

# Thyroid Federation International

## Thyroid Patients Worldwide

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## Thyroid Federation International

Established in September 1995 in Toronto, Canada

### Founder

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

### Mentor & First President

Lawrence C Wood, MD FACP (USA)



### Officers of the Association 2017 – 2018

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Katherine Keen (Canada)

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Harald Rimmele (Germany)

### Member Organizations

*The names of the organizations and their current addresses are given on page 32.*

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## Message from the Editors

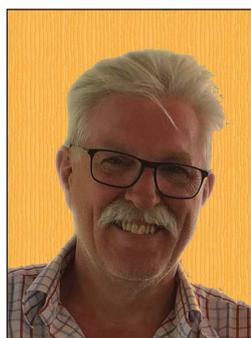
In 2018 we are delighted to welcome our newest members: Croatia, Nepal and Nigeria. That brings our current roster of member organizations to 26! Now in our 24th year, we are proud of our work in finding and distributing accurate information to patients and physicians who deal with all the intricacies of thyroid illnesses.

This year's newsletter has articles about patients, national organizations like Bulgaria, Nepal and Norway, people that have left us and declarations important for thyroid patients. The Krakow Declaration on Iodine is an initiative of the World Iodine Association, supported by TFI amongst many others. The other declaration is a statement of Thyroid Federation International on Thyroid Hormones and changes in the formula of these life-essential drugs for thyroid patients.

In the scientific section of ThyroWorld is an article about the change in the treatment of hypothyroid Swedish women. The results show that the proportion of the population treated for hypothyroidism increased by 32% during a 10 year period. Is it earlier diagnosis by doctors or the attention for thyroid disease raised by the patient organizations?

Wishing all delegates an enriching stay in Newcastle (a city with a long history of thyroidology!) and at the 41st Annual Meeting of the European Thyroid Association.

PETER LAKWIJK AND NANCY HORD PATTERSON, EDITORS



Peter Lakwijk



Nancy Hord Patterson

### ThyroWorld

Deadline for the next issue: June 20, 2019

Send all submissions to:

The Editors, ThyroWorld

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## President's Message

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

Dear Readers,

Welcome to the historical city of Newcastle upon Tyne. From woolen garments to coal and now digital technology, the city has kept pace with changing times. To all delegates, a big welcome to the 41st ETA annual meeting.

I have been associated with the Thyroid world since 1999 and during this time I have met thousands of patients and heard about their experiences of how they deal with their issues and try to live a normal life. Some of the stories are unforgettable, e.g. in 1999, I met a lady who told me how, as a young girl in the early 1950's, she had to stand in line at the butcher's shop to buy desiccated pig thyroid. Now in 2018 in San Diego, CA, USA, I heard a story from a 12 year-old-girl, Isabella, about how she was bullied at school because her physical abilities were impacted by Graves' Disease (read her story on page xx) which disrupted her otherwise normal school life. When I hear this, I realize why TFI people get into volunteering for this organization; it is a blessing to be able to help another person and share your experience.

Much has happened in Thyroid Federation International in the past year. We have kept pace with our increase in spreading education and awareness to three new countries in 2017-18. The Thyroid Foundations in Croatia, Nepal and Nigeria are our newest TFI members. It's good that Thyroid patients can have access to information on education and awareness in their own language.

Recognition of patient organizations and their contributions has taken a while; however, it's here and continues to be of help to both physicians and manufacturers of medication. It was very heartening to see TFI recognized at the 40th ETA Annual Conference in Belgrade on their 50th Anniversary celebration associated with a publication. ETA and ATA have further strengthened their collaboration with TFI through joint declaration and endorsements on clinical practice guidelines and the Krakow Declaration on Iodine to name a few during the past year 2017-18. We take this opportunity to thank ETA officials for a great collaboration with TFI over the years.



Ashok Bhaseen

On the Industry front we continue to witness a patient centric approach and were glad to participate in two advisory board meetings so that we could share our own experience and patient journeys. Both ETA and Industry continue to appreciate the importance of taking the patient perspective in the deliverance and manufacturing of medicines for thyroid patients.

TFI has worked hard on establishing May 25th as World Thyroid Day and also celebrated its 10th Anniversary of International Thyroid Awareness Week

May 25th - May 31st 2018. Merck Serono has played an important role in Thyroid Awareness Week and has supported this initiative throughout the past 10 years. Thanks to ETA, ATA, LATS, AOTA for their partnership and all the Endocrinologists and Physicians throughout the world who gave their precious time to educate patients and helped with programs on creating awareness on thyroid related issues. It is good to see ETA, ATA, LATS and AOTA recognize World Thyroid Day on May 25th each year and it's also great to see them provide a platform of communication and partnership to TFI.

TFI also participated at the AOTA, Busan, Korea, LATS Rio de Janeiro, Brazil and ATA, Victoria, Canada conferences apart from the Belgrade, Serbia, ETA meeting.

TFI now has a presence in Nigeria, Africa and there is so much more to do in the African continent, however, undertaking some initiatives also requires funding, which continues to remain a challenge. Similarly, Nepal in Asia is a developing country and needs a lot of tools in the local language to be able to help its population having thyroid issues. Iodine deficiency is still prevalent in some parts of the world and a strategy with some funding behind it will help alleviate the problem.

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

We look forward to meeting each one of you.

# TFI AGM and ETA congress 2017

## Belgrade, Serbia

BEATE BARTÈS, SECRETARY, THYROID  
FEDERATION INTERNATIONAL

As every year, TFI held its Annual General Meeting in the days before the 40th ETA congress. In 2017, it was in Belgrade, the capital of Serbia. The TFI members were from USA, India, France, Netherlands, Sweden, Germany, Philippines, Spain, Bulgaria, Italy, Australia and Finland.

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

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

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



TFI Annual General Meeting 2017 in Belgrade, Serbia.



TFI president A. Bhaseen addressing the audience during the ETA welcome reception in the Belgrade townhall.



TFI AGM 2017, participants (from left to right): sitting: U. Slama (Finland), M. Porrey (Netherlands), C. Villar (Spain), B. Bartès (France), A. Tirronen (Finland), Y. Andersson-Lakwijk (Sweden)  
Standing: T. San Luis (Philippines), L. Henderson (Italy), M. Silyanovska (Bulgaria), A. Bhaseen (India/USA), H. Rimmele (Germany), P. Lakwijk (Sweden), B. Garside (Australia), M. Hamers (Netherlands)

# In Memoriam Dr. Theo Visser

A couple of years ago I happened to sit in the plane next to Theo Visser on the flight back to Amsterdam from an ETA congress. I had seen him earlier during congresses with groups of students around him.

We were not introduced but he remembered seeing me during the congress. He asked me in which hospital I worked assuming I was a physician. I told him that I had been to the congress as a patient and chair of the Dutch patient thyroid association.

He was not really aware of an organisation for thyroid patients in the Netherlands but he asked why patients would be interested in a medical congress where only new research and the latest in medical treatment were discussed.

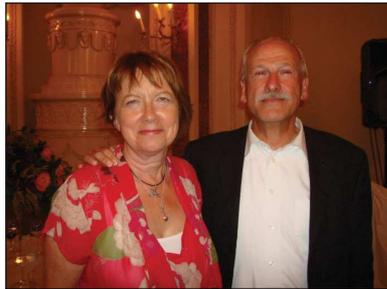
I explained to him that as patients we want to know about the newest treatments in order to be able to influence the decisions made about us. Personally I am interested in basic research of what causes thyroid diseases and what might be done to avoid these causes.

Theo told me that he, with his students, was such a researcher and he told a little bit about some research his teams were doing.

I can't say that we became close friends after this flight, but we greeted each other at future congresses. When Theo became president of the ETA I introduced him to my wife, Yvonne, Past-President of TFI. It was no surprise to us that he hadn't a tie, because he never wore a tie.

His death on March 21<sup>st</sup>, 2018 has taken a very kind and inspiring person from us.

We will miss Theo deeply, and express our sincere sympathy to his family.



Yvonne and Theo

ON BEHALF OF TFI,  
PETER LAKWIJK



## Upcoming Events

**June 20-23, 2019**

17th LATS Congress  
Buenos Aires, Argentina  
[www.lats.org](http://www.lats.org)



**August 18-21, 2019**

13th Congress of the AOTA  
Sydney, Australia  
[www.esa-srb-aota.org](http://www.esa-srb-aota.org)



**September 7-10, 2019**

42nd Annual Meeting of the ETA  
Budapest, Hungary  
[www.eurothyroid.com](http://www.eurothyroid.com)



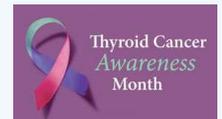
**Oct. 30 to Nov. 3, 2019**

88th meeting of the ATA  
Chicago, Ill., USA  
[www.thyroid.org](http://www.thyroid.org)



**September**

Thyroid cancer awareness month



**May 20 to 27, 2019**

11th International Thyroid Awareness Week  
[www.thyroidweek.com](http://www.thyroidweek.com)

**May 25th  
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.



# E-news ThyroWorld

## It's time for a thyroid patient E-newsletter.

20 years ago Thyroid Federation International (TFI) published the first ThyroWorld with articles from all over the world about the activities of TFI and the member associations.

Every year you can read about the World Thyroid Day (May 25th) and the International Thyroid Awareness Week.

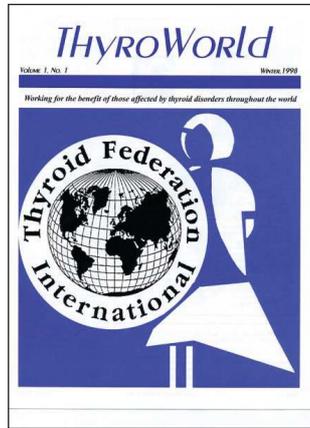
We also publish articles on a variety of aspects of the thyroid and thyroid diseases, mostly written for our member associations but of interest to all involved in thyroid diseases.

ThyroWorld is highly appreciated by our members but also by the professionals from ETA, ATA, AOTA and LATS.

### There is more information.

The information about thyroid research is growing and it is no longer possible to cover this with a magazine once a year.

It is not the role of TFI to publish scientific articles but we do want to bring more science to the patients and their organizations.



In addition to the annual ThyroWorld TFI has decided to introduce an electronic newsletter with articles for layman and links to scientific articles from all over the world from magazines like the Thyroid Research Journal, New England Journal of Medicine, Clinical Thyroidology and less specialized scientific magazines.

Now it's time for your input

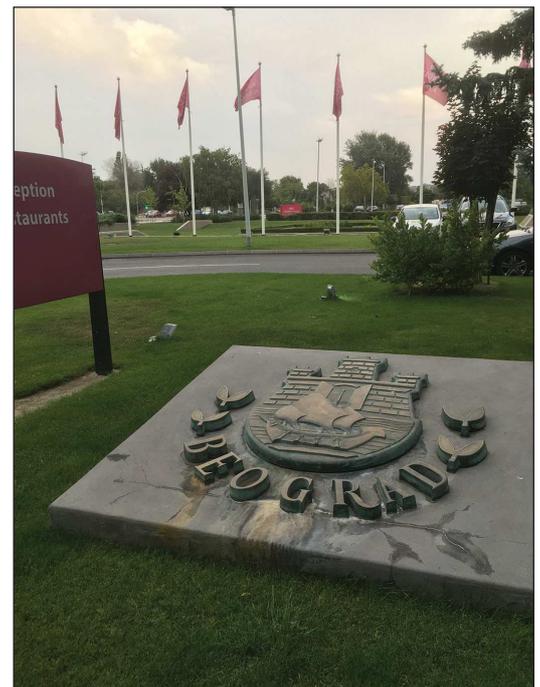
We would like to invite you to join us, as well as inviting you to help us with articles or links to articles that are interesting to thyroid patients. If you agree

we will put you on our mailing list for the newsletter.

