



Thyroid
Federation
International

Thyroid Patients Worldwide

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Thyroid Federation International

Established in September 1995 in Toronto, Canada

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

Mentor & First President

Lawrence C Wood, MD FACP (USA)



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Member Organizations

The names of the organizations and their current addresses are given on page 28.

Message from the Editors

Once again, another year has passed with the TFI. Initially, at its creation in 1995 in Toronto, the organization included five members. Today we have more than 20 member countries all over the world.

To think, twenty years ago, there was no international patient organization, and only a few national organizations. Physicians had never heard of us, and communication, much less collaboration, was almost unheard of! Now, organizations are active in all the above-mentioned countries, and include joint Patient-Physician meetings and work together on various projects (like the TED meeting in England, the ITAW, the Amsterdam Declaration, the TRUST study ...). We have had the opportunity to have a booth and to present patient forums at ETA conferences for many years, as well as to present posters and having our President speaking at opening ceremonies and receptions.

We look forward to a bright, and busy, future, working together for the benefit of Thyroid Patients worldwide!

We welcome you to Belgrade, the capital of Serbia, center of culture, education, economy and science. We hope that you will enjoy not only the 40th meeting of the European Thyroid Association, but also the unique spirit of Belgrade!

BEATE BARTÈS AND NANCY PATTERSON, EDITORS



Beate Bartès



Nancy Patterson

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President's Message

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

Dear Readers, welcome to the 40th Annual Meeting of the European Thyroid Association in beautiful Belgrade, Serbia.

Thyroid Federation International (TFI) has been serving for over 22 years now, and Europe has played a key role in spreading education and awareness of Thyroid disease. Patients in the European region have easy access to materials and information in their own language.

May 25th was World Thyroid Day which was endorsed by all key Thyroid Societies around the world. International Thyroid Awareness Week (ITAW) was celebrated through education initiatives and awareness programs across the world. "It's not you, it's your Thyroid" was the topic for ITAW, May 22-28, 2017. Programs under ITAW were held across the globe in Europe, Asia, Australia, North America and Latin America regions.

We encourage the formation of Thyroid Foundations in Eastern Europe, Asia, Latin America and Africa Regions. This will help us to reach more thyroid patients in other countries and ensure that some basic things like iodized salt is available in every part of the world. Finding the right people and forming credible organizations that are volunteer based continues to be a challenge in Latin America, Asia, and Africa regions. Our wish list and priorities include the following:

- Consistent availability of quality levothyroxine without unexpected change in formulations
- Credible and proven patient information in the language that they understand
- Global reach of International Thyroid Awareness Week and World Thyroid Day
- Continue to build on the credibility and partnership with ETA, AOTA, LATS, ATA and many endocrine societies

I often hear the question from people "How can I form a Thyroid Patient Foundation?" It's simple - just talk to one of the TFI members at our booth or write an email to the address provided on our website, www.thyroid-fed.org. If you are a doctor you may also help by becoming a speaker, contributing an article on thyroid related issues for ThyroWorld (deadline for articles is May of each year) or simply become a volunteer in a Thyroid



Ashok Bhaseen

Foundation in your own country (please refer to the member countries of TFI on the back page of ThyroWorld). Patient related outcomes (PRO) are a key requirement for new drugs in clinical studies. However, once the medication is approved, PRO is forgotten and some patients do not get optimum treatment as their doctor does not have either the time or sometimes the will to listen to how the patient feels on the medication. Patient and physician partnership is key to success in thyroid related treatments. The gland is tiny but has a tremendous impact

on the functioning of the human body. PRO can make a difference on how you can improve upon your approach to better patient outcomes. I wanted to share some of my thoughts on patient related outcomes that may be of interest to medical doctors:

- As a doctor or healthcare professional, what can you do to educate people? Can you spare an hour in your year's practice to do a Q&A with patients on a public forum?
- How can you make your patients more involved in their wellbeing? Talk to them and you will be surprised at how ready and willing they are to cooperate to get better.

Thyroid patients can greatly benefit from local foundations in countries from Asia, Africa and South America; the key remains to find the right leadership in these geographical areas. Our member organizations are mostly made of volunteers and some of them are physicians who put in many hours to add value to the lives of thyroid patients. TFI looks forward to helping patients and physicians from these areas of the world so that they can help set up organizations that will help in education and awareness of thyroid related issues for early diagnosis and treatment. We look forward to hearing from you and helping you in setting up an organization in your country that can help thyroid patients.

I would like to thank all of you who have worked with TFI affiliated members and encourage our readers to develop, help and support local thyroid foundations and organizations in your individual countries. Medical doctors involved in Thyroid Practice can help these organizations with education and awareness programs. Please visit our sites at www.thyroid-fed.org and www.thyroidweek.org to learn more, and do not hesitate to talk to any TFI members at the booth during the congress.

TFI AGM & International Thyroid Congress 2016

Copenhagen, Denmark

Each year TFI holds its annual meeting in conjunction with the ETA Annual Meeting. In 2016 it was held in Copenhagen, Denmark. It is great to have our annual meeting in a country where the local organization *Thyreoida Landsforeningen* has a strong following among a large group of members. *Thyreoida Landsforeningen* hosted a good program and had a house full of members at the congress site. TFI was created in Toronto in 1995, by 6 organizations: British Thyroid Foundation, TED (Thyroid Eye Disease), Thyroid Foundation of Canada, Thyroid Foundation of America, National Graves' Disease Foundation and Australian Thyroid Foundation. Over the years, it has become a truly international umbrella organization, with over 20 members all over the world, participating in all major events (ETA, ATA, LATS and AOTA congress), and cooperating closely with the medical profession.

Our TFI 22nd Annual meeting started before the ETA congress with representation from France, India, Netherlands, Russia, Sweden, Denmark, Germany, Finland and Spain. During the meeting we had elections and confirmations for the board members. Astra from Finland resigned as Treasurer and as Board member, as the activities in her own country's thyroid organization had increased and it was becoming difficult to manage



ETA Copenhagen – patient conference organized by the Danish organization.

both roles. Marion Hamers-van der Boer (Netherlands) was elected as the new Treasurer for TFI.

One of the good parts of TFI meetings is the sharing of what is happening in each member's country; it's great to see what they did and how they were able to do it. This platform at the annual TFI meeting provides an opportunity to get to know each other better and to appreciate what challenges and opportunities each country organization has to go through. One thing common to see is that, as patient organizations, we have challenges with health issues with some of the key people in each of the organizations.

(continued on page 5)



TFI in Copenhagen



Colin Dayan speaking at the patients conference in Copenhagen

The theme for International Thyroid Awareness Week 2017 was finalized as “Its not me, its my thyroid”. This topic resonated well with all; as patients we know how this impacts our lives. The annual meeting always gives TFI a great opportunity to meet leading Endocrinologists from not only Europe but from around the world.

This year’s ETA recetion was held at the old Carlberg Brewery, where TFI President Ashok Bhaseen addressed the ETA delegates. The old horse carriages and the stables which still have horses, were a delight to see and it was interesting to learn how things worked when motorized vehicles were not so prevalent.



Ashok Bhaseen, President, TFI Addressing ETA delegates at Copenhagen, Denmark Sep 2016.

Upcoming Events

September 7-8, 2017

23rd Annual Meeting of Thyroid Federation International
Belgrade, Serbia
www.thyroid-fed.org

September 9-12, 2017

40th Annual Meeting of the ETA
Belgrad, Serbia
www.eurothyroid.com



October 18-22, 2017

87th meeting of the ATA
Victoria, BC, Canada
www.thyroid.org

September 2017

Thyroid cancer awareness month



May 22 to 28, 2018

10th International Thyroid Awareness Week
www.thyroidweek.com
“It’s not you – it’s your thyroid!”



May 25th, 2018

World Thyroid Day



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.



