. There has been much progress in thyroid surgical procedures over the past 20 years, requiring it to be practiced only by surgeons experienced in thyroidectomy. The advantages of surgery are a definitive solution that no longer requires ultrasound scans. Disadvantages of surgery: hypothyroidism (if the entire gland is removed), need for general anesthesia, need for hospitalization (1-4

nights) and, obviously, the presence of a surgical scar. The possible complications of surgery are:

- hypoparathyroidism in 2-6% (only in cases of total thyroidectomy), with the need to take calcium and vitamin D for life. In the case of lobectomy there is no risk of having hypoparathyroidism, because 2 parathyroids are left;
- permanent damage of the recurrent laryngeal nerve, in about 1% of the operated patients, with paralysis of a vocal cord and consequent dysphonia, which requires a speech therapy to rehabilitate the voice. This complication has a strong impact on the patient’s quality of life;
- superior laryngeal nerve damage in 3.7% of cases, which causes difficulty in singing, shouting and making high-pitched sounds, things that can be a very serious problem for professional singers, and have an impact on quality of life for all;
- haemorrhage in about 1.2% of cases, with a need for rapid re-intervention.

In the last 2 decades, several minimally invasive treatments have been proposed, aimed at the ambulatory treatment of symptomatic nodules, without the need for general anesthesia and with minimal risk of damage to the skin and cervical tissues (1).

US-guided percutaneous alcoholization (PEI) is a consolidated alternative to surgery, safe and effective for voluminous recurrent thyroid cysts (with liquid content). First the cystic liquid is aspirated, to examine it in order to exclude the rare neoplastic cysts. In case of cyst recurrence, the liquid is redrawn and ethanol is injected to “dry” the cyst walls. Currently PEI is considered the treatment of choice for large recurrent cysts, since the efficacy (considered as a volume decrease of at least 50%) is about 90% with one or more injections of ethanol and the complication rate is very low. The major complications are exceptional and mostly transient (transient paralysis of the vocal cords). Because the reduction in volume is maintained over time, PEI is considered to be the most cost-effective treatment for recurrent benign thyroid cysts after aspiration. In contrast, PEI is not considered a safe option for solid nodules, since the possible spread of ethanol in adjacent cervical soft tissues can cause vocal cord paralysis with hoarseness, or severe cervical pain or tissue fibrosis cervical (bridles of hard scar tissue).

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Innovative Therapy of Benign Thyroid Nodules (continued from page 9)

For some years, in Europe and Asia, it has been possible to perform a non-surgical therapy of the symptomatic solid benign thyroid nodule, thanks to the use of laser waves or radiofrequency waves (RF) through a needle. The waves overheat the inner part of the nodule to cause cell death (necrosis). This technique, called thermoablation of the thyroid nodule, is very well tolerated, is performed under local anesthesia and does not require hospitalization. The operator uses an ultrasound unit to check the correct positioning of the needle and the amount of “burned” tissue. It is important to point out that, before proceeding with thermoablation, it is necessary to be certain that it is a benign nodule, through the execution of 1 or 2 needle aspirates.

Thermoablation is not indicated in the case of very large nodules or the presence of several large nodules (multinodular goiters), because it does not allow satisfactory results to be obtained. In these cases, a part or all of the thyroid gland is surgically removed. The advantages of thermal ablation are:

- absence of surgical scar;
- absence of general anesthesia;
- no need for hospitalization;
- preserved thyroid function.

Complications during and immediately after the procedure are infrequent and mostly transient. In expert hands they do not exceed 1% of cases and consist of:

- hemorrhage within the thyroid (1% of cases);
- cutaneous hematoma (0.5% of cases);
- skin burn (0.5% of cases);
- pain: mild in 10% of cases and moderate in 0.5%;
- transient damage of the recurrent nerve that controls the voice (0.5% of cases).

Serious complications are rare (few cases described in the world, which do not occur when the operator is experienced): rupture of the nodule or permanent damage to the recurrent laryngeal nerve with persistent dysphonia and dyspnea.

The thermal ablation, both with Laser and with RF, allows to obtain a reduction of about 50-80% of the volume of the nodule in the following months. If the reduction in the volume of the nodule is not considered sufficient, a second thermoablation session is carried out. The reduction in the size of the nodule persists for many years (even 5-10). Some nodules start growing again after 5 years, so it may be necessary to repeat the procedure.

In conclusion, benign thyroid nodules in most cases can be kept under observation with periodic ultrasound scans. Surgery is still the only therapeutic choice for very large nodules or in cases of multinodular goiters with different large and/or growing nodules. Less invasive treatments, such as thermoablation, are currently available as an alternative to traditional surgery, for reducing the size of single symptomatic benign nodules. To make the best choice, remember to ask the doctor what are the results and complications of the proposed treatment and what is his experience in performing the surgical procedure or the new ablative technique, since, as already mentioned, the complication rate decreases when the invasive procedure is performed by medical experts in highly specialized centers.

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The 16th INTERNATIONAL THYROID CONGRESS
第十六届国际甲状腺大会

2020年9月8-13日
Sept.08-13, 2020
西安曲江国际会议中心
Qujiang International Conference and Exhibition Center

Sept
08-13, 2020

The percutaneous laser thermal ablation treatment for thyroid nodules

SCOTTI BRUNO (ELESTA, ITALY)

The percutaneous laser thermal ablation treatment is indicated for treating benign and malignant lesions of the thyroid with a micro-invasive approach. It employs laser energy to heat and destroy pathologic tissues, avoiding the surgical approach with its real discomfort and possible complications.



Depending on the tissue, anatomical location, size and nature (benign or malignant) of the thyroid nodule to be treated, the indications for this procedure include:

- **For benign lesions (benign thyroid nodules):** to produce a volumetric reduction of the nodule by cytoreduction (reducing the number of cells in the nodule), a process induced by laser ablation with consequent regression of the size of the nodules;
- **For malignant lesions (metastatic lymph nodes of the neck and thyroid microcarcinoma):** to destroy cancerous tissue masses with a sufficient safety margin.

This outpatient procedure, performed without any kind of anesthesia, consists in the insertion of one or two extremely thin optical fibers into the thyroid nodule under ultrasound guidance which will deliver laser

energy that heats the tissues to be treated until they are destroyed. The procedure entails no incisions or stitches with the entire treatment session, including preparation time, lasting for approximately 30 minutes.

Recovery times are very short and the patient can return to normal activities just a few hours after the treatment. In the months following the procedure, the patient just needs to carry out follow-up examinations to monitor the outcome produced in a single treatment session.

Advantages

- It is an outpatient procedure requiring no local nor general anesthesia
- It entails a short duration of time (about 30 minutes - including preparation of the patient)
- It uses very fine, painless and minimally invasive needles causing no damage to the skin nor underlying tissues
- It does not leave any marks on the neck (no scarring) ensuring good cosmetic results
- It significantly reduces compressive symptoms – in case of benign lesions
- It does not require life-long thyroid hormone replacement therapy, as is the case of surgical removal

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About Elesta & ModiLite treatment:

Scotti Bruno is Product Marketing Engineer for Elesta.

ModiLite is the EchoLaser Therapy for treating neck lesions.

The name of the treatment contains in a single word the application area (the neck, "Modi" was the nickname of Tuscan painter, Amedeo Modigliani, who portrayed female subjects with very long, slim necks) and "Lite", which on one hand refers to the lightweight and micro-invasiveness of the treatment, and on the other, the therapeutic source (Light, therefore Laser).

The name ModiLite marks the difference of the procedure performed with EchoLaser (micro-invasiveness and multi-fiber approach in a single system) from the other thermal ablation techniques.

COSMIC-311

EXELIXIS®

RICCARDO SIBILANO, PH.D., ASSOCIATE SCIENTIFIC COMMUNICATIONS DIRECTOR, EXELIXIS, INC.

A Phase 3 Study of Cabozantinib in Patients with Differentiated Thyroid Cancer

The number of people diagnosed with thyroid cancer has steeply increased over the last several decades to more than 50,000 annually in the United States alone (from the American Cancer Association website: <https://www.cancer.org/cancer/thyroid-cancer/about/key-statistics.html>). By 2030, thyroid cancer is predicted to be the second-leading cancer that is diagnosed in women



and the ninth-leading in men (Lim et al., Trends in Thyroid Cancer Incidence and Mortality in the United States, 1974-2013. Journal of the American Medical Association, 2017). The most common types of thyroid cancers are known as differentiated thyroid cancers (DTC) and the two most effective approaches to cure DTC are surgery and radioiodine therapy, which destroys cancerous thyroid cells. Patients can also be prescribed drugs such as lenvatinib and sorafenib (which are both therapies targeting VEGFR). Unfortunately, some patients will eventually become unresponsive to these therapies and will need additional treatments. Because of this important medical challenge, an investigational drug, cabozantinib, is being tested in the phase 3 COSMIC-311 trial, which is designed to explore its safety and efficacy in patients with DTC who have been previously treated with a VEGFR-targeted therapy. In the COSMIC-311 trial, patients are randomly assigned to take cabozantinib or placebo. Patients assigned to the placebo group may have the opportunity to receive cabozantinib later in the study, when they experience disease progression.

Patients whose disease progresses after radioiodine and previous treatment with radioiodine and previous treatment with lenvatinib and/or sorafenib may be eligible for this study. COSMIC-311 is currently enrolling patients. More information regarding this trial is available at www.clinicaltrials.gov (search for NCT03690388) or by contacting Exelixis Medical Information, who can also provide further details on eligibility criteria, at +1-888-EXELIXIS (+1-888-393-5494) or druginfo@exelixis.com.

September is
Thyroid Cancer Awareness Month



May 25th
World Thyroid Day



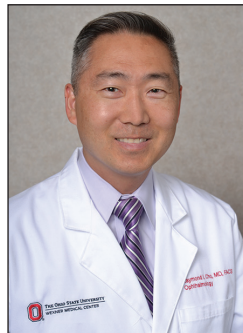
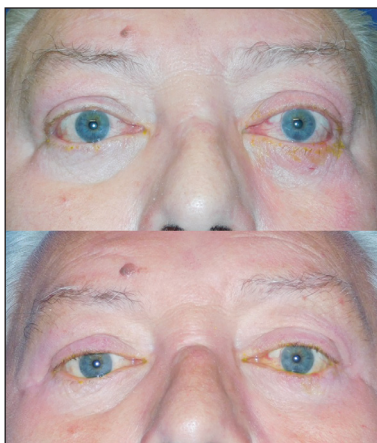
3D Modeling can help Surgeons Maximize Orbital Decompression

DR. RAYMOND I. CHO, MD, FACS

Dr. Cho is an Associate Professor and Director of Oculoplastic & Orbital Surgery at The Ohio State University Wexner Medical Center, and an Executive Board member of the North American Society of Academic Orbital Surgeons.

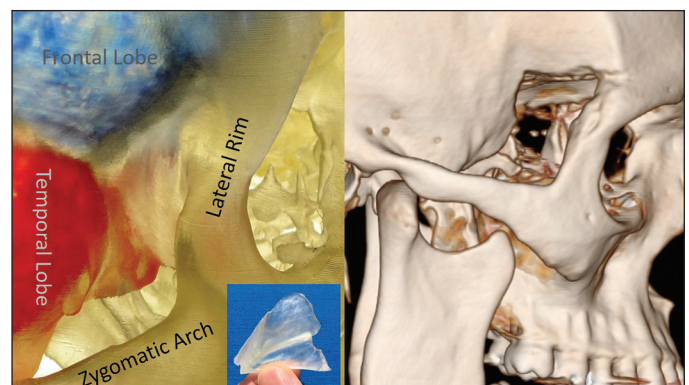
Patients with thyroid eye disease (TED) can develop many different symptoms, including bulging of the eyes (proptosis), pain or pressure, eyelid retraction (causing a “staring” appearance), poor eyelid closure, dry eyes, and vision loss due to pressure on the optic nerve. While these problems can sometimes improve with medical treatment or even simple observation, some patients ultimately require orbital decompression surgery. Many different decompression techniques have been tried over the years, but today the most common involve removal of the lateral wall, the medial wall and floor, and/or orbital fat. By creating more space in the bony orbit or reducing the amount of tissue, the eyeball can sink back into a more normal position. Most orbital surgeons will customize treatment for each individual patient by performing one or more of these procedures in combination.