Join us on: [http://www.thyroid-fed.org/tfi-wp/enews\\_1701/](http://www.thyroid-fed.org/tfi-wp/enews_1701/)



The ETA congress venue in Belgrade.



Pr Elina Gasparyan, Thyroid Foundation of St Petersburg, Russia, and Ashok Bhasen, president of TFI.

# 1st Conference of the World Iodine Association - Iodine in Food Systems and Health

**Thyroid Federation International /  
CAPE Italia**

**Pisa - 15-17 November, 2017**

L. LINDA HENDERSON - FOR CAPE ITALIA (COMITATO DELLE ASSOCIAZIONI DEI PAZIENTI ENDOCRINI)

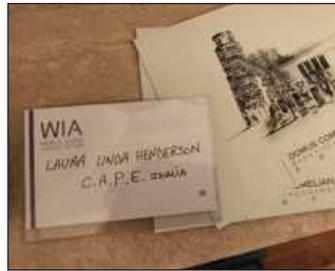
The meeting opened the evening of November 15 in the beautiful Domus Comeliana - literally a stone's throw from the Leaning Tower. I arrived just in time hear Prof. Michael Zimmermann (Professor of Human Nutrition at the Department of Health Sciences and Technology in Zurich) talk about "Global Elimination of IDD, a light at the end of the tunnel?"

Unfortunately, Italy is one of the nations that is iodine deficient as shown from the last statistics of the Superior Health Institute (the chart refers to data received from 2007 to 2012, the only data published to date). The updated data pertaining to the years 2015-2017 will be published in 2018 and will be sent to the IGN and the WHO.

On the second day of the meeting, several work sessions took place in the Palazzo dei Congressi in Pisa. The vast majority of the presenters and the participants were highly specialized, a few physicians and some industry representatives. I was told that all the continents were represented (except for Australia) - a total of approximately 90 participants.

## First Session:

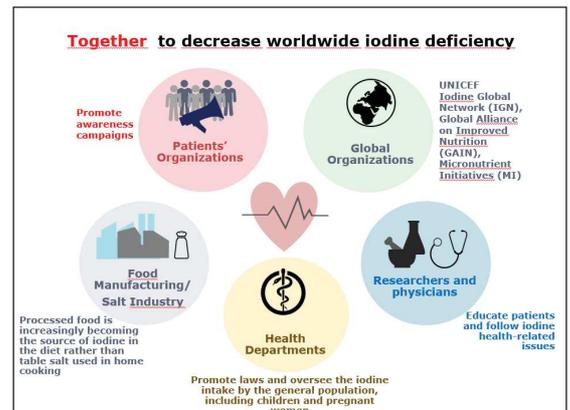
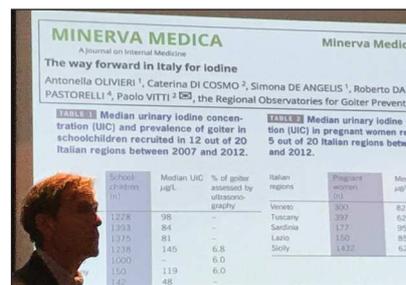
Dr. Vincenzo Costigliola, President of the European Medical Association, underlined the importance of patients and the efforts that must be conducted jointly by physicians and patients. The level of the other presentations in the session was very technical: from the utilization of iodine in the food industry to the harmonization of iodized salt, and to iodine in livestock feeds.



My presentation, the last in the first session, was a little briefer than intended, due to the previous lengthy presentations. I hope that the audience, consisting for the most part of highly qualified specialists and researchers, were able to grasp the importance that Patient Organizations hold and the necessity that they

work together with the other stakeholders to efficiently contribute to reduce IDD.

I was able to underline the work that Patient Organizations promote, such as Awareness Campaigns. Interest was shown during my presentation when I spoke about educating children (who in turn educate adults) and an example of a small Italian coloring book entitled Signor Iodino (Little Mister Iodine) as an example.



In conclusion, I was privileged to represent the Thyroid Federation International (TFI) through CAPE Italia and I feel that the information that CAPE brought forward, together with the help of Dr. Theo San Luis from the Philippines, was fundamental in presenting Patients' Organizations during the first WIA meeting. My impression was that many researchers and highly specialized scientists and industry representatives are not aware of the importance of POs. I can conclude that this may be a first step in working together and that the presence and cooperation between stakeholders is important towards reducing/debilitating IDD.



"Together with patients' organizations, Thyroid Federation International plays an essential role in promoting awareness of #thyroid disorders" says Ms. Laura Linda Henderson, on behalf of @ThyroidFed #iodinedeficiency #WIAconference2017

# The Krakow Declaration on Iodine

This year TFI started cooperation with the World Iodine Association and together are among Signatories of the Krakow Declaration on Iodine

Attilio Caligiani, Director General of the WIA states: *“The Krakow Declaration on Iodine represents the cornerstone of a multi-stakeholder approach to implement a harmonized and coordinated strategy to prevent and tackle IDD at a global level. The World Iodine Association (WIA) recognizes and supports the valuable work done by EUthyroid. It provides the basis to develop effective measures for improving and optimizing iodine intake in Europe in close cooperation with European and national authorities, while creating societal awareness via patient organizations, the medical community and the industry”*

**Read Declaration: [www.iodinedeclaration.eu](http://www.iodinedeclaration.eu)**

Ashok Bhaseen (President of Thyroid Federation International) endorses the Krakow Declaration on Iodine:

*“The Krakow Declaration on Iodine developed by EUthyroid represents an important step towards the prevention of IDD, through a multi-stakeholder approach. The Thyroid Federation International (TFI), as a Patient Organization, endorses the valuable work done by EUthyroid. The TFI believes that it is important to increase awareness to the public through promotions and campaigns. Together with the Medical Community and Industry, joint actions will certainly strengthen this cause and bring to the EU a wider sensitivity on this topic. **Together, a nice step forward”.***



## Krakow, April 18, 2018

Present were the Signatories of the Declaration: Attilio Caligiani – World Iodine Association; Greg Garrett – GAIN (Global Alliance for Improved Nutrition); Linda Henderson for Ashok Bhaseen – Thyroid Federation International; John Lazarus – Iodine Global Network; Henry Völzke – Universitätsmedizin Greifswald; Alicja Hubalewska-Dydejczyk – Jagiellonian University Medical College.



The World Iodine Association is an international non profit organisation established:

- To support and represent iodine producers, processors, formulators, distributors and end users in relevant industry bodies, and in relevant official government bodies around the world with respect to guidelines and regulations on iodine and its derivatives,
- To develop, support and promote the use of iodine and its derivatives in existing and novel uses and applications in the domains of human and animal health and industry,
- To provide information about the purposes, uses and applications of iodine and its derivatives to interested parties,
- To help eradicate global iodine deficiency.

The purpose of the WIA is to become an iodine industry-wide promoter of iodine uses and applications. WIA aims to be a leading source of information about benefits related to human and animal health and to industrial applications, for the benefit, health and wellbeing of humans and animals throughout the world.

By bringing together industrial partners from all sectors, WIA can be the authoritative iodine industry representative in relevant industry and government bodies.

### Contact:

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[www.worldiodineassociation.com](http://www.worldiodineassociation.com)  
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# An Overview of Thyroid Disorders in Nepal

GANDHI PRASAD SHARMA – GENERAL SECRETARY, THYROID FOUNDATION OF NEPAL

Thyroid dysfunction is one of the most commonly encountered endocrine abnormalities in Nepal. The screening of thyroid dysfunction is recommended in Nepal with its high risk population.

Many factors are responsible for exacerbating the thyroid dysfunction in the context of Nepal.

According to a study carried out at Dhulikhel Hospital-Kathmandu University Hospital (DH-KUH), a hospital based retrospective study, 825 subjects (residents of Kavre) that were subjected to a thyroid function test panel (free tri-iodothyronine, free thyroxine and thyroid stimulating hormone) were enrolled and the thyroid dysfunction was stratified as hypothyroidism, subclinical hypothyroidism, hyperthyroidism, and subclinical hyperthyroidism with reference to hormonal levels.

Among the 825 subjects, the prevalence of thyroid dysfunction was 25%. Females had more thyroid dysfunction than males. Hypothyroidism (8%) and subclinical hypothyroidism (8%) had higher prevalence compared to subclinical hyperthyroidism (6%) and hyperthyroidism (3%).

Higher prevalence of thyroid dysfunction was observed in subjects aged over 30 years.

In conclusion, this study revealed the higher prevalence of abnormal thyroid function and concurs with previous reports in other populations. Hypothyroidism and subclinical hypo-thyroidism are preponderant followed by subclinical hyperthyroidism. Females and advanced aged people are more vulnerable to thyroid dysfunction in the population. Since it



Nepal Thyroid Association board and members at large with TFI President.

was a hospital-based study, the prevalence of thyroid dysfunction may not be applicable to the general population. Extensive field-based, countrywide epidemiological studies are necessary to provide accurate data about thyroid dysfunction in the community.

Thyroid dysfunction is also a major health problem of Nepal with a prevalence of nearly 30% of the population affected in the eastern region of Nepal alone. However, the prevalence and pattern of hypothyroidism depend on ethnic, geographic, and environmental factors including iodine intake status. Hypothyroidism and hyperthyroidism are two widespread thyroid problems, of which hypothyroidism is much more common. These disorders are eight times more common in women than in men.

## Conclusion

Because the present study was a hospital based study, it may not represent the whole population, but the study has identified the burden of thyroid dysfunction in Kavre and can be used as baseline data for future studies. The present study has revealed the prevalence of thyroid dysfunction, typically hypothyroidism and subclinical hypothyroidism, were higher in the Kavre region but the etiology of the disease remains unidentified. Moreover, the diseases were preponderant in women and the elderly.

## Recommendation

Further population-based epidemiological studies are needed to establish the accurate prevalence and predominant etiological factors of thyroid dysfunction in this region of the country. In addition, the role of depression, obesity and diabetes must be extensively studied and explicitly defined. The study recommends thyroid dysfunction screening and treatment campaigning in the population of Kavre district to reduce the burden of disease.

The above study shows that people are severely affected by thyroid diseases. So, we have formed an organization, Thyroid Foundation of Nepal, a non-profit organization to serve the needy population of Nepal.

## Organizational Structure of Thyroid Foundation of Nepal :

- Mr. Surendra B.C. – Chairman
- Mr. Kajiman Atreya- Vice-Chairman
- Mr. Gandhi Prasad Sharma – General Secretary
- Mr. Raj Kumar Shrestha – Treasurer

(continued on page 10)

## Thyroid Disorders in Nepal *(continued from page 9)*

### Members:

Mr. Shankar Shah  
Dr. Bonugnong Monica Biswas, MD, Cardiology  
Dr. Madhu Pandey, MD, Endocrinology & Thyroid Disorder  
Mr. Mahendra Bhushal  
Mrs. Tekan Shova Gurung  
Mr. Sita Ram Dhungel

### Advisory Board :

Mr. Rameshwor Roy Yadav, Ex-Minister and Member of Parliament  
Mr. Arjun Kumar Shrestha, Former Secretary, NRNA

We are very much thankful to our Vice-Chairman, Mr. Kajiman Atreya for his great initiation and unforgettable contribution to form this organization in Nepal. We are grateful to our Global President, Mr. Ashok Bhaseen, M.Pharma, MMS, Thyroid Federation International, for believing in us in establishing Thyroid Foundation of Nepal and we are looking forward to his visit to Nepal in August, 2018. Warm welcome to our respected International President in Nepal! We are pleased to welcome you here in Nepal sir.