Dr. Saul Hertz Discovers the Medical Uses of Radioiodine (RAI)

BARBARA HERTZ, DAUGHTER OF DR SAUL HERTZ
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Dr. Saul Hertz (1905 - 1950) discovered radioactive iodine as a tracer/diagnostic tool, as a therapy for Graves' disease, and as thyroid cancer treatment. Radioactive iodine (RAI) is the first targeted Cancer therapy. Dr. Hertz established a cornerstone of Nuclear Medicine as being the first and foremost person to develop the experimental data on RAI and apply it to the clinical setting.

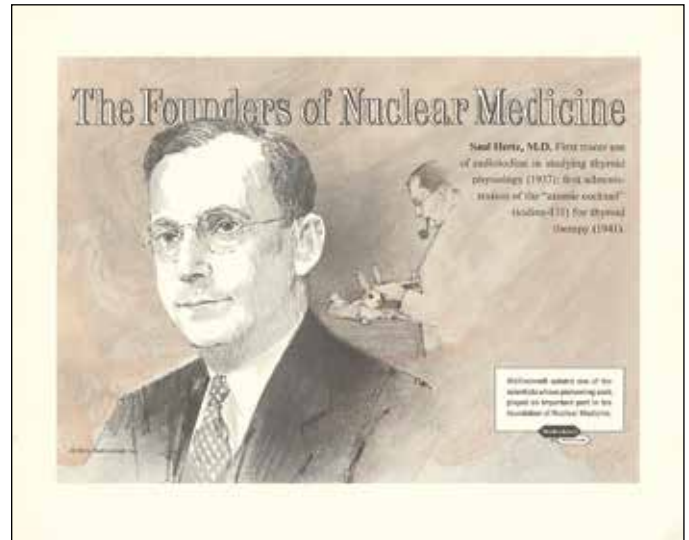
Dr. Hertz was born to Jewish immigrant parents in Cleveland, Ohio on April 20, 1905. He received his B.A. from the University of Michigan in 1925 with Phi Beta Kappa honors. After graduating from Harvard Medical School in 1929, at a time of quotas for outsiders, he fulfilled his internship and residency at Mt. Sinai Hospital in Cleveland. In 1931 he came back to Boston to join the newly formed Thyroid Clinic at The Massachusetts General Hospital serving as Chief of the Thyroid Unit from 1931 - 1943.

On November 12, 1936 Dr. Karl Compton, president of the Massachusetts Institute of Technology, spoke at a luncheon lecture. His topic was *What Physics can do for Biology and Medicine*. After the presentation Dr. Hertz spontaneously asked Dr. Compton, "Could iodine be made radioactive artificially?"



Dr. Compton responded in writing on December 15, 1936 that in fact "iodine can be made artificially radioactive." A collaboration between Dr. Hertz (MGH) and Dr. Arthur Roberts, a physicist of MIT, was established. In late 1937, early experiments involving 48 rabbits demonstrated that the normal thyroid gland concentrated Iodine 128, and the hyperplastic thyroid gland took up even more Iodine.

In early 1941, Dr. Hertz was the first to administer radioactive iodine therapeutically at The Massachusetts General Hospital that led to a series of twenty-nine



patients with hyperthyroidism. This proved to be a success. At the outset of the experiments in 1937, Dr Hertz thought there might be equally promising therapeutic possibilities in the treatment of carcinoma of the thyroid. Hertz reported two patients with cancer of the thyroid in 1942 treated with RAI. In 1943 Dr Hertz was commissioned into the war effort.

After serving in the Navy during World War II, Dr. Hertz wrote to the director of the Mass General Hospital in Boston, Dr. Paxon on March 12, 1946, «it is a coincidence that 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 1946, Dr. Saul Hertz established the Radioactive Isotope Research Institute, with a major focus on the use of fission products for the treatment of thyroid cancer, goiter, and other malignant tumors. He went on to perfect the use of RAI in the treatment of thyroid cancer, thus establishing RAI as the first and Gold Standard of targeted cancer therapies.

Dr. Hertz's use of radioactive iodine as a tracer in the diagnostic process, as a treatment for Graves' disease and in the treatment of cancer revolutionized the treatment of thyroid disease. Dr Hertz left a profound and enduring legacy of prolonging the lives of countless generations of patients. Hertz's breakthrough research changed the paradigm establishing the field of Nuclear Medicine.

TSH-Receptor Autoantibodies in Autoimmune Thyroid Diseases

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Autoimmune thyroid disease (AITD) represents a complex group of disorders with diverse clinical manifestations including hyperthyroidism and hypothyroidism. AITD is commonly associated with the presence of autoantibodies (Ab) to a number of thyroid antigens such as thyroid peroxidase (TPO), thyroglobulin (Tg), and thyrotropin (TSH) receptor (TSHR). Anti-TPO and anti-Tg-Ab, though frequently detected in patients with AITD, are not thought to be directly involved in any specific pathology or particular disease entity whereas Ab to the TSHR (TSHR-Ab) are unique in that they are directly involved in the pathophysiology of certain types of AITD (1). Most Ab causes disease by precipitating an inflammatory process. TSHR-Ab, in contrast, bind to the TSHR and act as either an agonist which stimulates thyroid growth and thyroid hormone production albeit in an unregulated manner, or as antagonist which blocks the activity of TSH. Thus, TSHR-Ab can be classified into three functional groups: stimulating, blocking and neutral Ab (2).

Graves' disease (GD) is caused by persistent, unregulated stimulation of thyroid cells by TSHR-stimulating Ab (TSAb) that activate the TSHR. TSAb, like TSH, bind primarily to the large extracellular domain of the TSHR. For the majority of Ab tested, TSAb and TSH compete for binding to the TSHR. Since the discovery of TSHR-Ab as the causative agent of GD, there have been several studies on the significance of the measurement of these Ab during the course of the disease as well as during anti-thyroid drug treatment. Other types of TSHR-Ab can antagonize or block the action of TSH and in doing so can cause hypothyroidism in certain patients with various types of autoimmune thyroiditis such as Hashimoto's thyroiditis (HT). TSHR-blocking antibodies (TBAb) have been less well-studied compared with TSAb and the clinical utility of their detection is less well-established. Neutral TSHR-Ab are neither able to induce the cAMP signal pathway, nor do they block the binding of TSH and currently do not seem to have a functional effect. The significance and clinical relevance of the neutral TSHR-Ab in AITD needs further investigation.

Ever since it has been known that TSHR-Ab exhibit different functional activities it has been suspected that

certain patients might contain both TSAb and TBAb, and that this might explain certain clinical presentations. Recent evidence has proven that a patient can have both TSAb and TBAb by isolating MAb with stimulatory and blocking activity from the lymphocytes of the same patient. In addition, there has been speculation that patients with GD and/or HT may shift between stimulating and blocking antibodies as they transition from hyperthyroid to hypothyroid and vice versa.

Numerous assays have been developed to measure TSHR-Ab. In general, these assays fall into one of two types: 1) immunoassays that measure binding to the TSHR or 2) bioassays that assess the functional activity of these Ab (3). A variety of types of immunoassays have been described, but the most commonly used assays clinically are competitive binding assays based on displacement of a tracer, either an anti-TSHR monoclonal antibody (MAb) or previously used radioiodine labeled bovine TSH. These assays have been referred to as TSHR-binding inhibitory immunoglobulin (TBII) assays. Bioassays are cell-based assays that measure induction of cyclic adenosine 3', 5'-monophosphate (cAMP) signal transduction mediated by binding of ligand to the TSHR. Historically bioassays that measure TSAb were based on measurement of cAMP levels in cells using radioimmunoassays. More recently, cell lines that contain a cAMP-inducible reporter gene such as luciferase have been employed to measure TSAb. Bioassays that measure TSHR-blocking activity are based on the same cell-based systems, but they detect the ability of patient antisera to block TSH or TSAb stimulated cAMP levels or luciferase expression (4).

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Flexible New Method for Early Cancer Diagnosis

ARTICLE FROM UNIVERSITY OF GOTHENBURG / SAHLGRENSKA
ACADEMY (SAHLGRENSKA.GU.SE/ENGLISH)

NEWS: MAY 18, 2017



Earlier discovery of cancer and greater precision in the treatment process are the objectives of a new method developed by researchers at Sahlgrenska Academy and Boston University.

