



Thyroid Federation International

Thyroid Patients Worldwide

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Thyroid Federation International

Established in September 1995 in Toronto, Canada

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Mentor & First President

Lawrence C Wood, MD FACP (USA)



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Message from the Editors

We welcome you to the 2022 edition of our ThyroWorld newsletter. After more than 2 years of pandemic and travel restrictions, where nearly all our meetings were only virtual, we are very happy to be able to meet “face to face” again at our AGM and the ETA meeting in the beautiful city of Brussels, and to show a paper copy of our newsletter again!

Thyroid Federation International celebrated its 25th anniversary in 2020. From 6 founding members when the organization was created in Toronto, back in 1995, it has now grown to more than 35 member organizations in all parts of the world! TFI has been present at the meetings of the European Thyroid Association from the very beginning. Please come and visit our booth in the exhibition area, or contact us for more information!

We encourage everyone who provides evidence-based information to thyroid patients to apply for membership. We are very glad to welcome patient-led and patient-oriented organizations.

Wishing all delegates an interesting congress!

BEATE BARTÈS, PETER LAKWIJK
AND NANCY HORD PATTERSON, EDITORS



Beate Bartès



Peter Lakwijk



Nancy Hord
Patterson



ThyroWorld

Deadline for the next issue: June 20, 2023

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The Editors, ThyroWorld

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President's Message

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

Dear ThyroWorld Reader,

It is great to once again be able to meet face to face, after over 2 years of the pandemic, at the ETA 2022 in the historic and beautiful city of Bruxelles.

Much has changed during the pandemic, however, zoom and other meeting platforms have kept us in touch with each other. Pandemics leave some devastation behind, and we all know one or more people that did not survive its fury. The new variants of Covid continue to pose challenges, however, most governments the world over have relaxed their mask and travel mandates. We must take the necessary precautions as we move on with our lives.

For our 13th International Thyroid Awareness Week (ITAW) in May 2021, the focus was on "Mother-Baby-Iodine", iodine playing a vital role in maintaining a healthy thyroid functioning. Thanks to Dr Zimmerman, Switzerland and Prof Dr Leonidas Duntas, Greece, who presented the topics. For the 14th International Thyroid Awareness Week, May 25-31st 2022, thanks to Dr Kelsey Roelofs, Canada/Fellow UCLA, who presented on Thyroid Eye Disease, while Dr Nancy Patterson, founder of the Graves' Disease and Thyroid Foundation of USA, and Dr Terry Smith, USA, presented on neuropsychiatric complaints in Graves'. We are very thankful to all our supporters and sponsors who provided us with financial support and enabled us to bring these webinars to a global audience. Those of you who would like to listen to these webinar series can also visit our Youtube channel: www.youtube.com/c/ThyroidFederationInternational

TFI had undertaken a big responsibility on a patient survey about hypothyroidism, the E-MPATHY (E-Mode Patient self Assessment of THYroid therapy) study, where many of our member countries were involved. The plans were put down in 2019 and it took 2020 and 2021 to complete & present the survey findings. Picker institute, IBSA, ETA members and TFI partnership were responsible to make this happen. Above all, it was our patients who deserve a big thanks from us to have completed the survey (see article on page)

During this global lockdown period, we have maintained communication with our member organizations, Medical Advisory Board, ETA, ATA, ITC,



Ashok Bhaseen

EEC, EURORDIS, WIC and some other organizations. TFI participated and invested in virtual booths during several online conferences.

Despite the difficulties and barriers the pandemic posed, it did not stop TFI from reaching out to its patients - and with the online meeting platforms, we were able to reach out to a much larger group. We now have our own Youtube channel, where you can access all our webinars and recorded programs.

We therefore:

Continue to leverage the online platforms for meetings.

This year, we are again having an in-person live AGM - however we will maintain the online platform as well, since it is not feasible for everyone to travel yet.

Remain financially responsible in our decisions, stay nimble yet participate in the international forums and meetings.

SAFETY is important and we respect those who take necessary precautions.

Keep moving ahead with our goals, plans and agenda for 2022-23 and beyond.

We know the impact of the pandemic on the populations and on different countries. Yet now we see a ray of hope in moving ahead towards a new normal in the future. As an organization, we are growing and now have over 30 countries as TFI members. TFI remains dedicated to addressing issues related to thyroid patients and ensuring we are present on platforms and organizations that address these issues and find solutions.

On this note of optimism, hope and a brighter tomorrow, let us do our best to keep moving ahead and prepare and save for normal times. We remain upbeat, financially viable, growing and continuing to remain dedicated to doing work for TFI that is very dear to us.

Thanks to all our TFI members, medical advisors, ITAW 2022 speakers, board members, sponsors and supporters and those who follow us in helping us to move ahead in 2022-23.

Looking forward to meet many of you, on site or virtually, during the AGM and ETA meeting in Bruxelles - and hoping to see you all during the ITAW 2023 (May 25th to 31st, 2023).

Ashok Bhaseen, President

Thyroid Federation International
ashok.bhaseen@thyroid-fed.org

Social Media Communications

ANNA BOKOR, SOCIAL MEDIA COORDINATOR

TFI is actively present on social media platforms to inform patients and their families about thyroid conditions, encourage them to consult with their specialist doctor and help them make informed decisions. We always emphasize that early recognition of symptoms and the start of timely treatment are essential to prevent further complications. Thus, we collected some of the most recent research articles and processed them in a way that they would be clear and easy to understand for patients. We also updated our visuals by adding some new design elements for the pictures of the posts, so patients can see at a glance what topic the post would discuss. From this year, we publish articles three times a week, or more on special events (ITAW or important international days).

We currently use Facebook (with 3180 followers), Twitter (with 2200 followers), LinkedIn (started in 2021, with 1460 followers), Instagram (started in 2022, with 3550 followers), and YouTube to reach patients from all over the world. In a short time, Instagram has become the fastest-growing platform. It has also had the most active and the most responsive audience this year. The most remarkable social media activity from our audience in terms of likes and comments was related to our article on Graves' Disease on Instagram (74 likes with organic reach), posts related to levothyroxine on the other two patient-centered platforms, Twitter and Facebook, and articles about thyroid cancer on LinkedIn, a platform that aims to reach professionals. We have received valuable comments and feedback from patients from all over the world (sometimes in diverse languages) and also from endocrinologists who often regard our posts as good reminders.



Here are some topics we have touched upon this year: hormone replacement therapy, thyroid autoimmune diseases, Hashimoto's disease, Graves' Disease, Thyroid Eye Disease, thyroid nodules, thyroid cancer, thyroid disorders in pregnancy, and various conditions that we may regard as separate from thyroid diseases, but are often shown to be linked to thyroid diseases.

We have reached our largest audience with posts that offered information on taking levothyroxine. We discussed differences in administration time, conditions, and medications that may affect its absorption, and we highlighted studies that examined whether changing brands of levothyroxine may impact thyroid function tests. We wrote about persistent symptoms of patients with hypothyroidism despite hormone replacement therapy, brain fog, and other cognitive issues, and we emphasized that there is ongoing research on combination therapy of levothyroxine and new formulations of liothyronine. Similarly, we collected important information for pregnant women who present with hypothyroidism and raised awareness of the issue of iodine deficiency in pregnant women by pointing out MotherBabyIodine, an ongoing project that aims to bring attention to the consequences of Iodine Deficiency Disorders in pregnant women.

We have written several articles that revolved around thyroid autoimmune diseases. We discussed diverse factors that may lead to either Hashimoto's disease or Graves' Disease, and we pointed out the significance of stress and vitamin D deficiency in the development of thyroid autoimmune disease. On ITAW 2022, Dr. Nancy Hord Patterson and Dr. Kelsey Roelofs held webinars about Graves' Disease and Thyroid Eye Disease. We made these videos available on YouTube, and we are glad that more and more patients view them every month.

We have also dealt with topics such as thyroid nodules and thermal ablation as a safe treatment method for benign thyroid nodules, and we gathered relevant information

(continued on page 5)

Social Media *(continued from page 4)*

based on recent studies on thyroid cancer. As thyroid diseases are chronic conditions where patients need extra effort to manage various symptoms, we focused on coping strategies and tips to deal with stress, worry, and anxiety.

Last but not least, we believe it is within TFI's mission to raise awareness of the importance of effective communication between doctors and patients. Therefore, we dealt with this topic in our posts. On the one hand, doctors need to pay attention to the diverse symptoms patients may experience and ensure that consultations are more than a review of ultrasound and lab test results. On the other hand, we encourage patients to do their part by getting timely and appropriate treatment. In our posts, we offered tips on how they can prepare ahead of the consultations with a list of symptoms, other health conditions they are treated with, current medications they are taking, and recent lab results. It is important to understand that every patient has a unique set of symptoms and family history. An in-depth examination enables the identification of various co-morbid conditions which can explain patients' symptoms.



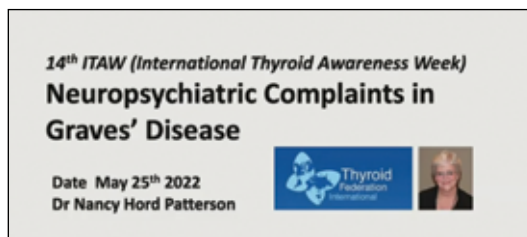
We thank all our followers for regularly reading our articles and sharing their experiences, and we are committed to offering up-to-date information in the future as well.



International Thyroid Awareness Week 2022 TFI webinars

As in 2021, TFI organized webinars during the ITAW (May 25 to 31). We had two speakers:

On World Thyroid Day, May 25th, we had a webinar on the Neuropsychiatric Complaints in Graves' Disease, by Nancy H. Patterson, founder of the Graves' Disease and Thyroid Foundation of the United States. <https://youtu.be/CatnmMKEdsg>



On May 28, we had a webinar on Thyroid Eye Disease (TED) by Dr. Kelsey A. Roelofs MD FRCS Dip ABO.

https://youtu.be/K_iQoAFnECM



All our webinars, and various other videos on thyroid disease, can be found on the TFI YouTube Channel:

<https://www.youtube.com/c/ThyroidFederationInternational>

TFI online AGM 2021

In 2021, as in 2020, due to the ongoing pandemic, our AGM was organized online, with the help of Porter Novelli. This was a challenge, but also an opportunity, allowing members from all around the world to participate, without need to travel and without any expenses.

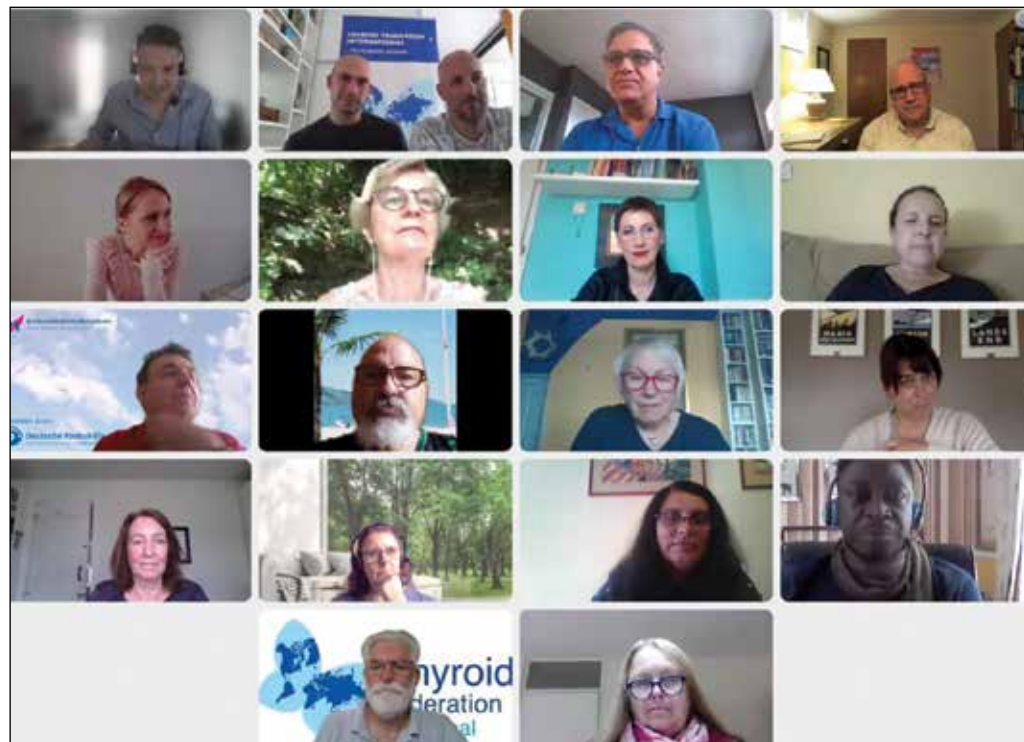
The AGM took place on Friday and Saturday afternoon, from 2 to 5 pm CET. We had over 20 representatives of our member organizations, and also interested patients and endocrinologists from approx. 20 countries. The members presented their

organizations and others attending spoke on minimally invasive treatment for thyroid cancer, on Thyroid Eye Disease, on Targeted treatments, on the European Society of Endocrinology, on Eurordis, on EUPATI, on the European Patient Forum and on the E-MPATHY study on hypothyroidism. The TFI board also presented the yearly activity report, the financial report, the TFI projects and activities, and various votes were done online.