Lateral decompression is a good option for many patients with moderate to severe proptosis because it can theoretically offer the most proptosis reduction. However, it is also the most technically challenging, because it requires the removal of thick bone from the outer wall of the orbit. (The medial wall and floor are much thinner and easier to remove, and the orbital fat is very soft.) The amount of proptosis reduction depends on how much bone the surgeon is willing and able to remove, and the highest volume of bone is in the deep orbit, next to the brain. Understandably, many surgeons are hesitant to venture this far into the orbit out of fear of damaging the brain or other important nerves and vessels.



Dr. Raymond I. Cho

The key to removing as much bone as possible is knowing the anatomy. At first glance, the anatomy of the lateral orbital wall may not seem very complicated, but in the operating room, knowing exactly where and where not to drill can be quite challenging. 3-dimensional (3D) modeling based on computed tomography (CT) scans can be a valuable tool in helping surgeons understand the bony contours of the lateral wall and the relationships between the orbit, the brain, and other structures.

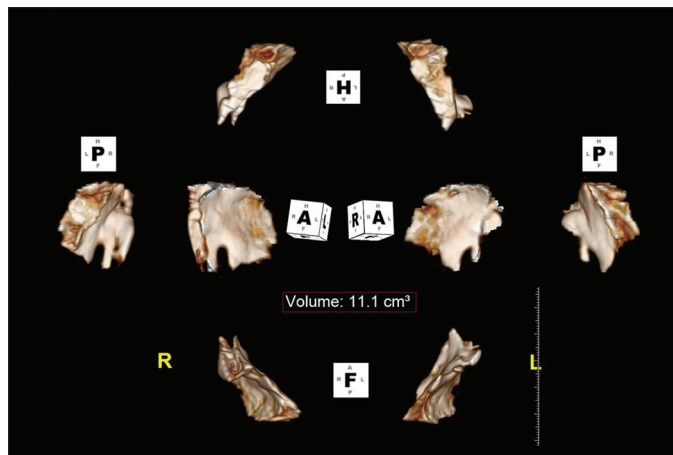


I have used this technology in several different ways to teach orbital surgeons how to maximize their lateral orbital decompressions. First, working with a translucent stereolithographic model of a human skull, I colored the bony surface of the brain cavity to make it visible from the outside. This provides a perspective on the relationship between the orbit and the brain not normally seen in real life. I then cut out the lateral wall from the model and sculpted it to simulate the shape of the bone as it would look if it were removed in a single piece. This “reverse sculpture” helps the surgeon visualize the shape and contours of the bone that will be removed. Finally, the radiology department at Ohio State created 3D images from the CT scans of one of my orbital decompression cases and performed digital subtraction to show the size and shape of the bone that was removed from many different angles. This work has been presented at national meetings of the American Society of Ophthalmic Plastic and Reconstructive Surgery (ASOPRS) and the North American Society of Academic Orbital Surgeons (NASAOS).

(continued on page 14)

3D Modeling... (continued from page 13)

Other technologies that are increasingly being used to improve the safety and effectiveness of orbital decompression include the ultrasonic bone aspirator and intraoperative navigation. However, no technology can replace the role of proper surgical training. Not everyone with thyroid eye disease needs orbital decompression, but if you are considering having this procedure done, make sure to enlist the expertise of a fully-trained orbital surgeon.



Rare Diseases – Viva the Revolution

REBECCA STEWART, TEDDINGTON TRUST (UK)

In 2016 my sister, Nicola Miller and I were frustrated by the lack of opportunities to raise meaningful awareness for the charity that we had founded to support patients with the rare genetic condition xeroderma pigmentosum. We had received some press coverage for Teddington Trust however, the sensational slant they always placed on the feature wasn't the kind of good quality coverage we wanted for our condition or families.

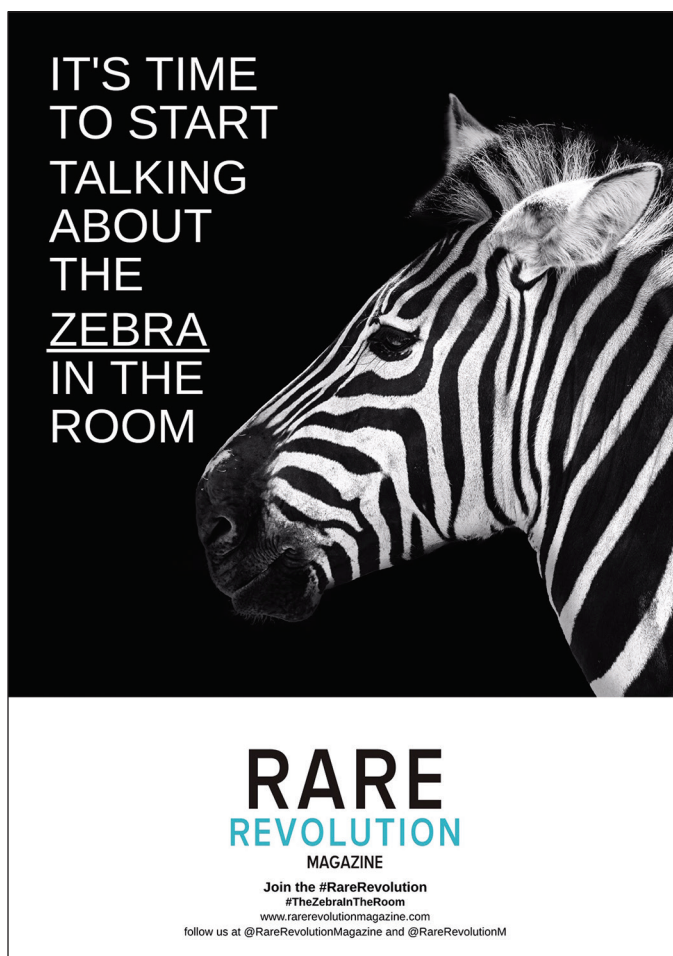
We also struggled to find information on research, and we wanted to connect with other people in the rare disease community to share in their collective experiences. It was these frustrations that led to the idea of a dedicated rare disease magazine, one that was easily accessible and that would provide a platform and voice for the whole rare disease community. In September 2016 the very first issue of Rare Revolution launched. The response was overwhelming. It seemed this was just what the community had been waiting for. Over the last three years we have worked to grow the publication, in readership, geographic reach and in the disease areas and subjects we cover.

It is important to us that we are working with all the invested stakeholders in the rare disease field to bring meaningful awareness raising, reporting and explaining the science and research in rare disease, and signposting to the community.

We wanted to create a publication that regardless of whether you are a patient, carer, industry, researcher or healthcare professional you could gain value, be educated, be inspired or be signposted.

Providing beautifully curated content for multiple audiences can be a challenge, but each issue the community outdo themselves by getting involved and sharing their voices.

We are immensely grateful to everyone who works with us to provide the valuable content in each edition



and to our micro team of five who work tirelessly to ensure that each magazine that goes out is leveraging the voices of our community.

With an annual readership of over 16,000 international readers we couldn't have imagined the appetite for a magazine like ours when we began, and we are proud to spend each day ensuring rare disease is part of the conversation. We are looking forward to raising awareness for rare thyroid diseases in our future issues.

(continued on page 15)

Viva the Revolution... (continued from page 14)

Viva the Rare Revolution – to bring about a dramatic and wide reaching change in conditions and attitudes for the rare disease community. It's time to turn the tide!

TFI has become a member of EURORDIS in order to give and get more attention for rare thyroid diseases. One of the channels for raising awareness for rare diseases in general and thyroid diseases in particular is a patient driven nonprofit magazine. We asked them to introduce themselves.

If you would like to find out more or subscribe for free to Rare Revolution Magazine, please visit <https://www.rarerevolutionmagazine.com/>

For editorial submissions, email Nicola on editor@rarerevolutionmagazine.com

If you would like to know more about our Charity Partnership scheme, email Catherine at cdeval@rarerevolutionmagazine.com

Teddington trust:
www.teddingtontrust.com

Rebecca Stewart – Bio

Rebecca is Co-founder of the International charity Teddington Trust an organisation, founded in 2012, supporting those affected by the Ultra-Rare Disease Xeroderma Pigmentosum and NRG Collective, home of the dedicated rare disease publication Rare Revolution Magazine and youth programme #RareYouthProject. Rebecca founded these organisations with sister Nicola Miller.

Passionate about appropriate and accessible resources Rebecca and Nicola work to provide a platform for the whole rare disease community and are dedicated to supporting and signposting patients.



Rebecca Stewart



Nicola Miller

TFI now a EURORDIS member

ASHOK BHASEEN, PRESIDENT, TFI

EURORDIS or Rare Diseases Europe is a unique, non-profit alliance of 864 rare disease patient organisations from 70 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. It often takes a good network of EURORDIS patients, governments, EU commission and the Industry to make treatments viable and available to the rare disease patients. Extensive and costly research is one of the factors that plays an important role in finding the right treatment to manage a patient during their journey with these rare diseases.

By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.

Thyroid related issues are not just the very common ones that we know of, some of these also fall in the rare disease spectrum. In Graves' Disease we have rare variants of Graves' Orbitopathy, very rare MCT8 Deficiency, also known as Allan-Herndon-Dudley syndrome (AHDS). Rare variants of parathyroid related issues

e.g. Hypoparathyroidism cause low levels of Parathyroid Hormone and Calcium. Hypoparathyroidism is a rare disorder in which the parathyroid glands in the neck secrete low levels of parathyroid hormone (PTH).

There is nothing worse for a patient, from a psychological and human standpoint, than being severely ill or even dying from a disease, when experimental treatments are out there, pending final evaluation. Hence, compassionate use prior to marketing authorization is also made possible by EURORDIS.

Why did TFI become an Associate Member of EURORDIS? Since some thyroid patients fall under the rare disease areas it has become increasingly important to have a TFI voice in the rare disease spectrum. This makes it possible for those patients to have access to treatment. This was the 1st Annual Conference of EURORDIS that TFI participated in that was held in Bucharest, Romania during the month of May 2019. For TFI, it's important to work in the rare disease areas that our Thyroid patients suffer in rare variants of Graves' Orbitopathy, Hypoparathyroidism and MCT8 Deficiency.



Ashok with Yann Le Cam, President and Enja Helm of EURORDIS.

A Joint Project to Decrease Worldwide Iodine Deficiency

LINDA HENDERSON, CAPE/TFI

TFI, together with WIA, IGN, GAIN, EMA AND EPMA has taken the initiative to launch a multi-stakeholder campaign to raise awareness about the consequences of Iodine Deficiency Disorders (IDD) with the general public, initially in Europe, and subsequently throughout the world.

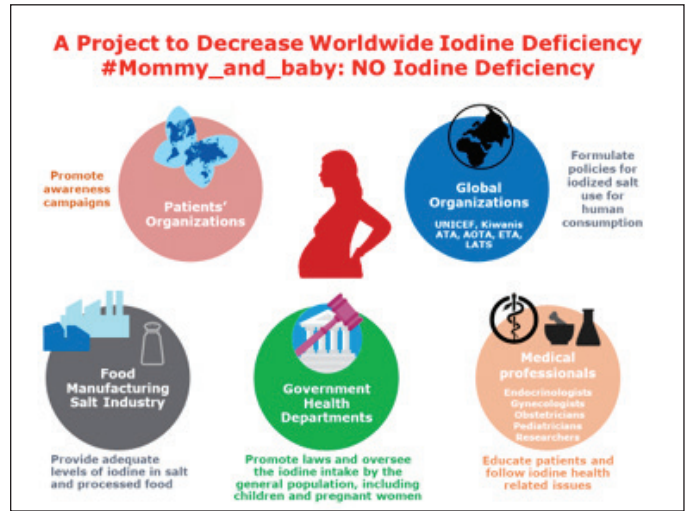
Iodine deficiency during pregnancy results in adverse health effects, not only to the mother but more so to the child during its first 1000 days of life, beginning from conception. The mother with IDD and consequent hypothyroidism will give birth to a child threatened with cretinism and growth retardation with even mild iodine deficiency causing a significant loss of 10-15 IQ points. Iodine supplementation is recommended for women living in iodine-deficient countries who are planning pregnancy and throughout its various stages and even beyond lactation. Universal salt iodization is the first-line strategy for this supplementation of iodine.