Investments are now being made to roll out this innovation across healthcare and broaden the scope of the research in this field.

“We can screen at-risk patient groups, and we also plan to spot the cancer patients who are relapsing so that we can adapt their treatment,” says Anders Ståhlberg, docent in molecular medicine and corresponding author for two articles about the method.

The technique was created based on the fact that people with cancer also have DNA from tumor cells circulating in the blood, molecules that can be discovered in a regular blood sample long before the tumor is visible via imaging such as tomography, MRI, X-ray and ultrasound.

The researchers have now increased the sensitivity of detecting tumor DNA in blood thousand-fold by eliminating the background noise from the measurements using “DNA barcoding”.

Soon Ready for Patients

“One of the benefits of the technique is that it makes use of available instrumentation, which means it can be applied in most labs. We are not first in the world to show that barcoding concept works, but in our case we have developed a fast and flexible method that is simple, flexible and cost-effective to use,” says Anders Ståhlberg.

In articles in *Nature Protocols* and *Nucleic Acids Research*, he and his colleagues talk about how the ultra-sensitive mutation analyses find individual tumor cell molecules among 10,000 healthy molecules.

The method is now also being implemented as a generic platform at Sahlgrenska University Hospital by the Wallenberg Center for Molecular and Translational Medicine at University of Gothenburg, in close collaboration with the hospital, and with the backing of Astra Zeneca and Region Västra Götaland.

“The method has major potential and should soon be ready for patients. However, first the application need to be tested on patient material in clinical studies, there really is no way around that,” says Göran Landberg, a professor and director of the Wallenberg Center, who has the task of bringing research and clinical work together.

“We work together closely both at the hospital and the university, and with Astra Zeneca. These efforts are completely in line with our ambitions,” says Göran Landberg.

Treatment Customized More Effectively

Screening of at-risk groups for certain types of cancer, leading to earlier diagnosis, is being described as an area with major potential, both with regard to saving lives and saving money within healthcare. No tissue samples are needed for the method, and the tumor does not even need to be located.

It can also be used in the calibration of chemotherapy treatments, and help to avoid problematic under- and overdosage. It can also be used to discover whether a patient is becoming resistant to a certain cancer drug, according to Anders Ståhlberg.

“There is a great need for something like this in this area. After all, targeted treatments work well for some patients at the moment, but not others. We hope to be able to find out how well a treatment is going, detect relapses at an early stage and improve our options with regard to changing treatments,” he says.

Read more in *Nature Protocols* (<https://www.ncbi.nlm.nih.gov/pubmed/28253235>) and *Nucleic Acids Research* (<https://www.ncbi.nlm.nih.gov/pubmed/27060140>).

Send an email to head researcher Anders Ståhlberg (anders.stahlberg@gu.se).

Get in contact with Julia Grönros (julia.gronros@gu.se), research coordinator at Wallenberg Center (www.wcmtm.gu.se).



Anders Ståhlberg
(photo: Elin Lindström Claessen)



Göran Landberg
(photo: Johan Wingbord)

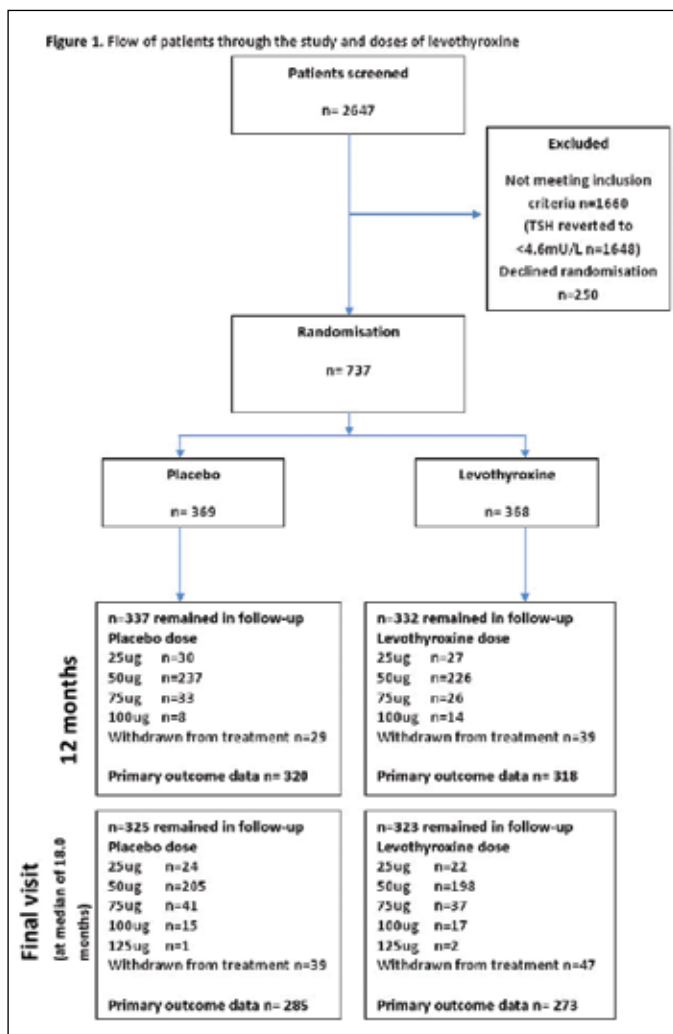
Thyroid Hormone Therapy for Older Adults with Subclinical Hypothyroidism

YVONNE ANDERSSON LAKWIJK

The use of levothyroxine to treat subclinical hypothyroidism is controversial. This study aimed to determine whether levothyroxine provided clinical benefits in older persons with this condition.

Involvement of patient organisation

From the start of the project Thyroid Federation International was invited to support the study in order to get funding from the EU. TFI gave the support and offered to join the team to give continuous patient view on the study. Yvonne Andersson Lakwijk (former President of Thyroid Federation International) took part in the meetings and gave her views and advice regarding patient information, trial design and conduct towards patients.



Methods

This was a double-blind randomised placebo-controlled parallel group trial of 737 subjects aged ≥ 65 years with SCH (elevated TSH 4.6-19.9 mU/L on minimum of two occasions ≥ 3 months apart and fT4 levels within the laboratory reference range); 368 were allocated levothyroxine, starting dose 50 μg daily (25 μg if weight $< 50\text{Kg}$ or coronary heart disease) with dose titration according to TSH level; 369 were allocated placebo with mock titration. Co-primary outcomes were change in Hypothyroid Symptoms and Tiredness scales of the thyroid-related quality of life questionnaire (ThyPRO) at one year.

Results

Mean age was 74.4 years with 396 (53.7%) females. Median dose of levothyroxine at 1 year was 50 μg . Baseline TSH was 6.40 (SD 2.01) mU/L, reducing to 5.64 (3.43) at 1 year in the placebo group, and 3.65 (2.11) in the levothyroxine group ($p < 0.001$); the change in Hypothyroid Symptoms score was 0.2% (SD 14.4) in the placebo group and 0.2% (14.4) with levothyroxine (95% CI for between-group difference -2.03, 2.06); respective changes for Tiredness scores were 3.2% (17.7) and 3.8% (18.4) (95% CI -2.11, 2.87). No beneficial effects of levothyroxine were seen on a range of secondary outcome measures.

Conclusions

Levothyroxine gave no symptomatic benefits for older people with SCH; this drug should not be routinely prescribed to older people with mild SCH (TSH $< 10\text{mU/L}$) for the purpose of symptomatic improvement.

Full Article

David J. Stott, M.B. et al. Thyroid Hormone Therapy for Older Adults with Subclinical Hypothyroidism. *N Engl J Med* 2017; 376:2534-2544 June 29, 2017 DOI: 10.1056/NEJMoa1603825

All information is also available (in 4 languages) on the website www.trustthyroidtrial.com.

(Funded by European Union FP7, Grant agreement number 278148; Clinicaltrials.gov number NCT01660126).

Patient Related Outcomes and Measurements

ASHOK BHASEEN, M.PHARM, MMS

Patient Related Outcomes (PRO) is a topic that is dear to my heart. It's a value based proposition that involves and engages the patient in his/her own health outcome. PRO could also serve as an active treatment coordination where patients provide valuable insights into their perception of delivery of care and transform protracted or multi-step care paths into real-time situations. It involves patients before, during and after treatment.