It was good to meet everybody “online” – but it will be even better to be able to meet again “face to face”!



Screenshots of the participants to the TFI online 2021 AGM– day one and two.



We thank our Sponsors and Supporters



MERCK KGaA Darmstadt, Germany



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.

Upcoming Events

To view the most up-to-date information, visit our website:

<https://www.thyroid-fed.org/tfi-wp/events/>

September 15-17, 2022

ESPE, European Society for Paediatric Endocrinology, Rome, Italy

October 1, 2022, , 2022

WCTC4, virtual meeting

October 20-23, 2022

EndoBridge, Antalya, Turkey

October 19-23, 2022

91st annual meeting of the ATA, American Thyroid Association, Montreal, Canada

June 15-17, 2023

WCTC 2023, London, England

September 9-12, 2023

45th meeting of the ETA, European Thyroid Association, Milan

September 27-October 1, 2023

92nd Annual Meeting of the American Thyroid Association, Washington, DC, USA

Annual Awareness Events

January

Thyroid Disease Awareness Month



May 25

World Thyroid Day



May 25 to 31

International Thyroid Awareness Week
www.thyroidweek.com



June 1

International Hypoparathyroidism Awareness Day



July

Graves and TED Awareness Month

September

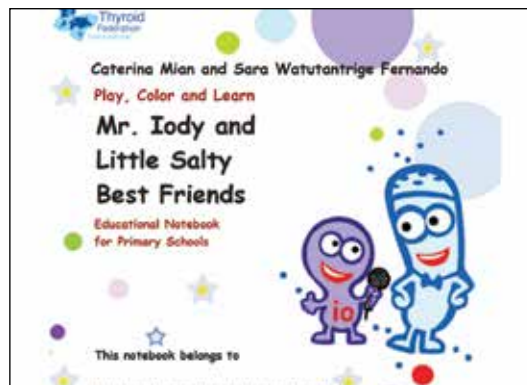
Thyroid Cancer Awareness Month



Mr. Iody and Little Salty

Thyroid Federation International worked closely with Caterina Mian and Sara Watutantrige Fernando and the illustrator Maria Teresa Santinato to translate from Italian into English this educational and whimsical book entitled “Mr. Iody and Little Salty – Best Friends” for children (6-10 years) to further their knowledge on Iodine and the correct use of salt. It is a 38 page booklet in PDF format that can be downloaded upon request – or it can be printed to distribute in schools for educational purposes.

Don't hesitate to contact us:
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Thyroid Federation International would like to thank for their collaboration:

- The authors Caterina Mian and Sara Watutantrige Fernando
- The illustrator Maria Teresa Santinato
- The translator Linda Henderson
- All the Italian supporters that made this book possible
- Editor Peter Lakwijk

More reliable information about the need of iodine can be found on:

- www.MotherBabyIodine.org
- www.ign.org
- www.gain.org
- www.NutritionIntl.org



The E-MPATHY Project

PETROS PERROS, LASZLO HEGEDŰS, ENDRE NAGY, ENRICO PAPINI, HARRIET HAY, JUAN ABAD-MADROÑERO, AMY TALLETT, MEGAN BILAS, PETER LAKWIJK, ALAN POOTS

E-MPATHY (acronym for E-Mode Patient self-Assessment of THYroid therapy) is a remarkable achievement that emanated from collaboration between TFI, thyroid experts and Picker Institute Europe. This month sees the first peer-reviewed publication from E-MPATHY in the prestigious journal of the American Thyroid Association “Thyroid”¹. Many of the readers of this newsletter took part in the survey and we are grateful to them for their time and effort.

Why do the survey?

Over the past 20 years several studies have documented that a significant minority of hypothyroid patients experience persistent symptoms, usually attributed to lack of effectiveness of the thyroid medication. This phenomenon continues to be poorly understood. E-MPATHY was constructed in order to gain more insight into the experiences of hypothyroid patients. In particular, we were interested to get as broad a spectrum of responses as possible, preferably from several different countries and diverse cultures.

Who was involved?

TFI, a team of doctors specialising in the thyroid and Picker (an international charity dedicated to improving people’s experiences of health and social care). IBSA Biochimique SA provided financial support.

How was it organised?

Following a series of meetings, an online questionnaire was constructed with contributions by the thyroid experts, Picker and TFI. It was tested, piloted and translated from English into four languages: French, German, Italian, and Spanish. TFI disseminated the questionnaire to patient organisations using its global networks. The data were collected and analysed using sophisticated statistical methods by the Picker team.

What were the major findings?

We found that satisfaction with care and treatment was not associated with type of treatment for hypothyroidism. Dissatisfaction correlated strongly with having no confidence and trust in healthcare professionals. In addition, there were indications of differences in satisfaction rates between countries. Respondents taking levothyroxine alone, were more likely to report a positive impact on everyday living than those taking liothyronine-containing treatments.



What was the most important finding?

The association between dissatisfaction with care and treatment for hypothyroidism and lack of confidence and trust in healthcare professionals perhaps will not surprise the readers of this newsletter.

Trust is a crucial part of interaction between people. Trust between patient and doctor is the cornerstone of the medical consultation and even plays a major role in how well treatments work². So, what makes people trust their doctor? One fundamental determinant of trust is time. That is, the time patients are given to tell their story. Too often patients are not given enough time with their doctor. One reason is that doctors, like many other professionals, need to do so much paperwork and documentation, that it eats into the consultation with the patient. Ironically that paperwork is required because our institutions demand accountability in order to ensure that professionals can be trusted.

What are our reflections on these findings?

The value of E-MPATHY lies primarily in the message it sends to doctors who treat patients with hypothyroidism: there is a need to gain trust. The British philosopher Onora O’Neill has written extensively about trust³. Her proposition goes like this: it would be silly to expect the public to trust healthcare professionals, because although most can be trusted, some cannot and should not. Instead we should try and judge if someone is trustworthy based on competence, honesty, and reliability. It is still tough for a patient to judge whether they can trust their doctor. One can make sure that they have the required qualifications and that they are accredited in their specialty. Being members of recognised professional organisations also helps. If they

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E-MPATHY (continued from page 9)

have published in peer reviewed medical journals on a particular area of medicine, that would give an extra point. In some countries it is possible to find out if a doctor has been subjected to restrictions in their practice by regulatory bodies. Finally, in this era of “TripAdvisor” culture, online reviews of doctors may also be available in some countries. None of these are totally reliable. Some untrustworthy individuals will find ways of slipping through the net and conversely trustworthy doctors will be judged unfairly.

Onora O’Neill has an additional interesting piece of advice to those who wish to become more trustworthy: show your own vulnerability. Doctors can and should share with their patients that existing knowledge is limited, that there are uncertainties and that predictions about outcomes of treatment are far from perfect. Doctors can also learn from what hypothyroid patient organisations do so well. When a person posts about their troubles and difficulties fellow sufferers immediately shower them with their kind, thoughtful messages and good wishes. In other words empathy. Perhaps the acronym of this study was prophetic of its findings.

What was the most surprising finding?

A great deal has been said in social media, hypothyroid patient sites and in the medical literature about combination treatment (L-T₄+L-T₃ or desiccated thyroid extract). Patient testimonies seem to favour combination treatment, however several randomised controlled studies have failed to show a difference between L-T₄ and combination treatment in quality of life, symptom control, neurocognitive function and psychological well-being⁴. We expected E-MPATHY to show that satisfaction with treatment and care of hypothyroidism to cluster around combination treatment

and desiccated thyroid extract. We found no association between type of treatment for hypothyroidism and patient satisfaction. Furthermore, better outcomes on everyday living were associated with levothyroxine, compared to liothyronine-containing treatments. This may reflect how respondents were selected and the impact of different cultures on expectations and perceptions, an area that needs to be explored further.

What next?

E-MPATHY is a huge resource and there are still data to be mined and several other important questions that may be possible to address. For instance how dissatisfied hypothyroid patients differ in their characteristics from those who are satisfied? Ultimately E-MPATHY will hopefully be a basis upon which new hypotheses can be formulated and tested using robust scientific methodology.

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NEWS FROM THE THYROID FIELD

European Society of Paediatric Endocrinology

Thyroid Federation International is invited to exhibit on the 60th Annual ESPE Meeting to be held in Rome, Italy, from 15-17 September 2022. The theme for the Meeting is “Personalized Medicine in Paediatric Endocrinology”.

The tremendous advancement in molecular biology has led to innovative approaches to many endocrine conditions thus permitting more accurate diagnoses, tailored therapies, and adequate genetic counselling.



Whereas the personalized medicine approach has been increasingly applied to diagnose and treat endocrine disorders in adults over the last decade, its implementation in paediatrics is still at the beginning. The meeting will focus on the application of personalized medicine to the child with endocrine disorders. The main discoveries in genetic/genomic research as well as their present and future impact on the management of paediatric conditions will be extensively covered in plenaries and symposia.

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ESPE (continued from page 10)

The programme will include Plenary and Symposia lectures by outstanding international speakers, Meet-the-Expert and How Do I... sessions by experienced clinicians who are world leaders in their fields, Controversy and Novel Advances sessions are designed to make professionals re-evaluate the way they think and work. Free Communications will allow both experienced professionals and their younger trainees the opportunity to present their work in oral sessions, and there will be ample opportunities for further presentations and discussion in the poster sessions, which will include both physical and electronic posters.



The Meeting will be held in the “La Nuvola” Convention Center. “La Nuvola” is one of the most iconic buildings in the entire city of Rome. This visionary building by Massimiliano Fuksas has been inaugurated in 2016 and since then it has been acknowledged worldwide as a fine example of contemporary architecture, characterized by eco-friendly materials and innovative technological solutions.

TFI is proud to be part of this meeting and will show their dedication to all thyroid patients, young and old, as well as common and rare.

NEWS FROM THE THYROID FIELD

EndoBridge

BULENT O. YILDIZ
FOUNDER & PRESIDENT, ENDOBIDGE

Endocrinology has become a large and rapidly growing field of medicine that is instrumental in addressing several disorders including pandemics of diabetes, obesity and cancer.

As physicians and scientists from different countries and cultures we really need to learn from each other so that we could successfully prevent and treat endocrine diseases.

EndoBridge is a unique educational initiative with the vision of bridging the world of endocrinology supported by leading international organizations in the field, Endocrine Society and European Society of Endocrinology in collaboration with Society of Endocrinology and Metabolism of Turkey. In the last two years, American Thyroid Association and Brazilian Society of Endocrinology and Metabolism have also joined us as program partners.

The 10th Annual Meeting of EndoBridge is being held from October 20 to 23, 2022 in Antalya. Accredited by the European Council, the three-day scientific program of EndoBridge® includes inspiring state-of-the-art lectures by world leaders and interactive discussions of several interesting and challenging clinical cases, covering all aspects of endocrinology including diabetes and lipid disorders.

More importantly, the meeting provides a great opportunity for our colleagues from around the world to



EndoBridge, Okan Bülent Yıldız

interact with each other and share their experience and expertise.

The unique and highly influential model of EndoBridge enhances cross cultural dialogue, understanding and collaboration beyond the national borders in the world of hormones.

It is our great pleasure to welcome our colleagues at the Bridge, in Antalya this October.



Effects of Common Genetic Variation in 96 Genes Involved in Thyroid Hormone Regulation

ROSALIE STERENBORG MD; MARCO MEDICI MD, PHD
 DEPARTMENT OF INTERNAL MEDICINE, DIVISION OF ENDOCRINOLOGY, RADBOUD UNIVERSITY MEDICAL CENTER, NIJMEGEN, THE NETHERLANDS
 ACADEMIC CENTER FOR THYROID DISEASES, DEPARTMENT OF INTERNAL MEDICINE, ERASMUS MEDICAL CENTER, ROTTERDAM, THE NETHERLANDS

With a prevalence of 5-10%, thyroid diseases are among the most common diseases in the general population. Thyroid dysfunction, even mild, increases the risk of various adverse clinical outcomes, including myocardial infarction, atrial fibrillation, stroke, depression and mortality. The current goal of treatment is normalization of the patient’s serum thyroid parameters to levels within the population-based reference ranges. Despite having corrected thyroid hormone levels to the normal range, a substantial part of the treated patients still experiences residual disabling hypo- or hyperthyroid complaints.