And, we have anticipated your support in running this organization for the benefit of the needy population of Nepal. We would like to be a part of the TFI society to mitigate the thyroid problems in Nepal.



The European Thyroid Association presented a book about celebrating 50 years of ETA. Yvonne Andersson Lakwijk, former TFI President, was invited to the presentation representing the patients part of the history of the ETA.



Dr Teofilo San Luis and his wife Victoria from The Philippines, with Ashok Bhaseen, TFI president, on a boat trip during the congress in Belgrade

**May 25th**  
**World Thyroid Day**

# Thyroid Hormones Patient Statement 2017

AGM 2017 – BELGRADE, SEPTEMBER 8, 2017

The correct dosage has an enormous impact on the quality of life.

- Thyroid replacement hormones must be available in all – including small – dosages at all time.
- The quality and stability of the medication must be guaranteed.
- Transparent patient information is critical in case of formula changes.

## Small Dosages are Needed!

Hypothyroidism is treated with LT<sub>4</sub> (levothyroxine), in some cases associated with LT<sub>3</sub> (liothyronine).

These drugs have a narrow therapeutic range: a few micrograms make a big difference for the patient in terms of morbidity and quality of life.

In many countries, only a small number of different dosages of LT<sub>4</sub> and LT<sub>3</sub> is available. This makes it extremely difficult, or not possible, to precisely adjust the dosage as recommended in medical guidelines 1.

Individual adjustment (“fine-tuning”) requires that LT<sub>4</sub> and LT<sub>3</sub> are available in small dosages.

## Brands are not Interchangeable!

The formula of the thyroid replacement hormone has a tremendous influence on its absorption – different brands can also have a different bioavailability with variations up to 20%. When patients switch between brands, there is a need to re-check blood values and to re-adjust the dosage<sup>2</sup>. As a consequence, it can take several months before the patient is stabilized again and returns to his or her previous physical and psychological status and quality of life. This also increases the cost for the healthcare system, in terms of physician consultants and symptomatic treatments, as compared to the production costs for thyroid hormones and their cheap market prices.

In the last years, there have been shortages of levothyroxine in several countries. In some cases, companies left the market and patients had to switch to other brands. This has an enormous effect on the stability of the patient thyroid health and quality of life.

The availability of thyroid replacement hormones must be guaranteed at all times and in all dosages. Patients must have the possibility to always stay on their usual brand.

## Safety and Stability First!

Thyroid hormones are among the most prescribed chronic medicines in the Western industrial countries. Patients are on thyroid hormone replacement for a lifetime.

In the past years, this has led to strong competition between manufacturers. This has been intensified by the pressure of national health authorities to make the prices even lower. As a consequence, less and less money is invested in the reliability and quality of the production process, leading to shortages and quality issues.

The national health authorities must look not only at the sale price of the thyroid replacement hormones, but also at the reliability and quality of the medication.

## Patient Information is Critical!

Side effects resulting from changes in the formulation or switch in brands of levothyroxine impact the patients’ quality of life. These side effects, even if they subside after dosage adjustment, can have important consequences in patients’ lives – stress and anxiety, lack of sleep, palpitations, chronic pain, rashes, inability to work or perform daily activities.

Extensive patient information is the key: patients need to be informed that their formula will be changed, why it will change, and what side effects they might possibly expect; while reassuring them on the outcome of this transition period and informing them of the steps to take. During the transition period, communication between doctors, patients, and the manufacturer is of paramount importance.

The examples of formula changes in various countries and for various brands, over the past years, have shown that when patients were duly and extensively informed, no major problems were encountered during the transition period. In countries where patients had insufficient information or did not even know that their medicine had changed, the transition period led to inappropriate media coverage, rumors, fake information and even - as presently in France – a “protest movement” which eventually harms all parties involved – not only the patients, but also the regulatory authorities, manufacturing companies and health professionals.

Pharmaceutical companies, health authorities and health professionals must work together with patient organizations, as soon as a change in formulation is envisaged and throughout the development and marketing periods, so that all critical issues can be identified and addressed early enough.

Extensive, transparent complete information for doctors and patients must be prepared well in advance and adequate resources must be identified to support the transition and rapidly identify issues for positive patient outcomes.

# Changes in levothyroxine: key points and challenges

The pharmaceutical industry is constantly trying to improve their medication, for different reasons. It can be changed to improve the shelf life or potency specification, to remove excipients that could cause adverse reactions, to make the medication better accepted by more patients, or standardize the production.

The American Food & Drugs Administration (FDA) has concluded that levothyroxine sodium is a narrow therapeutic index (NTI) drug based on the following evidence:

- The range between serum levothyroxine therapeutic and toxic concentrations is narrow;
- Some levothyroxine-associated toxicities are serious and/or irreversible;
- Sub-therapeutic levothyroxine concentrations result in inadequate treatment and lead to poor clinical outcomes;
- Levothyroxine sodium requires individual dose titration to achieve a satisfactory balance between maximizing efficacy and minimizing serious dose-related toxicity;
- Therapeutic drug monitoring based on serum TSH and total or free-T<sub>4</sub> levels is routinely employed to facilitate levothyroxine dose titration; and
- Levothyroxine has small-to-medium within-subject variability.

In the last decade, we have seen unannounced changes of the formula in several countries, with

serious consequences for patients. In countries like New Zealand, Denmark and Israel, the changes were driven by standardizing of the production. In France, they were driven by the request of the health authorities to narrow the potency specification. The bioequivalence of the new formula introduced in France was tested by an independent university on healthy volunteers (males and non-pregnant females of the general population) and no unusual side-effects were noted.

Many patients experienced no problems with the changed formula, but in all countries, the change led to unexpected side-effects for a number of patients.

Testing new formulas on healthy volunteers gives an impression of how the new formula will be absorbed. The precise working of levothyroxine in the body is still not well known, and the interaction with the other substances in the tablets and with other medication and food is still a mystery.

New formulas should be tested on thyroid patients in “real-life” conditions without exclusions. The side-effects should be listed in a Medication Guide to be issued with each prescription of the new formula.

Before introducing a new formula, the patients and doctors should be informed about the change and the risk of side-effects. For all patients, TSH and FT<sub>4</sub> tests should be analyzed before the change to the new formula and 6-8 weeks after the change.

During the 2017 ETA conference in Belgrade, TFI issued the “thyroid hormone statement” (see page11).



## Mark your Calendar!

### September 7-10, 2019

### 42nd Annual Meeting of the ETA

### Budapest, Hungary

[www.eurothyroid.com](http://www.eurothyroid.com)

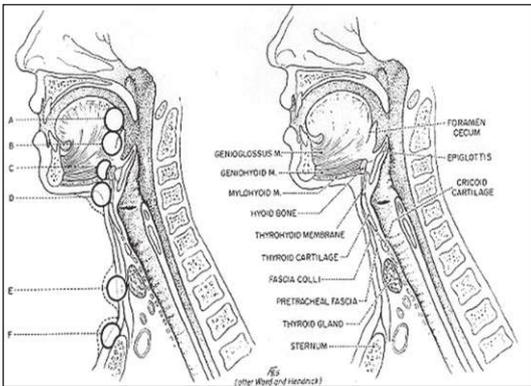


# Thyrothymic Rest – Misdiagnosis or Missed Diagnosis?

DR M.S. SENTHIL KUMAR M.S., MCH (ENDOCRINE), SR FACULTY, ENDOCRINE SURGERY, MADRAS MEDICAL COLLEGE;  
 DR E PRABHU MD DRM, PROFESSOR OF NUCLEAR MEDICINE-OMANTHOORAR MEDICAL COLLEGE, CHENNAI  
 DR S SUBASHINI MD, ASST PROFESSOR, SAVEETHA MEDICAL UNIVERSITY, CHENNAI

Thyrothymic Rest is an embryological remnant Rest tissue which has led to missed diagnosis in the past and misdiagnosis with the advent of modern diagnostic modalities.

## Ectopic vs Thyrothymic Rest

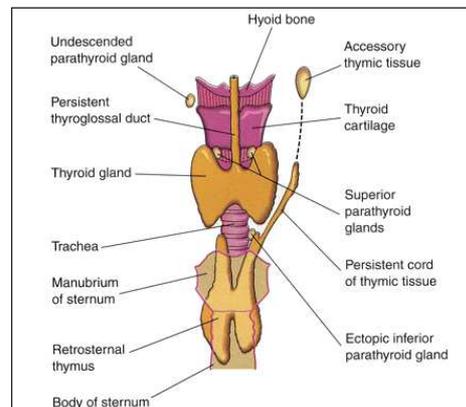
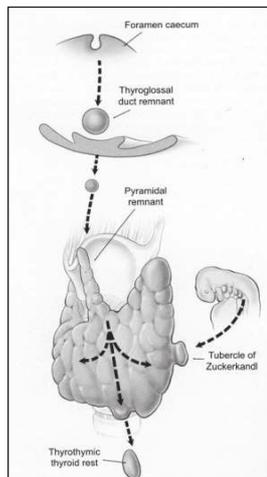


The above diagram from the classical textbooks of Medicine stands testimony to the fact that ectopic thyroid tissue will be found only in the embryological line of descent to thyroid.

The prevalence of an ectopic thyroid is between 7% and 10%, with lingual thyroid tissue accounting for 90% of the abnormalities.(9) However, ectopic thyroid tissue can also be found throughout the mediastinum. The embryological development of the thyroid parenchyma is closely associated with the aortic sac and the heart; as the heart descends into the mediastinum, it draws the thyroid gland with itself caudally and this causes the development of ectopic mediastinal thyroid tissue.

## Hypothesis-Migratory or Heterotrophic tissue?

Contrary to the conventional teaching the Thyrothymic Rest tissue is found in the lateral divergence from pyramidal tract or tubercle of Zuckerkandl or in the mediastinum.



## Intrathoracic or Mediastinal goiter vs Thyrothymic Rest

True primary intrathoracic (substernal) goitres are quite rare, occurring in less than 1% of all substernal goitres. Sometimes isolated normal thyroid tissue residues can be coincided.

## Misdiagnosis or Missed diagnosis ??

True incidence of the organogenesis of throid gland is uncertain with numerours studies implicating heterotrophic thyroid tissue as ectopic thyroid and lateral aberrant thyroid as heterotrophic tissue .Thyrothymic rests are often discussed as missed diagnostic rest tissue and numerous studies by Reeve etal and Delbridge et al have in the past pointed to their presence and to a certain extent plotted their incidence and anatomical relationship to the thyroid gland within the line of the thyrothymic tract below the inferior pole of the thyroid during thyroidectomy.



(continued on page 14)

## Forgotten Goitre

Sackett et al has defined and classified thyrothymic rest depending on the size and relationship with the thyroid tissue. Thyroid resection requires the awareness of and attention to pyramidal remnants, to abnormalities associated with the ZT, and to thyrothymic thyroid rest. Casadei *et al* detected a mediastinal thyroid mass in a patient after total thyroidectomy and defined it as a “forgotten goitre”.