The extent of iodine deficiency in the world has fortunately gone down over the years due to activities of organizations like TFI, WIA, IGN, GAIN, EMA and EPMA and of responsible persons in healthcare and the industry.

However, the level of awareness of why iodine is necessary for human consumption is declining not only with the general public, but also with policy makers leading to resurgence of iodine deficiency.

The ultimate goal is to complement the ongoing advocacy efforts undertaken by these organizations with policymakers and generate wider momentum for the promotion of iodine and iodized salt use during and after pregnancy.

The project aims to bring attention to the extent and consequences of IDD which continue to affect both developed economies and countries in development.



A Multi-Stakeholder Approach

The project leaders visualize building a coalition of cross-sectored, like-minded stakeholders who are sympathetic to the Mission of raising awareness around IDD, its causes and solutions. It is envisioned to involve International Organizations, Industry (salt and food and feed), Medical Professionals (especially Endocrine, Obstetrical & Pediatric Societies), Patients' Organizations, and Ministries of Health, among others.

Ideally, the Projected Launch of the project is May 2020 to coincide with the next International Thyroid Awareness Week.

- | | |
|-----------|---------------------------------------------------------------|
| TFI | Peter Lakwijk, Linda Henderson, Teo San Luis, Nancy Patterson |
| WIA | Attilio Caligiani |
| IGN | John Lazarus, Jonathan Gorstein |
| GAIN | Greg Garrett |
| EMA, EPMA | Vincenzo Costigliola |

For more information: info@thyroid-fed.org



Phase 2 Trial to Test Potential Drug for Thyroid Eye Disease

JEFFREY W. SHERMAN, MD, FACP, CHIEF MEDICAL OFFICER AND EXECUTIVE VICE PRESIDENT, HORIZON THERAPEUTICS PUBLIC LIMITED COMPANY

A new Phase 2 trial is underway to assess the effectiveness and safety of RVT-1401 in the treatment of active, moderate to severe thyroid eye disease (TED).

Participants must be older than 18 years of age and have a recent onset (within 9 months) active, moderate to severe TED. Restrictions include patients with recent steroid therapy for TED, those who have previously received monoclonal antibody treatment (such as Rituximab), and patients with vision-threatening optic nerve compression.

The trial is sponsored by Immunovant Sciences GmbH. At press time, recruiting was not yet open, but study locations had been confirmed for the following sites in North America, with additional sites in Germany, Italy, and Spain.

- Multispecialty Aesthetic Clinical Research Organization (MACRO), Beverly Hills, California, United States, 90212
- Doheny Eye Center UCLA, Pasadena, California, United States, 91105
- University of Miami Miller School of Medicine Bascom Palmer Eye Institute, Miami, Florida, United States, 33136
- University of Michigan - Kellogg Eye Center, Ann Arbor, Michigan, United States, 48105
- Mayo Clinic, Rochester, Minnesota, United States, 55905
- University of Rochester Medical Center, Rochester, New York, United States, 14642
- Eye Wellness Center, Houston, Texas, United States, 77005
- UW Health - University Station Clinic - Eye Care Services, Madison, Wisconsin, United States, 53705-3644
- University of British Columbia, Vancouver, British Columbia, Canada, V5Z-1M9
- Toronto Retina Institute, North York, Ontario, Canada, M3C 0G9
- University of Ottawa Eye Institute, Ottawa, Ontario, Canada, K1H 8L6
- Ophthalmology University Center- Hôpital Maisonneuve-Rosemont, Montreal, Quebec, Canada, H1T 2M4

For more information, please visit clinicaltrials.gov and search for identifier NCT03938545.

Horizon Therapeutics announces Phase 3 Results for Teprotumumab

On February 28, Horizon Therapeutics announced the main results from its Phase 3 trial of teprotumumab, a potential treatment for active thyroid eye disease (TED). The study found that more patients treated with teprotumumab compared with placebo had a meaningful improvement in proptosis (eye bulging).

“Patients treated with teprotumumab had an unprecedented reduction in proptosis, which is currently only treatable via surgery after the active disease has ended,” said Raymond Douglas, M.D., Ph.D., the study’s co-principal investigator, director of the orbital and thyroid eye disease program at Cedars-Sinai Medical Center, and a member of the GDATF’s Physician Advisory Board. “If approved, teprotumumab would give physicians the first medicine shown to reduce proptosis during active thyroid eye disease.”

In April, Dr. Douglas presented the results of the trial during a late-breaking session at the American Association of Clinical Endocrinologists 28th Annual Scientific and Clinical Congress in Los Angeles, CA. The active phase of the disease “gives a window for treatment.” Once the disease reaches the inactive phase, surgical options are available, but as Dr. Douglas noted, “Obviously, that is a non-ideal approach.”

Dr. Douglas also explained that currently available non-surgical treatment options—including steroid therapy and radiation—fail to address proptosis and double vision and do not reverse the underlying alterations of orbital tissue.

Eighty-three patients were assigned to either receive teprotumumab or a placebo in eight intravenous infusions (10mg/kg for their first infusion followed by 20mg/kg for the remaining seven infusions) every three weeks for 21 weeks. Both groups were evenly matched in terms of smoking status. (In the prior teprotumumab trial, statistical methods were used to account for an imbalance between smokers versus nonsmokers in the two study groups; this is important, as smokers are generally not as responsive to medical therapy for TED.)

The primary endpoint (a benchmark that determines success or failure) of the trial was a 2 mm reduction of proptosis at Week 24 for patients receiving teprotumumab. Dr. Douglas noted that a 2 mm reduction is visible to the naked eye; a typical

(continued on page 18)

Phase 2 Trial to Test Potential Thyroid Eye Disease Drug (continued from page 17)

orbital decompression surgery provides 3-4 mm of reduction. The 2 mm reduction was achieved by 82.9% of teprotumumab patients compared to 9.5% of placebo patients. In addition, patients receiving teprotumumab reported a subjective improvement in double vision.

There were no deaths during the study. Of the patients receiving teprotumumab, one patient had pneumothorax (considered unrelated to study drug) and another discontinued treatment after an infusion reaction. Muscle spasm was the most common reported side effect, but this tended to resolve on its own.

Horizon expects to submit a Biologics License Application to the U.S. Food and Drug Administration (FDA) in mid-2019. Teprotumumab has received Breakthrough Therapy, Orphan Drug and Fast Track designations from the FDA. Detailed Phase 3 data will be submitted for publication in a peer-reviewed journal.

References:

Horizon Therapeutics. 2019, February 28. "Horizon Pharma plc Announces Phase 3 Confirmatory Trial Evaluating Teprotumumab (OPTIC) for the Treatment of Active Thyroid Eye Disease (TED) Met Primary and All Secondary Endpoints." [Press Release]. Retrieved from <https://ir.horizontherapeutics.com/news-releases/news-release-details/horizon-pharma-plc-announces-phase-3-confirmatory-trial>.

Douglas, R. 2019. "Teprotumumab treatment effect on proptosis in patients with active thyroid eye disease: results from a phase 3, randomized, double-masked, placebo-controlled, parallel-group, multicenter study." Presented at the American Association of Clinical Endocrinologists 28th Annual Scientific and Clinical Congress.

NEWS FROM THE THYROID FIELD

"Mct8 Deficiency in a nutshell"

VERONICA MARIA POPA; MCT8-AHDS FOUNDATION, ROUMANIA

MCT8 Deficiency, also known as Allan-Herndon-Dudley syndrome (AHDS), is an X-link recessive disorder. According to orphan.net data base there were 320 documented cases in 2016, all over the world. Recent research shows however that MCT8 Deficiency is severely under-diagnosed due to lack of information and awareness.

A conclusive AHDS diagnosis can be reached only by genetic testing, but there are certain blood tests that may indicate the need to perform a genetic test in this direction. Patients affected by MCT8 Deficiency will show high T3 levels, low or borderline low T4 and low reverse T3.

Some of the symptoms associated with MCT8 Deficiency include: lack of head control, motor delay, intellectual disability, central hypotonia, peripheral hypertonia, inability to gain and maintain weight, increased heart rate, low bone density and delayed myelination.

The mutation affecting the MCT8 protein is not unique and there are rarely two patients with the same mutation. Be it a point mutation or a frame shift mutation, it affects the delivery of hormones to the brain. As a consequence, the brain develops as if affected by severe hypothyroidism.

Meanwhile, due to T3 peripheral toxicity the body reacts as if affected by severe hyperthyroidism. The risk of organ failure is an important cause of death in children affected by MCT8 Deficiency with heart and liver being most at risk. Other life threatening risks are: recurrent pneumonia, aspiration during sleep and undetected infections.

While only boys may be affected by MCT8 Deficiency, girls can carry the mutation as well but without presenting any symptoms. To carrier mothers, the risk of having a child (boy or girl) that carries the mutation is, statistically, 50%; while the risk of having an affected child (a boy) is 25%.

At this moment there is no effective treatment for MCT8 Deficiency.

The MCT8-AHDS Foundation was created by patient families for patients and it aims to stimulate medical research in order to find a cure, empower the MCT8 community and raise awareness for this syndrome in the hope of earlier diagnosis.

MCT8-AHDS foundation:
www.mct8.info/what-ahdsmct8



The Australian Thyroid Foundation

As the Australian thyroid patient support, advocacy, education, information and awareness organisation, the ATF helps patients through their journey to Good Thyroid Health, Australia wide and beyond.

The ATF began in 1995 and has been at the forefront of thyroid patient support ever since. The organisation is managed by a wonderful team of volunteers who give their time, skills and energy to the organisation and provide many services for thyroid patients and their families.

The ATF Medical Advisory Team are world leaders in all forms of thyroid disorders and support the organisation and its members, giving advice, information and speaking on behalf of the organisation when needed.

The ATF is recognised by the Endocrine Society of Australia, Endocrine Surgeons of Australia and New Zealand, Asia Oceania Thyroid Association, Thyroid Federation International and many other organisations through our region and the world. The ATF is the patient representative organisation on many thyroid research and reporting committees.

Supporting patients and offering a link between doctors and patients is the essence of the organisation. The ATF provide the best information available to meet individual needs and guidance through a sometimes difficult journey.

The ATF's Thyroid Awareness Month each year connects to World Thyroid Day and International Thyroid Awareness Week. Thyroid Awareness Month gives the ATF the opportunity to promote the Benefits of Good Thyroid Health and How to Achieve it, through messaging and media opportunities. Reaching out and connecting to thyroid patients and their families Australia wide.



As statistics show 1 million Australians are undiagnosed with a thyroid disorder, it is our aim to promote thyroid health messages throughout the country and provide services to members of the organisation and the general public. Ensuring thyroid disorders are recognised, diagnosed, treated and managed. Especially amongst women who are 10 times more often affected than men. The

ATF website www.thyroidfoundation.org.au includes a Members Section with comprehensive information for online access.

The ATF also has a Medication Travel Pack available for patients to purchase and store Australian brands of Levothyroxine whilst travelling. Protecting the medication and providing a safe and secure travelling environment for Levothyroxine medication is paramount.

The ATF has joined with Thyroid Federation International to hold an exhibit and the AOTA Congress in Sydney. Come and speak to our representatives about the organisation, our services and how we can connect with you and your thyroid patients.

The ATF is holding a 'Check Your Neck' Gala Ball on Friday 18th October at Le Montage on the waterfront at Lilyfield in Sydney. Booking on the ATF website. Come along and enjoy a fun night and celebrate the ATF!

www.thyroidfoundation.com.au



May 25 to 31, 2020

**12th International
Thyroid Awareness Week**

www.thyroidweek.com

Brazilian Thyroid Institute



Who are we?