Twin studies have shown that 57-71% of the total variation in blood thyrotropin (TSH) and free thyroxine (FT4) levels is determined by genetic factors. In 2018, a large genetic genome-wide association study (GWAS), in which small differences in the DNA are investigated, identified 109 genetic variants determining variations in TSH and FT4 levels. These genetic variants are common in the normal population and are also known as single nucleotide polymorphisms (SNPs) [Figure 1].

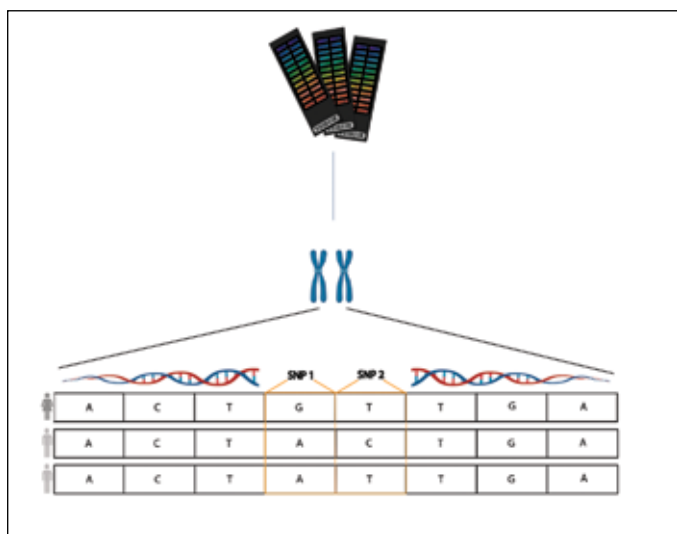


Figure 1. Variations at single sites in DNA (SNPs) are detected by a SNP array, which is a blood test. Each SNP represents a difference in a single DNA building block, called a nucleotide (C=cytosine, G=guanine, A=adenine, T=thymine). For example, a SNP may replace the nucleotide guanine (G) with the nucleotide adenine (A) in a certain stretch of DNA (SNP 1).

Surprisingly, most SNPs are allocated to genes with a yet unknown role in thyroid hormone regulation. For these reasons, we performed a large candidate gene study to look at the contribution of common genetic variation in genes that do play a known role in the regulation of thyroid hormone.

Specifically, we investigated candidate genes which play a central role in the production of thyroid hormone via the hypothalamic-pituitary-thyroid axis (HPT-axis). We furthermore included genes that are of importance in different peripheral organs where thyroid hormone exerts its effect, such as metabolism genes responsible for the conversion of inactive thyroid hormone (T4) into active thyroid hormone (T3), thyroid hormone transporters, as well as thyroid hormone binding proteins. In total, we included 96 candidate genes and assessed the effects of common genetic variants within these genes on normal range TSH and FT4 levels in blood using the data of the aforementioned thyroid function GWAS from 2018.



Figure 2 Current state of knowledge of the variation in normal range thyroid function explained by genetic factors.

Within these 96 candidate genes we found 78 SNPs, of which 48 were novel: 23 novel SNPs determining TSH levels, which were mainly located in HPT-axis genes, and 25 novel SNPs determining FT4 levels, which were predominantly located in peripheral metabolism and transporter genes. The remaining 30 SNPs were already previously identified in GWAS. All common SNPs in the genome accounted for 21% of the total variation in both TSH and FT4 levels, of which only 1.9% and 2.6% is determined by genetic variation in the 96 studied candidate genes respectively. [Figure 2]

In conclusion, these results provide novel insights into the role of common genetic variation in genes with a known role in thyroid function. Importantly, the fact that these variants only explain a minority of the

(continued on page 13)

Thyroid Hormone Regulation (continued from page 12)

variation in thyroid function shows that many genes in thyroid hormone regulation still need to be discovered. We are therefore currently performing several large genetic studies in our ThyroidOmics Consortium (www.thyroidomics.com) to identify these responsible genes. In this manner we will not only learn more about thyroid hormone (patho)physiology, but we will also study whether these genetic markers could be used to improve the diagnosis and treatment of thyroid disease patients.

Full paper

Sterenborg et al. The Effects of Common Genetic Variation in 96 Genes Involved in Thyroid Hormone Regulation on TSH and FT4 Concentrations

Clin Endocrinol Metab. 2022 May 17;107(6):e2276-e2283. doi: 10.1210/clinem/dgac136.

References:

Hansen PS, Brix TH, Sorensen TI, Kyvik KO, Hegedus L. Major genetic influence on the regulation of the pituitary-thyroid axis: a study of healthy Danish twins. J Clin Endocrinol Metab. 2004;89(3):1181-1187.

Kus, A., Chaker, L., Teumer, A., Peeters, R.P. & Medici, M. The Genetic Basis of Thyroid Function: Novel Findings and New Approaches. J Clin Endocrinol Metab 105(2020).

Teumer A, Chaker L, Groeneweg S, et al. Genome-wide analyses identify a role for SLC17A4 and AADAT in thyroid hormone regulation. Nat Commun. 2018;9(1):4455.

NEWS FROM THE THYROID FIELD

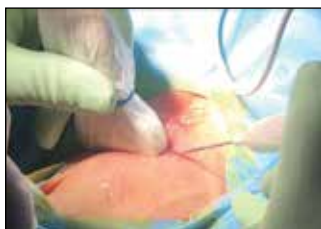
T.N.T. (Thyroid Nodule Therapies Association)

ROBERTO VALCAVI, MD, FACE, ECNU (T.N.T. PRESIDENT)

The T.N.T. (Thyroid Nodule Therapies) Association is an International Medical Organization focused on improvement and the worldwide dissemination of Thyroid Ultrasound-Guided thermal ablative techniques to treat Thyroid nodules in a minimally invasive way. Different medical specialties are involved in the TNT Association: endocrinologists and interventional endocrinologists, head & neck and endocrine surgeons, interventional radiologists, nuclear medicine and other specialists.

The TNT Association hold International Meetings, webinars and training courses on new thyroid ablative procedures. The president of the TFI Mr. Ashok Bhasen has been invited to lecture on "Patient Advocacy: a Patient' Point of View" at the 2nd TNT Meeting. Furthermore, the TFI will have a booth in this Meeting.

Thyroid nodules are very common and are found more frequently in the female gender. Nodules are generally diagnosed through an ultrasound examination of the neck. The fine needle aspiration cytology allows the diagnosis of the nature of thyroid nodules. Lumps may be visible and create cosmetic concerns. Large thyroid nodules compress the anatomical structures inside the neck, causing problems with swallowing or breathing.



Radiofrequency Thermal-ablation (RFA) is a minimally invasive ultrasound guided procedure that is used as an alternative to classic surgery. The treatment involves the introduction of a needle-electrode in the nodule lesion and the delivery of high-frequency energy that heats and destroys the nodule. Best results are obtained on benign nodules with a volume <30 ml, oval-shaped and with a colloid-cystic spongiform echostructure, or in cystic or partially cystic benign nodules. There is evidence that in non-metastatic T1 N0 M0 primary papillary cancers thermal ablation technology obtains the same results as open surgery

Side effects are minimal in a dedicated setting. They include discomfort in the neck, skin bruising, dysphonia (hoarse voice due to overheating of the recurrent laryngeal nerve. The infusion of cold glucose solution + 2 ° C dissecting the inferior laryngeal nerve from thyroid nodule minimizes the risk of recurrent laryngeal nerve injuries.

The advantages of ultrasound-guided radiofrequency over traditional "open" surgery are: absence of scars, organ preservation and normal function of the thyroid after thermal ablation, no need to take any therapy, minimal side effects, no need of deep general anesthesia, absence of postoperative drainage tubes, no need

(continued on page 14)

T.N.T. (continued from page 13)

of hospitalization, much faster recovery, minimized aggression, improvement of the quality of life.

Website: <https://thyroidnoduletherapiesassociation.com/>

Following the success of the 1st TNT Meeting, Nov 15th-16th 2019, and of the TNT Webinar on thyroid RFA, I warmly invite you to participate in the 2nd TNT (Thyroid Nodule Association) Meeting. This will be an in-person Meeting.

Purpose of the 2nd TNT Meeting is disseminate worldwide knowledge on thyroid thermal ablation techniques. Diagnosis, indications, technologies and techniques used for thyroid ablation, side effects, international guidelines, and future directions will be covered in this Conference. Hands-on practice will be available for participants.

Register for the 2nd TNT Meeting in Reggio Emilia, Italy.

<https://thyroidnoduletherapiesassociation.com/2nd-tnt-meeting-landing/>

Save the date: June 23rd-24th, 2023.



International Clinical Trials Methodology Conference 2022

The MRC-NIHR Trials Methodology Research Partnership is delighted to welcome you to the 6th International Clinical Trials Methodology Conference 2022.



ICTMC is the leading international platform for researchers and practitioners to present the very latest in trials methodology research. The meeting also offers valuable networking and training opportunities, with over 750 delegates from 22 countries attending in 2019.

The conference will take place October 3-6, 2022 in the beautiful and vibrant spa town of Harrogate, located in the heart of Yorkshire and on the edge of the Yorkshire Dales National Park, a designated Area of Outstanding Natural Beauty. Nearby is the historic city of York, as well as a number of attractive market towns, which altogether



make an extended visit to the region appealing.

The meeting venue is Harrogate Convention Centre, which is both spacious and modern. A diverse programme is prepared by the Scientific Committee and Education

Committee, which promises to make this a highly rewarding and enjoyable meeting for all.

The International Clinical Trials Methodology Conference has adopted the Patients Included Conferences Charter to demonstrate the commitment of the conference organisers to incorporating the experience and insights of patients and carers into the planning and running of the conference and to making the conference open to patient and carer delegates.

Thyroid Federation International is invited to introduce their ThyroCAB at the conference. ThyroCAB is a Community Advisory Board for different thyroid diseases.

We look forward to welcoming you to ICTMC 2022!

ICTMC 2022 LOCAL ORGANISING COMMITTEE

<https://ictmc.org/>

A Tribute: 80 Years Diagnosing and Treating Thyroid Carcinoma

Dr Saul Hertz (1905-1950) Originator of the medical uses of radioiodine (RAI)

“Somewhere in the basement of the Bulfinch Building, Dr. Hertz carried out experiments with results that would forever change medicine.”

DAVID F.M. BROWN, MD PRESIDENT, MASSACHUSETTS GENERAL HOSPITAL (OCTOBER, 2021 – AMERICAN CHEMICAL SOCIETY (ACS) NATIONAL HISTORIC MEDICAL MIRACLE LANDMARK INSTALLATION)

Let us pay tribute to Dr. Saul Hertz, who conceived and brought from bench to bedside the medical uses of radioiodine. In November, 1936, at a lecture by the president of the Massachusetts Institute of Technology (MIT), Dr. Hertz spontaneously asked, « Could iodine be made radioactive artificially?» Dr Hertz, Director (1931-1943) of The Massachusetts General Hospital (MGH) Thyroid Unit, had been working on a non-surgical method of treating hyperthyroidism. Dr Hertz collaborated with MIT’s Arthur Roberts, PH.D., in 1937 to design and perform preclinical studies. Hertz and Roberts demonstrated the tracer qualities of non-cyclotron produced I-128, to study thyroid physiology. It is important to note that at that time, Dr. Hertz hypothesized RAI to treat thyroid carcinoma.



On March 31, 1941, Dr. Hertz administered the first therapeutic use of MIT cyclotron produced RAI. This first clinical study demonstrated the success of RAI to diagnose and treat Graves’ disease/hyperthyroidism. He made use of uptake testing and dosimetry to determine an effective dose to establish a precision-targeted approach.

In 1942, he conducted and reported his trials of thyroid cancer patients to the Markle Foundation, that funded the MIT cyclotron. After WWII, with funding from the Navy, Dr Hertz refined the use of RAI in diagnosing and treating thyroid carcinoma, at Boston’s Beth Israel Hospital.

In June, 1946, The American Magazine quotes Hertz, stating, “...demand is expected for radioactive iodine and as research develops in the field of cancer and leukemia, for other radioactive medicines.” Additionally predicting, “My new research project is in Cancer of the Thyroid which I believe holds the key to the larger problem of Cancer in general.” In September 1946, he founded The Radioactive



Isotope Research Institute, with facilities in Boston and New York.

He successfully treated thyroid cancer and researched the use of radionuclides and hormones for other forms of cancer. In May 1949, a Harvard

Crimson headline read “Hertz to Use Nuclear Fission in Cure for Cancer”.