## Why is this article highlighted?

The issue for discussion is focused on the organogenesis and developmental anomaly and heterotrophic tissue so that the findings may shed new light on the possible causative factor of **Recurrence** in total thyroidectomy patients.

Sackett et al Grading	
according to the relationship of the thyrothymic residues (rests) with the thyroid gland	
Grade I	Thyroid rests consist of a protrusion of thyroid tissue, recognisably distinct from the lower border of the thyroid lobe in the region of the thyrothymic ligament
Grade II	Thyroid rests include thyroid tissue lying within the thyrothymic tract and attached to the thyroid proper only by a narrow pedicle of thyroid tissue
Grade III	Thyroid rests are similar to grade II but are attached to the thyroid gland only by a fibrovascular core
Grade IV	Thyroid rests have no connection to the thyroid



Dr. Senthil, President of Thyroid Federation of India, speaking at the International Surgeons conference, Nagpur, India in December 2018.



Ashok Bhaseen, TFI president, with other important key guests at the International Surgeons Conference, Nagpur, India, Dec 2018.

# Women with thyroid problems

PROJECT LEADER: CLAES FALCK, SOFIA COLLIN AND BENGT DANIELSSON. HEAD OF THE UNIT: MARIA STATE.  
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 TRANSLATION: PETER LAKWIJK, CHAIRMAN OF THE SWEDISH  
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## Summary

Within the framework of an assignment of the Swedish government in the area of obstetric care and women's health, Socialstyrelsen (National Board of Health) has highlighted the treatment of the underactive thyroid function (hypothyroidism).

The issuing by pharmacies of registered medicines for hypothyroidism has been followed from 2006 to 2017 with respect to, i.e. gender, age and geography. Among other aspects that have been studied are the prescription of licensed preparations containing natural hormone in the form of dried porcine thyroid glands.

The results show that the proportion of the population prescribed for hypothyroidism increased by 32 % during this period. In 2017, a total of approximately 460,000 people had a prescription for hypothyroidism. Women accounted for the vast majority of patients (more than 82 %).

One reason for the increase may be that a new type of hypothyroidism, so-called subclinical hypothyroidism, has become a clinical reality. The criteria for the treatment of subclinical hypothyroidism differ from the traditional treatment of hypothyroidism.

It was among younger women (20-40 years) that the highest rate of increase in treatment took place, doubling between 2006 and 2017. This has led to the median age being lowered by 11 years for starting anti-hypothyroidism drugs in this period. The high increase in the proportion of younger women may be associated with increased awareness of the significance of thyroid hormones for normal foetus development as well as the screening program initiated to detect hypothyroidism in connection with pregnancy.

The largest prescription increase during the observation period refers to patients admitted for treatment by regional physicians, maternity care and gynaecological care.

In the county with the highest number of prescriptions in 2017 (Gävleborg), 8.5 % of all women were prescribed

Year	Total	Part of the population (%)	Women (%)	Men (%)	New diagnoses in the population per year	New diagnoses in the population per year (%)
2006	309484	3,4	84,3	15,7	-	-
2007	322820	3,5	84,1	15,9	27405	0,30
2008	336227	3,6	83,9	16,1	27116	0,29
2009	351443	3,8	83,7	16,3	29168	0,31
2010	367127	3,9	83,5	16,5	30563	0,32
2011	381330	4,0	83,3	16,7	30807	0,32
2012	393847	4,1	83,1	16,9	30122	0,32
2013	405816	4,2	83,0	17,0	30105	0,31
2014	418271	4,3	82,8	17,2	29998	0,31
2015	432195	4,4	82,6	17,4	32005	0,32
2016	445718	4,5	82,5	17,5	32723	0,33
2017	457629	4,5	82,3	17,7	32663	0,32

**Table 1 Number of patients with medicines for hypothyroidism, from 2006 to 2017**

The table shows the number and percentage of patients in the Swedish population who have medicines for hypothyroidism (at least one prescription of levothyroxine or liotyronin), the percentage of women, compared to men, as well as number and percentage of new diagnoses per year.

with anti-hypothyroidism drugs, which is comparable to 5.6 % in the county with the lowest number of prescriptions (Gotland). Prescriptions have increased in all counties from 2006 to 2017, but the size of the increase varies. In Uppsala, prescriptions increased by 68 %, while in Örebro (the county with the lowest increase) there was only a 22 % increase. In terms of the highest level of education, there are small differences between women treated with hypothyroidism and women without such treatment. On the other hand, antidepressant drug issuing is more than 60 % higher among those treated with anti-hypothyroidism drugs than women without such treatment.

Levothyroxine, which is the recommended first-choice therapy in hypothyroidism, also predominates in prescriptions. The number of patients treated with levothyroxine increased by approximately 140,000 between 2006 and 2017. Even alternative treatments that are more questioned, such as combination therapy of liotyronin and levothyroxine, or dried porcine thyroid glands, increased significantly during the study period.

In view of the large increase in the number of patients, the large variations in prescriptions between different counties and the discussion about criteria for diagnosis and choice of treatment, it is concluded that this knowledge is valuable for this area. Socialstyrelsen therefore intends to conduct a dialogue with the National Program of Endocrine Diseases, patient organisations and other stakeholders in this area.

# “Tiroide E’ Energia” (Thyroid is Energy)

## Italian Thyroid Week

BY PAOLA POLANO, LINDA HENDERSON AND DOMINIQUE VAN DOORNE

To kick off the International Thyroid Week this year in Italy, a press conference was held at the Ministry of Health in Rome on May 15th. To spark interest in this event there was a combination of speakers, among which were the presidents from the three Endocrine Scientific Societies (Italian Society of Endocrinology, Association of Medical Endocrinologists, and Italian Thyroid Association). Also present were members from scientific societies who represent Endocrine Pediatrics, Gerontology and Geriatrics, Endocrine Surgery and Nuclear Medicine. The Institute of Health was represented by the National Observatory for Monitoring Iodine Prophylaxis in Italy. And, to conclude, CAPE Italia, the Italian umbrella endocrine patient organization was represented by Luisa La Colla. All together, there was a great synergy.

“Thyroid is Energy” was decided together by CAPE Italia and the scientific societies in order to stress the huge impact that thyroid hormones have on our body’s energy” declared Dr. Dominique Van Doorne, member of the Association of Medical Endocrinologists.

Luisa La Colla, President of CAPE Italia stated “The new precision or personalized medicine based on the individual, on genetic variation, on environmental variation or the lifestyle of each person, allows patients today to participate actively in their therapeutic clinical pathway collaborating with the experts involved. In this context, it’s become more important that patient organizations remain active in informing patients regarding correct lifestyles and prevention. General



ultrasound screening programs should not be performed on the population - only those persons with risk factors for thyroid diseases and cancer should be screened.”

During the press conference, Antonella Olivieri from the National Observatory for Monitoring Iodine Prophylaxis in Italy acknowledged the relevance and importance of the Krakow Declaration on Iodine <https://www.iodinedeclaration.eu/> which was presented in Krakow, Poland on April 18th. The actions of the Declaration lay out clear measures needed to prevent the lifelong and debilitating effects of Iodine Deficiency Diseases.



Paola Polano, Vice President of CAPE Italia stated that CAPE, together with ATTA Lazio Onlus, signed the Krakow Declaration on Iodine and will sustain the Declaration in the future. CAPE includes 14 Patient Associations in 10 different Italian regions and is a member of the Thyroid Federation International, one of the endorsers of the Declaration.



# Nigeria: Report on Activities to Commemorate World Thyroid Day in Partnership with Lagos State Primary Healthcare Board

## Held at Ikeja Local Government Secretariate Lagos State – 25<sup>th</sup> & 26<sup>th</sup> May 2018

IRUOMA OFORTUBE, *EXECUTIVE DIRECTOR*

FOR: THYROIDISM AWARENESS AND SUPPORT INITIATIVE (TASI)

Thyroid Awareness Day was established in 2008, initiated by Thyroid Federation International (TFI), a network of patient-support organizations worldwide, working together for the benefit of those affected by thyroid disorders, by providing information and raising awareness. It is a day set aside globally to spread awareness on thyroid health, thyroid disease, its risks and dangers, with more emphasis on the preventive and treatment measures.

The Lagos State Primary Healthcare Board offered us a letter of recommendation to the Ikeja Local Government Chairman which was swiftly given approval, and handed over to the Medical Health Officer to work directly with us, to give us all the necessary assistance we needed to facilitate the success of the event. In response to that, we were offered a very comfortable hall suitable for the Press Conference on the 25<sup>th</sup> of May also on the 26<sup>th</sup> of May, though the hall given on the second day did not have chairs and tables, so we had to rent the chairs and tables to accommodate the participants, but we were satisfied.

The staff from the local Government and Health Department committed themselves and their time for the two days we worked there giving us assistance in relevant areas to ensure a hitch-free event. There was no major corporate sponsor for the event.

### Publicity

We sent letters to media as a pre-sensitization exercise. On the 24<sup>th</sup> of May we were able to have a broadcast on Max FM 102.3, informing the general public about the program of events coming up. It evidently generated a massive feedback, given the number of people that turned up for the event that heard it from radio.

Five major newspaper companies were invited – This Day, Punch, Vanguard, Telegraph, The Guardian. Two radio stations were invited as well- Max FM and Radio Nigeria. We wrote to four television stations – AIT, TVC, NTA and LTV. We also wrote the Nigerian Police Force, Area F Command Ikeja for security.

### The Events

#### 25<sup>th</sup> of May – World Thyroid Day Press Briefing

To mark the global event, a press briefing was held on Friday 25<sup>th</sup> of May at Ikeja local Government Secretariat, from 3.00pm - 4.30pm. The program had in attendance, five newspaper reporters, the Health Educator for Onigbongbo LGA, a Representative of the Director Health Education Lagos State PHCB, members of the TASI board, some members of TASI, MECURE staff and other guests.

The press briefing started and ended in success. We also gave some T-shirts to some of the PHCB working with us. They offered us selfless and amazing support.

#### 26<sup>th</sup> May 2018 – The Thyroid Awareness March

Ikeja local Government Area Secretariat was also used as the assembly point for the event. The program was scheduled for 10.00am; participants started arriving at 9.00am.

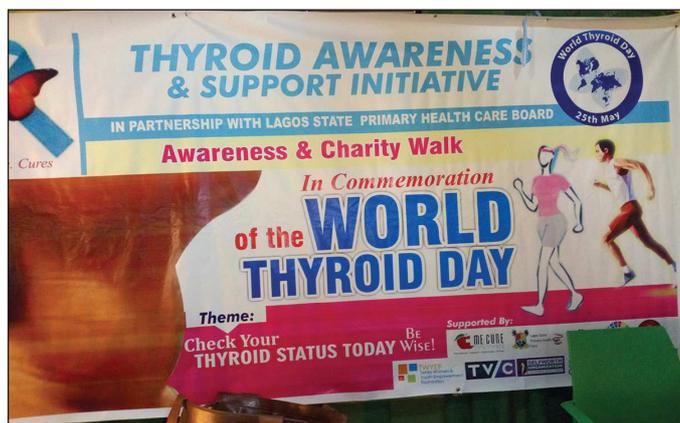


Mecure Healthcare Limited arrived by 10.00am with their team of Doctors and a big ambulance bus, which was offered to us at no cost, this is their own support to ensure that safety measures are put on ground. Mecure Healthcare also conducted a free eye test for all the participants and other people that came around for that purpose.