The patient actually is at the centre of the healthcare system, and the care and caregivers are designed, educated and groomed for the wellbeing of the patient. Increasingly there is realization for the patient-centered healthcare system. The outcomes of clinical intervention obtained by the patient, i.e. patient-reported outcomes (PROs) are seen as important outcomes in the future more than any other reported outcomes, e.g. physician generated clinical report, physiological or other caregiver-reports. Many related publications indicate that enhanced treatment adherence and outcomes can be obtained by giving more attention to patients' feedback on healthcare outcomes and patient changes in behavior.

As per US-FDA, a PRO is any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or others. As per my ThyroWorld 2016 Summer issue publication, no new product by regulatory authorities and health agencies are approved without a PRO assessment. PRO depicts the actual impact a drug has on a patient and hence an important part of a new product submission and approval.

Patient Reported Outcome Measures (PROMs) assess the quality of care delivered to patients from the patient perspective. PROMs calculate the health gains after surgical treatment using pre- and post-operative surveys. Unfortunately, PROMs either do not exist or are not much talked about or published when procedures of the Thyroid Gland are performed. On the other hand some countries leverage PROMs for orthopedic surgical procedures.

Conclusions

Medical technology is advancing each year and it allows measuring physical, physiological or biochemical data of the patient; however, it is not able to give all the data about the treatment or the disease. Some of the data can only be obtained directly from the patient.

In summary a patient can tell many things like effects of procedure or drug, thoughts, complaints, opinions that technology or any caregiver can't and which may actually be more valuable. As discussed earlier PRO are the measurements that come directly from the patient. Quality of life plays an essential role in the treatment. e.g. thyroid related issues. Therefore, PROs are gaining in importance in the clinical world.

The mindset at the caregiver level is changing slowly and the realization of the importance of engaging the patient at the healthcare level and among the pharmaceutical industry is gaining some traction. As patients we embrace this and hope to see our patients benefit from this collaboration. We all win when we have better and more positive patient and health outcomes. Research has shown that prevention and early detection saves lives, and creates long term returns.



Patients conference held in Copenhagen.

Thyroid Surgery and Voice Preservation

DIPTI KAMANI MD¹ AND GREGORY W. RANDOLPH MD FACS FACE^{1,2}

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2. DEPARTMENT OF SURGERY, ENDOCRINE SURGERY SERVICE, MASSACHUSETTS GENERAL HOSPITAL, BOSTON, HARVARD MEDICAL SCHOOL MA, USA

Thyroid surgery has evolved from a 19th century procedure challenged by high mortality to an innovative and graceful modern day operation with emphasis on decreasing morbidity. Presently, the most significant complications of thyroidectomy relate to vocal cord paralysis (VCP) and postoperative voice changes, recurrent laryngeal nerve (RLN) injury is one of the most common underlying cause.

Recurrent Laryngeal Nerve Injury

Rate of recurrent laryngeal nerve (RLN) paralysis after thyroidectomy have been reported to be 9.8%, ranging from 0-18.6%; almost 1 in 10 patients has temporary laryngeal nerve injury after thyroidectomy and 1 in 25 patient have longer lasting voice complaints.¹ Unilateral vocal cord paralysis (VCP) usually presents with breathy voice due to air leak, but it may be associated with variable symptoms. Initially there maybe vocal fatigue and minor pitch changes with otherwise fairly normal voice. These changes may not be present for several days as they may be offset by postintubation vocal cord edema. Later, the paralyzed vocal fold atrophies with resultant worsening of voice. The unpredictable remaining cord function, variability in paralytic cord position and contralateral cord compensation, all contribute to varying symptoms in unilateral VCP patients. Bilateral VCP usually presents acutely after extubation and is associated with stridor and respiratory distress necessitating tracheotomy.

External Branch of Superior Laryngeal Nerve (EBSLN) Injury

Postoperative voice changes after thyroidectomy can also occur because of injury to the external branch of the superior laryngeal nerve (EBSLN), resulting in decreased vocal projection and inability to attain higher vocal registers. EBSLN injury is not associated with distinguishable findings on laryngoscopy. EBSLN is known as the “nerve of Galli-Curci” after the famous soprano Amelita Galli-Curci whose career purportedly ended due to likely injury to the EBSLN during thyroid surgery. Both RLN and SLN are depicted in figure 1.

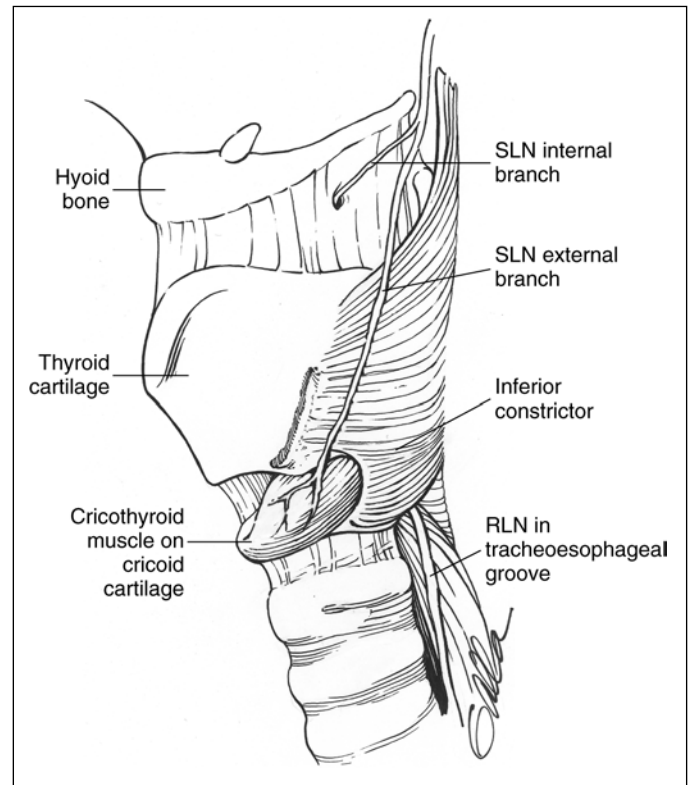


Figure 1: Side view of recurrent laryngeal nerve and Superior laryngeal nerve- External and Internal branches.

Normal Vocal Cord Motility with Abnormal Voice

Postoperative voice changes can occur in patients with intact vocal cord function and typically present with transient voice fatigue and difficulty with singing voice.

VCP and Normal Voice

VCP may be present without significant vocal symptoms, sensitivity of voice change for predicting VCP is reported as 33% to 68%.^{2,3} Subtle voice changes may often be overlooked by the patients and be difficult for clinicians to detect.

Preoperative and Postoperative Voice Assessment

In 2013, the American Academy of Otolaryngology-Head and Neck Surgery (AAO-HNS) published guidelines for improving voice outcomes after thyroidectomy.⁴ These guidelines emphasize the importance of RLN identification and preservation during thyroidectomy. The guidelines recommend communication with the patients regarding possible voice abnormalities and documentation of preoperative

(continued on page 12)

assessment of voice. Preoperative laryngoscopy was recommended in the cases of impaired voice or those with thyroid cancer, suspected extra thyroidal extension, or prior neck surgery. Post-operatively, laryngoscopy should be performed by a qualified physician in cases with postoperative voice issues. Postoperative laryngeal exam is essential as presently, it is the only accurate outcome measure for postoperative RLN function as voice changes and VCP can present independently.

Thyroidectomy and Professional Voice Users

Post thyroidectomy Voice changes caused by neural or non-neural etiology, can cause substantial morbidity for any patient, but have a greater implication in professional voice users. In a series of thyroidectomy performed with IONM, 100% of the times singers and professional voice users returned to performance with a mean duration of 2.26 months post-surgery. This information should be included in preoperative counseling in these patients.⁵

Voice Preservation in Thyroid Surgery and IONM

Prevention of injury to the laryngeal nerves during thyroid surgery is most important for preservation of voice.