Financial pressures created a challenge for RAI’s acceptance. The cost of RAI was dramatically reduced with production of RAI from the atomic piles. There was significant push back to RAI being a less expensive treatment than surgery. Discrimination played out in educational and medical institutions with quotas and other restrictions. In 1931, he was not paid or allowed on the staff as was customary at that time for outsiders. Questionable ethics regarding medical publication as well as false information created fear. A world war shut down normal daily life, just as the pandemic has done recently.

In 1949, he established the first Nuclear Medicine Department at the Massachusetts Women’s Hospital... reported as, “Opening a new division where radioactive isotopes will be used to study and treat diseases.” Hertz’s enduring treatment and the process of targeted therapy has extended the lives of countless generations of patients worldwide. A thyroid cancer survivor emailed, “Treatment with radioactive iodine knocked the thyroid cancer (metastatic to a little bit of bone and lung) right out of me, exceeding my doctor’s expectations... We have a large family. Many were praying for me. The cure delivered on the wings of prayer was Saul Hertz’s discovery, the miracle of radioactive iodine. Few can equal such a powerful and precious gift.”

The history of Dr Saul Hertz’s paradigm changing work will be displayed at the European Thyroid Association (ETA) 2022 Annual Meeting in Brussels, September 10 – 13. Concurrently, The World Federation of Nuclear Medicine and Biology (WFNMB) will be granting a “Dr Saul Hertz Young Investigator Award” in Japan, in the presence of Dr Hertz’s daughter Barbara.

Several awards have been established to honor Dr Saul Hertz and his profound contribution to modern medicine by The Society of Nuclear Medicine, The British Society of

(continued on page 16)

Australian Thyroid Foundation 2022 Review

GP Education

The last two years has been very difficult for all of us to get through, due to COVID infections, isolations and ensuring environments are safe without any risk.

Here in Australia, we have lived through many lockdowns and restrictions, which has made it extremely difficult to connect to our members, the public and hold events.

The ATF's number one priority is to improve outcomes for patients. The ATF and our Medical Advisory Board have been working with a GP educational platform which provides different avenues of education to give GP's and other HCP's the opportunity to broaden their knowledge on particular health issues.

The ATF Medical Advisors produced seven podcasts which will be available for doctors to learn from Australia's leading thyroid experts.

The ATF is acknowledged as the link between doctors and patients with an advertisement on each podcast.

We have been given access to the podcasts for our HCP Section on the ATF website.

The ATF, with our Medical Advisors, is very proud to have the opportunity to be part of this program, which will help improve doctors' knowledge of all aspects of thyroid disorders, with the awareness that the ATF is available to support and educate patients through their thyroid journey.



ATF Medical Advisors and Podcast Presenters:
Professor Bruce Robinson, Professor Creswell Eastman, Professor Leigh Delbridge and Associate Professor Roderick Clifton Bligh.

Dr. Saul Hertz *(continued from page 15)*

Nuclear Medicine, The South African Society of Nuclear Medicine and The Theranostics World Congress.

A video from the recent installation (October 2021) of the American Chemical Society's (ACS), Dr. Saul Hertz and The Medical Uses of RAI, National Medical Miracle Historic Landmark at The Mass General Hospital:

<https://vimeo.com/648309750/95ab6b31a7>

Before you Plan a Family, How is your Thyroid Health? (Media Release May 2022)

May is the time of the year for the Australian Thyroid Foundation's (ATF) Thyroid Awareness Month. Recent research from The Lancet – March 2022 emphasises the consequences and risks of an inadequate amount of thyroid hormone at conception, during pregnancy and whilst breastfeeding.

‘Without an adequate amount of thyroid hormone mothers can be exposed to hypertensive disorders of pregnancy, including gestational hypertension and preeclampsia or eclampsia, which affect around 10% of pregnant women and are the leading causes of maternal and neonatal mortality worldwide. Mothers who suffer from hypertensive disorders during pregnancy are at increased risk of long-term cardiovascular consequences and hypertensive disorders in subsequent pregnancies. Evidence also indicates a risk of reduced cognitive ability to their offspring.

Knowing if you are genetically predisposed to Hashimoto's or Graves' Diseases, which are both thyroid autoimmune disorders is important to be aware of, to ensure all appropriate tests are ordered. Autoimmune disorders may predispose mothers to a thyroid problem during pregnancy, says Professor Creswell Eastman, ATF Principal Medical Advisor.’

Read more at: https://www.thyroidfoundation.org.au/resources/Documents/Media_Release

ATF Magnet

The ATF have produced a magnet in the shape of a thyroid gland with ATF information and contacts. The magnet has been distributed to GP clinics around Australia. Its purpose is to be placed on the clinic's refrigerator door, so when doctors reach for milk to be added to their tea or coffee, they will be reminded the ATF is available as a resource for their thyroid patients.



Continuing our Commitment

The ATF is now in our 27 year and proud to be supporting patients with one-on-one support, education and information. Reaching out to the Australian community with awareness about the benefits of good thyroid health and how to overcome iodine deficiency, particularly for pregnant women.

www.thyroidfoundation.org.au

Bangladesh Thyroid Society, Active in Social Services



PROF FARIDUL ALAM MD PHD.
SECRETARY GENERAL BTS. COUNCIL
MEMBER AOTA, BOARD MEMBER
THYROID FEDERATION INTERNATIONAL

The Bangladesh Thyroid Society (BTS) was formed in 2017. Initially the BTS was formed by Nuclear Medicine Physicians, Endocrine specialists and ENT specialists. The objects of our Society are to increase the quality of service to patients, research of thyroid sciences, awareness to the public regarding thyroid disease and its consequences and holding seminar-symposiums. BTS is making communications among other international and national thyroid organizations. The Bangladesh Thyroid Society is a member of the Asia-Oceania Thyroid Association and Thyroid Federation International (TFI), among others.

Since its inception, BTS has been carrying out its activities regularly for improvements in thyroid science practices among our members and other scientific communities. The BTS is making social responsibility its main activity. In this regard, in 2019, 2020 and 2021, the month of January was made thyroid awareness month. Five thousand posters, focused on hyperthyroidism and hypothyroidism and displaying clinical features of the diseases, were placed in various public places; thus, a good number of the public were made aware of the thyroid and its main diseases.

BTS held a series of webinars regarding different thyroid diseases where both thyroid experts and patients were present. We used social media, print media and electronic media to reach the general public and patient population.

We know that iodine is important in pregnancy for sufficient production of thyroxin, which is essential for the physical, intellectual and neural development of the healthy baby. Iodine deficiency can lead to poor pregnancy outcome and low IQ in children. Recently we



have been working with TFI for the improvement of iodine in mother and baby. Approximately ten thousand leaflets and posters will be distributed throughout the country, targeting preconception and pregnant women. This leaflet is designed by the IDF. We translated

it in our mother language Bangla so that all the target groups can understand easily.

Young women of reproductive age are the most vulnerable group for iodine deficiency disorders, because of the strong demand of iodine during pregnancy and early life for the production of thyroid hormones in the offspring, which are required for their neurocognitive development. While severe iodine deficiency during pregnancy may cause cretinism, a syndrome including growth and mental retardation in children, also mild-to-moderate iodine deficiency is related to impaired neurocognitive development in children. With respect to the latter, iodine deficiency increases the risks of lower cognitive and intelligent scores, less reading and language skills, lower school performance, diminished executive function, and Attention-Deficit/Hyperactivity Disorder in the offspring. Further potential sequels of mild-to-moderate iodine deficiency during pregnancy include increased risks for preterm birth, low birth weight and fetal growth retardation. Considering the above facts, the Bangladesh University of Health Science with the help of the Bangladesh Thyroid Society will take part in the Project Euthyroid 2, the project of the European Union for assessing the iodine status of women in the reproductive age group.

(continued on page 18)



Bangladesh (continued from page 17)

A Successful Session on the Mother-Baby-Iodine Project

The 5th National Conference and Scientific Meeting of the Bangladesh Thyroid Society was held in the Ballroom of the Pan Pacific Sonargaon Hotel on 17th June, 2022. Each year thyroid related problems are increasing among our population. About 20% of the population are suffering from thyroid disorders, the majority of which are hypothyroidism, hyperthyroidism and thyroid nodular diseases. Undiagnosed hypothyroidism during pregnancy is responsible for abortion, miscarriage, preterm delivery, low IQ babies and cretinism. We wished to take advantage of the opportunity to disseminate knowledge to the target groups. The dignitaries gracing the occasion were the President of the Diabetic Association and National Professor A K Azad Khan, the Secretary General of the Society of Head, Neck and Otolaryngologist and Prof. President of Society of Obs and Gynae. Attending the conference were nuclear medicine specialists, endocrinologists, head-neck & otolaryngologists, thyroid specialists, medicine specialists, general surgeons, obstetricians, general physicians and media personnel. The program began with two scientific sessions, one on Parathyroid Gland and the other on Thyroid Gland, followed by an inaugural session.



Ordiance of seminar.

A seminar was held with the theme of Mother Baby Iodine, in line with the project of Thyroid Federation International (TFI). Prof Faridul Alam, Secretary General Bangladesh Thyroid Society, was the keynote speaker. Two obstetricians were chair and co-chair of the session. A number of renowned panelists discussed this issue. As the iodized salt of many countries including Bangladesh is not reliable and not adequately iodized, the speakers could not rely on it. Therefore, they suggested that expecting mothers as well as teenagers be educated on the consequences of inadequate iodine intake. They thanked TFI for taking on this project which will increase the knowledge about the need for iodine among doctors and health care providers, in addition to teenagers and expecting mothers. The speaker emphasized that in pregnancy, profound changes in thyroid physiology occur. Healthy pregnant women with adequate iodine



Seminar on mother baby iodine.

intake, properly assure that both fetal and maternal needs have sufficient thyroxin produced. Inadequate iodine supply - fetal neurological and physical development may be seriously hampered. In the last two decades, strategies such as salt-iodization and iodine supplementation have contributed to a progressive eradication of severe iodine deficiency. Still, several countries have mild-to-moderate iodine deficiency. Even in iodine sufficient areas, vulnerable populations, such as pregnant women, fetuses, and young children are at risk.

There was a symposium in the evening on Congenital Hypothyroidism; a number of renowned panelists discussed this issue. There was also a session on Newborn Screening (NBS) in Bangladesh: Present Status and Barriers for Implementing NBS as a Sustainable National Program. The speaker was Dr. Mohammad Anwar-Ul-Azim.



President, Secretary Chairperson and organizing committee.

Thyroid Foundation of Canada

LAZ BOUROS, PRESIDENT

This past year has been a banner year for the Thyroid Foundation of Canada. We managed to capitalize on last year's webinar experience to provide three interesting educational webinars. We lost a key board member quite suddenly in December and some of our members reduced their work due to personal demands on their time. In the spring, we entered negotiations to acquire a sister charity and are fortunate to welcome two new board members from Thyroid Cancer Canada to our board.

Financially, we continued the trend of the last four years of ending our fiscal year with a surplus. Next year will be the fifth and final year of our Strategic Plan. We have completed well over half of the initiatives and continue to make incremental progress in the plan.

I have structured my report based on our traditional mission with updates from our Strategic Plan.

Awareness

This past year, we produced three successful educational webinars. This included presentations by Dr. Sana Ghaznavi on Thyroid Nodules in November, Dr. Franco Lopez on Hypothyroidism and Thyroid Replacement Therapy, and Dr. Kelsey Roelofs on Thyroid Eye Disease in April. These presentations were recorded and are available for viewing on our website at <https://thyroid.ca>. Donna Miniely, past TFC president, gave a Zoom overview presentation of thyroid disease to the Black Aging Community of Montreal and to the Horizon Place Retirement Community in London, Ontario. More presentations are planned.

We have prepared two great issues of our Thyrobulletin newsletter, one on the fall and one in the spring. The Thyrobulletin is now being produced in French!

Support

Our Help Line Team continues to provide moral support and information on thyroid disease through our toll free 1-800 line and through emails we receive through our info@thyroid.ca. Dr. Deric Morrison, our Medical Advisor, continues to provide us with feedback

on our medical queries from thyroid patients as well as providing speakers for our educational webinars.

Research

This year, in partnership with the Canadian Society of Endocrinology and Metabolism (CSEM), we awarded a \$50,000 research grant to Dr. Ralf Paschke for his research on the Classification of Thyroid Tumours. The aim of the proposed project is to improve diagnostic strategies for thyroid cancer tumours while limiting unnecessary diagnostic surgeries for patients.

We established a new section on our website for research information. There are articles on new thyroid research, past thyroid research and other related research. We will continue to add articles of interest in this new section.

Advocacy to Improve Thyroid Care

Improving Thyroid care for patients was a new component that was added to our Strategic Plan in 2018. We established an Advocacy Plan back in 2018 to address this area through advocacy with key health care stakeholders.