About one hundred participants were expected to turn out for the event but we recorded about seventy people which includes Thyroid support group members, friends and fans of TASI, some staff of the local Government, people that got the information of the program via different media.

The march commenced with two banners indicating the purpose of the event, and some small banners with

(continued on page 18)



awareness inscription on them- “Thyroid disease is not a death sentence”, “Iodine deficiency causes thyroid disorders”, “Do not stigmatise thyroid patients”, “Primary healthcare board supports thyroid awareness”, etc. We were also dressed in a uniformed T-shirt with the theme of the program inscribed on it \*Check Your Thyroid Status Today!

We marched from Ikeja Local Government to Allen Avenue Roundabout, with a bus playing music to energize participants and to also add some fun, while we distributed our fliers and enlightenment materials. As we marched, the ambulance with medical personnel was right behind us.

Two television reporters and their cameramen, NTA and TVC, were fully on ground for the event coverage from the beginning to the end of the event. As we came back, the participants joined the free eye screening.

We concluded and left the venue at 4.30 pm.

## Results

1. Other thyroid patients connected to us and are already in our support groups.
2. So far, out of five newspaper reporters that attended the press briefing, only the Telegraph newspaper has published the report of the press release; still awaiting the rest of the reports.
3. Radio Nigeria aired the program on their 11.am news on Sunday 27<sup>th</sup> of May and Saturday 3<sup>rd</sup> of June.
4. Out of four television companies invited, only two, NT and TVC, turned up; as of now only TVC has been able to air the event, on Saturday 26<sup>th</sup> of May, while NTA said they are taking their time to file the report so that it can make more impact at the national level.
5. Mecure Healthcare Limited has indicated their interest in more involvement in supporting us, mostly in the area of diagnosis and treatment of thyroid patients.



## Challenges

We did not record many challenges while in the period of preparation and implementation of this project. However, our major challenge was limited funds. We were able to pull through, through the donations and free will giving by members of the board of trustees and individuals. There was no corporate sponsor.

## Recommendations

Given the success of the awareness program and the feedback recorded, this awareness will make more impact if extended to other LGAs and LCDAs within Lagos State.

There is dire need of all tiers of governments, ministry of health, corporate organizations and international organizations to get involved in creating awareness and educating the public on preventive measures. Given the massive impact made so far by Thyroid Awareness and Support Initiative (TASI) with little funds at hand, we are ready to penetrate every nook and cranny of Nigeria and Africa at large with thyroid awareness proffering solutions with free diagnosis to people and assisting the victims.

More research is also needed to ascertain the rise in the rate of thyroid disease in Nigeria.

## Conclusion

Empirical evidence shows that at least 60 million Nigerians are at risk of iodine Deficiency Thyroid disorders, due to the fact that the landscape of Nigeria predisposes the country to iodine deficiency. Serious intervention is required urgently to sensitize people more on the symptoms of thyroid disorders adding to the risks. There is also need for more thyroid associations to be able to reach the rural areas where stigmatization thrives due to lack of awareness. Some thyroid patients are abused and molested, even stoned, as a result of ignorance, some commit suicide.

We are most grateful to have a partnership with Lagos State Primary Healthcare Board. It was both interesting and inspiring. It's a great credit for Lagos State to be the first state to flag off sensitization on thyroid health. We

would not have achieved much without their support. We hope to continue the mutual relationship. We also seek for more support and sponsorship to do more.



## The Philippines celebrates ITAW

The observance of the International Thyroid Awareness Week (ITAW) in the Philippines took the high road with events organized on May 22-25, 2018 in the cities of Iloilo & Davao and in the towns of Zarraga & Tagum, all in Central & Southern Philippines

The activities in ITAW were primarily educational as they were directed to primary care physicians and barangay (village) health workers who are in direct contact with their constituents. The Department of Health (DOH) Central Office coordinated the events with the Regional Health Offices and Local Government Units in the targeted cities and towns. Lay forum and thyroid screening supplemented the capacity-building programs for the health providers. The mayor of Zarraga graced the occasion which was attended by many women, even coming from remote villages in his municipality.



ITAW's theme "Thyroid Gland as the Control Panel of the Body" was used to emphasize the early recognition of the clinical manifestations of hyper- and hypothyroidism and the palpation of the thyroid gland and presence of nodules and other physical abnormalities.

The Philippines observes three thyroid-related events throughout the year to enhance awareness of thyroid



diseases which are of high prevalence in the country: the Goiter Awareness Week (every 4th week of January), ITAW, and the Thyroid Cancer Awareness Week (every 4th week of September). The major medical professional organizations like the Philippine Thyroid Association (PTA) and the Philippine Society of Endocrinology, Diabetes & Metabolism (PSEDM) assist DOH in implementing these activities with the support of Merck, Inc.

Philippine Thyroid Cancer Survivors, Inc.  
and  
The Philippine Society of Endocrinology,  
Diabetes & Metabolism, Inc.

5th National Thyroid Cancer Awareness

**THYROID KANSER:**  
Wastong Pag-Alaga  
Tungo sa Masaya at  
Buhay na Mahaba  
*Right Care for a Happy and Long Life*

September 15, 2018 at 1pm  
University of St. Tomas Auditorium  
España Blvd. Sampaloc, Manila

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ASSOCIATION OF NURSING SERVICE ADMINISTRATORS OF THE PHILIPPINES - BULACAN CHAPTER  
PHILIPPINE ALLIANCE OF PATIENT ORGANIZATIONS  
YOUNG PHARMACIST GROUP PHILIPPINES

# The 10th International Thyroid Awareness Week in Portugal

## “The Thyroid – Check your body’s control panel”

The 10th International Thyroid Awareness Week campaign, in Portugal, was held by **ADTI - Associação das Doenças da Tiroide** (Portuguese Thyroid Association) with the support of the **SPEDM - Sociedade Portuguesa de Endocrinologia, Diabetes e Metabolismo** (Medical Society of Endocrinology, Diabetes and Methabolism), **Ordem dos Farmacêuticos** (Pharmaceutical Society) and **Merck**.

With the motto “**The Thyroid – Check your body’s control panel**”, the main concern was to raise awareness for hypothyroidism, its signals and symptoms in order to increase diagnosis.

The initiative in Portugal, represented by ADTI, highlighted the “25th of May” with a street event. The busy railway station of Cais do Sodré was the place that hosted this initiative with the participation of medical specialists, technicians, ADTI Board Members and the Pharmaceutical Society. All together, ADTI, managed to have eight HCPs directly engaged with the initiatives for the ITAW and educated people how to identify signs for thyroid disorders.

Throughout the day several hundred people participated in the initiative and, approximately three hundred free screenings were done. This was a successful initiative that reached out to more than a thousand people.

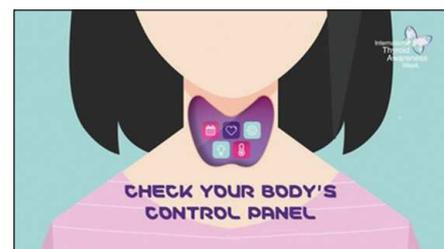


For this action to be so successful, four different areas were created: an area for screenings, another for palpation with medical specialists who explained to each person which signals they should pay attention to, a location with educational sessions given by the Healthy Generation project of the Pharmaceutical Society representatives and yet another area with a quiz that challenged everyone to test their knowledge about thyroid disorders.

An important on-site media coverage also highlighted the 10th International Thyroid Awareness Week assuring its broadcast on all the Portuguese TV Channels. With this initiative the campaign accomplished 36 media results in the context of the ITAW and had more than an hour of TV Coverage.

From the social media this campaign got 339 new views on the ADTI facebook page. And, between May 21st and May 27th, this page reached over 9.000 people with an increase of 52% viewers.

Overall, the campaign’s main goal was accomplished and created a strong impact in Portugal.



## May 20 to 26, 2019

## 11th International Thyroid Awareness Week

[www.thyroidweek.com](http://www.thyroidweek.com)

# Is it the Pharmacist's choice of formula... or the Patient's?



BEVERLEY GARSIDE, CEO, THE AUSTRALIAN THYROID FOUNDATION

In Australia there are different formulas of Levothyroxine on the market. All formulas are made by Aspen Pharma. Two of these formulas are manufactured in Australia. Both of these formulas are passed by the Australian Government on the Pharmaceutical Benefits Scheme (PBS). Therefore they are sold at cheaper prices and subsidised by the Australian Government. However one of these formulas is known as a generic and is sold at a cheaper price than the other. Both of these formulas need to be kept at refrigerated temperature.

An additional formula has been brought onto the Australian market. This formula is manufactured in Germany and has 10% less active ingredient than the Australian produced formulas. It is sold on the international market by Aspen. It has a larger dosage range with two more doses available than the other formulas. It is not on the Pharmaceutical Benefits Scheme (PBS) and is therefore more expensive than the other two. It does not need to be refrigerated. As it is a different formula, it will depend on the individual as to whether it works well for the patient.

Doctors need to discuss the options and pros and cons of all three formulas available before prescribing Levothyroxine for their patient.

The Australian Thyroid Foundation (ATF) receives regular calls and emails from patients who want to speak about their experience with different formulas they are taking. They are usually reporting a range of hypothyroid symptoms, weight gain, irregular blood results and many times, symptoms unrelated to typical thyroid symptoms.

Australian pharmacists encourage patients to purchase generic formulas and in many cases dispense generics without the patient being aware it was not the formula their doctor had prescribed. Apparently, Australian pharmacists either receive a rebate from the Australian Government for dispensing generic brands or purchase generics at a cheaper price.

When a patient presents their prescription to the pharmacist, they are usually asked, i.e. Is the Pharmacy Brand OK for you, Do you want the cheaper brand, or the Australian brand, or many other descriptions without realising they are buying a generic brand. This is usual for all prescriptions, not just Levothyroxine.

I am not saying generics are bad at all, I am also not saying that if a patient wants a generic formula that is not OK either. What I am saying is, It Is **The Patient's**

**Choice Which Formula They Purchase.** If a patient has been taking a particular formula for many years and the Pharmacist gives them a different formula without the patient realising, it can be detrimental to the patient's health. Being established on a formula is extremely important to how it works for the patient.

There definitely needs to be a much better way Pharmacists communicate with patients and provide the formula the patient wants, or was prescribed and not the formula the Pharmacist has in stock. Pharmacists need to explain the difference of formulas and prices to the patient, before starting the process of dispensing a prescription.

I had a personal experience where I had prescriptions for both 75 mcgs and 50 mcgs of Levothyroxine. Of course I said when I handed over the prescription I wanted my usual formula after being asked if the Pharmacy Brand was OK. I have been taking this formula since I was diagnosed with a thyroid disorder, some 30 years ago. The Pharmacist would have also seen this on my file. When I was called to pick up my prescription, I was given 75 mcgs of one formula and 50 mcgs of another. I pointed out to the assistant which one I had asked for and her reply was, 'We don't have 50 mcgs of that formula in stock.' I had only a few tablets left at home and told the assistant I would not be taking either dose and I would take my prescription elsewhere to ensure both doses were the same formula. This is totally unacceptable, misleading and detrimental of patients' thyroid health and choice, as is the many, many stories we hear from patients.