“I am convinced that the best management of RLN injuries is of the preventative character”

Frank Lahey 1938

Visual identification of the RLN during thyroid surgery is the gold standard, thorough anatomical

knowledge and experience are essential tools and Intraoperative nerve monitoring (IONM) is a valuable adjunct to these tools. At the present time, in an effort to optimize the postoperative voice outcomes IONM of the recurrent laryngeal nerve (RLN) is increasingly becoming an integral part of thyroid and parathyroid surgery world-wide. EBSLN monitoring is also gaining popularity due to the fact that neural monitoring of the EBSLN is associated with higher rates of EBSLN identification than through visual identification alone.⁶

The International Neural Monitoring Study Group (INMSG) has published standardized guidelines for the IONM of RLN and EBSLN in order to improve IONM application and to achieve comparable outcomes.^{6,7} The guidelines essentially address IONM technique, equipment set-up, loss of signal (LOS) interpretation and troubleshooting during IONM. The IONM set-up is depicted in figure 2.

Applications of IONM

Neural mapping and identification

Neural mapping is associated with nerve identification rates of 98-100%⁷.

Insight into Pathologic States of the RLN:

In a patient presenting with VCP caused by malignant invasion of the nerve, sometimes IONM may show a significant partial EMG activity. When such a nerve is resected; postoperatively, the patient should be informed about worsening of voice despite having VCP preoperatively.

(continued on page 13)

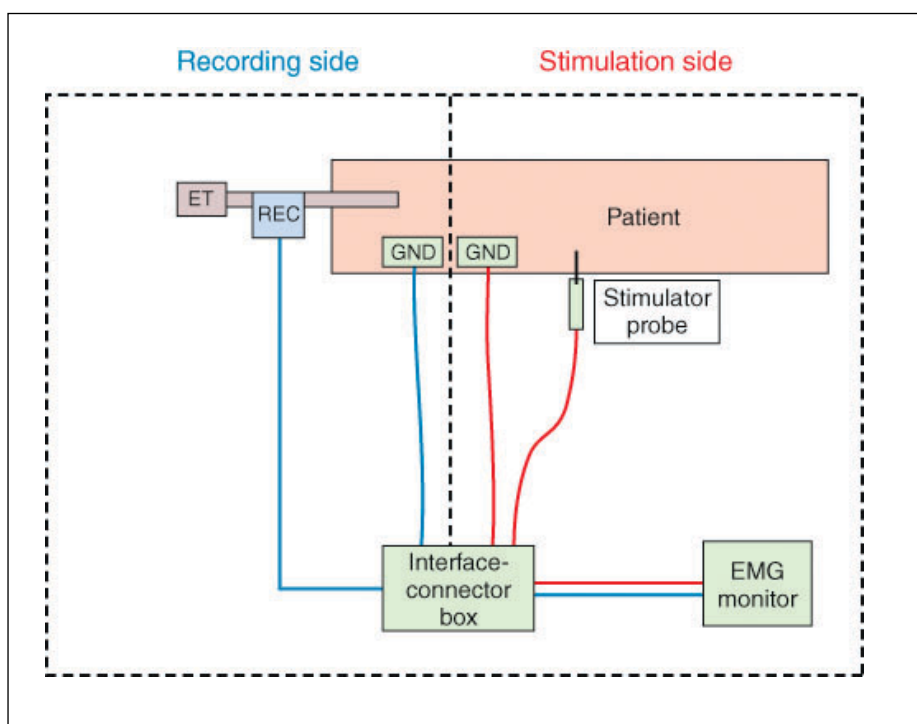


Figure 2: Intraoperative nerve monitoring set-up

IONM and RLN injury

By far, the most essential function of RLN monitoring is the prevention of bilateral VCP. It allows objective assessment the functional status of the RLN intraoperatively and thereby permitting the surgeon to make decision regarding postponing the contralateral surgery if RLN injury on the first side is suspected based on IONM parameters. Additionally, IONM may assist in localizing the injury site.

IONM and Anatomical Variations of RLN

IONM can help in identifying RLN branches and also identifying non-recurrent laryngeal nerve (NRLN), which has higher vulnerability to injury due to its unexpected anatomic course.⁸

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Ashok Bhaseen with Prof. Dr George Kahaly at ATA Denver Oct 2016.



Dr Birte Nygaard and Bente Lasserre presenting at the Patient conference of the Danish organization.



Ashok Bhaseen with Serbian Endocrinology team starting from 3rd from left (to Right) Milos Zarkovic, Ashok Bhaseen, Biljana Nedeljkovic, Milan Petakov and other colleagues from Serbia at ETA, Copenhagen 2016.

ITAW 2017 Results Summary

This May, we partnered again with Merck to support the 9th International Thyroid Awareness Week (ITAW), the annual disease awareness campaign.

The objective of our thyroid awareness campaigns is to raise awareness of the symptoms of hypothyroidism and hyperthyroidism and encourage people with potential symptoms of thyroid disorders to see their doctor if concerned.



This year's campaign 'It's not you. It's your thyroid.' highlighted the striking similarities between the symptoms of thyroid disorders and the effects of today's fast-paced lifestyles.



At least 23 countries rolled out the campaign this year, supported with a toolkit of materials. A range of educational materials and resources were made available and are now hosted on the campaign website: www.thyroidweek.com/

Thanks to the activities conducted, a total of 145 pieces of media coverage were secured globally, with an estimated reach of over 13 million people.

The campaign has also come alive on social media, with more than 125 posts throughout the week, reaching more than 158,000 users on Facebook and Twitter.

Please see some of the work that was rolled out for ITAW 2017 in the pictures below which were provided by Merck.



(continued on page 15)

May – Thyroid Awareness Month 2017

The Australian Thyroid Foundation

The ATF embraced the 2017 message, **It's Not You, It's Your Thyroid!** during the Australian Thyroid Awareness Month of May.

The media connected to this message which raised awareness throughout the country. ATF Memberships increased during the month with more and more Australians realising the importance of **Good Thyroid Health!**

The ATF's Thyroid Awareness Month, incorporates Thyroid and Pregnancy, World Thyroid Day and International Thyroid Awareness Week.



May is
THYROID
AWARENESS MONTH

**It's Not You
It's Your
Thyroid!**

Learn About the Importance of Recognising
Thyroid Symptoms, Thyroid Testing &
Available Treatments

This May, make sure you are informed about:

- Recognising Thyroid Symptoms
- Available Thyroid Tests and Treatments
- Reasons to Be Aware
(i.e. hypothyroidism, hyperthyroidism, enlarged or nodular thyroid, contemplating pregnancy, pregnant or breastfeeding)

THE AUSTRALIAN
THYROID
FOUNDATION LTD

Support the ATF and Raise Awareness about the Importance of Good Thyroid Health
To learn more, visit www.thyroidfoundation.org.au

ITAW 2017 ... (continued from page 14)



Patients write their personal story on our Facebook Page

The Danish patient organization, Stofskifteforeningen, had a small campaign on Facebook during International Thyroid Awareness Week.

We offered three of our members the use of our Facebook page as a platform for a larger audience during International Thyroid Awareness Week. Here they wrote their personal story under the headline “It’s not you, it’s your thyroid”, reported Vice President Kristina Schønnemann Jensen.



The first post was authored by Helle Kold Jespersen who was diagnosed with Hashimoto’s Thyroiditis nine years ago. She wrote about how we as patients, instead of using objective medical terminology, can find a better

way to describe our symptoms. Helle Kold Jespersens’ post had a Facebook reach of 11,000 people in the first few days. For the Danish patient organization with 4,500 likes that is quite a lot of people.

The other two authors were a patient with hyperthyroidism who wrote about her Thyroid Eye Disease (TED) and a next of kin describing his experiences with his partner when her thyroid disease is stirring.

“We hope that people not familiar with the symptoms of thyroid disease learned something during the campaign”, said Kristina Schønnemann Jensen.



Helle Kold Jespersens’ Facebook post on May 22nd (translated)

How are you? – Oh my inner freezer is doing just fine and the armrest on my chair stops me from collapsing completely from fatigue, thank you. How are you?