The purpose of Indatir, the Brazilian Thyroid Institute, is to bring clear and reliable information on thyroid diseases to the greatest number of Brazilians and Portuguese-speaking populations.

Here you will have access to complete information about one of the most important glands of the human body, its function and diseases.

The purpose is not only to bring information to patients with thyroid diseases, but also to those who wish to have a better quality of life and take good care of their health.

At the same time, through its Medical Area, we stimulate discussions among health professionals, in order to generate information exchange, as well as becoming a reference point in the Brazilian Internet, regarding the thyroid.

Indatir – Thyroid Institute is a non-profit institution, founded in December 2001 in São Paulo, bringing together specialists in thyroid diseases from Brazil. Affiliated to the Thyroid Federation International, Indatir is known abroad as Brazilian Thyroid Institute and aims to:

- Disclose on the internet reliable and accessible information to the general public about thyroid and related health problems;
- Bring the latest news on medical research in the area;
- Assist the development of medical sciences in the areas of research and medical care, clinic and thyroid surgery.

Iodine Deficiency Disorders and their Prevention in Brazil

For the last several years, INDATIR has been involved in Programs for the Prevention of Iodine Deficiency Disorders together with the Ministry of Health of Brazil and ANVISA National Health Surveillance Agency.

In addition, INDATIR is involved in many exciting research projects designed to gather new knowledge such as “Piloting Programme Guidance on the Use of Iodised Salt in Processed Foods” together with the Ministry of Health and Iodine Global Network, and “Iodine Nutrition During Pregnancy in Brazil” together with the Ministry of Health.



Rosalinda
Camargo MD



Eduardo
Tomimori MD

A visit to the Brazilian salt industry.



Ministry of Health of Brazil; ANVISA National Health Surveillance Agency; Iodine Global Network; Brazilian Thyroid Institute.

Continuing Medical Education

INDATIR Neck Sonography Course

This course is designed to review new knowledge and technology that is not available in formal training programs for endocrinologists and head and neck surgeons in Brazil.



The learning objectives are:

- Discuss the indications of thyroid ultrasound and how it integrates with other thyroid tests to improve the diagnosis and management of thyroid disease.
- Successfully perform fine needle aspiration biopsy guided by ultrasonography.

Board of Directors

Honorary President: Professor Geraldo Medeiros-Neto
 President: Dr. Eduardo Tomimori
 Administrative Officer: Mr. Reginaldo Ramos
 Chief Financial Officer: Dr. Rosalinda Camargo

Supervisory Boards:

Dr. Denise Engelbrecht Zantut Wittmann
 Dr. Adriano Namor Cury
 Dr. Cley Rocha de Farias

Joined We Stay Stronger

For the first time in Bulgaria, two events were jointly held - the First Central and Eastern Europe Scientific Conference on Thyroid Diseases and the First Central and Eastern Europe Patient Conference on Thyroid Diseases (organized by VIOM - the Bulgarian Thyroid Diseases Patients Association).

The headlining topic of the Scientific Conference was the latest trends in the diagnosis and treatment of thyroid cancer. Three sessions were devoted to it with the participation of leading Bulgarian and foreign endocrine surgeons, endocrinologists, radiologists and patomorphologists. Autoimmune thyroid diseases, calcium-phosphorus exchange disorders, iodine deficiency problems, pregnancy and hypothyroidism, as well as approaches to the treatment of hyperparathyroidism, were also discussed.

The aim of the Patient Conference was to bring together patient organizations from the region - Romania, Bulgaria, Macedonia, Greece, Turkey, Croatia - with patient organizations from Western Europe to learn about the problems that patients encounter in different countries and to exchange good practices. The participants also had the opportunity to visit the most interesting sessions of the scientific conference program.

Among the lecturers at the Patient Conference were Peter Lakwijk (Sweden), Yvonne Andersson (Sweden), Marika Porrey (Netherlands), Dr. Roco Granic (Croatia) etc.



Dr. Marko (Croatia), Roko Granic (Croatia), Peter Lakwijk (Sweden), Yvonne Andersson Lakwijk (Sweden), Marika Porrey (Netherlands) and Dr. Diler (Turkey) standing in front of the Bulgarian presidential palace.



First Central and Eastern Europe Patient Conference on Thyroid Diseases – participants.

One of the most important missions of the two events was the establishment of the South-eastern European Club of Endocrine Tumors (SECET) on the initiative of Professor Rumen Pandev, an endocrine surgeon, the establishment being supported by VIOM. The idea of the club is to go beyond the framework of a purely „scientific organization“ and in today's global world to seek a more active, non-standard interaction between doctors, patients, coaches, rehabilitators, etc. This is the reason why not only endocrinologists, endocrine surgeons, nuclear physicians, pathologists, specialists in imaging diagnostics, but also patients and patient organizations and lecturers from the National Sports Academy are included. The club was joined by specialists from Austria, Greece, Russia, Ukraine, Turkey, Georgia and Romania. The initiative was also supported by Prof. Dr. Kung Te - Secretary General of the Asia-Pacific Association of Thyroid Surgery.



Southeastern European Club of Endocrine Tumors (SECET) – founding meeting.



ВИОМ

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от заболявания на
щитовидната жлеза

Thyroid Foundation of Canada AGM

LAZ BOUROS, PRESIDENT

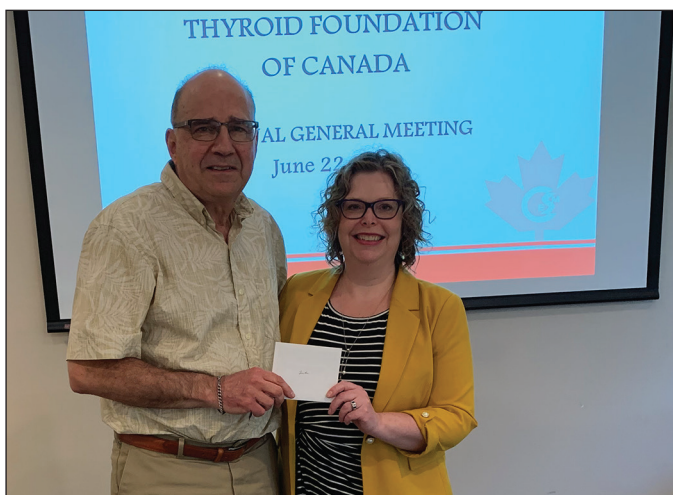
The Thyroid Foundation of Canada (TFC) held a very successful Annual General Meeting on June 22 in Toronto. This year, Ms. Inika Anderson, Executive Director of the Canadian Society of Endocrinology and Metabolism (CSEM) attended the AGM and delivered an excellent presentation to the board on the mandate and work of CSEM. Dr. Morrison, our Medical Advisor, teleconferenced in for the presentation and we discussed future developments for Thyroid research as well as other topics. Ms. Tracy Hey was elected as a new board member. Tracy will be supporting Mabel Miller in the education and publications. Board members were able to relax in a more casual setting at a Saturday night dinner. On Sunday, plans for next year's 40th Anniversary AGM were discussed with great enthusiasm.

This past year has been a productive one! Following the Strategic Plan which was approved by the board in November 2017, we have completed more than half of the 19 initiatives in this first year of the plan. This was accomplished while having four director positions vacant on the board. This report highlights some of the past year's accomplishments.

Advocacy

As part of our Public Relations initiative, an Advocacy Plan was approved by the board on November 2018. The objectives of the plan are to: improve thyroid patient care through advocacy with key health care stakeholders; establish strategic alliances with other charities and establish research projects on patient care and thyroid statistics.

Work on implementing the Advocacy Plan started immediately. A working relationship was established with the Canadian Society of Endocrine and Metabolism



TFC President Laz Bouros and Inika Anderson of CSEM.



Thyroid Foundation of Canada

La Fondation canadienne de la Thyroïde



TFC Board Members and Chapter Representatives.

(CSEM) whereby TFC would provide CSEM with feedback on patient concerns and statistics on Help Line Call information categories.

An information sharing arrangement was established with our sister organization, Thyroid Cancer Canada. Emails and Thyrobulletins were exchanged with the American Thyroid Association (ATA). TFC met with MP Diane Finley on April 4th. Ms. Finley is a big supporter of Thyroid disease and TFC.

Research

A Statement of Requirements for the Patient Care Research Project was approved by the board in November 2018. The objective of the project is to conduct a research survey on the quality and quantity of Thyroid care provided by all provinces and territories and collect statistics on the number of patients affected by Thyroid disease in Canada.

A meeting was held with Statistics Canada in February to discuss the available research on Thyroid disease. The 2005 Canadian Community Health Survey (CCHS) which asked the question "do you have a thyroid condition" indicated that 7% of the population in Canada has some form of Thyroid disease. Based on a Canadian population of about 35 million, there are about 2.5 million Canadians with Thyroid disease. TFC has requested that the question on thyroid disease be reinstated in their next CCHS survey.

TFC is entering into a working agreement with CSEM for Thyroid research. TFC will provide research grants and general research requirements and CSEM will provide administration support (Awards Committee and communication with CSEM endocrinologists to solicit research proposals).

(continued on page 23)

TFC AGM (continued from page 22)

We have received some bequests for research which will allow us to begin providing research grants annually.

Local Area Development

A Local Area Development Plan was prepared and approved by the board in November 2018. The purpose of this plan was to establish a new business model for providing local educational support for thyroid patients and to prepare a plan for establishing local area volunteers across Canada. The new plan will keep existing chapters on the old system where feasible and engage local area volunteers to conduct public education events for each area (e.g. town, city, region, etc.). So far, we have identified local area volunteers for the Halifax Area and Brandon, Manitoba.

Fundraising

This year, we established a Long-Range Fundraising Plan. The plan included some fundraising strategies as well as identifying some specific initiatives. We held our Christmas Light a Tree fundraiser again this year. It was the most successful Light a Tree fundraiser to date as both donations were increased and expenses were reduced.

Education and Publications

We published two great issues of the Thyrobulletin this year for our members! We maintained the TFC website for the general public and Thyroid patients, ensuring that there was a continuous supply of news articles, and managed our Facebook site. Our Medical Advisor updated the medical information on our website to keep it current. We entered into an agreement with Mylan to publish several videos that they are preparing on hypothyroidism on our website. We hope to publish these in the fall.



TFC AGM Dinner.

Patient Support

To support Thyroid patients, we established a Help Line Team to ensure that patient calls received were assigned to team members and promptly answered. This year, we started tracking all the calls and began providing statistics on call categories. A new enquiry log was created in Excel that allowed patient queries to be assigned to specific categories for reporting purposes.

Organizational

From an organizational improvement perspective, we created seven new director positions for Awareness & Public Relations, Patient Support, Fund Raising, Thyroid Research, Education & Publications, Volunteer Recruitment & Development and Local Area Development. The Strategic Plan was updated in the spring to improve the clarity in certain areas. We developed an Annual Operational Plan and a Volunteer Code of Ethics. Finally, we updated our corporate Bylaws.

Our Board is looking forward to continuing with the effort in the coming year! At next year's AGM, we will be celebrating the Thyroid Foundation of Canada's 40th anniversary in Kingston!

ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

Croatia

Croatian Association for Thyroid Disease

Initiated and started by Dr Zvonko Kusic, the Croatian Association for Thyroid Disease established its roots. Dr Tomislav Jukić from Zagreb was one of my contact persons for becoming members of TFI. It was a pleasure and honor to be invited by the Croatian Association to be part of World Thyroid Day in Zagreb on May 25th, 2019.

Dr Roco and Tomislav and their team put up a great show in Zagreb where the Zagreb Mayor, Dr Zvonko Kusic, leading opera singers, government officials and thyroid patients participated in a 2 day program.

The Zagreb Fountains were lit up for World Thyroid Day, with a full day program, along with full fanfare, in the heart of Zagreb downtown where thousands of people got an opportunity to be aware of Thyroid issues.

Thanks to the Croatian Association for organizing up a great 2019 World Thyroid Day show that was shown on the TV and broadcast on the radio.