If a doctor prescribes a particular formula for a patient, that is what the patient should be given, regardless of the pharmacist buying power or stock control in the Pharmacy. If the Pharmacist cannot supply what the patient asks for, it is possible for the Pharmacist to order it that day and have it available within 24 hours, or the Pharmacist can decline to dispense if it is urgent that the patient have the prescription the same day and the patient go elsewhere.

Generic brands are usually made with different binders or fillers, which is why many patients can have a reaction, if not their usual formula. Therefore it is important for the Pharmacist to communicate very clearly the situation, so the patient understands and can make a decision which is best for them.

I would be very interested to hear if other Thyroid Federation International (TFI) member organisations receive the same sort of reported issues in their country and ask if patients report any similar experiences as those described above.

# Bulgaria: VIOM Activites



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.

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.

(continued on page 23)

On 25th May, a big outdoor event was held:



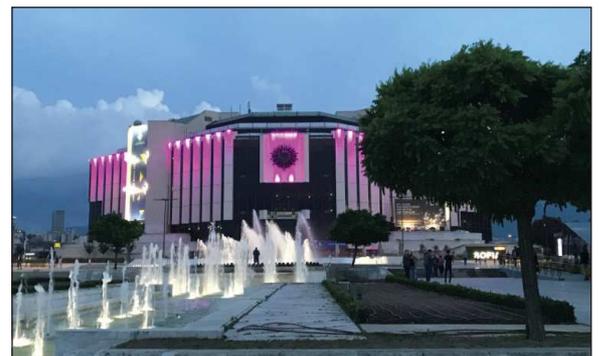
Dr. Shinkov, Maria Silyanovska and students from medical highschools



Quick self-check tests for general public



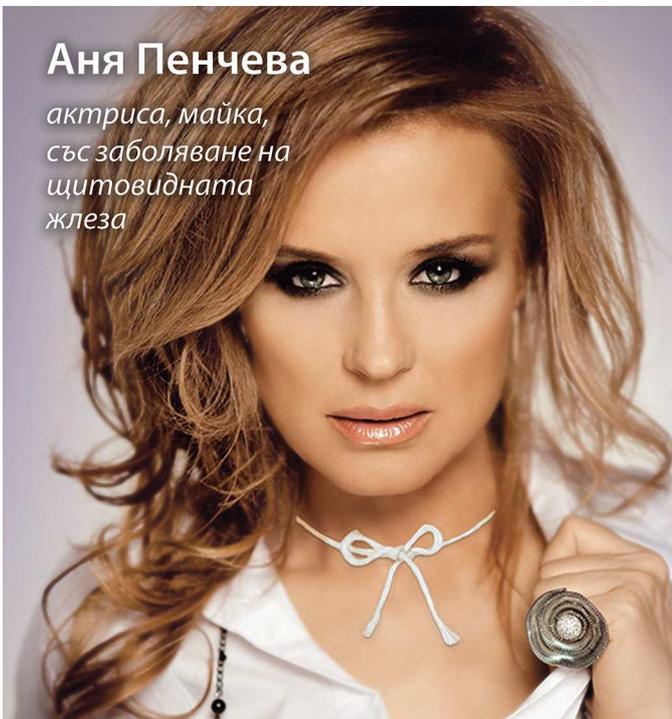
Quick self-check tests for the general public



25th of May 2018 - The National Palace of Culture lit up in purple

## Аня Пенчева

актриса, майка,  
със заболяване на  
щитовидната  
жлеза



ИНФОРМАЦИОННА  
КАМПАНИЯ ЗА  
ЗАБОЛЯВАНИЯ НА  
ЩИТОВИДНАТА ЖЛЕЗА

Международна  
Тиреоидна  
Седмица



## Bulgaria: VIOM Activites (continued from page 22)

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 endocrinologists in Bulgaria and different articles on the subject of thyroid diseases. A telephone number and e-mail address through which patients could get in touch are also available on the web site.

Since 2014, VIOM is taking part in ITAW activities with information brochures, print and on-line media publications, press conferences, radio spots, and others. Every year more than 2500 people are screened, most of whom have never been tested before.

Some of our initiatives are already established as traditions. On the 25th of May, for a second consecutive year, we light up in purple the The National Palace of Culture (Congress Centre Sofia - the largest multifunctional complex in Southeastern Europe) as a symbol of empathy and support for the people suffering from thyroid diseases. One of the most successful ITAW



Thyroid Academy - Prof. Hristozov giving a lecture

activities, the Thyroid Academy with an Ultrasound education course for endocrinologists, took place for the 4th time. The purpose of the event is to define and fulfil unmet medical needs in diagnosis and treatment of thyroid disorders. More than 150 participants attended the academy and the speakers included some of the most experienced thyroid specialists in the country. For a

second year in a row we have organized quick self-check tests for the general public (in the form of questionnaires) in Sofia, and our presence in the health forums “Mission Health” (a forum open to the public) and “Bulmedika” (screenings) marks the 3rd year since the start of our participation.

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.

## ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

## CANADA

# A Tribute to Marjorie Miniely

## March 10, 1924 – July 22, 2018

ASHOK BHASEEN

**Founding President of London, ON, Canada chapter of Thyroid Foundation of Canada and also served on the board of the Thyroid Foundation of Canada**

Marjorie Miniely (age 94) passed away in London, ON, Canada on July 22nd 2018, surrounded by her family. Marjorie was part of the TFC group in 1995 when TFI was born in Toronto, ON during the International Thyroid Congress. When I became President of Thyroid Foundation of Canada in 2008, Marjorie was on my team as one of the Directors. She played an important role during that difficult period of TFC and stood strongly with the team in resurrecting the organization. Her young heart, her laughter and her dedication and diffusing tensions are some of the things I will always remember.



Let's go back in history to the early 1980s, when Marjorie Miniely struggled with getting treatment for her thyroid condition (she was hypothyroid) as physicians disagreed about the dosage of medication she required. In her own words “I read about the founding of the Thyroid Foundation in Kingston, ON, Canada,” she told us. “It was a time when I knew I had thyroid problems and not much information.” She eagerly read anything that came from the TFC and leveraged people and resources to educate and generate awareness for thyroid patients in London. Since she was a teacher, Marjorie recognized the need for greater patient awareness. She also felt that endocrinologists need to be trained to realize that not everyone responds the same way to medication.

Thyroid issues are a family affair sometimes; her daughter, Donna Miniely, followed in her mom's footsteps and served as President of Thyroid Foundation of Canada from 2014-16.

# Reaching Out to Thyroid Patients

## New Website

This past year, making TFC more visible and accessible to patients and the public was top priority and a challenge for us.



Recognizing that the internet is the most popular means of obtaining information on any topic, it was felt our website needed some attention. Our website had been a concern in this area for some time so this project was our main focus during the year and we're happy to say we met this challenge head on.

The website now has a new face with new avenues that make it easier to access information, along with some special areas for TFC members with new opportunities to come.

## Board of Directors 2018-2019

The Thyroid Foundation of Canada held its 2018 Annual Meeting in Toronto in June and we are pleased to announce our new Board of Directors for 2018– 2019:

- President, Laz Bouros
- Vice President and Patient Support, Kim McNally
- Treasurer, Deb Walker
- Fundraising, Susey Harmer
- Director-at-Large, Gabriela Albarracin
- Past President and Education & Publications, Mabel Miller



Mabel Miller, Past President, is awarded a certificate of appreciation for her hard work and dedication, presented by Laz Bouros, TFC's new National President.



Thyroid Foundation of Canada

La Fondation canadienne de la Thyroïde

## Public Education Meetings

The TFC Kitchener-Waterloo Ontario Chapter holds two Public Education Meetings each year with guest speakers on various topics of thyroid disease. In October 2017, the speaker was Dr. Nadira Husein, an Endocrinologist and Assistant Clinical Professor at McMaster Medical School in Hamilton, Ontario. Dr. Husein gave an informative and interactive session on “How to Identify and Manage Thyroid Disease.”

In April 2018, the speaker was Dr. Deric Morrison, Endocrinologist, Assistant Professor, Part of the Cancer Team Division of Endocrinology, Dept. of Medicine, University of Western Ontario, London, Ontario, and Medical Advisor to the Thyroid Foundation of Canada. Dr. Morrison's topic was “Thyroid Cancer Treatment: One Size Does Not Fit All.”

In recognition of the great work the chapter does, the Chapter was awarded with a certificate of appreciation. Cassandra Howarth, K-W Chapter President and Joan DeVile, Education Chair received the award.



Cassandra Howarth, President K-W Chapter (left) and Joan DeVile, Education Chair (right), receiving their certificate from Mabel Miller, President

## Patient Education Workshop

Following the AGM, TFC's Medical Advisor, Dr. Deric Morrison, met with us for a Patient Education Workshop. We discussed ways of reaching family physicians and endocrinologists, improving our patient information, and the protocol for setting up a new research program.



Dr. Deric Morrison

# Denmark Stofskifteforeningen: A year of changes and a celebration of one of our dedicated volunteers.

This year Stofskifteforeningen has been focusing on information, money for research and the nomination of Bente Julie Lasserre for Volunteer of the Year.

This year Stofskifteforeningen has been focusing on information, money for research and the nomination of Bente Julie Lasserre for Volunteer of the Year.

We have had a busy year so far with information meetings throughout the country. We have been in Aarhus, Kolding, Aalborg, Copenhagen and Hvidovre. The topics have been pregnancy and thyroid disease, hyperthyroidism and the treatment of thyroid disease



Steen Bonnema giving lecture in Kolding for patients.

in general practice. The meetings were a great success and more information meetings are being planned after the summer break.

## Booklet for parents

The meetings were not the only way Stofskifteforeningen has done public information this year. After long and hard work,



Translation: To have a child with a thyroid condition.

we published a booklet for parents with children with a thyroid condition and it has now been finalized and printed.

We hope to reach all parents with children with a thyroid condition to support and provide information during the difficult period when your child is diagnosed with a lifelong disease.

## On TV

Sometimes opportunities for reaching new audiences present themselves. Luckily for Stofskifteforeningen, we have the always present Bente Lasserre on the Board. Bente is an excellent networker and has befriended her local university hospital in Odense. Here the endocrinologist Steen Bonnema took a chance when a research project testing the effect of supplementing hypothyroid patients with selenium was short of money. He signed in the research project in a local competition at Odense University Hospital. The competition got a lot of local TV coverage.

Bente who had never been on TV before was interviewed in her home and live in the TV studio speaking about thyroid disease. Due to a huge effort from Steen Bonnema and Board member Bente Lasserre, the project was voted in and was awarded 1.000.000 DKK (135.000 EUR).



Steen Bonnema receiving the grant money and is interviewed by TV2 Fyn a local network. Also in the picture is Pernille Kjær Nielsen and Stephanie Lose.

(continued on page 26)

# Voluntary organizational activities and peer support in Finland



## How to meet new challenges?

Traditionally, organizational activities in most associations have been based on face-to-face communication and regular meetings. However, it seems that such a way of participating is no more ideal for many young and working age adults. For many of them work and family life is energy- and time-consuming. In addition, people suffering from rare disorders often live scattered all over the country, which makes it difficult to meet in person.

At the same time, a population is aging and the number of participants in face-to-face meetings is decreasing in some areas. The majority of young people are used to utilizing the internet, including all modern means of communication, on a daily basis. So, associations also should stay up to date and offer new, modern ways of participating and peer support, including online services.