Last fall, Thyroid Federation International hosted a presentation on thyroid nodule ablation treatment used in Italy. Thermal ablation for thyroid nodules has the potential to greatly reduce the incidence of thyroid surgery and speed up patient recovery. However, it's not widely practiced in Canada. We contacted CSEM and arranged to have them review this procedure. It is hoped that this procedure will be more prevalent as a thyroid nodule treatment in the coming years.

Another area that we're looking into is the use of combination therapy for hypothyroidism. This treatment was reviewed by Dr. Franco Lopez at our February webinar. We are looking into promoting this new treatment and preparing an educational video on the subject for endocrinologists and family physicians with support from CSEM.

We are also monitoring the progress of the Tepezza drug for thyroid eye disease produced by Horizon Therapeutics Canada. This drug was also reviewed by Dr. Kelsey Roelofs in our April webinar.



Dr. Sana Ghaznavi
Thyroid Nodules



Dr. Kelsey Roelofs
Thyroid Eye Disease



Dr. Hernan Franco Lopez
Hypothyroidism and Thyroid Replacement Therapy

(continued on page 20)

Thyroid Foundation of Canada *(continued from page 19)*

Future Plans

The big news for next year is that our sister organization, Thyroid Cancer Canada (TCC), has approached the Thyroid Foundation with an offer to join our organization. They plan to close down their TCC operations and move their assets to TFC. This makes sense as TFC already supports thyroid cancer patients. Moreover, thyroid cancer patients who have undergone a thyroidectomy or radioactive iodine treatment to become hypothyroid can continue to be supported by TFC.

We are pleased to welcome to our board, Sarah Eadie and Gillian Vankempfen from TCC. They have gone through our Nominating Committee process and have become official members of our board. A number of TCC volunteers are also expected to join TFC. A Transfer Agreement is being prepared by TCC to facilitate the transfer of TCC financial and intellectual property assets to the Thyroid Foundation. The agreement will be subject to a review by our legal advisor and final approval by our board.

Next year, we plan to provide three additional educational webinars for thyroid patients to follow up on the success of our last three webinars. We will continue our CSEM agreement to provide grants for thyroid research. We plan to update our medical information and enhance our website. Internally, we will continue to manage the investment of our research funds, update our support software, and update our bylaws and policies. I hope that we will find new innovative ways to get things done with our small group and continue providing quality services to our members and thyroid patients across Canada!



Thyroid Foundation of Canada

La Fondation canadienne de la Thyroïde

ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

Germany

Schilddrüsenliga Deutschland e.V.

Umbrella Organization of German Thyroid Support Groups

Information about the organisation



The “Schilddrüsenliga Deutschland e.V.” (SDL - 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. The association is executed by a five-member board. The association’s 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 represents the parent organisation of the thyroid support groups in Germany.

The objectives of the league are:

- Knowledge promotion of 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 all kinds of thyroid queries

Current activities

A tutorial for the better understanding of thyroid disorders was launched in February 2022. This tutorial has been accessible free of charge on the website of the SDL since February 2022. The video is available on platforms such as Youtube, Instagram and Facebook.

Basic principles of the normal thyroid function and pathologic conditions are explained and illustrated. The video clip is for anyone who is interested in thyroid disorders.

The video has a length of 3 min and has been developed in cooperation with Sommer and Co., Inc., Cologne. The production has been supported by a statutory health insurance (Deutsche Angestellten Krankenkasse - DAK).

(continued on page 21)

The Schilddrüsenliga Deutschland e.V. (continued from page 20)

The tutorial is available also in sign language as well as in a version for the visually impaired. Until the end of May 2022, 400 reads have been registered.

Since the SDL has acknowledged the importance of supportive and complementary care, a webinar entitled „Thyroid disorders – Yoga and Ayurvedic medicine“ will be carried out in June 2022. In this webinar the Yoga and Ayurvedic medicine expert Andrea Haase will be interviewed by Prof. Dr. Michael Cordes, Nuremberg.

A one day seminary for interested persons will be held in Bonn in August 2022. The topic of this seminary will be: „The thyroid in pregnancy and obstetrics“. The talk will be given by Prof. Dr. Markus Kupka, Hamburg.



https://youtu.be/_bY0wvemyi4

ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

Ghana

Thyroid Ghana Foundation (TGF)



The Thyroid Ghana Foundation (TGF), since its inception on 13th July 2018, has been engaged in creating awareness of thyroid disorders, supporting thyroid patients, and encouraging thyroid research. The foundation embarks on advocacy programs which aim at addressing several thyroid health related issues at the policy and institutional levels and facilitates closer working relations between departments involved in thyroid disease treatment and research. The foundation is mainly supported by the College of Health Sciences (University of Ghana, Legon) including departments such as Medicine and Therapeutic (Endocrine Unit), Child Health, Obstetrics and Gynecology, and Psychiatry. We also work closely with the School of Biomedical and Allied Health Sciences such as Nutrition and Dietetics, Medical Laboratory Science, Pathology and Surgery and Center for Radiography and Nuclear Medicine. The TGF also seeks to engage government agencies such as the Ministry of Health, and Food and Drugs Authority to introduce policies toward promoting thyroid health. More critically, the foundation aims to ensure that most thyroid drugs are covered and supplied under Ghana's National Health Insurance Scheme. The TGF, since its launch, has conducted various programs and campaigns on thyroid awareness in the country and beyond, using mediums such as webinars, health walks and talks, and regular engagements with thyroid patients and the media.



The foundation is managed by staff and volunteers who readily avail themselves to support its activities.

Past and Present Activities

The Thyroid Ghana Foundation (TGF) has in place a patient support program which pays regular visits to the Endocrine and Surgical Clinics to educate patients on lifestyle changes needed for managing thyroid conditions. The foundation maintains contact with, and tracks the progress of thyroid patients from these clinics to enable us to support them throughout their treatment process. We offer voluntary registration for patients to join the Foundation's Patient Support Program and gain invitations to seminars, provide financial support and a 24hr help line for patients who may experience crisis or require urgent information. The TGF has reached an agreement with three (3) medical laboratory companies and currently offers

discounts on all related blood tests and thyroid scans for members of the foundation. The TGF organizes patient forums regularly, which gives patients the opportunity to seek clarity about their condition. For the second year running, TGF in collaboration with the University of Ghana Medical Centre (UGMC), will be performing surgeries for 20 thyroid patients at a subsidized fee. So far, 15 thyroid patients have benefited from this initiative.

(continued on page 22)

Thyroid Ghana Foundation (continued from page 21)

COVID 19 and Thyroid Disorders

Due to the corona virus pandemic, the Foundation moved most of its activities online. We provided education on coronavirus and thyroid disorders which was reviewed by the Endocrine Clinic of the Korle Bu Teaching Hospital. The circulated information focused on how thyroid patients could prevent contracting coronavirus and updated them on measures put in place by the Clinic to cater for thyroid patients during the pandemic. Further, we assisted patients in adjusting to new online systems at the Clinic by helping book appointments and sending laboratory results to doctors electronically for review. With the relaxation of some covid-related restrictions in Ghana on 27th March 2022, the foundation has started in-person engagements.

Media Campaigns

Thyroid Ghana Foundation has been very active within the media space to increase the awareness of thyroid and its related issues. The local restrictions on social gatherings shifted our operations from physical meetings and fora to making frequent appearances on TV and radio to create awareness of thyroid disorders. Recently, the foundation has been hosted on platforms such as United Television (UTV), Angel Broadcasting Network, Metro TV, Original TV, and Amansan TV. The launch of the 14th International Thyroid Awareness Week was covered by Citi TV, Amansan TV, and various clubs in Ghana under the Rotary International.



Our media campaigns have been extremely effective, with viewers and listeners who either suffer from thyroid conditions or are related to someone who has a thyroid disorder contacting us for further assistance. There is continued support from the various media outlets, who invite us for subsequent appearances to create more awareness.

Thyroid Research

The Foundation is pursuing its first thyroid-related research: An assessment of thyroid screening practices among pregnant women and newborns in Ghana. The research team is being constituted, while steps have been taken to expand and re-organize our patient's data in a research friendly format to support further studies.

Upcoming Projects

Thyroid Ghana Foundation intends to sustain our media campaigns to increase awareness of thyroid disorders. Plans are underway to organize a major fundraising event in some churches in the country to support the refurbishment of the Surgical Floor at the Korle Bu Teaching Hospital dedicated to thyroid patients. Extra funds will be committed to supporting thyroid surgeries for needy patients. Further, the foundation is working on producing a book to serve as a guide to all persons in Ghana and beyond living with thyroid disorders on how to access treatment and adopt appropriate lifestyles for better management of the condition.

Report on International Thyroid Awareness Week (May 25 – 31, 2022)

The 14th World Thyroid Awareness Week (25th – 31st May, 2022), themed: “Thyroid and Communication – It’s not you, it’s your thyroid”, was marked by Thyroid Ghana Foundation with a series of week-long activities. The celebration commenced with a launch and webinar by the Thyroid Ghana Foundation in collaboration with the University of Ghana Medical Centre (UGMC).

In attendance were staff of UGMC, medical practitioners, academics, persons with thyroid disorders, beneficiaries of the subsidized thyroid surgeries intervention, and members of the general public. Notable guests included the CEO of UGMC – Dr. Darius Osei, Directors of Medical Affairs and Nursing of UGMC, the Board Chairman of the Foundation – Rev. Prof. P. F. Ayeh-Kumi, medical practitioners, staff, and volunteers of TGF.



Founder/President, TGF

The speakers at the webinar were Dr. Solomon Brookman, a Consultant General Surgeon at UGMC who spoke on “Communication on thyroid surgeries: Myths and the real facts”; and Dr Ama Bema Osei-Wusu, a Paediatrician at UGMC who gave a presentation on “Advocacy for Neonatal Screening for Congenital Hypothyroidism”. The launch was covered by media personnel from Citi TV and Amansan TV.



Dr. Darius Osei, CEO, UGMC

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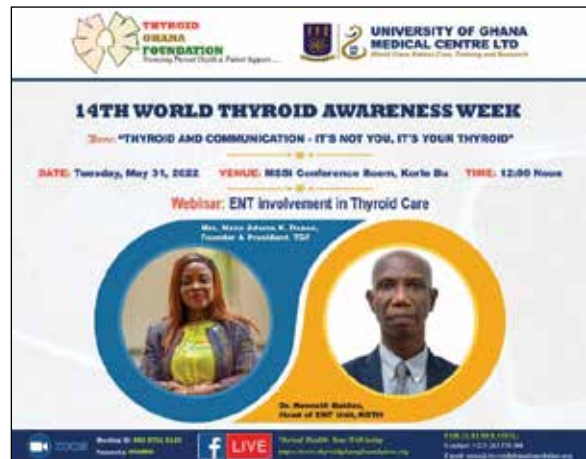
Thyroid Ghana Foundation (continued from page 22)

In celebrating the 2021 International Thyroid Awareness Week, the Thyroid Ghana Foundation and UGMC collaborated to provide subsidized thyroid surgeries for people with thyroid disorders. At a time where thyroid surgeries were being delayed and critical surgeries prioritized as an unintended consequence of the COVID pandemic, the intervention did not only help bring relief to persons who were due for thyroid surgeries, but also helped allay the fears of other people who had been scheduled for thyroid surgery as part of the management of their thyroid disorders. It also aimed at increasing the awareness among people and make them more conscious of the thyroid and its related diseases.

In marking this year's celebration, UGMC and the Foundation announced another round of subsidized surgeries for patients with thyroid conditions. The CEO of UGMC, Dr. Darius Osei, in his speech made it known that this was to support persons with serious thyroid disorders but did not have the means to pay for surgery. He further indicated that of the twenty surgeries earmarked for the first batch of beneficiaries, fifteen (15) had been successfully completed. Based on the successful outcomes, he encouraged others with the condition to seek medical attention.




In her speech, founder and president of the Thyroid Ghana Foundation Mrs. Nana Adwoa Konadu Dsane noted that the collaborative effort came as a great relief in helping needy thyroid patients. She used the opportunity to celebrate beneficiaries of the surgical intervention and also encouraged others with thyroid disorders to seek medical assistance or reach out to the foundation for support.




Other activities to mark the celebration included a session on “Nutritional considerations after thyroid surgeries” which was conducted as a food bazaar. Resource persons included Mr. Frank Ayimadu, a Registered Dietician and Ms. Elizabeth Ama Lawoe, a Culinary Dietician. The webinar on “My thyroid disorder journey so far” was hosted by Mrs Nana Adwoa Konadu Dsane, Founder and President Thyroid Ghana Foundation, during which persons with thyroid disorders shared their experiences and sought clarity on issues pertaining to their thyroid health. The celebration concluded with a webinar on “ENT involvement in thyroid care”, with Dr Kenneth Baidoo, Head of ENT Unit, KBTH as the resource person.