Zagreb Mayor, Health Minister and Croatian President's representative with TFI president Ashok Bhaseen, May 2019.

Giving by Taking!

Stofskifteforeningen joining DrugStars ApS ®

In 2019 the Danish patient organization, Stofskifteforeningen, joined the partnership, DrugStars.

The Danish company, DrugStars ApS, was founded in 2015 by Claus Møldrup, a former professor in modern medicine at the University of Copenhagen. The company's aim is to improve the daily lives of patients by reminding them of their medicine, monitoring their experiences and providing them the opportunity to support health charities for free.

DrugStars is an app that reminds patients to take their medicine and awards them with stars which, when accumulated, can be converted to money and donated to a participating health charity of the patients' own choice. Thus the slogan of DrugStars: Giving by taking!

By verifying their medications in the app, patients will also be able to track progress, receive advice and gain a better understanding of how their medications are working.



All health charities can join the DrugStars app for free – and by joining – help to improve the lives of their members and let the members support their important work for free. More than 60 health charities from different countries have joined DrugStars so far.

To cover the cost of the donations, the anonymized and aggregated data are distributed by DrugStars to companies wanting to use the patients' experiences in order to improve products and treatments. The hope is not only to improve the daily lives of many patients, but at the same time affect the development of new and better medicines around the world.

XVII LATS Congress, Buenos Aires, Argentina



LATS President Dr Ana Luiza Maria with TFI President Ashok Bhaseen.



Ashok at the LATS TFI booth.



Ashok Bhaseen with Dr Javier Belmonte, Bolivia.

International Thyroid Awareness Week, Denmark

Personal stories posted as videos on Facebook

During the International Thyroid Awareness Week the Danish patient organization, Stofskifteforeningen, held a video campaign on Facebook to raise awareness and show diversities of thyroid diseases. Four different patient stories were posted as videos on Facebook, afterwards to be found on Stofskifteforeningen's website.

The first video was posted Monday May 27th showing Ida Marie who suffered from hyperthyroidism during her last year in High School. Losing 14 kilos although eating six meals a day, sleeping more than 12 hours a day and suffering from exhausting mood changes affected her everyday life. Medical treatment, relapses and allergic reaction to the medicine finally led to surgical removal of her thyroid gland.



On Tuesday May 28th the second video showed Juliana's story about hypothyroidism and her experience from not responding to standard medical treatment with levothyroxine, and her satisfying results from changing to combination therapy.



On Wednesday May 29th a video about Eva's thyroid cancer was posted. Eva, working as a radiographer, discovered a tumor on her own neck, and was soon diagnosed with cancer which led to a complete thyroidectomy of the entire thyroid. The specialized doctors are still keeping an extra eye on potential tumors while Eva is learning to live with hypothyroidism as a lifelong companion.



The last video posted on Thursday May 30th showed Hanne and her experiences with hypothyroidism for a period of 20 years. Since Hanne was diagnosed, she has been treated successfully with levothyroxine. Just once, when the levothyroxine formula for "Eltroxin" was modified, she experienced side effects. But since changing to levothyroxine product "Euthyrox", she has never again experienced any problems and she sometimes almost forgets about her disease.



With these four videos the Danish patient organization reached between 3,400 to 4,000 people each day. "We find these interactions quite satisfying as a total of approximately 5,500 people follow us on our Facebook", says Helene Kremmer Andersen, Board Member. "Hopefully these videos can help us reach a larger audience and we consider them an important step in raising awareness of thyroid diseases, which -often hidden - affect the daily lives of many people."

Finnish visibility campaign for good thyroid and parathyroid care

JOHANNA ERKKILÄ, PROJECT COORDINATOR, FINNISH THYROID ASSOCIATION

In the summer of 2018, the Finnish Thyroid Association launched a campaign in order to raise awareness of thyroid and parathyroid disorders. The campaign, called "Kunpa siivet kantaisivat", can be freely translated as "I wish I could trust in my own wings". The name comes from thyroid, which is a butterfly-shaped gland, but at the same time it also refers to optimism and hope in chronic disease: tomorrow everything will be better. But why was this campaign created and what did we learn from it?

In Finland, there are over 350 000 people who are diagnosed with some thyroid or parathyroid disorder. This means that over 5% of Finnish women and 1% of Finnish men have problems with these endocrine glands. Even though these disorders are common, there are still plenty of people living with thyroid or parathyroid disorder without diagnosis. Getting a diagnosis can be a long and difficult process as the symptoms are often nonspecific. Even after the diagnosis, there are patients who feel unwell and are dissatisfied with their treatment. Because of these reasons, it is important to increase awareness of the many sides of thyroid and parathyroid disorders in the health service. Only this way can individual, *good care* for people with thyroid and parathyroid disorders come true.

So, the idea of the campaign was to show the many faces of thyroid and parathyroid disorders. What could be a better way to do this than to ask people to participate and tell their story by art, handcraft and personal stories? The rules were simple. The campaign was open for anyone and participation was actualized by creating some kind of butterfly artwork. A free hand was given when it comes to size, material or colour of the butterfly. Besides the handwork, we encouraged people to write something they wanted to share with others: some wrote their personal thyroid or parathyroid story, others wrote about things they wanted to draw attention to.

During the campaign time, from August 2018 until April 2019, we received hundreds of butterflies and dozens of stories from patients and their loved ones from all over Finland. There were all kinds of butterflies from



small paper ones to huge felt works. Some of the handcrafts were done alone whereas others gathered into peer support groups where butterflies were made together. Age range was wide as well; the youngest participants were just infants in arms and the oldest were well over 80 years old.

The campaign culminated in an exhibition, which took place in a gallery called Art Kaarisilta. The gallery is in Helsinki, right next to the *busiest train stations in Finland*. During this three-week exhibition, hundreds of people visited the gallery and feedback was exclusively positive. People were touched by the stories and many told they felt empowered by all the art works which represented something important to them.

We were surprised by how many people wanted to take part in our campaign. It's not something taken for granted that people wanted to spend their time and send handcrafts for this kind of purpose. We learned that people are eager to share their experiences and help others who might be going through the same difficulties – you just have to encourage them to do so. We were also delighted to learn how much the campaign brought

(continued on page 27)

Finnish visibility campaign... (continued from page 26)

happiness and faith for a better tomorrow to people. Not only to those who send their handcrafts and stories to us, but also to those who visited the exhibition or saw pictures of the artworks online on our web page or social media channels.

As mentioned previously, the exhibition took place in Helsinki. The initial idea was that our member associations could order parts of the exhibition to their area for local people to see it, too. To our pleasure this is indeed happening. The beautiful butterflies and touching stories will fly at least to



western and northern Finland. We will also create a permanent online exhibition so that everyone, regardless of where they live, can see the creations. This way the butterflies will continue to do their original purpose online as well – show the many faces of thyroid and parathyroid disorders to the world.



ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

Germany

The Schilddrüsenliga Deutschland e.V.

Umbrella Organization for German Thyroid Support Groups

Information about the organisation

The „Schilddrüsenliga Deutschland e.V.“ (engl. Thyroid League Germany – registered association) was founded in 1995 by the German thyroidologist Prof. Dr. Peter Pfannenstiel. The association has been chaired by Ms. Barbara Schulte since 1998 and is managed by a five-member board. The board is supported by an advisory council with 12 experts of thyroidology. Currently, the league has approximately 1000 members.

According to its statutes, the league is the umbrella organization for thyroid support groups in Germany.

The objectives of the league are:

- Promotion of knowledge regarding prevention, early recognition, and state-of-the-art therapies in diseases of the thyroid gland;
- Joint meetings of patients and experts of thyroid disorders;
- Endorsement and coordination of local thyroid support groups;
- Publishing the monthly members' journal;
- Online information on different thyroid pathologies.

Current activities

The “Schilddrüsenliga Deutschland” has been involved in approval procedures of novel drugs. These novel drugs might be applied in radioiodine refractory progressive thyroid carcinomas. There is scientific evidence that these therapies can have a positive influence

on the course of malignant thyroid disease. However, the use of these drugs is not exempt from side effects.” Therefore, a benefit/risk consideration has to be taken into account. Statutory health committees have requested the league's opinion concerning the benefit of the tyrosine kinase inhibitors lenvatinib and caprelsa for the patients.

Under the auspices of the league, complimentary ultrasound screening examinations have been performed. These ultrasound examinations take place, for instance, at trade fairs. The screening is also offered for members of public authorities and companies. The ultrasound examinations are performed and documented by experienced physicians. For the screening examinations the league has acquired a transportable ultrasound device.

Recently, a commission for the development of the S3 guideline for thyroid carcinomas has been constituted. As a representative for patients the Schilddrüsenliga Deutschland e.V. has been appointed to this body as patient representative.

The annual seminar for patients and physicians will be held in Bonn. Seminar topics in 2019 focus on diagnosis and treatment of Graves' disease and endocrine ophthalmopathy. The seminar will be held at the University's Club, and guests are welcome to attend.



Launch of Thyroid Ghana Foundation (TGF)

MR. LESLIE C. KUMAHOR, HEAD OF OPERATIONS,
THYROID GHANA FOUNDATION



The Thyroid Ghana Foundation (TGF) was launched in July 2018, after the Founder, Mrs. Nana Adwoa Konadu Dsane was diagnosed with Graves' disease. She was surprised at how long it took for her condition to be accurately diagnosed considering the fact that she had worked in the nation's major hospital for over fifteen years and had access to virtually all its clinical departments and medical specialists. She was diagnosed seven (7) months after showing major symptoms. This we came to realize was because thyroid disorders are not well known among health professionals who do not primarily handle thyroid cases and therefore the probability for misdiagnosis at the general clinics is extremely high. This called for immediate steps to create awareness of the condition and promote closer working relations between departments that are directly and indirectly involved in thyroid disease treatment and research.

Surprisingly, recruiting staff and volunteers for the foundation have been relatively easy. Almost everyone we spoke to was willing to assist and we have not been short of helping hands since we began our operations.

The Foundation is mainly supported by the College of Health Sciences, University of Ghana with strong backing from various departments, including Medicine and Therapeutics (Endocrine Unit), Child Health, Obstetrics and Gynaecology, and Psychiatry. We also work closely with departments from the School of Biomedical and Allied Health Sciences such as Nutrition and Dietetics, Medical Laboratory Science, Pathology, Surgery, the Ear, Nose and Throat Unit, and Centre for Radiotherapy and Nuclear Medicine.

TGF shares similar goals with other thyroid organizations across the world. We seek to create awareness of thyroid disorders, support patients and encourage thyroid research. We also intend to embark on advocacy programmes which would be aimed at addressing several thyroid health issues at the

Some Members of the TGF Medical Education Team: *From Left to Right* – Dr. Dadzie (Specialist Radio Oncologist), Dr. Adabayeri (Consultant Paediatrician) Mr. Repasky (Co-Director, Skywater Gh), Dr. Asante (Head of Dietetics Dept.) Very Rev. Duah (Methodist Church), Rev. Prof. Ayeh-Kumi (Provost, College of Health Sciences/ TGF Board Chair) Mrs. Dsane (Research Development Officer – University of Ghana /Founder-TGF) Dr. Baidoo (Consultant -ENT Unit), Dr. Tetteh (Consultant Surgeon), Mr. Abraham (Co-Director, Skywater Gh), Dr. Mrs. Akpalu (Consultant Endocrinologist).



Section of invited guests at the TGF launch.

governmental level. This involves inviting agencies, such as the Ministry of Health and Food and Drugs Authority, to introduce and revise policies towards promoting thyroid health; which would hopefully include a revision of the iodized salt project and stricter regulations on foods that may contain thyroid damaging agents. More critically we also want to ensure that most thyroid drugs are covered and supplied under the national health insurance scheme.

After the launch we followed up with a series of awareness campaigns on social platforms and media outlets

Patient Support Programme

Most patients reporting for medical care fall below the poverty line and cannot readily afford the high costs of treatment associated with their condition. The inability to afford hospital care has compelled some patients to seek alternative treatment outside the clinics (traditional medicine) which usually turns out to worsen their condition.