## A new three-year project started in Finland

At the beginning of March 2018, the new project started at The Finnish Thyroid Association



Johanna Erkkilä, Project Coordinator, MSc in Human-Technology Interaction

financed by STEA (The Funding Centre for Social Welfare and Health Organisations). In Finland, STEA manages the funding granted for non-profit projects which promote health and wellbeing. For this three-year project the budget granted by STEA is 211,000€. The aim is to increase the awareness of thyroid and parathyroid diseases, especially among young and working age adults. In addition to sharing information, the project will facilitate online peer support for those in need.

To find out what kind of information is valued by the target audience, face-to-face interviews and online surveys were conducted. The result was that personal experiences from others, video lectures, short but informative video clips, professional articles, podcasts, tests and answers to FAQs would be most beneficial and desired. During the next three years such material is made available online. As a vital part of the project, online peer support such as group chats will also be developed.

## A year of changes (continued from page 25)



Steen Bonnema with Bente Lasserre.

## Volunteer honored

This TV competition was yet another reminder for the Board that Bente Lasserre is quite an asset. During this year she also played a big role in setting up information meetings throughout the country, and therefore the Board nominated Bente for Volunteer of the Year, a prize given at the Danish Patient Award during The People's Political Festival in Bornholm.

We did our best to tell family, friends, colleagues and all who cared to listen to vote for Bente. And what a joy it was to be told that Bente did in fact win the prize and was honored in Bornholm for her many years of volunteer work in Stofskifteforeningen.

On this happy note Stofskifteforeningen went on summer holiday with high spirits after a year's work of public information.



## Putting a face on a faceless disorder

**Brazilian Soccer Legend Ronaldo's openness about fighting hypothyroidism recently earned him an ambassadorship from the Norwegian Thyroid Association.**

Ronaldo Luís Nazário de Lima, or just simply Ronaldo, is a man whose sporting exploits are well known. The Brazilian, now 41, is the greatest soccer striker of his generation and arguably of all time. His retirement on February 14th 2011 signified the end of an unbelievable career marked by the fullest appreciation from soccer fans all across the globe.

The Brazilian, also known as “El Fenomeno”, scored a total of 405 goals in his professional club playing career. For his country he found the net 62 times, meaning he retired on 467 goals in 678 games.

In June, Ronaldo visited Oslo, Norway along with his Brazil team mates from the 1998 World Cup. Their bid – a rematch against the Norwegian team that sensationally beat them 2-1 in France 20 years ago.

The day before the rematch in Oslo, representatives from the Norwegian Thyroid Association and an affiliated Medical Doctor attended a press conference for the upcoming soccer event along with reporters.

Well aware of Ronaldo's struggle with hypothyroidism, Secretary General Eddy Kjaer of the Norwegian Thyroid Association asked the soccer legend to elaborate on the origins of his illness and how it's affected his career.

Replying to Kjaer's question, Ronaldo opened up about his troublesome and unwanted weight gain while playing for Italian side AC Milan in 2008. The striker's



L to R: Dr. Lars Omdal, Ronaldo Luís Nazário de Lima, Eddy Kjaer

extra weight hardly went unnoticed among supporters from rivaling clubs, earning him malicious nicknames such as El Gordo (The Fat One).

As Milan doctors would later reveal, Ronaldo's weight gain was not a result of laziness or over-eating, but hypothyroidism.

“I couldn't have proper treatment as I still had an active career. Eventually it got increasingly harder for me to maintain my physical condition,” Ronaldo told Kjaer.

After a two-year spell at AC Milan, Ronaldo returned to Brazil, playing for an additional two years before retiring in 2011.

From a hotel podium in downtown Norway's capital, Ronaldo reflected on the high number of people struggling with thyroid disorders throughout the world.

“Hypothyroidism is a serious problem. Millions of people have the same problems as I. We have a lot of big problems in the world and I generally feel we should be a lot more tolerant towards a lot of things,” the Brazilian stated, adding:

“I think it's important to direct attention at this problem (hypothyroidism), which is experienced by people in every country. For example, I live in Madrid.

(continued on page 28)



## Putting a face on a faceless disorder (continued from page 27)

In Spain, 60 per cent of the population either have hypothyroidism or hyperthyroidism. These people don't necessarily get the treatment that they need," Ronaldo claimed.

Ronaldo's openness about his medical problems earned praise from Eddy Kjaer of the Norwegian Thyroid Association.

"Ronaldo opening up about his fight with hypothyroidism sends an important signal. He's putting a face on a faceless disorder", Kjaer told Norwegian newspaper VG at the press conference in Oslo.

Lars Omdal, a Norwegian physicist specializing in hypothyroidism and member of the Norwegian Thyroid Association's medical council, shared Kjaer's sentiment.

"I'm happy that Ronaldo is directing attention towards hypothyroidism. It's one of the most widespread diseases out there. A great number of women and men are struggling with it, yet a lot of people don't understand what it entails. The ones who are affected typically gain weight, feeling tired, heavy-headed and a depressed. A lot of dominos fall when your metabolism is off. People might think that the

person is lazy, eating only junk food or having mental problems, when the truth is it's hormonal. That's why it's great that Ronaldo is talking about this publicly," Omdal told VG newspaper.

The physicist, speaking Portuguese very well due to his wife being Brazilian, shared a lengthy conversation with Ronaldo at the press conference, discussing, among other things, the soccer legend's vitamin intake.

At the end of the press event, Secretary General Eddy Kjaer approached Ronaldo with an invitation to become the organization's ambassador. The Brazilian smilingly accepted and was presented with a framed diploma, reading: The Norwegian Thyroid Association appreciates your effort in raising public awareness regarding thyroid diseases.

The following day, Ronaldo and his team mates went on to achieve that which they failed to do 20 years earlier, beating the Norwegians 3-0 at the National stadium in Oslo.

*Follow us on facebook.com/Stoffskifteforbundet and Youtube (Stoffskifteforbundet).*

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## Is thyroid disease a chronic disease?

MABEL MILLER, THYROID FOUNDATION  
CANADA PRESIDENT

For quite some time, we have been asking that question of medical professionals and government officials only to be told it's not included in the list of chronic diseases. So why not?

The definition of chronic diseases is: "generally they are conditions that cannot be prevented by vaccines or cured by medication, nor do they disappear". The Public Health Agency of Canada's list of Chronic Diseases includes heart disease, stroke, cancer, asthma, chronic obstructive pulmonary disease, diabetes, arthritis, Alzheimer's disease or other dementia, mood disorders and anxiety disorders. No mention of thyroid disease.

Well guess what? Those conditions cannot be cured nor do they disappear which is the same for thyroid disease. In the case of diabetes – it's a chronic condition that stems from the body's inability to sufficiently produce and/or properly use insulin, which the body needs to use as sugar as an energy source. Hypothyroidism and hyperthyroidism stem from the body's inability to properly control how the thyroid functions.



The definition of thyroid disease is "a condition due to over- or under-functioning of the thyroid gland". The thyroid gland is an essential organ for producing thyroid hormones, which maintain body metabolism and has important roles to regulate numerous metabolic processes throughout the body.

So what's so different when looking at one being a chronic condition and another not? Diabetes is considered a chronic condition – thyroid disease is not. Both indicate something has gone wrong and is not working as it should and may never.

Again the question, "Is thyroid disease a chronic condition?" Relating to one condition, those diagnosed with Hypothyroidism will always have the condition – some may improve with time and some may get worse but there is very little hope that it will go away, be cured and not be an issue, not have to be managed.

Designating thyroid disease as a chronic condition is a challenge with the medical community and with those who define what a chronic condition is.

*Anyone wishing to comment on this article is welcome to do so at: [info@thyroid.ca](mailto:info@thyroid.ca)*

# The Graves' Disease and Thyroid Foundation



The Graves' Disease and Thyroid Foundation (GDATF) has been serving patients and family members in the USA for twenty-eight years. The Foundation is a 501(c)(3) charitable organization that is dedicated to providing educational and support services for patients and family members impacted by Graves' disease, Hashimoto's thyroiditis, and other thyroid-related disorders. The organization was founded in 1990 by Nancy Hord Patterson, Ph.D. as the "National Graves' Disease Foundation". In 2011, the Foundation changed its name to the "Graves' Disease and Thyroid Foundation", reflecting our commitment to assisting all patients with thyroid dysfunction.

Throughout 2017 and 2018, we were thrilled to meet with local patients and family members, particularly at our educational events in San Diego (California), Boston (Massachusetts), and Baltimore (Maryland).

In March 2017, GDATF Executive Director Kimberly Dorris travelled to Orlando for the American Thyroid Association's Spring Symposium, "Hypothyroidism: Where Are We Now?" Kimberly was selected to participate in a panel on patient experiences with hypothyroidism, where she shared her story of dealing with an unexpected diagnosis of hypothyroidism after a period of remission from Graves' Disease. This meeting was eye-opening for many physicians – and a great example of collaboration between the physician and patient communities!

In May, the GDATF was excited to share that GDATF Chief Medical and Scientific Officer Dr. Terry Smith and Physician Advisory Board member Dr. Raymond Douglas co-authored a paper in the *New England Journal of Medicine* regarding Teprotumumab, a new treatment for thyroid eye disease! This new drug has been designated as a "breakthrough" treatment by the U.S. Food and Drug Administration, with a Phase 3 clinical trial currently underway.

For the last several years, the GDATF has hosted half-day events around the country, which has allowed us to provide programming at little or no cost to participants. However, we also received feedback from members who missed our old multi-day format, which provided the ability to connect on a more personal level with fellow attendees. Thanks to grant funding from The Bell Charitable Foundation, Horizon Pharma, and the County of San Diego Community Enhancement Grant Funding Program, we were able to host a Patient Conference in San Diego June 14-17, 2018.

At press time, planning was underway for a patient education event in Chicago in conjunction with the annual meeting of ThyCa: Thyroid Cancer Survivors Association, Inc. – as well as a Patient Forum in Washington, DC co-hosted by the American Thyroid Association (ATA) and the ATA's Alliance for Patient Education. We partner with a number of physician organizations, including the ATA, the American Association of Clinical Endocrinologists, the American Association of Endocrine Surgeons, and the American Society of Ophthalmic, Plastic, and Reconstructive Surgery.

For patients and family members who are unable to travel to our patient seminars, we continue to use technology to further our education and support efforts! We launched a new group on Facebook, which is moderated by GDATF staff to eliminate spam and to ensure that the information presented is accurate. At press time, we were closing in on 1,000 members! Patients can also visit our original moderated support forum on our website at [gdatf.org](http://gdatf.org) – or for one-on-one support, they can reach us at 877-643-3123 or [info@gdatf.org](mailto:info@gdatf.org).

Nancy Patterson presenting at the GDATF's San Diego conference.



**Board of Directors**—*Front Row (Left to Right):* Nicole McDonald, MD Medical Advisor, Kathleen Bell Flynn - Co Chair, Ashok Bhaseen, Pres. TFI. *Back Row (Left to Right):* Terry J. Smith, MD Chief Medical Director, Steve Flynn, Co-Chair, Carla DeMare, Esq., Nancy Patterson, PhD Founder.



## Isabella's Journey: a 12-year-old's Story of Graves' Disease

ISABELLA WELLS

Two years ago I was diagnosed with Graves' Disease, and Thyroid Eye Disease. Overall I think it was very hard to go through both diseases, but I got through the worst of it. It definitely had some big impacts on my life from my initial signs and symptoms, to my diagnosis and now every day.

