



# 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 2013 – 2014

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Katherine Keen (Canada)

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#### Member Organizations

The names of the organizations and their current addresses are given on page 24.

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## Message from the Editors

This is my first experience as a co-editor of an issue of the ThyroWorld magazine. First of all, thank you to all member organizations for contributing with articles and news updates from your country. It's very useful and inspiring to see the results of others, in order to be able to set new goals for one's own work. Also, thank you to Ineke Bink for your contributions in previous issues. And last, but not least, thank you to Beate Bartès for being such a great 'profesora' in teaching me about the making of the Magazine!



Dag Lund-Fallingen

In 2014, we met in the city of Santiago de Compostela in Galicia, Spain for the conference on thyroid diseases and endocrine medicine, and the member organizations in TFI also met for its annual general meeting. My first visit to Santiago de Compostela was during Easter of 2003, which I still remember well. It's a city for contemplation, calmness and pilgrimage. In 2014, it was also a city for a conference on thyroid matters.

This edition of the ThyroWorld magazine brings us various news and updates from our member organizations throughout the world. We hope that there will be something interesting for every reader of the magazine.

Enjoy the magazine and enjoy the conference!

DAG LUND-FALLINGEN, CO-EDITOR

After Pisa, Italy, in 2012, and Leiden, The Netherlands, in 2013, the 2014 European annual thyroid meeting took place in the beautiful city of Santiago de Compostela in Galicia, a region in the North West of Spain. The city originated from the shrine of Saint James the Great, which was the destination of the "Way of St. James", a Catholic pilgrimage route begun in the 9th century. Galicia has a well-known relationship with thyroid disease since iodine deficiency and endemic goitre were historically present in this broad area. The Hospital (Hostal) of the Catholic King and Queen, fully operative from 1511 to attend to the medical



Beate Bartès

(continued on page 5)

## President's Message

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

Dear Readers,

I wanted to wish all LATS 2015 attendees a very productive and successful conference at Salvador, Brazil.

2015 is the year of 15th International Thyroid Congress. It is also the 20th Anniversary of Thyroid Federation International (TFI) that continues to grow as a Global organization. More countries are finding the need for their own patient organization and we now have Spain and India joining as members of TFI. Our members' organizations are mostly made of volunteers and some of them are physicians who put in many hours to add value to the lives of thyroid patients. I do hope you had an opportunity to visit [www.thyroidweek.com](http://www.thyroidweek.com) and [www.thyroidweek.org](http://www.thyroidweek.org) to see what we do during that week and beyond.

Thyroid Federation International (TFI) takes great pleasure in announcing the topic for the seventh International Thyroid Awareness Week (25 - 31 May, 2015). The topic for ITAW 2015 is: "Hypothyroidism: Causes and Treatments"

We understand that different countries have different priorities when it comes to thyroid related issues; we need to focus our attention and awareness to:

- Iodine in salt remains top of the list for many countries. ICCDI members are doing a great job to accomplish this goal; we would like to support this in countries where it is most needed
- Fukushima, Japan and the Chernobyl leak have impacted the thyroid functioning of their populations. What proactive measures should be taken for people living within a 20 mile radius of such locations?
- In the UK the importance of iodine in the diet needs renewed awareness for the new generation
- Deploying thyroid collars prior to taking X-rays at diagnostic, dentist and hospital settings



Ashok Bhaseen

- Rise of thyroid cancer in North America and some European countries, why?

We deeply care for the patients and we work with the medical professionals to ensure credible and clinically tested information is provided. We also advocate prudence when it comes to some people who are making headlines in the media but with little or no credibility to their

suggested remedies. Patients and physicians have a common goal to make choices that ensure patients lead a normal life. Hence, it is important to make sure that you are looking at credible information and sources. TFI's logo on its affiliated members' websites provides that confidence. Credibility is very important to us and plays an integral role in managing a person's health.

We continue to work closely with organizations and their members like ETA, ATA, AOTA and LATS, and provide evidence based information to thyroid patients to alleviate their condition.

I would like to thank all of you who have worked with TFI affiliated members and encourage our readers to develop, help and support local thyroid foundations and organizations in your individual countries. Every bit of help counts and your volunteer time helps people in managing their disease better. Please visit our sites at [www.thyroid-fed.org](http://www.thyroid-fed.org) and [www.thyroidweek.org](http://www.thyroidweek.org) to learn more and do not hesitate to talk to any TFI member at the booth during the congress.

One person at a time and a few hours of your volunteer time can bring a positive change in a patient's life. Look for volunteer help at your local thyroid foundations; we need your time and involvement.

We encourage more countries under LATS to have a Thyroid Foundation that can help in generating awareness on thyroid related issues and help their population in managing it better. We look forward to hearing from you, so that we can help you in establishing your organization.

# Echoes from TFI AGM and ETA in Leiden, 2013



## September, 2013 – Leiden, Netherlands

AUTHOR: BEATE BARTÈS  
SECRETARY, THYROID FEDERATION INTERNATIONAL

As every year, TFI held its Annual General Meeting in the days preceding the ETA congress, in the beautiful city of Leiden, Netherlands.