<https://fb.watch/d8AHxxhU2w/>
https://www.linkedin.com/posts/nana-adwoa-konadu-dsane-fcilg-chpa-cmc-46099125_god-bless-you-for-the-media-support-activity-6942400443968835584-AzdU
<https://youtube.com/channel/UCK5bsKGNHYLnCN3cCazWvtg>



May 25th World Thyroid Day



News from Italy

International Thyroid Awareness Week 2022

MARIA D'ACQUINO, HEALTHCOM CONSULTING, MILAN

Thyroid And Communication: I Am Well Informed

International Thyroid Awareness Week is back, from 25 to 31 May 2022, to raise awareness and promote correct information on the health of this gland.

The theme chosen for the 2022 edition of International Thyroid Awareness Week (ITAW) is: "Thyroid and communication: I am well informed" and, on the occasion of this annual event, we will try to answer the many questions that people with thyroid disease ask themselves. The expansion of the Internet and the great availability of medical information on the net has contributed to making the patient believe that he is "his own doctor", thanks to the help of "Doctor Google", often with harmful results: the search for health on the web records "Thyroid health" as one of the most searched questions on search engines.

"The issue of the use and the availability of health information online is extremely up-to-date. There is no doubt that the web has proven to be a useful tool within everyone's reach, but precisely because of its nature, it often collides with the difficulty of checking the quality and truthfulness of information. The 2022 edition of ITAW is an opportunity to address the most common false myths and dispel them, but above all it represents a time to urge you to refer to family doctors and specialists and to help identify qualified sources to draw on for information on the web" declares Marcello Bagnasco, President of AIT, Italian Thyroid Association and Scientific Director of ITAW.

ITAW not only aims to raise awareness of the prevention and proper management of thyroid disease, but above all to emphasize the importance of using authoritative sources of information and not blindly trusting what is on the net. It will be an opportunity to highlight the most common inaccuracies that circulate about the thyroid as a cause of disease: overweight and obesity (automatically associated in the common imagination with hypothyroidism); disorders such as anxiety, depression or insomnia, are often attributed to thyroid diseases, even when laboratory tests indicate normal gland function; or attributed to thyroid disorders such as tightness in the throat (which can only be caused by acute inflammatory disease or by very large thyroid nodules, not so frequent and easily identifiable by the doctor or specialist).



We will also address the topic of hypothyroidism therapy with desiccated thyroid, proposed (unreasonably) as a "natural" alternative to the use of purified thyroid hormone, as well as the current problems and opinions on thyroid diseases in children and in the elderly. There are also doubts, which must be dispelled, on the use of iodized salt in the diet, to which are added offers of supplements containing iodine in the most varied quantities. Finally, there are fears, often unjustified, about the possible effects on the thyroid gland of the radiation used in diagnostic procedures (e.g., scans).

ITAW 2022 is promoted by leading endocrinological, medical and surgical scientific societies, such as the Italian Thyroid Association - AIT, the Medical Endocrinologists Association - AME, the Italian Society of Endocrinology - SIE, the Italian Society of Endocrinology and Pediatric Diabetology - SIEDP, the Italian Society of Gerontology and Geriatrics - SIGG, the Unitary Italian Society of Endocrine Surgery - SIUEC, the Italian Association of Nuclear Doctors - AIMN, together with the Committee of Endocrine Patients' Associations - CAPE and the participation of the Superior Institute of Health (Istituto Superiore di Sanità).

As in previous years, information and awareness-raising activities can be followed through the dedicated Facebook page "International Thyroid Awareness Week" <https://www.facebook.com/settimanamondialetiroide> where you can also listen to video interviews with specialists.



Thyroid Disease Awareness Kenya

SARAH KATULLE, CEO AND FOUNDER, THE TDAK FOUNDATION

The Thyroid Disease Awareness Kenya (TDAK) is a non-profit organization legally registered in Kenya under the society’s act ‘Cap 108’ of the Constitution of Kenya. Founded in 2017, TDAK is dedicated to improving thyroid care within Kenya and the surrounding region. TDAK focuses its efforts on creating awareness, promoting research, and advocating to improve the quality of life for people living with thyroid disorders.

In the year 2022, we have seen a substantial growth in the number of people joining our organization. It has been an equal blend of both thyroid disease patients and thyroid disease care givers, all who want to learn more about thyroid disease, how to treat it, and how to manage it. As the numbers grow, so have the number of activities that we have held as an organization. One of our objectives here at TDAK is to ensure that there are as many treatment options as possible so that patients have more choices when it comes to treatment of thyroid disease. In this regard, we have held a number of educative webinars, where we have had both conventional and functional practitioners educate our members on the approach and treatment of this disease as the options available in Kenya continue to increase.

Men Living with Thyroid Disease In Kenya

It is important to note that though thyroid disease is mostly found in women, especially those of reproductive age, it can also affect men. Here at TDAK, we encourage and campaign for men suffering from thyroid disease to come out and speak up as the disease is being increasingly diagnosed in this region. We have seen quite a number of men joining the platform to learn about this disease. In the process, we had one gentleman who has been very brave, speak about his experience of living with thyroid disease. He shared his journey and experience with diagnosis and treatment, including his recent thyroid surgery, with the members in our platform. This act of bravery encouraged three other men who were watching silently in the members group, to come out and speak up, and two out of the three chose to undergo surgical treatment after battling thyroid disease



symptoms for a long time.

Therefore, we continue to educate and campaign for men diagnosed with thyroid disease to come out and speak up, as we also encourage men that are caregivers to learn about the disease in order to better understand their loved ones.

Partnering with Doctors

As the number of our members grow, data has shown us that General Physicians are still ranking high as the number one choice of our patients in search for thyroid disease treatment. This is due to factors like affordability, accessibility and availability. In Kenya, the number of endocrinologists is still low and populated within Kenya’s capital, Nairobi. Furthermore, their consultation fees are very high making them inaccessible to many patients especially those who do not have a good insurance cover. Our patients come from different parts within Kenya. Therefore, those who would like to seek professional services from an endocrinologist have to travel from different parts of the country to Nairobi. This becomes an extra cost incurred on top of the already heavy burden of high cost of treatment of thyroid disorders in Kenya.

We therefore found a way to bridge this gap. We have engaged one of the Doctors Union here in Kenya, where we will be mediating in the training of general physicians on endocrinology, targeting the basics of diagnosing, treating and managing thyroid disease. We shall work with the union to have an endocrinologist who will be training the doctors using an online educative platform specifically meant for doctors called [www. daktarionline. co.ke](http://www.daktarionline.co.ke), which is an online platform accessible only to doctors and clinicians in the country. The word “Daktari” is a Swahili word which means “Doctor”.

The platform will give online courses on thyroid health and endocrinology for a period of time, where upon completion, the doctors will be awarded Continuous Professional Development (CPD) points. In turn we shall add them to the list of doctors on our platform who will be able to consult and work with our patients. This will be one way that we shall achieve our objectives as we create thyroid health awareness among healthcare providers, and our contribution in helping scale thyroid treatment services across the country because these doctors are situated in different parts within the country. Therefore, our patients will have access to these doctors without having to travel in search of thyroid treatment.

(continued on page 26)

TDAK (continued from page 25)

International Thyroid Awareness Week and World Thyroid Day

This year's theme was "Thyroid and Communication, it's not you it's your thyroid" and here in Kenya we organized for a webinar where patients and care givers were educated on thyroid disease, what it is, its symptoms and how to diagnose it. We also touched on the relationship/ communication between thyroid patients and their doctors, and what measures we as patients can take to ensure that we relate to our doctors in a better way for optimal health care and treatment services. Our organization's doctor was also able to equip us with knowledge on the correct way to approach professional malpractice incidents resulting in the death of a thyroid disease patient.



Creating Awareness through Mainstream Media

The TDAK Foundation uses every available platform to create awareness about thyroid disease. We have been featured in the mainstream media in both print and TV, as we continue to encourage the dialogue of thyroid health in Kenya.



<https://www.businessdailyafrica.com/bd/lifestyle/health-fitness/living-with-thyroid-disease-patients-open-up-3828270>

<https://www.youtube.com/watch?v=TuaEAI6BrA4>

Home Visits

We do home visits periodically, to encourage and support our members emotionally, which is among one of our objectives and goals, to make thyroid patients feel supported and heard. This year we had the honor of visiting Kenya's youngest Thyroid Cancer survivor, Haimana Wairimu, who due to lack of early diagnosis, and misdiagnosis, mis advice and mis treatment, had the cancer spread to her lungs and has been on an oxygen breathing device to support her lungs when they fail. She travelled to India for further treatment and corrective

surgery and is now faring well at home. Though her tests show that the cancer is gone, the oxygen device on her is still a reminder of what misdiagnosis can do. She is a brave girl who is performing well with home schooling, and bravely fights every sickness that attacks. Haimana was diagnosed with Thyroid Cancer at the tender age of seven years after being misdiagnosed with TB and Pneumonia several times. By the time of diagnosis, the cancer had widely spread; she had surgery to remove the cancer but it quickly spread to her lungs. During surgery, her vocal cords were interfered with and she had to undergo vocal therapy to restore her voice. She had donations from well-wishers and was able to travel to India where she underwent RAI therapy. Today she is cancer free, strong and active like her peers.



For more details:

<https://www.tuko.co.ke/419430-haimana-wairimu-11-year-old-cancer-survivor-marks-emotional-milestone-graduating-grade-3.html>

Challenges

The cost of treating thyroid disease in Kenya is high in terms of consultation fees, thyroid function testing and medication. We have patients who lack the financial resources to get quality health care in Kenya. After the COVID-19 pandemic, many patients lost their jobs and are struggling to maintain a consistent treatment plan of the consultation, thyroid function tests and buying the medication. Soon after the Pandemic, the war in Ukraine happened, and its impact has also caused a rise in the cost of living making the affordability of thyroid treatment a luxury to many here in Kenya.

Future Activities

We have various activities planned for the remaining part of the year including a National meeting in Nairobi for all members, as well as educational sessions from specialists like dieticians, endocrinologists, and counsellors, as we continue to create awareness.



Thyroidism Awareness and Support Initiative



Thyroidism Awareness and Support Initiative (TASI) is the foremost patient-led not-for-profit organisation, established in Nigeria in 2017 primarily to create awareness of thyroid disease, and to support people affected by thyroid diseases in Sub-Saharan Africa. TASI is the first in Africa to join Thyroid Federation international (TFI).

TASI emerged from what will always be referred to as a journey from “pain to purpose”. The pain, suffering, hopelessness, frustration and near death experience the founder of the organisation passed through while she battled thyroid disease for four years, before she got cured, exposed her to what victims of this disease must be passing through and what potential victims will face due to ignorance, therefore TASI was established to bridge the gap. It’s been an amazing but tough experience adapting to and managing the new realities presented by the Covid 19 pandemic. We leveraged virtual media to advertise most of our programs and events, except 2022 where we do both physical and virtual.

Empirical research has shown that in Nigeria more than 4 million people have been estimated to be suffering from different types of thyroid diseases, while 50% of them are not aware of their condition; apparently they are either undiagnosed or misdiagnosed, to say the least. The cases of thyroid disease are under reported according to researchers, which could be attributed to the fact that thyroid diseases mimic other common health conditions that may easily be diagnosed, undermining the underlying cause. Yet, the issue has not been properly addressed nor given significant attention in Africa at large.

However, in TASI we have not relented on focusing on our core objectives in driving and spreading thyroid health awareness in the Sub-Saharan Africa. The increasing number of calls and volume of feedback messages and mail we receive on a daily basis from People Living With Thyroid Disease (PLTD) put us on our toes to intensify our efforts in eradication of this disease that has obviously become a scourge. We are inspired by the impact



2nd Annual Public Lectures on IWAD.

of our consistent advocacy and massive widespread of awareness evidenced by the increasing number of diagnosed cases; people now visit the hospital for screening when confronted with strange symptoms.

Here in Africa, societal stigma causes patients to live in denial, but our constant advocacy and community engagements/awareness have demystified these and changed the narratives. It is now easier for us to reach the patients and provide them accessible, affordable and quality healthcare in collaboration with medical specialists and other relevant stakeholders, giving them financial, emotional and psycho-social support.

Leveraging on media (conventional, print, social media, virtual) as a veritable instrument for massive visibility and publicity in the spreading of thyroid awareness in Nigeria and Sub-Saharan Africa, we have succeeded in using both local and international media organisations to communicate our objectives. In 2021, the British Broadcasting Corporation featured our work and interview in 3 languages - English and two major Nigerian local languages (Igbo and Yoruba). The visibility generated so much unprecedented awareness that we became overwhelmed with the invasion of patients from the Eastern part of the country where their major language is Igbo.