For me it makes no sense to tell others that I’m tired, sensitive to cold, unfocused and so on. That’s something most people experience from time to time. And using these same words to describe my symptoms when my thyroid is off feels all wrong. I think we as patients would do better by elaborating on our symptoms, giving examples and using different scales to describe them for others.



I’m not sensitive to cold. I suffer from the “deep frozen spine-symptom”. I’m not “could take a 10 minute nap every afternoon”-tired. I’m “lacking the muscle energy to wash my hair without a break”-tired. I don’t have loss of appetite (on the contrary I love good food and sweets). I just don’t get hungry and suffer from “whoops, I forgot to eat for 24 hours again”-symptom. So let me ask you, what symptoms do you suffer from?

By HELLE KOLD JESPERSEN.



THYREOIDEA
LANDSFORENINGEN

The Philippines and the Thyroid

The Philippines joined the observance of World Thyroid Day within the International Thyroid Awareness Week last May 2017 with a series of activities designed to raise awareness, build human resource capacities and enhance collaboration among institutions.

The lead organizations included the Philippine Thyroid Association (PTA), the Philippine Society of Endocrinology, Diabetes & Metabolism (PSEDM) and the Iodine Global Network Philippines (IGNP). Members of these organizations joined up with the

Department of Health of the Philippines (DOH) in conducting lay forums, teleconferences, radio-TV interviews, scientific-technical meetings to develop clinical practice guidelines on thyroid & pregnancy and to finalize a draft of National Policy on Thyroid Disorders.

The Philippine Thyroid Diseases Study (PhilTiDeS 1) in 2012 showed that 8.53% of Filipino adults had thyroid functional abnormalities. The National Nutrition Survey conducted by the Food & Nutrition Research Institute in 2013 revealed that large

areas of the country still have iodine deficiency disorders especially among pregnant & lactating women.

The Philippines devotes three national events that focus on thyroid disorders: Goiter Awareness Week in January, World Thyroid Day in May, and the Thyroid Cancer Awareness Week in September.

(continued on page 18)



Department of Health
Assembly of Stakeholders
to finalize draft of Policy
on Thyroid & CPG on
Thyroid & Pregnancy
June 22-23, 2017
Kimberly Hotel
Tagaytay City



CNN Philippines TV Interview, May 25, 2017



Teleconference with
5 Hospitals linked to
St Luke's Medical Center
May 24, 2017
Topic: "It's Not You...
It's your Thyroid"

The Philippines ... (continued from page 17)

The following is a summary of the upcoming activities prepared in the Philippines in observance of World Thyroid Day within the International Thyroid Awareness Week:



May 16

- Thyroid Disorders in Pregnancy Clinical Practice Guidelines meeting, Holiday Inn, Makati City
- Radio interview at DZMM Magandang Gabi Dok (Dr. Nemencio Nicodemus), 8:30 – 9:30 pm

May 22 – DOH Kickoff

- DOH Central Office, Regional Offices, Hospitals (c/o Dr. Clarito Cairo)
- Start of lay forums in hospitals
- Radio interview at DZBB Easy Easy Lang (Dr. Teofilo San Luis Jr), 11:00 am – 12:00 nn

May 23 – National Nutrition Council

- Salt Colloquium, NNC Conference Room, Taguig City

May 24

- Inter-hospital web-based teleconference forum: The Great Thyroid Masquerade St Luke's Medical Center Quezon City, 2:00 – 3:00pm (c/o Dr. Jeffrey Domino)

May 25 – World Thyroid Day

- Public Hearing, National Policy on Thyroid Disorders, Madison 101 Hotel, Quezon City
- Radio-TV Interview at CNN Philippines Newsroom Ngayon (Dr. Teofilo San Luis Jr), 10:00 – 11:00 am

May 27 – ITAW Culminating Event

- Robinsons Novaliches, 2:00 – 6:00 pm
- Lay forum with Dr. Wenceslao Llauderer and Dr. Teofilo San Luis Jr; Program starts at 5:00pm

TFI Booth in Copenhagen



Thyroid awareness week in Portugal

The 9th International Thyroid Awareness Week (22-28 May, 2017) highlighted the similarities between the symptoms of thyroid disorders and the effects of today's fast-paced lifestyles, and the tendency for people to blame themselves for the symptoms of the condition through the 'It's not you. It's your Thyroid' campaign.

In Portugal, the campaign was held by Thyroid Disease Portuguese Association (ADTI), Portuguese Society of Endocrinology Diabetes and Metabolism (SPEDM) together with Merck.

This year's International Thyroid Awareness Week campaign, 'It's not you. It's your thyroid.', revealed that many women might be blaming themselves and their lifestyle choices for symptoms like weight changes, irritability, anxiety, insomnia, and excessive tiredness, not realizing that a thyroid disorder could be the underlying cause.

In Portugal, ITAW 2017 was quite busy with several activities, such as, development of a new logo "Know the Thyroid" in addition to the existing international one, quiz with relevant questions and answers, special banners, posters, leaflets, roller-ups, interactive website, awareness on facebook, wide media coverage in the prime time of the main TV channels and newspapers...

... but the real highlight was the Open Day with a Health Screening Event on the main shopping centre of the Oporto City (North Portugal).

Thyroid Disease Portuguese Association (ADTI) had the opportunity of performing more than 1,000 tests and detecting some people with the disease.

The presence at the event of the ADTI Advisory Medical Board was of the most importance in helping to clarify these new patients and their families.

The event was a huge success...



New Logo



Website Banner



(left to right) Dr. Mario Vaisman, President Local Committee, Ashok Bhaseen and Dr Ana Luiza Carvalho, President LATS at the Rio da Janeiro, 2017 Conference.



Prof. Eduardo Tomimori, President, Instituto da Thyroide, Brazil busy at the TFI booth at LATS, Rio da Janeiro, Brazil June 2017

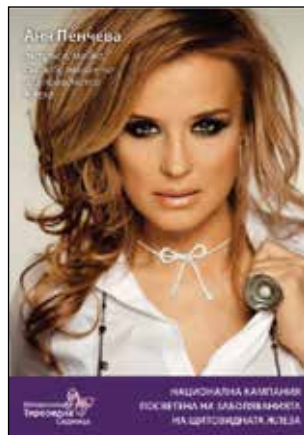
VIOM – about our goals and who we are

VIOM is a non-profit organisation founded in 2012 in Sofia, Bulgaria with the aim to support patients suffering from thyroid diseases and their families. The main goals are to provide patient oriented information for thyroid diseases, especially for thyroid cancer, to improve the contact between physicians and patients (a serious problem in Bulgaria), to ameliorate the communication and exchange of experience between patients, and to support patients and their families to overcome the consequences of the disease. VIOM strives to increase society's awareness of thyroid diseases and work together with communities to improve the quality of diagnostics, prevention, treatment, and follow up for such patients.



25th of May 2017 – The National Palace of Culture (the largest multifunctional complex in South-eastern Europe) light up in purple thanks to the joined efforts of VIOM, the Bulgarian Endocrinology Society, and Merck.

VIOM is governed by a Board of three individuals, two of which are patients. The current president of the Board is Maria Silyanovska. The organisation is part of the National Patient Organisation (an umbrella patient organisation in Bulgaria) and is a member of the Thyroid Federation International and European Patient Cancer Coalition.



Anya Pencheva –the face of VIOM



25th of May 2017, Press conference: Tzvetomir Alexandrov, Tzvetomir Mitkov, Maria Silyanovska, Ana Tsakova

The organisation has good connections with Bulgarian and European specialists and organizes consultations with them for complicated cases.

VIOM has developed a web page with detailed information about thyroid diseases, including a map of specialized hospitals and endocrinologist in Bulgaria and different articles on the subject of thyroid diseases. A telephone number and email address through which patients could get in touch are also available on the web site.