This necessitated an early start to our patient support programme. First we paid routine visits to the Endocrine Clinic and Surgical Clinics to educate patients on the measures and lifestyle changes necessary for managing their condition. We keep in contact and track their



(continued on page 29)

Launch of TGF (continued from page 28)

progress from these clinics to enable us support them throughout their treatment process. We offer voluntary registration for the patients to join the Foundation's Patient Support programme and gain invitations to patient seminars, financial support, information on thyroid conditions and treatment and a 24hr help line for patients who may experience crisis or require urgent information. The TGF has an active social media platform (WhatsApp) for our registered patients for easy interactions.

The first TGF Patient Forum was held on the 20th October, 2018 within the premises of the Korle-Bu Teaching Hospital. The Forum was chaired by Rev. Prof. Patrick F. Ayeh-Kumi, Provost of the College of Health Sciences and hosted a panel of physician specialists from the Endocrine Unit, Surgical Department, Centre for Radiotherapy and Nuclear Medicine, and Psychiatry Department. We had a research assistant from the Dietetics to provide information on diet requirements for the various thyroid disorders. The forum was organized because we realized that patients who visit the clinics for treatment do not get ample opportunity to ask questions relating to their condition mainly because the clinics are



Mrs. Nana Adwoa Konadu Dsane (TGF Founder/President) welcoming participants to the Patients Forum.

very busy and time allocated per patient is very limited. The forum was hosted in English and local languages to cater for a wide category of patients. The environment at the event was also very informal to prevent any feeling of intimidation.

TGF has reached an agreement with two medical laboratory companies and currently offers discounts on all thyroid related blood tests and thyroid scans.

ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

India

Thyroid Federation of India

DR M S SENTHIL KUMAR

In India, we are focusing on CME (Continuing Medical Education) for Physicians, so that the medical community can correctly identify and treat Thyroid issues. An Inter-institute National CME on Thyroid and Breast Cancer was organized by the Thyroid Federation of India at SVM Medical College, Tirupati. Dr G V Prakash was the organizing Secretary and Dr N V Ramanaiah was the organizing Chair.

In the year 2019-20, we have planned to organize four Thyroid Camps for patients in rural areas, continue with CME programs at the National Level and consolidate our organization's presence in other parts of India.



Thyroid Camp in the state of MP

In India, urban areas have good doctors but we need to make sure that hypothyroid issues are not over diagnosed and treated. In the rural areas we have a challenge and a need to get patients identified and treated.

We have good pharmaceutical products with multiple doses; however, we need to work on interchangeability issues at the pharmacy level. I was planning on attending the 2019 AGM in Budapest, however, due to a meeting in London, this was not possible. I hope to meet you all at the 2020 AGM.



World Thyroid Day Celebrations in India

TDAK – Who We Are

SARAH KATULLE , FOUNDER, THE TDAK FOUNDATION

The Thyroid Disease Awareness Kenya Foundation (TDAK) was formed and legally registered as a non-profit organization under the Society's Act (CAP) 108 in Kenya, in 2017.

As a thyroid patient, I have personally experienced the difficulties and challenges in the journey towards finding the right medical care and treatment here in Kenya. The journey has involved a lot of mistakes, misdiagnosis, mis-advice from different medical practitioners, which in turn led to not only a waste of time and financial resources but delay in treatment as well, which in turn forced me to resort in having a sub total thyroidectomy (partial thyroid surgery). Through this whole process, I very quickly noted that there was a huge gap between thyroid disease patients and the medical world.

I began by having people come to me, asking for more information about my journey with thyroid disease, how I got treated, which doctor I was seeing, etc. In the process, a childhood friend of mine was struggling with thyroid disease symptoms for so long without having them detected. Neither the family nor the doctors know what was ailing my friend. By the time the doctors came to know, she had already developed the thyroid storm condition due to undetected Graves' hyperthyroidism. Not knowing what to do, they administered some steroidal drug into her blood through IV. Her body and heart couldn't handle it and she died. I was shocked to the core. I was so scared and questioned how I managed to detect it when she couldn't and yet she was my friend. We both had just become new mothers with our babies only a few months apart. Our thyroid conditions were triggered by pregnancy. If I had known, I could have helped her by taking her to see a doctor. Unfortunately, she lived in another city far away from where I was so I couldn't have known. She left a few months old little boy without a mum. It was then that I decided on this mission of ensuring that no one else loses their lives to a condition that, if detected on time, can be treated.

We started with just a Facebook page, where I would post information about thyroid disease. It took some time to build momentum but we had started the ball rolling. Later in the year of 2017, we managed to register our organization and we have been making slow, but sure strides towards our intended outcome every day.

I approached the doctor who had helped me achieve my euthyroid status on creating a collaborative partnership to help me consult the patients I would send to him. Being an auto-immune internal medical practitioner with



a PHD in Internal Medicine, he was the right fit for TDAK. He is employed by the county government but also runs a private practice clinic within the city and outside of the city. However, working with the county government has been a plus for us because he has helped to advise many patients on alternative treatment methods available in the country right now for those who use the public health care system, and cannot afford to use the private health care systems.

What we do and How we do it

Our Mission is to: *Provide accessible, accurate thyroid disease information and affordable, quality, healthcare in Kenya.*

We create thyroid disease awareness across Kenya and its regions, to help save lives through arming people with the right information, guidance and provision of accessible quality thyroid medical care and medication.

We provide information about the causes of thyroid disease, its impact on our bodies and the necessary life style changes required to maintain an overall healthy thyroid gland.

Our aim is to reach people by disseminating information through the organization of medical camps across the counties, holding support group meetings, speaking at events and any other available means that will support us and help to ensure that we reach as many people as we possibly can.

TDAK is the only Thyroid health organization in Kenya. We provide a platform where thyroid disease patients can feel supported and understood, enabling them to come out of the shell of isolation, victimization and even depression. Though advancing technologically, there are still some interior parts of the country where cultural beliefs are very strong. With thyroid disease symptoms being so hard to detect and diagnose, many people are considered "cursed" or under some evil spell.

TDAK's Raison d'être

Most people suffering from thyroid disease in Kenya are oblivious to its causes, symptoms, and forms of treatment. This lack of information has created a big gap between thyroid patients and the world of medical care. There is a dire need for this bridge to be closed by:

1. Giving people the right information about thyroid disease that will ensure that people are armed with information that empowers them to demand the right action in terms of diagnosis which involves a

(continued on page 31)

TDAK – Who We Are (continued from page 30)

- full endocrinology blood work/ test and identifying the right medical practitioner, in this case a thyroid specialist.
2. Decentralizing thyroid treatment access, and ensuring that the right resources are in supply and accessible to everyone in the country. Most thyroid patients are at a greater risk of not identifying their condition, without the right thyroid hormone testing equipment, and medication. This problem is mostly found in the “lower class” level in the city of Nairobi, and the interior parts of the counties within Kenya where people may not be well informed about this condition, or do not have the technological know-how or tools like internet access to research more about it.
 3. Creating thyroid disease awareness across the country. Early detection of thyroid disease makes it easier to treat and avoid other complications in future.
 4. Helping newly diagnosed patients cope with the disease by creating platforms like support group meetings that will help create a safe environment for the patients to come out, talk and share their experiences with fellow victims as well as giving them an opportunity to interact with a Thyroid specialist who will tackle any questions and bring more clarity about the condition.
 5. Decentralizing affordable access to medical services and treatment: Most of the best thyroid specialists are densely populated in Nairobi, the capital city of Kenya. Their consultation fees are also very high,

adding to the fact that the tests themselves are also very expensive. If one does not have medical insurance, it becomes very difficult to follow through with the strict thyroid treatment protocol, which requires routine checkups in order to adjust drug dosage accordingly. Our ultimate goal is to ensure that every major hospital in every county has at least one thyroid testing machine and a thyroid practitioner in order to enable people from those far to reach areas, have access to them with ease and ensure that everyone within Kenya is catered for. In very serious cases after diagnosis, the patient can be referred to Nairobi County where they can get further specialized treatment.

Advocacy:

We are also hoping to advocate for some policy changes within the country to ensure Thyroid testing becomes a pre- requisite test like other tests done before consulting with any doctor. If any inconsistencies in thyroid hormone levels are identified, referral to the right doctor, in this case a thyroid specialist, is done. This is with an aim to detect and arrest the condition early enough to increase the chances of going into remission and avoiding complications later which may lead to unprecedented adverse forms of treatment mentioned above.

As we work hard to achieve our mission and goals, any help and support will really be of value to the people of Kenya. My desire is to have TDAK’s mission implemented in every county within this country.

ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

Nepal

Nepal Thyroid Foundation

GANDHI PRASAD SHARMA, SECRETARY & BC SURENDRA, PRESIDENT

As most new organizations experience, the Thyroid Foundation of Nepal has met with some challenges in the 2018-2019 period. The inauguration was held with great fanfare, with TFI President Ashok Bhaseen’s personal visit to Nepal in August 2018. We managed to find some loyal volunteers and patients who were dedicated to the cause. We went on live radio network and had some direct talks with Thyroid patients, thus spreading education and awareness on thyroid issues.

We have planned for two Thyroid Camps in two major cities of Nepal; one in Kathmandu during the month of Sep-Oct 2019 and another in Pokhara in December 2019. We see more thyroid-related patients in the furthest east and west geographical areas of Nepal.

In 2019-20, we have identified our priority areas, i.e. to streamline our structure and organization. We have



With Nepal ex Prime Minister, J N Khanal (center) a thyroid patient, Ashok Bhaseen and Kajiman Atreya at Kathmandu, Nepal

identified an office location and charted a strategy to seek funding for our operations. We also need to develop our website so that patients can have access to education and information. We are currently forming an education advisory board that includes Endocrinologists and Pharmacists.

Thyroidism Awareness and Support Initiative

Thyroidism Awareness and Support Initiative (TASI) was established and fully registered in Nigeria in 2017. Full operation commenced as soon as legal registration was completed the same year.



THYROID AWARENESS
& SUPPORT INITIATIVE

TASI is a nonprofit, nongovernmental and nonpolitical organisation poised and committed to creating awareness of thyroid disease and as well, providing support for people affected by thyroid disease in Nigeria and Sub-Saharan Africa. The organization was born out of the experience of the founder who passed through the trauma and challenges of her thyroid disorder for four years, before she finally got cured. The fear, financial constraint, negligence by healthcare providers, lack of awareness and the fragile state of Medicare encountered by patients are some of the factors which cause severe suffering for them. TASI was therefore established to bridge the gap. TASI was the first thyroid awareness organisation in Nigeria and the first African member country approved by TFI.

Thyroid Disease in Nigeria

Research has proven that cases of thyroid diseases are underreported in Nigeria and by extension Africa, due to lack of awareness and misdiagnosis.

Empirical research also shows that in Nigeria, in 1993, Thyroid Disease and Goitre prevalence was 20% with 20 million people estimated to be affected by Iodine Deficiency Disorders. There is a goitre endemic belt across Nigeria which is characterised by low iodine content food and lack of sea food.

Solution

TASI has primarily embarked on creating awareness of thyroid disease in community outreaches and diverse media: social, electronic and print. We have a policy push to include thyroid disease as a primary health condition to be given significant attention to risk factors, prevention, eradication and treatment modalities, starting from diagnosis. We have been able to achieve these through collaborations with healthcare providers, relevant stakeholders and medical experts in Nigeria.

In a short while TASI has become a point of reference and a rallying point for gathering information from researchers, medical experts, the general public, thyroid patients and families, concerning thyroid disease and counseling. We also care for the patients and offer them support emotionally, financially and, most of all, free thyroid function tests and other related diagnoses with the support of our major partnering diagnostic company

(MECURE). We also direct them to the proper channels for their treatment and the right specialists that will handle their respective conditions. These are part of our greatest strengths, from the impact made so far.

Impacts

Since we launched into full operation in 2018, we have held our awareness outreaches in more than 10 communities, both rural and urban.

Thyroid awareness is spreading fast in Nigeria due to our relentless efforts in employing diverse media to disseminate information.