The need to provide adequate medicare for our people residing in the Eastern part of Nigeria gave birth to the Eastern Regional TASI branch, managed by a regional coordinator. More than 50 patients in the East have benefited from our subsidised treatment and about 12 patients have benefited from free /subsidised surgery.

A total of 30 communities have benefited from our awareness activities, free thyroid screening, and free drugs so far. About 85 people have benefited in our free surgery (Thyroidectomy) and subsidised surgery with 100% success, no casualties, no complications.

(continued on page 28)

TASI (continued from page 27)

International Thyroid Awareness Week (ITAW) 2022 and World Thyroid Day 2022

Commemoration of International Thyroid Awareness Week and World Thyroid Day, from the 22nd of May to the 28th, coincided with our first half of the year's projects. This year, 2022, we had the opportunity and the privilege to host our ITAW AND WTD activities both physically and online; most interesting as we had many participants across the globe. In collaboration with our medical experts, partners, Media, TASI Thyroid Support group, and the support of State Government, TASI hosted 3 major successful events within the week of the International Thyroid Awareness Week.

On the 25th of May 2022 in commemoration of World Thyroid Day, TASI hosted its 2nd annual public lecture, with the theme: **Its Not You, Its Your Thyroid**. This event was massively attended by guests from different backgrounds, healthcare providers, medical experts, and the general public. It was a convergence of top medical experts coming together to teach and be taught the management of thyroid disease. The major aim for the public lecture was to teach, educate and sensitise the general public on the need for proper thyroid health and how to communicate the invisible and visible nature of thyroid disease in different perspectives.

The keynote speaker for the public lecture was Prof. Olufemi Fasanmade, Head of Endocrinology and Metabolism, Department of Medicine, University of Lagos Teaching Hospital, Nigeria. Our second guest



Community Road Sensitisation Walk

speaker was Dr. Adebambo Bankole, Consultant General Surgeon, Gbagada General Hospital Lagos, Nigeria. Another guest speaker was Mr. Frank Ayimadu, Registered Dietitian, clinical Dietitian at Greater Accra Regional Hospital, Ghana, West Africa. All the speakers brilliantly delivered their topics in such a way that the audience was glued to their seats and yearning for more.

The second event was a Media Sensitisation Drive, using both social and electronic media. Television stations hosted us in giving thorough interviews on thyroid awareness and thyroid health on May 26-27, 2022.

We concluded the commemoration of ITAW on the 28th of May with a Community Road Sensitisation Walk in the Odilowo Local Government Area where we walked through the local community to communicate our vision in different local Languages. The impact was phenomenal, feedback on the events is still pouring in.

We are working towards achieving our 2nd half of the year's projects/programs.

Achievements 2021/2022

- Awareness on various media platforms with massive impact.
- The number of our treatments and surgeries increased by 50%.
- Establishment of TASI Eastern Zonal Center.
- Government endorsement and partnership.

Challenges

- Our major challenge remains paucity of funds.
- Lack of defined policy action to promote thyroid advocacy to a wider targeted audience in the rural communities.
- Prevailing security issues in the country.

Future Projects

A thyroid Transition Center which will stand as a safe space for people living with thyroid disease to access affordable and quality healthcare and therapeutic support.

A rallying point and a domain for people seeking support on thyroid disorders and medications, resource materials and medical facilities.

Collaborations/Partnership

We are open to strategic partnership and collaborations, and mutually beneficial relationships both locally and internationally that will promote our vision and bring more solutions to people suffering from thyroid disease in the Sub-Saharan Africa.

Wishing TFI a very successful AGM 2022.

Goldheart Thyroid Awareness Foundation

FLORENCE OKETONA, GOLDHEART THYROID AWARENESS FOUNDATION

General Online Activities

The past years have been very challenging for our organization due to the pandemic which crippled a lot of our activities and prevented us from carrying out awareness campaigns physically. Thanks to technological advancement, we were able to keep our organization above water by engaging in online activities and social media campaigns.

Through our social media pages and online meetings, we were able to create awareness on the menace of Thyroid malfunction.

Surprisingly we reached more people on social media with our messages of hope to come out and beat the stigma associated with thyroid disease in our country.

From our Facebook page, Goldheart Thyroid Awareness Foundation grew from a mere followership of 97 to about 230 with a lot of mentions, notifications and shares. We had

people contacting us from all over the country with questions about thyroid disease which we meticulously answered. We had four people travel down to our part of the country to see our endocrinologist Dr. Austin who placed them on medication and referred some who had an inflamed thyroid for surgery.

Mrs. Olabisi Jethro who got to know about her thyroid condition through a post on our Facebook page travelled all the way from Abuja, Nigeria to Jos where our foundation is domiciled to see our endocrinologist; she was placed on carbimazole tablets to treat her overactive thyroid which was giving her insomnia, palpitations and extreme weight loss. She initially thought she was under a severe spell or spiritual attack because she had carried out a series of tests at hospitals and they found nothing. I made a post on a Facebook group known as LIFE where I spoke at length about thyroid disease and its symptoms (the post was one of the awareness posts



Nigeria Goldheart sensitizing women.



Nigeria Goldheart Awareness Outreach, sensitizing women on thyroid disease.

during the 2022 International Thyroid Awareness Week). The post reached more than 80,000 people and had over 1,000 engagements and likes. She contacted me privately as a result of the post and an appointment was booked for her to see the endocrinologist; she has since gotten her life back and has become one of our foundation's ambassadors in Abuja. Due to her activities of creating awareness in Abuja, our foundation is considering opening an office in Abuja, Nigeria to cater for the needs of thyroid sufferers in the city.

Radio And TV Programs

We organized a number of radio and TV programs which we discovered got a wider reach than the street awareness campaigns that we normally do, and the feedbacks are usually amazing. A good number of people who are living with thyroid malfunction are scared to openly admit that they need help; we sadly lost one woman who initially reached out to us concerning an overactive thyroid. We began to follow her up for treatment, but she suddenly stopped taking our



Nigeria Goldheart Speaking on the Radio on Thyroid Disease.

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Goldheart (continued from page 29)

calls because her husband wanted her to go for prayers insisting that her severe weight loss and bulging eyes were a result of spiritual affliction. She however went into a coma sometime in March and died after few days.

We are working on presenting our radio programs in the local language of our region which is Hausa in order to get a wider reach.

Collaboration with Women's Organizations

We decided to reach women's organizations through religious bodies like churches and mosques in order to get to more people who are living with thyroid disease. We attend women rallies and ask for time to speak to the women about thyroid disease. A good number of them submit themselves for tests and treatment through such awareness programs.

Challenges

Apart from the pandemic and the general economic downturn in Nigeria that has made it difficult for a good number of the population to access good healthcare, our region is notorious for insecurity. Terrorism and banditry have made it difficult for our organization to reach the rural areas to create awareness of thyroid disease. The region where our foundation is situated is plagued with political and security upheavals which

has made it difficult to reach a wider society with our message. We are however hopeful that the security challenges and the rising activities of the terrorist organizations will soon become a thing of the past.

Dearth of Medical Personnel

More than ever before, Nigeria in the last two years has witnessed a dearth of medical personnel as most of the medical people have migrated to Europe and the Arab countries in search of greener pastures. Because of bad governance and security challenges many doctors and medical consultants have left the country and there are more people at the mercy of less medical personnel. Mrs. Jethro had to travel down to our location because the consultant endocrinologist who was in charge of the medical centre in her location has relocated to Oman in search of better life and better working conditions; she was in a long queue to see the only available endocrinologist and as such had to travel down about 4 hours to get to our location where she was treated by our endocrinologist. This has caused untold hardship in the country in general as many have died due to self-medication.

We continue to hope that the situation of the country will improve in the coming years.

Website: www.goldhearthyroid.com

Instagram: @goldhearthyroid



Do you speak thyroid? Portugal now speaks a little more

CELESTE CAMPINHO, PRESIDENT

The Portuguese Thyroid Disease Association (ADTI) was founded in 2012 from the urge to support patients and their families. Supporting the interests of thyroid patients and representing them, is the main mission of ADTI, which also educates and clarifies thyroid dysfunctions, partners with health professionals, and intervenes to assure the interests of these patients.

Within the ADTI's work, we highlight International Thyroid Awareness Week as an important milestone of the year to increase the awareness of thyroid problems, which still remain little known to so many. This year the focus was on communication and its importance for a timely diagnosis following an early treatment to be as effective as possible.



Hence, several actions were carried out, such as press releases, interviews, and social media, enabling us to reach hundreds of thousands of people.

The partnership made with national influencer Vanessa Martins had a big impact. She managed to take the thyroid theme further using social media. This message was reinforced on ADTI's social networks, where the importance of good communication with health professionals was highlighted, impacting both thousands of Portuguese patients and the general public.

Thyroid Support Facility of Pakistan

FAIZ RASOOL, FOUNDING CHAIRMAN

The Thyroid Support Facility of Pakistan is a non-government and non-profit organization is the latest member of TFI, whom joined in 2022. We have a vision of “Transforming communities to productive Societies”. Our strategic framework is under progress, but according to our mission the key activities would be focused on:

Establishment of a national level platform with the following objectives:

- Creating awareness of “Thyroid Disease”
- Engaging relevant professionals (Medical & Nutrition) across the country.

Thyroid Disorders, Background and Challenges

Hypothyroidism and hyperthyroidism are the major thyroid disorders caused due to malfunctioning of the thyroid gland. Thyroid diseases have been observed in more than 100 countries, affecting approximately 1.6 billion populations worldwide. Many people are at risk and desperately need iodine supplementation.

Thyrotoxicosis is the term mostly used for hyperthyroidism, but not all cases of hyperthyroidism signify thyrotoxicosis. Hypothyroidism and hyperthyroidism are caused because of low or high production of thyroid hormones. Causes of hyperthyroidism are thyroid hyperplasia related to Graves’ disease, high intake of thyroid hormones, multi-nodular goiter and hyper-functional goiter and thyroid adenoma.

Iodized salt plays an integral role in hypothyroidism as well as hyperthyroidism. Need of iodine is compensated by water and foods if there is a deficiency in sources of iodine; then it results in malfunctioning of the thyroid gland resulting in the development of cretinism, hypothyroidism and many other iodine related issues.

Thyroid disease and its prevalence vary from country to country. The prevalence of hyperthyroidism in Pakistan was observed¹ to be 5.1% while sub clinical hyperthyroidism accounted for 5.8%, however hypothyroidism was observed to be 4.1% and 5.4% in cases of sub clinical hypothyroidism respectively. The prevalence of hypothyroidism, hyperthyroidism, sub clinical hyperthyroidism as well as sub clinical hypothyroidism was higher in the female population as compared to males²

Severe iodine deficiency causes hypothyroidism that results in impaired somatic growth and motor development in children. Mild and moderate iodine



deficiencies cause multifocal autonomous growth of thyroid, which results in thyrotoxicosis. On the other hand, iodine excess is associated with the development of hypothyroidism and thyroid autoimmunity. In areas of

iodine deficiency, a sudden increase in iodine intake is associated with transient hyperthyroidism. Recent studies demonstrated that long-term thyroid function of subjects who experienced both iodine deficiency and iodine excess during childhood tended to be abnormal despite optimization of their current iodine intake.³

Iodine consumption through “Iodized Salt” has been recognized as the most cost effective⁴ and impactful approach to address iodine deficiency. Iodine is essential for thyroid function and for physical and mental development. Daily use of adequately iodized salt is the best strategy to overcome iodine deficiency disorders (IDD’s). Across Pakistan, almost four out of five households consume iodized salt. A greater proportion of households in urban settings consume iodized salt compared to households in rural areas.⁵ Consumption of iodized salt is very low (31.6 percent) in KP-NMD (KP Province - Newly Merged Districts). By contrast, in ICT, Punjab, AJK and GB, consumption of iodized salt exceeds 85%.

Median Urinary Iodine Concentration indicate adequate iodine intake. The survey showed that median urinary iodine of school-aged children (6-12 yrs) in Pakistan was 122.9 µg/L. (urban:126.8 µg/L; rural: 121.5 µg/L). Median urinary iodine values were better for boys (126.7µg/L) than for girls (121.3 µg/L).⁶

In the environment of the current situation, key challenges for public and private sectors in Pakistan are closely associated with the regulatory landscape and these are:

- Public Sector: Creation of an enabling environment to ensure that producers/industry is complying with the existing regulatory standards and that robust enforcement mechanisms are in place.
- Private Sector: Capacitating and mobilizing the private sector to adopt the global best practices to ensure the quality of iodization at internal and external levels.