Screening tests

Since 2014, VIOM has been taking part in ITAW activities with information brochures, print and on-line media publications, press conferences, radio spots, etc. Every year more than 2,500 people are screened, most of whom have never been tested before. One of the most successful ITAW activities is the Thyroid Academy with Ultrasound education courses for endocrinologists. The purpose of the event is to define and fulfil unmet medical needs in diagnosis and treatment of thyroid disorders. Last year, more than 150 participants attended the academy and the speakers were among the most experienced thyroid specialists.

In 2016 VIOM became part of the workgroup on Joint Action on Rare Cancers – a multi-stakeholder collaboration between 18 EU Countries and the European Commission.

The activities of VIOM are endorsed and supported by many public figures. Currently one of them, Anya Pencheva, who is a famous Bulgarian actress and thyroid patient, is the face of the organisation.

Moving Ahead and Making Progress

Thyroid Foundation of Canada

Our 2017 Annual General Meeting was held on May 5–7 in Ottawa, Ontario, the nation's capital. This being Canada's 150th anniversary of the founding of our nation we found it fitting to meet there during this momentous year.

The Board elected at the AGM consists of Mabel Miller, President, Jennifer Olchow, Vice President, Jeff Griffith, Treasurer and Directors Frances Salvaggio, Gabriela Albarracin, Kim McNally, Michael Miller and Laz Bouros.

Our focus this year has been mainly financial. Our financial practices were reviewed, and a new Policy put in place which we saw many benefits from.

Costs have been cut to TFC's newsletter, Thybulletin, by making better use of space to decrease the number of pages, printing in black and white for the inside pages instead of colour throughout, and sending to the majority of members electronic copies vs mailed printed copies.

Our annual Light a Tree for Thyroid fundraiser saw increased results with contacts being made to all in our data base through email. In addition, solicitation through email vs regular mail where possible resulted in considerable savings.

We have received a bequest which will provide much needed funds for thyroid research projects. We will be seeking input from the medical community to assist us in putting together a research awards plan.

An important project we are currently working on is the revitalization of our website and rebranding. A review of contacts to our website shows we had 833,000 visitors over the past year. It is recognized that technology plays a big part in how we operate and how we provide



Mabel Miller,
President

information. It is necessary to bring our resources and our image up to date.

Patients and others from all over the world continue to contact us looking for information on thyroid disease. Our 1-800 enquiry line and our email continues to receive enquiries of various sorts, such as not feeling well despite TSH levels not changing, how to find an endocrinologist, information on thyroid disease, wanting to form a support group, speaker for an event, etc. The Thyroid Foundation of Canada provides information on the various types of thyroid conditions that has been written and reviewed by highly qualified endocrinologists.

We are striving to find a better means of communication with thyroid specialists and government health bodies so as to bring about changes in how thyroid disease is seen by some medical providers. The attitude –“Here are some pills, go home and you'll be fine” is not a good fit for all and that needs to be recognized more broadly.

To strengthen our ability to serve patients in the best way possible, the Thyroid Foundation of Canada is looking into forming an association with other health groups where there is a relationship with thyroid disease, such as Mental Health organizations.

We look forward to many great advances and positive moves in the coming year. We are always interested and pleased to hear of what's happening regarding thyroid disease throughout the world through Thyroid Federation International.



Thyroid Foundation of Canada

La Fondation canadienne de la Thyroïde

May 22 to 28, 2018
10th International
Thyroid Awareness Week
www.thyroidweek.com



Come from Away— The Day the World Came to Town

The importance of volunteering can never be underestimated.

During our AGM Saturday evening dinner, TFC President Mabel Miller and her husband Ralph Miller, relayed their experiences during the 9-11 attacks on New York’s Twin Towers when planes were diverted to their small town of Gander, Newfoundland, Canada. As Red Cross volunteers, they were called to action.



Gander Airport. 38 overseas planes were diverted.



A couple met, fell in love and later married.



Schools and churches became makeshift sleeping quarters.

Over two hundred planes were diverted from landing in the US on September 11, 2001 and redirected to various airports in Canada. Thirty-eight went to Gander, which saw their population of 10,000 grow within 24 hours by an additional 6,000. There were people from all corners of the world on the planes plus animals, including a gorilla on route to a zoo. Organizing and taking care of all those distressed people was a challenge, however the citizens came together immediately and all were welcomed with open arms and made as comfortable as possible with food, lodging and kindness which was



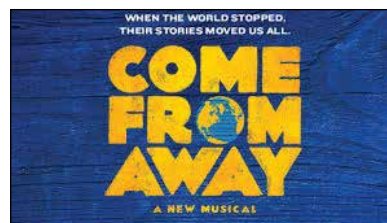
Long lasting friendships were made. 15 years later, many return to visit.

badly needed due to the unknown of what was happening to the world at that time. From the generosity and caring shown, long lasting friendships evolved and many of those passengers regularly return to the Gander area to thank the people for their outstanding efforts at the time. The Gander experience has inspired several books, including “The Day the World Came to Town”, and the award-winning theatre production “Come From Away”, which is now playing on Broadway in New York.

Volunteering can be a positive experience for the volunteer as well as the recipient. As one volunteer put it, “You never know what a plate of sandwiches can do in a disastrous situation – lending a hand reaps many rewards”. The message was – there are people out there – thyroid patients, asking for our help and we cannot let them down.



Unga was on her way to the Columbus Zoo in Ohio. Later her daughter was named after the town of Gander.



The Gander experience inspired a musical. “Come from away” is a Newfoundland term for those who are not native to the island.

Thyreioidea Landsforeningen celebrates its anniversary with a change of name

Thyreioidea Landsforeningen – 20 years and a new name

A milestone was passed when Thyreioidea Landsforeningen - the Danish Thyroid Foundation - celebrated its 20th anniversary. Since January 23rd 1997 our organisation has advised and informed patients in order to broaden their knowledge about the thyroid gland. Over the years we have tried to raise public awareness of metabolic diseases, as well as supported research projects financially in order to enhance the over all awareness of symptoms, quality of life, treatment etc.

In this spirit, our organisation invited its members to attend a conference on Saturday, March 25th, an event that was fully booked with 110 participants. On the agenda were workshops with endocrinologists and other experts that we collaborate with. During the day the participants attended academic presentations of the newest research results in the field and finally a personal talk was given by Lene Beier, a Danish TV-journalist, who told her story about how her body nearly collapsed because of her low metabolism, before she coincidentally was diagnosed with a metabolic disease.



On the same day our organisation held its annual General Assembly. The board proposed – as a birthday present – a new name for the organisation. The reason for this is that the pronunciation of the Latin word “Thyreioidea”, for many years has been a tricky one for Danish tongues and not many Danes know what “Thyreioidea” stands for. But they do know what metabolism is. With a large majority the General Assembly agreed to go forward with the proposal so that from now on our organisation is called Stofskifteforeningen in Danish (Metabolism Organisation). In English, however, the name will still be The Danish Thyroid Foundation. The board is extremely happy and content with this decision and is now starting to promote our organisation under the new name.



THYREOIDEA
LANDSFORENINGEN
FORENINGEN FOR
STOFSKIFTEPATIENTER

Thyroid Federation of India 2016-2017 activity

DR SENTHIL KUMAR SANRAN, PRESIDENT AND ASHOK BHASEEN

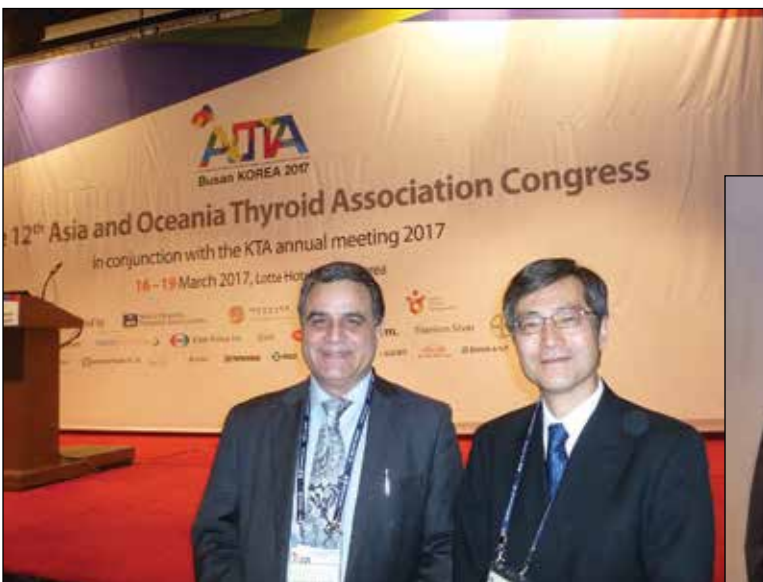
The organization in India is in its early stages and we are taking baby steps in building a viable and strong organization for thyroid patients. During Sept 2016-July 2017 we held 3 important programs in the thyroid world that were targeted at different audiences. India and particularly the southern part of the country is different from the Northern sub Himalayan region and similarly the Eastern and Western parts differ from other regions as food habits and nutrients in the food differ.