I used to be really into sports, gymnastics in particular. We had to come to practice more than 20 hours a week so I always had joint and back problems. We went a few times to the chiropractor but it didn't really help at all which was unusual, but I didn't think anything of it. I was always excited to go to practice, but then things changed and I didn't want to go at all. I always cried every time we went. Mom decided that I should take a break from gymnastics for a while. Things started getting worse. I got sick with what we thought was a stomach virus. I didn't eat for about a week. Every time I ate I would get sick and throw up, I was also very emotional about everything. We decided that we would go and see the doctor. We had blood work done and my TSH levels were very low and my T3 and T4 levels were high. After they looked at my levels they had diagnosed me with Graves' Disease.

I was sent to an Endocrinologist in Vanderbilt, Tennessee (4 hours from my house) the Monday of the next week. I was put on Beta blockers, levothyroxine, and methimazole. During this time of my diagnosis of Graves' there were a lot of wildfires going on very close to our town. The air outside was filled with smoke and you couldn't stay outside for very long. My eyes started to get swollen and red but we thought it was from the smoke. The next time we went to the endocrinologist we mentioned it but they told us not to worry about it. After a while of just ignoring my eye problems they started to sort of bulge out of my head and I couldn't close my eyes completely. We decided to schedule an eye doctor appointment and they told us to go see a pediatric ophthalmologist. We went to Knoxville, Tennessee and they told me I had thyroid eye disease which is something that you often get with Graves'. I began seeing double, blurry, and then eventually developing blind spots from the pressure of the bulging. I had really high pressure behind my eyes so I had to take brimonidine eye drops in addition to selenium to help with my eyes which was really annoying. I started to get blind spots and double vision in my eyes. The ophthalmologist prescribed me with steroids that would



Isabella, her mom Cheree Wells and Grandmother.

help with my eyes but they didn't. I tried IV steroids, proton beam radiation (we had to stay in Knoxville Tennessee for this 2 hours from my house for 2 weeks), and methotrexate but that didn't even help. I started to get really frustrated thinking my eyes were never going to look normal again.

My eyes started to really change my appearance. When I looked at old pictures I really looked like a completely different person. I became really self conscious and refused to be in any pictures taken. At school I have sort of always been a popular person but now I was finding it hard to socialize with people and even my friends.

Our only other option was to have surgery, so we started looking for surgeons who did orbital decompressions. We finally found a surgeon to do the operation but we would have to fly to California to get it done. California is pretty much across the country from where I live. We decided we would do it anyway considering how bad my eyes were. We flew to California, and had a pre-op appointment. I wasn't really nervous at all because it felt like I had been waiting forever to have this done. The next morning I went to have my surgery and the pain wasn't bad but it looked like I had been punched in the face. I actually had to have 2 surgeries, 1 for each eye. Initially, my double vision got worse after surgery and then on the last day of our 2 week stay I felt well enough to go outside and walk around. Moving my eyes and trying to focus helped with my double vision. After about a

(continued on page 31)

## Isabella's Journey (continued from page 30)

month of recovering and doing annoying eye exercises my eyes looked amazing. They look normal and look as if I never had thyroid eye disease. I barely have any double vision and I can see better. After I had fully recovered, the doctors and our family decided to have my thyroid out to lessen the chance that my eye disease will flare up and to possibly keep the disease more controlled. We went to a ENT surgeon in Athens, Georgia. The surgeon couldn't do it so he recommended that we go to Augusta, Georgia to have the procedure done. We scheduled the surgery and went to Augusta. They put a scope down your nose and into your throat to see how well your vocal cords are and I thought that was pretty cool. The next day, we drove to the hospital to have my thyroidectomy. They rolled me back to the OR, I was put to sleep and when I woke up it felt like I had strep throat. They only took out half of my thyroid though so I don't lose my voice but I'm getting the other half out very soon.

I've learned a lot from going through this and I've become a better person. You truly never know what a person goes through. I've had comments said to me

from adults when my eyes were bad, I've even got laughed at by adults too but you know, who cares; move on and forget that person. This kind of stuff is what makes us stronger and more independent. I'm moving forward and focusing on today. Going through this also gives me a better perspective on "hidden diseases." You never know what someone is going through on the inside even though the outside looks fine. I've learned to show empathy to more people. Prior to this diagnosis, I wanted to be an epidemiologist but after all the mental, physical, and emotional challenges that I have been through my career choice has changed. I would like to practice oculoplastics and help others like me. My surgeon, my endocrinologist, the medication, the radiation, the infusions, my family, and the disease have changed my life and while I am not ready to openly advocate for the disease one day I will in both my personal and professional life. I get sad thinking about the life I had 2 years ago and how that has changed. It makes me mad to think about what I have lost and how some people have treated me, but in the end I know there is a reason and a purpose for this.

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## Canada: Patients asking about Thyroid Disease Management

MABEL MILLER, THYROID FOUNDATION CANADA PRESIDENT

Management of thyroid disease is still a concern for many thyroid patients, especially those with hypothyroidism and hyperthyroidism/Graves' Disease. The Thyroid Foundation of Canada continually receives enquiries from desperate thyroid patients asking for the latest information on their condition and wondering why there is no opportunity for access to an endocrinologist or other specialist. Many feel their family doctor does not take them seriously when they say they still don't feel well.

We have learned from various sources, for example the American Thyroid Association information, that it has been established that testing may not be the only means of determining how thyroid patients should be assessed. Many times the response from the family doctor is, "If the TSH test results show no problem, then there is no problem with the thyroid".

We know it has been recognized that this is not always true; it is not only the test results that should

be considered when discussing thyroid conditions. The challenge is to have all health providers made aware of this; however, as a patient organization, it presents the problem of, "How do we go about bringing this to the attention of physicians and other health professionals?". This is something we will continue to look into, to find avenues to make this happen.



# TFI Member Organizations

## AUSTRALIA

*The Australian Thyroid Foundation Ltd.*  
Suite 2, 8 Melville Street1  
Parramatta, NSW 2150 Australia  
[www.thyroidfoundation.org.au](http://www.thyroidfoundation.org.au)

## BELGIUM

*Leven Zonder Schildklier*  
Belgium  
[www.levenzonderschildklier.be](http://www.levenzonderschildklier.be)

## BRAZIL

*Instituto da Tiróide*  
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## BULGARIA

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Dimitar Hadjikozevstr. 88  
1142 Sofia, Bulgaria  
[www.thyroidbg.com](http://www.thyroidbg.com)

## CANADA

*Thyroid Foundation of Canada /  
La Fondation canadienne de la Thyroïde*  
PO Box 298,  
Bath ON K0H 1G0 Canada  
[www.thyroid.ca](http://www.thyroid.ca)

## CROATIA

*Croatian Association for Thyroid Disease*  
Ulica Frana Petrica 5,  
1000 Zagreb Croatia  
[www.stitnjaca.eu](http://www.stitnjaca.eu)

## DENMARK

*Stofskifteforeningen*  
Blekinge Boulevard 2,  
2630 Taastrup, Denmark  
[www.thyreoida.dk](http://www.thyreoida.dk)

## FINLAND

*Suomen Kilpirauhasliitto ry*  
Vilhonkatu 4 B  
FI 00100 Helsinki, Finland  
[www.kilpirauhasliitto.fi](http://www.kilpirauhasliitto.fi)

## FRANCE

*Association Vivre sans Thyroïde*  
2, av d'Expert  
Léguevin 31490, France  
[www.forum-thyroïde.net](http://www.forum-thyroïde.net)



## GEORGIA (EU)

*Georgian Union of Diabetes and Endocrine Associations*  
National Centre for Diabetes Research  
1, Chachavha str, fl. 4  
Tbilisi, 0159, Georgia (EU)  
[diabet@access.sanet.ge](mailto:diabet@access.sanet.ge)

## GERMANY

*Bundesverband Schilddrüsenkrebs – Ohne Schilddrüse leben e. V.*  
Rungestrasse 12  
10 179 Berlin, Germany  
[www.sd-krebs.de](http://www.sd-krebs.de)

*Schilddrüsen-Liga Deutschland e. V.*  
Ev. Kliniken Bonn GmbH,  
Waldkrankenhaus  
Waldstrasse 73,  
53177 Bonn, Germany  
[www.schilddruesenliga.de](http://www.schilddruesenliga.de)

## INDIA

*Thyroid Federation of India*  
No 1 kundan complex, Annasalai,  
Teynampet, Chennai 600086 India  
[thyroidhelp.in@gmail.com](mailto:thyroidhelp.in@gmail.com)  
[www.thyroidhelp.co.in](http://www.thyroidhelp.co.in)

## ITALY

*CAPE –Comitato delle Associazioni dei Pazienti Endocrini*  
Via Cola di Rienzo 28, Scala C  
00192 Rome, Italy  
[www.capeitalia.org](http://www.capeitalia.org)

## JAPAN

Dr Fumito Akasu (Contact)  
CBON Queen Building, 4th floor  
Roppongi 7-18-12, Minato-ku  
Tokyo 106-0032, Japan  
<http://tfj.jp>

## NEPAL

*Thyroid Foundation of Nepal*  
Post Box Number-14295  
Baneshwor-10, Kathmandu, Nepal  
[gandhiprasadsharma@gmail.com](mailto:gandhiprasadsharma@gmail.com)

## THE NETHERLANDS

*Leven Zonder Schildklier*  
The Netherlands  
[www.levenzonderschildklier.nl](http://www.levenzonderschildklier.nl)

*Schildklier Organisaties Nederland*  
Postbus 60, 3940 AB Doorn,  
The Netherlands  
[www.schildklier.nl](http://www.schildklier.nl)

## NIGERIA

*Thyroidism Awareness and Support Initiative*  
21 Abraham Akinola St.  
Onipetesi Estate, Mangoro Ikeja,  
Lagos, Nigeria  
<https://www.facebook.com/Thyroid-Awareness-and-support-Initiative-213412935467183/>

## NORWAY

*Stoffskifteforbundet*  
Fr. Nansens plass 9,  
NO-0160 Oslo, Norway  
[www.stoffskifte.org](http://www.stoffskifte.org)

## THE PHILIPPINES

*Thyroid Council of The Philippines*  
Room 1101, North Tower, CHBC  
St Luke's Medical Center  
Quezon City, The Philippines  
[tolsanluis@gmail.com](mailto:tolsanluis@gmail.com)

## PORTUGAL

*Associação das Doenças da Tiróide*  
Rua Ricardo Jorge, 55 – 1º C  
4050-514 Porto, Portugal  
[www.adti.pt](http://www.adti.pt)

## RUSSIA

*Thyroid Foundation of St. Petersburg*  
“Professor” Medical Centre  
42 Chaykovsky Street  
St. Petersburg 191123, Russia  
[gasparyan@peterlink.ru](mailto:gasparyan@peterlink.ru)

## SPAIN

*Asociación Española de Cáncer de Tiroides*  
San Nicolas 15  
28013 Madrid, Spain  
[www.aecat.net](http://www.aecat.net)

## SWEDEN

*Svenska Sköldkörtelföreningen*  
Postbox 10256,  
SE-43423 Kungsbacka, Sweden  
[www.skoldkortel.se](http://www.skoldkortel.se)

## UNITED STATES OF AMERICA

*Graves' Disease & Thyroid Foundation*  
P. O. Box 2793  
Rancho Santa Fe, CA 92067, USA  
[www.gdatf.org](http://www.gdatf.org)



[www.thyroid-fed.org](http://www.thyroid-fed.org)