Mitigation Approaches in Context of Public Policies

The Government of Pakistan has recognized the situation and has started taking measures to address these key challenges that will strengthen and further improve the enabling environment through tweaking of existing

(continued on page 32)

Pakistan (continued from page 31)

strategies and formulating new and more targeted public policies. The following are the policy approaches in this regard:

National Level

Pakistan National Food Fortification Strategy – 2017

<https://sunpc.org.pk/wp-content/uploads/2019/06/National-Food-Fortification-Strategy.pdf>

Food fortification programs (including iodization of salt) require the collaboration of the public and private sector and a regulatory environment in which appropriate government legislation is enacted and systems exist through which compliance can be effectively monitored and enforced. However, overall success also requires closer attention to strategies for improving the indicators of malnutrition. The National Fortification Alliance (NFA) under the Ministry of National Health Services, Regulations & Coordination (MoNHSR&C) has developed a Pakistan National Food Fortification Strategy to guide and give strategic direction to the food fortification interventions aiming for the prevention and control of micronutrient deficiencies and overall malnutrition in Pakistan.

This strategy will provide an overarching framework for developing a strategic plan and comprehensive fortification programs in which several staple food products could be fortified with key micronutrients necessary for adequate health and proper growth and will serve as a guide at both policy and implementation levels. The goal of this strategy is to create an enabling national environment for sustained salt, wheat flour and oil fortification programs implemented by private sector and public agencies and departments within various provinces.

Pakistan Multi-sectoral Nutrition Strategy 2018-25
https://www.pc.gov.pk/uploads/report/Pakistan_%202018-25.pdf

The Pakistan Multi-Sectoral Nutrition Strategy (PMNS) reflects the determination of government and other stakeholders to capitalize on opportunities to develop and implement the proven nutrition interventions to lower the human, social and economic burden of malnutrition.

PMNS at the national level has been formulated to broaden the scope of in country policy approach on nutrition and engage a diverse range of stakeholders/sectors. In addition to the above, the following are the strategic documents to improve nutritional challenges:

The political economy of undernutrition. National Report, Pakistan

<https://core.ac.uk/download/pdf/47262648.pdf>

Maternal Nutrition Strategy 2022–2027 Pakistan
<https://www.unicef.org/pakistan/media/4356/file/Pakistan%20Maternal%20Nutrition%20Strategy%202022-27.pdf>

Provincial Level

At the provincial level, the following are the policy docs to strengthen the interventions to improve nutrition, including consumption of iodine and other micronutrients:

The Balochistan Food Fortification Act, 2021. ACT No. XXVII of 2021.

https://pabalochistan.gov.pk/pab/pab/tables/alldocuments/actdocx/2021-12-10_09:10:45_f95b0.pdf

The Khyber Pakhtunkhwa Food Fortification Act, 2022

<https://www.pakp.gov.pk/acts/the-khyber-pakhtunkhwa-food-fortification-act-2022/>

The political economy of undernutrition. National Report, Pakistan

<https://core.ac.uk/download/pdf/47262648.pdf>

The Sindh Compulsory Iodization of Salt Act, 2013

<http://www.pas.gov.pk/index.php/acts/details/en/19/217>

<http://www.pas.gov.pk/uploads/acts/Sindh%20Act%20No.XXXVII%20of%202013.pdf>

Punjab Food Authority Act-2011

<http://extwprlegs1.fao.org/docs/pdf/pak115231.pdf>

Pakistan's quest for universal salt iodization (USI) reached a major milestone in Sindh. The province is the first to officially mobilize its all-female health worker force to help prevent iodine deficiency disorders (IDDs) through the common cooking ingredient. Similar approaches are required to get embedded into the public policies at provincial and national to improve the iodine intake and eventually improving thyroid function, as both iodine deficiency and iodine excess are associated with an increased risk of thyroid disorders.⁷

References

- 1 Naheed Shah, Tahira Jabeen Ursani, Nadir Ali Shah and Hafiz Muhammad Zeeshan Raza. Prevalence and etiology of thyroid disease: A review. Pure and Applied Biology. Vol. 10, Issue 3, pp691-702.
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<http://dx.doi.org/10.19045/bspab.2021.100071>
- 3 Chung HR. Iodine and thyroid function. Ann Pediatr Endocrinol Metab. 2014 Mar;19(1):8-12. doi: 10.6065/apem.2014.19.1.8. Epub 2014 Mar 31. PMID: 24926457; PMCID: PMC4049553.
- 4 https://apps.who.int/iris/bitstream/handle/10665/101509/9789241506694_eng.pdf
- 5 The 2018 Pakistan National Nutrition Survey (NNS 2018)
- 6 The 2018 Pakistan National Nutrition Survey (NNS 2018)
- 7 Chung HR. Iodine and thyroid function. Ann Pediatr Endocrinol Metab. 2014 Mar;19(1):8-12. doi: 10.6065/apem.2014.19.1.8. Epub 2014 Mar 31. PMID: 24926457; PMCID: PMC4049553.

The Thyroid Trust

JUDITH TAYLOR (CHAIR, THE THYROID TRUST)

Although the continuing pandemic meant that we were not able to meet face to face for over two years, meeting on line meant we were able to involve speakers and participants from all over the UK (and overseas) and our engagement on all social media channels has increased. Highlights of this past year included:



- a successful social media campaign for Thyroid Awareness Week using the strapline “Time to Talk About Thyroid Health” - focusing on community engagement and including a #TalkThyroid Butterfly Trek at the seaside, led by our Director Lorraine Williams, and a butterfly-themed tea party hosted by our Operations Manager Lee Mathers;
- Holding several interesting talks on line with speakers including two interactive talks by Professor Simon Pearce on getting the best treatment for hypothyroidism; ‘An Evening with Billy Kember’ talking about his new book ‘Sick Money: The Truth About the Global Pharmaceutical Industry’; and participating in an online Festival ‘The Power of the Patient Voice’ hosted by the Institute of Metabolism & Systems Research (IMSR) at the University of Birmingham;
- Launching a series of online thyroid cafes with a focus on thyroid cancer and Graves’ disease, and including informal creative and poetry cafes;
- Our first face to face event for over two years was a Patient Voices meeting in central London in February led by Karen George;
- Guest speaker and Thyroid Trust volunteer Kamal Mandalia spoke about his experience with thyroid cancer as part of our ITAW activities;
- Holding monthly online meetings with volunteers; and
- Contributing as a stakeholder to the NICE consultation on thyroid cancer.

An important, although not the only, focus has been on advocating for improved access to liothyronine (T3) for patients who do not thrive on levothyroxine alone.



Thyroid Trust Director Lorraine Williams (left) with Lord Hunt and Lyn Mynott, CEO of Thyroid UK.

In June the Thyroid Trust and partners published a new T3 Prescribing Report. This reveals that 58% of Clinical Commissioning Groups (CCGs) in England are not following national guidance for T3 and that patients in these areas are frequently being denied treatment with this specialist thyroid hormone, which some require in order to be well. The report calls on NHS England and the Department of Health to ensure that this situation is brought to a close and consistency is applied across the NHS, not just in England but also in the other nations in the UK, where we know that issues also exist. Following the release of this report, Lord Philip Hunt and Lord Jamie Borwick asked questions in the House of Lords in London which resulted in a response from the health minister Lord Kamall clarifying unequivocally that T3 is available on the NHS and that at a local level, doctors should be advised that they are able to prescribe it. The Thyroid Trust also coordinated an online Thyroid Champions event, a roundtable leadership discussion on T3 with leaders from most of the UK thyroid charities, chaired by Lord Hunt, to discuss next steps. This event was very well received, and Lord Hunt has agreed to chair a follow-up event later in the year. The story is not over yet but we have certainly made progress!

Lorraine stood down as Director of the Trust in July. The Trustees are immensely grateful to Lorraine for her role in building the Charity as a strong force in the UK. In recent months she has been particularly responsible for successfully delivering the T3 project. An Operations Manager, Lee Mathers, was appointed in 2021 and has worked in support of the Trustees to transform the administration of the Trust. We are now actively recruiting additional Trustees and we are preparing to advertise for a new Director.

Graves' Disease and Thyroid Foundation Webinars

Long-Term Use of Antithyroid Drugs

Antithyroid medications (ATDs) have been prescribed for decades as a treatment option for hyperthyroidism in Graves' disease patients. The U.S. Food and Drug Administration approved propylthiouracil in 1947 and methimazole (brand name Tapazole) in 1950.

In the past, endocrinologists typically prescribed ATDs for a limited period of time. Some doctors used 12-18 months as a benchmark, while others would keep patients on the medication for up to two years.

However, new research as well as patient and physician preference has brought changes to how these medications are used, with more patients remaining on antithyroid medications well past the two-year mark. This new approach has resulted in more patients achieving remission, and many others able to successfully control thyroid levels while taking a low dose of medication.

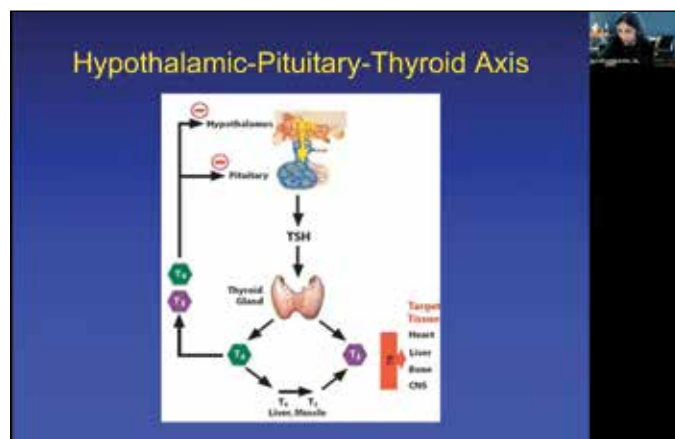
The topic of long-term use of ATDs has generated a great deal of interest in the patient community, so the Graves' Disease & Thyroid Foundation teamed up with Dr. Eve Bloomgarden and Dr. David Cooper to present a webinar to help inform patients about this treatment option.

Read this article in full:

Long-Term Use of Antithyroid Drugs

<https://gdatf.org/bulletins/long-term-use-of-antithyroid-drugs/>

(continued on page 35)



May 25 to 31, 2023

14th International Thyroid Awareness Week

www.thyroidweek.org

Webinars (continued from page 34)

Neuropsychiatric Complaints in Graves' Disease

A chance meeting at a medical conference in the early days of the Graves' Disease and Thyroid Foundation led to a groundbreaking research paper on neuropsychiatric complaints in Graves' disease. Founder Dr. Nancy Hord Patterson was exhibiting at a meeting of the American Psychiatric Association where she met Dr. Robert A. Stern, who (along with Dr. Arthur J. Prange) happened to be interested in doing a survey of Graves' disease patients. Dr. Patterson offered to assist with the distribution of surveys – which back then was done via snail mail!

Dr. James Arruda was brought in to assist with data analysis and interpretation. The results of the survey were published in the Spring 1996 issue of The Journal of Neuropsychiatry and Clinical Neurosciences under the title "A survey study of neuropsychiatric complaints in patients with Graves' disease" by Stern et al.

More than 20 years later, a member of the original research team set out to see if anything has changed. Dr. James Arruda and graduate student, Diane Fralix, who happened to have Graves' disease, reached back out to the GDATF, who agreed to help distribute a new survey – this time over the Internet! A webinar was recorded highlighting some of the key findings and to answer questions from Graves' patients.

Read this article in full:

Neuropsychiatric Complaints in Graves' Disease
<https://gdatf.org/bulletins/neuropsychiatric-complaints-in-graves-disease-webinar-highlights/>

Both videos can be viewed on the GDATF Youtube channel:

<https://www.youtube.com/user/GravesAndThyroid/videos>



TFI Welcomes Two New Organizations!

HONDURAS (candidate)

Cancer de Tiroides Honduras

www.facebook.com/cancerdetiroideshonduras

MEXICO (candidate)

AMECAT, Asociación de Pacientes Cáncer de Tiroides México A.C.

www.amecatmexico.org

TFI Member Organizations

AUSTRALIA

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

BANGLADESH

Bangladesh Thyroid Association (BTS)
www.buhs.ac.bd

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
www.thyroididea.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

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

PAKISTAN

Thyroid Support Facility of Pakistan
thyroid.pakistan@gmail.com

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

SERBIA

Inner Wings, Krila u nama
krilaunama.org

SOUTH KOREA

Korea Thyroid Association (KTA)
[south_korea\(at\)thyroid-fed.org](mailto:south_korea(at)thyroid-fed.org)

SPAIN

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

SWEDEN

Sköldkörtelförbundet
www.skoldkortelforbundet.se

UNITED KINGDOM

The Thyroid Trust
www.ThyroidTrust.org

UNITED STATES OF AMERICA

Graves' Disease & Thyroid Foundation
www.gdatf.org