TASI has created a Thyroid Support group comprised of thyroid patients, survivors, their families and medical experts. This support group is a rallying point where we learn, add knowledge, exchange ideas and share experiences.

Our awareness drive transcends the urban and rural areas, supporting and ensuring that the less privileged and indigents have equal access to healthcare. Reaching out to communities, educating and sensitising them, working with their leaders to advocate and create awareness helps to demystify their beliefs about thyroid disease. We also help the patients express themselves and conquer their fears about the treatment of thyroid disease, breaking the stigma around thyroid disease in rural communities where the patients are labeled and treated as outcasts. We are also pushing advocacy for the inclusion and prioritising of thyroid disease as part of primary health challenges to be given significant attention like other health issues, such as HIV AIDS, cancer, tuberculosis, diabetes, etc.

More than 20 entities and communities have benefitted from our outreaches and awareness programs and medical supports.

In less than 2 years, about 15 patients have benefitted from our free surgery and treatment, and so far we have not recorded any casualties or complications.

Future Projects

1. To escalate awareness campaigns, medical missions and outreaches across the 36 states of Nigeria, and extend it to the Sub Saharan African nations and Africa at large.
2. To establish a fully funded and equipped **Thyroid Transiting Center** where patients and survivors can visit at any time to seek and get solutions and

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support, a rallying point for counseling, trainings, seminars and empowerment for people suffering from thyroid disease. It will also build a support network where patients interface with medical experts, obtaining free or otherwise subsidized Medicare, a viable avenue for consultation, research, information and data collection.

3. We want to have more people engage in more extensive researches on thyroid disorders and solutions, most especially as it affects Africans.
4. Newborn screening- We are advocating for an Africa where every newborn is screened for thyroid disorders, as early detection would help to treat and eradicate thyroid issues.
5. Publish a book that will serve as a handbook for thyroid health, with a fusion of stories and information that will bring solutions.

Constraints

Our main constraints are inadequate funding and infrastructures, diminished support from governments, and scarcity of medical expertise (endocrinologists, thyroid surgeons, thyroid experts and researchers).

Our core goal is to see a healthier Nigeria and Africa, where people are well informed on health and well being, where healthcare delivery is made available to all and sundry, where adequate facilities are made accessible and affordable to people irrespective of their financial status. A society where patients are not stigmatized because of their health challenges, an Africa where resources are put together to fight and eradicate the scourge of thyroid diseases with sustainable solutions. This will align with the global vision of reducing the mortality rate on non-communicable; this is achievable through strategic collaborations with international organizations and governments across boards.

ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

Nigeria

Goldheart Thyroid Awareness Foundation

FLORENCE OKETONA, CEO/FOUNDER

Our Story

The foundation began when two of my loved ones came down with severe thyroid malfunction in 2015-2017. Those two years were trying times for us in the family as we battled with an ailment which went on without any diagnoses. In an average hospital in Nigeria, a thyroid function test is not part of the routine tests a patient is given in the event of an illness, so thyroid diseases always either go undiagnosed or misdiagnosed. My sister and my cousin suffered untold hardship, treated for different ailments for a very long time.

One day, as my cousin, Funmi Ayandele, waited to catch the bus to work, a young lady approached her after noticing her bulging eyes and emaciated body and advised her to go to a laboratory and ask for a thyroid test and take the results to the specialist hospital in Abuja, the Nation's capital. She did and she was found to have severe hyperthyroidism which had developed into Graves' disease. She hid the results from every other person except us, her family members, until she began treatment and gradually began to get better. She hid the results because it was difficult to explain to her friends what a thyroid malfunction was. She did not want to suffer stigmatization as the people living with HIV do.



Any sickness that causes a person to lose weight without control usually attracts a lot of stigma in Nigeria, because no one believes you should emaciate so much without being seriously sick.

My sister, Racheal Olawole, also suffered from thyroid malfunction without knowing. She gained weight uncontrollably, had problems with her heart rate, slow metabolism and depression. Luckily she had an opportunity to relocate to the United States, where she was diagnosed with hypothyroidism while she worked as a correctional officer in Texas.

A friend, Lisa Eglah Manomi, also walked into my house one day and looked so thin with bulging eyes and when I asked her what was wrong with her, surprisingly, she told me she had a misunderstanding with a relative of hers and the relative afflicted her with the disease which made her lose weight and develop bulging eyes. I proceeded to tell her she may be suffering from a thyroid malfunction and advised her to go and do a test. I also advised her to go to the teaching hospital with the results. She was diagnosed with hyperthyroidism. She has since begun to receive treatment and is one of our success stories in the foundation. She is currently pregnant with her third child.

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Ignorance and Lack of Awareness

As I began to read and research more about the thyroid, I found that there was little or no awareness at all about the disease and even remembered some people who had died with similar symptoms of the disease. I began to identify people with the disease and began telling them to avail themselves of tests. I went to a medical laboratory who told me that they hardly ever do a thyroid function test because very few people come and the few people who come have to wait for at least two weeks to get their results as they have to collect as many blood samples as possible so as not to waste the reagent on only one blood sample. This made me angry and I began to tell people about the malfunction.

In 2017, I met with people of like minds and submitted an application to the authorities to be registered as a legal organization to carry out awareness and start a test center for the purpose and after a very long time, in January 2019, our certificate of registration was finally received and we were free to operate as a legal entity.

Prior to that, we had begun to create awareness among friends and groups, especially women's groups because we discovered that more than 80% of the sufferers were women. On January 17th 2019, we had our very first public event, which was a huge success as we were able to get about 40 people to submit themselves for tests, and about 15 of those people were discovered to have thyroid disease and have begun the treatment.

Our Activities

We have discovered that thyroid malfunction is prevalent in the North Central region of Nigeria especially in the Benue, Plateau and Nassarawa states. In line with this, we have done a number of Radio programs, where people called in to inquire and ask questions on thyroid disease and how to get tested and begin treatment. We work in collaboration with two consultant endocrinologists who we refer our patients to; they are Dr. Austin Arthur who is with the Hope Haven Hospital, Jos and Dr Odoh, who is with the Jos University Teaching Hospital, a specialist in Cardiology. Among our board of Trustees is Dr Mohammed Zabah Jawa who is a consultant in Nuclear Medicine and who was with the National Hospital Abuja before he went to work at Sultan Qaboos University Hospital, Al Khoud Muscat, Oman. He still advises us whenever we have any complicated conditions.

We organize public lectures where our doctors speak on the symptoms of thyroid malfunctions and we record huge successes from the lectures as more people get to know their thyroid status.



Events to Mark World Thyroid Day

We started the week of 20th of May with radio programs and awareness creation. On the 25th which was World Thyroid Day, we organized a street awareness campaign which was a huge success. Our theme for that campaign was "GRAB THYROID BY THE NECK". We marched through the major streets with branded T-Shirts and banners bearing our awareness messages and invited two national television stations, the TVC, AIT and a local state TV, PRTV. These stations aired the march on their various stations. We also invited five national newspapers, Daily Trust, The Nation, Punch, The Sun and leadership newspapers who graciously came to cover the event. We had a lot of volunteers, who helped us share the fliers which contained our awareness campaign messages to people who had been calling our office to book appointments with us for counseling.

Our Social Media Handles

Our social media handles are our biggest platform for spreading our messages. We have our Facebook, Instagram, and Twitter handles where we post messages from time to time on thyroid malfunctions, symptoms and treatments. The response and the reach on our social media handles are overwhelming. Our website (www.goldheartthyroid.com) also helps us spread our message as we have since witnessed increasing traffic on our webpage.

Given the very expensive nature of the tests for thyroid function and the treatment, two hospitals in Jos, Hope Haven Hospital and El-Roi Christian Hospital, have offered generous discounts to patients referred by our foundation for tests and treatments.

We are talking to a number of hospitals in other states of Northern Nigeria to give discounts to patients referred by us in order to avoid having some of our patients travel down to these two hospitals in order to receive the discounts.

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Challenges

Nigeria being a very big country with a huge population and with little or no awareness of thyroid disease it stands the risk of having the condition turn to a huge pandemic. The situation is so bad that even the hospitals miss the symptoms and misdiagnose the condition due to lack of awareness. The huge population in rural areas who do not have access to radios, television or internet need to be reached and this has to be done with proper funding. The government already has other things like insecurity and insurgency to contend with, so about 95% of the rural people who have thyroid disorders end up dying and the cause attributed to affliction from real or imaginary illnesses. Churches and traditional healers are paid by a huge number of people who have thyroid disease and troop to them for healing. Most of these people never get healed and die from the condition.

Thyroid disease is considered a terrible disease; a large number of people in Nigeria who have the disorder either

hide it for fear of stigmatization or are misdiagnosed and treated for entirely different things. This results in deaths and eventually attributed to the 'will of God'.

Solutions

According to medical research carried out by students in the University of Lagos in 2014, about 60 million of the population of Nigeria is living with one form of thyroid disorder or another. This is due to our diets which are loaded with unhealthy carbohydrates and devoid of major nutrients. It is also a result of stress which is mostly prevalent among the people due to insecurity and economic instability. A serious intervention is needed in the following areas:

- More organizations to create awareness
- Establishment of tests and treatment centers
- Availability and affordability of medication
- Intervention for those who need surgery.

PATIENT STORIES

Nigeria

Aisha's Story: Branded A Witch Due To Thyroid Disorder

Aisha Bashir is a 21 year old student of NTA TV College Jos. She first began to have a thyroid disorder when she was 14 years old and in High School. She was treated for malaria and typhoid fever but her condition continued to get worse. She began to lose weight and her eyes began bulging as her condition worsened. She was taken from one hospital to another by her parents but she got no relief as her condition worsened.

She was stigmatized among her friends and classmates and branded a 'witch' because of her bulging eyes. In her boarding house dormitory, she was secluded from others because the school authority thought her condition was contagious. Her grades continued to drop and she almost dropped out of school until her uncle visited home from the



Ukraine and told her parents that Aisha may be suffering from a Thyroid disorder. She was taken to the Federal Medical Center, Lafia, a government hospital where she met with an endocrinologist who probably had never had any thyroid patient referred before due to lack of awareness (most specialised doctors choose another field of practice due to lack of patients).

Her treatment began and Aisha can now enjoy her studies and lives a normal life. She ran into our team in a bank where we went to create awareness and has volunteered with us, sharing her story with others during our awareness campaigns and public

lectures. Aisha is currently still on medication and the foundation at times assists her with money to buy medication.

International Thyroid Awareness Week 2019 in the Philippines

DR. TEOFILO O.L. SAN LUIS, JR.

The International Thyroid Awareness Week in the Philippines was celebrated with two events: the Thyroid Summit on May 22 in Manila; and a capacity-building and community awareness seminar on May 29 in Roxas City (in Central Philippines).

Both of these events featured info to participants regarding iodine deficiency as keystone in the development of thyroid disorders.

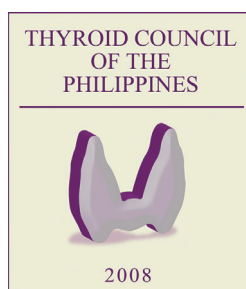
The pull-up tarpaulins on the Krakow Declaration showed the signature of participants who have been made aware of the thrusts of the KD. The Undersecretary of Department of Health (DoH), the Director of the Disease Prevention & Control Bureau and the Thyroid Program Manager led in the signing of the KD.



Thyroid Summit in Manila.

The Thyroid Summit brought together various health professionals involved in thyroid care – DoH officials, patient organizations, local government units (LGUs) and others – to discuss thyroid concerns and the strategies involved in developing partnerships towards thyroid prevention and control.

The Roxas City event was directed to primary care physicians and village health workers who are frontliners in the screening, assessing population groups for thyroid disorders as well as making appropriate referrals.



Sign up on Krakow Declaration.



Patients from the Philippine Thyroid Cancer Survivors (PhilThyCaS) with their president, Mr. Venerando Centeno, Dr. Roberto Mirasol and Dr. Teofilo O.L. San Luis, Jr. at the Thyroid Summit during World Thyroid Day.