The 1st Thyroid Camp was targeted at school teachers. They play an important role in the knowledge development of young students. These students play an important role in helping their families understand their health better. They are really helpful in places where literacy levels are low and they help educate their families in language they can understand. There are coastal parts of Southern India where iodine in the diet is not an issue and higher levels of iodine supplemented with iodized salt can contribute to excessive iodine in their system. Education is key to having iodine in moderate amounts.

The 2nd Thyroid Camp was organized in the Tsunami affected areas (2004). Also, heavy floods hit Chennai in December 2015 bringing consequences with it. Education to the impacted areas was provided on the importance of Potassium Iodide and its role in such emergency situations.

In the spirit of ITAW 2017, our 3rd Thyroid camp was held in an all boys school and an all girls school in the Southern state of Tamilnadu. This camp was dedicated to screening the thyroid gland for Hypothyroid condition. No blood test was allowed in the school and hence, we used non invasive ultrasound to do the testing among 34 boys and 38 girls. Three positive cases of hypothyroid female patients were detected and they were recommended for further investigation.

We are focused on regional issues that impact local people living in different parts of the country. This is a beginning and we remain ambitious and optimistic for the future where we can make a difference in patients' lives.



Ashok Bhaseen with Dr Akashi Akamizu (Japan), President AOTA at the March 2017 Congress at Busan, Korea.



(left to right) Beverly Garside, President Thyroid Foundation Australia, with Ashok and Prof. Duncan Topliss, Australia at AOTA, Busan, Korea 2017 Conference

The Importance of Patient Organizations: CAPE in Italy

LINDA HENDERSON, PAOLA POLANO (PRESIDENT, CAPE) AND DOMINIQUE VAN DOORNE

CAPE (Comitato delle Associazioni dei Pazienti Endocrini) includes 14 Patient Associations in 10 different Italian regions. The main objective of CAPE is to develop a number of projects to promote the lay public's awareness of the importance of thyroid function and of the negative impact of delayed thyroid dysfunction diagnosis. Iodine prophylaxis is of course our main goal and we are proud to say that Iodine deficiency is clearly decreasing all over Italy, although we still need to work on it, as in 2016, 60-70% of the population was using iodized salt. We struggle to arrive at the recommended rate of 90% of the population.

CAPE is collaborating with the **OSNAMI** (Osservatorio Nazionale per il Monitoraggio della Iodoprofilassi in Italia - National Observatory for the Monitoring of Iodine Prophylaxis, a part of the National Health Institute) and 12 scientific societies (endocrinology, pediatrics, gynecology and nutrition) to promote an Italian statement on iodine prophylaxis in Italy.

CAPE participated in the Conference entitled "*Prevention of Iodine Insufficiency Disorders: the national program of Iodine Prophylaxis*" that took place at the Ministry of Health in Rome in April 2017, with a paper entitled "*Iodine Prophylaxis and Patient Organizations*". During the meeting, the role that patient organizations have was underlined, and the importance that they hold in their regions for the prevention of thyroid pathologies was discussed. The representatives from the Institutions showed their appreciation for the contribution from CAPE, and strongly suggested further collaboration in the future.

Also an important Memorandum of Understanding was signed between CAPE and the Ministry of Education for Iodine Prophylaxis in primary and secondary schools.

CAPE was present and given space to share their ongoing projects, together with their Patient Associations during the three major Scientific Society meetings in Italy:

- November 2016 – Rome — **AME Congress** (Associazione Medici Endocrinologici): Session on Narrative Medicine
- December 2016 – Cagliari — **AIT Congress** (Associazione Italiana della Tiroide): Session on



"RadioIodine Therapy in Hyperthyroidism" with "Questions from Patients"

- June 2017 – Rome — **SIE Congress** (Società Italiana Endocrinologi): Round table on Road map of Patient Organizations

During the **2017 International Thyroid Awareness Week**, almost all of the 14 patient associations organized events and encounters in their respective cities with significant results. Events took place throughout Italy:



Last but not least, CAPE has been able to grow by generous unrestricted grants from a few pharmaceutical companies.



New Year's Day 2017 — All In For the GDATE!

A group of Texas Hold'em players kicked off the New Year by raising nearly \$8,000 for the GDATE at the first-ever Rancho Santa Fe Texas Hold'em Invitational Poker Tournament! The event was held at The Inn At Rancho Santa Fe and featured a great mix of skilled players, including popular reality TV show stars Rene and Casey Nezhoda from "Storage Wars" and author Richard Lederer, whose son and daughter are among the most successful professional poker players in the world. Many thanks to all who donated to a wonderful cause. Everyone who attended was a skilled player and in a class all their own!

Texas Hold'em is a skill game that challenges your brain in a variety of ways such as decision-making skills, reading people, patience, math, and playing the cards you are dealt in order to compete and win!

The first place Championship prize went to Lena Evans. Second place, On A Draw, went to Ranjit Randhawa. Third place, Runner-Runner, went to Jon Towers. But the big winner was the Graves' Disease and Thyroid Foundation! GDATE Board Co-Chairs Steve Flynn and Kathleen Bell Flynn organized the event, and GDATE board member and Rancho Santa Fe Senior Center Board President, Carla DiMare, also attended. Steve and Kathleen said of the event and the GDATE, "This charity is dear to our hearts. It is the only charity of its kind in the nation. We want to give a shout-out to our friends



and supporters. Your support in every way is HUGE! Our New Year's resolution is to continue going all-in for a wonderful cause, always!"

Are you interested in hosting an event in your community to benefit the GDATE's education and support programs? Contact us at info@gdatef.org or 877-643-3123 to let us know!



GDATF — From the patient's point of view

AUTHOR : NANCY PATTERSON

The information in the article about TED is both amazing and heart-warming. One of the reasons I founded the Graves' Foundation in 1990 was prompted by my own struggle with TED. It was in those early years that I became acquainted with Dr. Smith and Dr. Douglas, and I have considered them both colleagues and friends for about 25 years. What I have learned during that time is “that it takes a village”—in every sense of the word. Nothing is accomplished without the trust, cooperation, input and hard work of others. So when we were having a conference call Board meeting, and Dr. Smith was telling us about the success of the project that they have been working on for as long as I have known them, he kept referring to the “wonderful folks in our lab”, who work tirelessly to make all these things all come together. While we were talking, it occurred to me that rather than being in North Carolina (my home), I was actually in Ann Arbor, and would be at Kellogg Eye Center the very next day...and that's where the lab was. I know that sometimes the people who are supporting us with all their hard work are seldom adequately recognized. I decided to at least throw a small celebratory party for them. I was able to order a cake, and signed it “with thanks and gratitude”—from all the patients who will benefit from their efforts. Dr. Smith's administrative assistant arranged for the lab assistants to come out and into the office (no one could go back there). I think they were surprised, and I know they enjoyed the cake! It was a pleasure and an honor to meet them. Just like the research being done all over the world, they are from all over the world as well.



Remember to say “thank you” to those around you. It means more than you know, and they mean more than you can ever know.



May 25th, 2017
World Thyroid Day

TFI Member Organizations

AUSTRALIA

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

BELGIUM

Leven Zonder Schildklier
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FINLAND

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Schilddrüsen-Liga Deutschland e.V.
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