The Thyroid Trust

The Thyroid Trust is a new UK charity for everyone affected by thyroid disease, including friends, family and interested professionals. We are committed to providing access to reliable information and a quality peer support experience and we work hard to advocate for patients and to raise awareness of thyroid health issues. The charity has been set up by a group of thyroid patients who have been organising events for thyroid patients in London since 2010.

In 2017 we were offered funding to set up the new charity and appointed an experienced and committed Director, Lorraine Williams, who set up the original patient group, previously worked at Cancer Research UK and is a thyroid patient herself. Lorraine is accountable to a strong board of Trustees who have come together to help guide the new charity, including leading medics, Dr Paul Jenkins and Mr Fausto Palazzo as well as well respected scientific writer and thyroid cancer patient advocate, Judith Taylor.

Dr Anthony Toft kindly agreed to become an Honorary Trustee after speaking at our November 2018 event, which was filmed as is available to view online - search for the hashtag #ToftTalk to see his excellent talk on the Management of Hypothyroidism. We have also released a short 2 minute awareness film, Let's Talk About Thyroid Health and another Information Video, The Evolution of Thyroid Surgery, both filmed at our September 2018 event, with Mr Fausto Palazzo, who is one of our founding Trustees.

In April 2019 we received our registered charity number and so we are now starting to develop our fundraising activity. We have been accepted for listing on The Good Exchange and are starting to approach new trusts and foundations and developing our community fundraising activities with volunteer fundraisers.

Our meetings take place in Central London and thanks to one of our members' husbands who is a train driver, Transport for London have offered us meeting space at their prestigious Palestra Building, next to Southwark station, which we are now using in addition to the Crown Court Church hall in Covent Garden.



BBC SE liothyronine news broadcast with Mary Saunders

We took a leading role in producing a major report for the Department of Health and Social Care on issues with liothyronine prescribing in the UK, The Liothyronine Dossier, working with other thyroid patient groups and the British Thyroid Association, who agreed to be the medical advisors for the report. Subsequently, together with our partners, we have been successful in persuading NHS England, to update their liothyronine prescribing guidance for local health authorities which was reissued, substantially revised in July 2019. NHS England says that patients who require liothyronine should have it prescribed on the NHS but many local health authorities are trying to restrict it's prescribing because of the cost, citing the lack of evidence as their rationale. We have secured coverage for this issue in national, regional and local media, as well as healthcare publications.

Our next challenge is to influence the new NICE Guideline for thyroid disease: assessment and management. We submitted comments on the scope for the Guideline and were pleased that many of our comments were taken on board. We have submitted detailed comments on the draft Guideline in July 2019 and have arranged for the clinical lead, Dr Kristien Boeleart, to give a talk at our January 2020 event.

Please see our website for further information and get in touch if you would like to support us or find out more.

www.thyroidtrust.org



The Thyroid Trust stand at MES 2018. (photo by Judith Taylor)

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Awareness Activities in London

The Thyroid Trust organise regular Information, Support and Get Together events in central London, which are always well attended.

They held an Informal Get Together at the Wellcome Trust Café in London on International Thyroid Awareness Day 2019.

They are planning a follow up awareness roadshow at a Zone 1 Underground station, with the support of the Transport for London Disability Action Network, thanks to TfL train driver and Thyroid Trust volunteer team member, Mike Reid, who has been motivated to help the Trust after seeing how it has helped his partner who has a thyroid condition.

We are finding, more and more, that friends and family of people with thyroid conditions are interested in getting involved in our work.



The Thyroid Trust get-together.



Memories from the ITC 2000 in Kyoto, Japan

ULLA SLAMA, FINLAND

Professor Dr Kazuo Hashimoto was the son of the surgeon Hakaru Hashimoto, who published his discovery of struma lymphomatosa (Hashimoto's Thyroiditis) in 1912.

After meeting him in Japan, I had correspondence with Dr Kazuo Hashimoto. He liked Finland because of the classical music, his favourite composer was Jean Sibelius, and Dr Hashimoto had visited the home of Jean Sibelius together with his wife Suzuko. My son had also been invited to dinner at Dr Hashimoto's home in Nara. He gave me a video about his father. I had a technician

make a dvd copy of the video which I presented to the Endocrinology President of Japan in 2012 at the 100 year anniversary of Hashimoto's discovery (they only had some parts of the video in Japan). The anniversary took place on the island of Kos in Greece, the place where Hippocrates, called the father of medicine, did his life work.

In Orlando in 2015, Dr Professor Nagataki from Japan told me Kazuo Hashimoto had passed away. We shared nice memories of June Rose-Beaty, Dr Hashimoto and Fumi, Dr Fumito Akazu during the 2005 ITC in Kyoto, especially at the excursion to the ancient capital of Nara.



Graves' Disease & Thyroid Foundation

KIMBERLY DORRIS, EXECUTIVE DIRECTOR, GRAVES' DISEASE & THYROID FOUNDATION

It seems like the last twelve months have flown by for Graves' Disease and Thyroid Foundation. We took a collective breath after our three-day Patient & Family Conference in San Diego in June 2018, and went right back to work on our patient education programming!

On October 6th, the GDATAF participated in a community forum in Washington, DC hosted by the American Thyroid Association's Alliance for Patient Education. Two weeks later, we were off to Chicago for double duty: the annual meeting for the American Society of Ophthalmic, Plastic, and Reconstructive Surgeons and also a patient education event presented in conjunction with the 21st International Thyroid Cancer Survivors' Conference hosted by ThyCa: Thyroid Cancer Survivors Association, Inc.. This is a great opportunity for our respective communities, as Graves' patients have a higher risk of thyroid cancer. In a summary for *Clinical Thyroidology for the Public*, M. Regina Castro, MD, writes, "An increased risk of thyroid cancer in Graves' disease has been observed in many studies, particularly when patients with Graves' disease have thyroid nodules. Because of the high frequency of papillary thyroid cancer and a greater percentage of the more aggressive Tall Cell Variant, prompt and careful evaluation of nodules should be performed in any patient with Graves' disease."¹

In January, the GDATAF was represented at the inaugural meeting of the Graves' Disease and Thyroid Eye Disease (TED) patient council hosted by Horizon Therapeutics in Tampa, FL. This unique collaboration between patients and industry will hopefully lead to better care for our entire community!

April kicked off with the American Association of Endocrine Surgeons (AAES) meeting, where the GDATAF was honored to participate in a patient education event co-hosted by AAES as well as a panel to help surgeons understand the patient experience. Later that month, we headed to Los Angeles for the American Association of Clinical Endocrinologists Clinical & Scientific Congress. Teprotumumab was a hot topic at this meeting, with GDATAF Chief Medical & Scientific Officer Dr. Terry Smith and GDATAF Physician Advisory Board member Dr. Raymond Douglas presenting talks on teprotumumab for TED.

TED is a devastating condition, but this is an exciting time for research into potential new treatment options!

Horizon Therapeutics has submitted a Biologics License Application (BLA) to the United States Food and Drug Administration (FDA) for teprotumumab, a potential new treatment for thyroid eye disease. If the application is deemed complete by the FDA - and if Horizon's request for priority review is granted - the next step will be a six-month review process². Another company, Immunovant, is currently recruiting for a Phase II trial for RVT-1401, another potential treatment option³.

As this issue of Thyroworld was going to print, the GDATAF had just wrapped up a patient education event in Seattle, with plans in the works for additional events in Denver, CO and Chicago, IL - as well as one or two additional cities. We partnered with Horizon Therapeutics and rareLife solutions on the recently launched onegravesvoice.com - a site that curates credible medical research on Graves' disease and also provides users for an opportunity to connect with fellow patients. I was asked to write a forward for an e-manuscript on neuropsychiatric complaints in Graves' disease that has just been released on Kindle. To view or purchase a copy, visit Amazon.com and search for "Graves and Arruda". (Dr. James Arruda is the lead author.) And finally, we are also going through a complete overhaul of our gdadf.org website to improve the experience for mobile users. The next twelve months are going to fly by as well!

- 1 Castro, Regina M. "THYROID CANCER: Patients with Graves' disease have a higher incidence of tall- cell variant of papillary thyroid carcinoma." *Clinical Thyroidology for the Public*. Volume 7, Issue 7, Pages 8-9. Retrieved from <https://www.thyroid.org/patient-thyroid-information/ct-for-patients/vol-7-issue-7/vol-7-issue-7-p-8-9/>.
- 2 Horizon Therapeutics. 2019 June 10. Horizon Therapeutics plc Submits Teprotumumab Biologics License Application (BLA) for the Treatment of Active Thyroid Eye Disease (TED). Retrieved from <https://ir.horizontherapeutics.com/news-releases/news-release-details/horizon-therapeutics-plc-submits-teprotumumab-biologics-license>
- 3 Study of RVT-1401 for the Treatment of Patients With Active, Moderate to Severe Graves' Ophthalmopathy (GO). (2019). Retrieved from <https://clinicaltrials.gov/ct2/show/NCT03938545?term=NCT03938545&rank=1> (Identification No. NCT03938545)



TFI Member Organizations

AUSTRALIA

Australian Thyroid Foundation Ltd.
www.thyroidfoundation.org.au

BELGIUM

Leven Zonder Schildklier
www.levenzonderschildklier.be

BRAZIL

Instituto da Tiróide
www.indatir.org.br

BULGARIA

VIOM
www.thyroidbg.com

CANADA

*Thyroid Foundation of Canada /
La Fondation canadienne de la Thyroïde*
www.thyroid.ca

COLOMBIA

*Asociación colombiana de pacientes de
cáncer de tiroides*
www.acolcat.com

CROATIA

*Croatian Association for Thyroid
Disease*
www.stitnjaca.eu

DENMARK

Stofskifteforeningen Blekinge
www.thyreoida.dk

FINLAND

Suomen Kilpirauhasliitto ry
www.kilpirauhasliitto.fi

FRANCE

Association Vivre sans Thyroïde
www.forum-thyroïde.net

GEORGIA (EU)

*Georgian Union of Diabetes and
Endocrine Associations*
diabet@access.sanet.ge

GERMANY

*Bundesverband Schilddrüsenkrebs –
Ohne Schilddrüse leben e. V.*
www.sd-krebs.de

Schilddrüsen-Liga Deutschland e. V.
www.schilddruesenliga.de

GHANA

Thyroid Ghana Foundation
www.thyroidghanafoundation.org

GREECE

Hellenic Thyroid Patients Organization
ledunt@otenet.gr

INDIA

Thyroid Federation of India
medisen@gmail.com

ITALY

*CAPE –Comitato delle Associazioni dei
Pazienti Endocrini*
www.capeitalia.org

JAPAN

Dr Fumito Akasu (Contact)
www.akasu.com

KENYA

*Thyroid Disease Awareness Kenya
Foundation*
[www.facebook.com/
thyroiddiseaseawarenesskenya](http://www.facebook.com/thyroiddiseaseawarenesskenya)

NEPAL

Thyroid Foundation of Nepal
gandhiprasadsharma@gmail.com

THE NETHERLANDS

Leven Zonder Schildklier
www.levenzonderschildklier.nl

Schildklier Organisaties Nederland
www.schildklier.nl

NIGERIA

*Thyroidism Awareness and Support
Initiative*
www.tasinigeria.org

*Goldheart Thyroid Awareness
Foundation*
www.goldheartthyroid.com

NORWAY

Stofskifteforbundet
www.stofskifte.org

THE PHILIPPINES

Thyroid Council of the Philippines
tolsanluis@gmail.com

PORTUGAL

Associação das Doenças da Tiróide
www.adti.pt

ROMANIA

MCT8-AHDS Foundation
www.mct8.info

RUSSIA

Thyroid Foundation of St. Petersburg
gasparyan@peterlink.ru

SPAIN

*Asociación Española de Cáncer de
Tiroides*
www.aecat.net

SWEDEN

Svenska Sköldkörtelföreningen
www.skoldkortel.se

UNITED KINGDOM

The Thyroid Trust
www.ThyroidTrust.org

UNITED STATES OF AMERICA

Graves' Disease & Thyroid Foundation
www.gdatf.org



www.thyroid-fed.org