During the ETA congress, TFI, together with SON Netherlands, organized a patient-doctor workshop about the cooperation between patient organizations and the medical profession.

We had a booth in the exhibition area, with a video screen showing pictures of the international thyroid awareness week and its various activities around the world, and attended various interesting lectures and symposia.



*TFI AGM 2013—Left to right: standing – Peter Lakwijk, Ashok Bhaseen, Jan De Vries, Larry Wood, Yvonne Andersson-Lakwijk, Dag Lund-Fallinggen, Ulla Slama, Beate Bartès, Harald Rimmele, Ineke Bink; sitting – Asta Tirronen, Nancy Patterson, Elina Gasparyan, Janis Hickey, Beverley Garside.*

Several TFI members participated in the first “thyroid cancer awareness run” on Monday September 9th.

Our ThyroWorld newsletter was packed into the delegate’s bags of the approximately 1200 attendees of the congress, and also available on the booth.



*The ETA congress took place in the beautiful Concertgebouw.*



*At the TFI booth: Ashok Bhaseen, Larry Wood, Ulla Slama and Beate Bartès.*



*SON/TFI patient-doctor workshop at the ETA: Patient representatives from TFI and SON – Ashok Bhaeen, Joke van Galen, Rietje Meijer and Niko de Jong.*



*Thyroid cancer awareness run: Ashok Bhaseen, Beate Bartès, Shann Wood, Muriel Londres, Bente Julie Lasserre, Harald Rimmele, Peter Lakwijk, Carmen Villar B.*

*(continued on page 5)*

## Echoes from TFI AGM...

(continued from page 4)



TFI President, Ashok Bhaseen, addressing the ETA participants at the welcome reception in the 'Hooglandse Kerk' on Saturday, September 7th (photo courtesy of Monique Shaw).

## Message from the Editors

(continued from page 2)

needs of the multitude of pilgrims arriving to Santiago, succeeded in generating broad medical knowledge and clinical practice of extreme quality since medieval times, a tradition which has continued to today.

Thyroid Federation International, an umbrella group of thyroid patient organizations all over the world, is very happy to hold its 2014 annual general meeting and to attend the ETA congress in this beautiful and historic location – and proud to participate in the “camino”, a walk along the St James’ path, organized by its newest member, AECAT from Spain, to raise awareness for thyroid cancer!

Wishing you a successful meeting!

BEATE BARTÈS, CO-EDITOR

## 1995 – 2015 TFI celebrates its 20th anniversary !

The Thyroid Federation International first convened in Toronto at the 11th International Thyroid Congress in September 1995, with the vision of a world thyroid organization to deal with the problems of thyroid disease in a global perspective. Starting from a base of six member organizations, the Federation has grown to include more than 20 thyroid organizations in many parts of the world, including Europe, North and South America, Australia and Japan.

## Events

### September 25 to 28, 2014

11th Asia and Oceania Thyroid Association Congress (AOTA)  
Kochi, Kerala, India  
[www.aotacongress2014.com](http://www.aotacongress2014.com)

### October 29 to November 2, 2014

84rd Annual Meeting of the ATA  
Coronado, California, USA  
[www.thyroid.org](http://www.thyroid.org)

### May 25 to 31, 2015

5th International Thyroid Awareness Week  
Topic: “Hypothyroidism : Causes and Treatments”  
[www.thyroidweek.com](http://www.thyroidweek.com)  
[www.thyroidweek.org](http://www.thyroidweek.org)

### October 18 to 23, 2015

15th International Thyroid Congress (ITC)  
Orlando, Florida, USA  
[www.itc2015.thyroid.org](http://www.itc2015.thyroid.org)

### 2015

15th Latin American Thyroid Congress of the LATS, Latin-American Thyroid Society  
Salvador, Brazil  
[www.lats.org](http://www.lats.org)

### October 16 and 17, 2015

21st Annual General Meeting of Thyroid Federation International  
Orlando, Florida

*in conjunction with the 15th ITC*



## 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.

## ThyroWorld

Deadline for the next issue: June 20, 2015

Send all submissions to:

The Editors, ThyroWorld

**Thyroid Federation International**

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# TFI Statement on Thyroid Hormone Substitution

## T4/T3 Combination Treatment and Animal Thyroid Extracts (May 25th, 2014)

The standard treatment for hypothyroidism is levothyroxine (T4). In the majority of people with hypothyroidism levothyroxine reverses their symptoms. Levothyroxine has a long track record of safety, and treatment can be monitored reliably by blood tests. Because of the long duration of action, levothyroxine can be taken once daily. Levothyroxine is a “pro-hormone” and is converted in the body to T3, the really active thyroid hormone, which tissues and cells respond to.

Thyroid Federation International is concerned that many people with thyroid disease feel that their symptoms are not well controlled. The information available in the media on this topic may be confusing for patients. It includes suggestions of using large doses of levothyroxine, T3, combinations of levothyroxine and T3 or desiccated pig thyroid.

Thyroid Federation International believes that patients should be empowered by being well informed about their condition and the various treatment options and should take an active part in decision making about their treatment. Patients must also be well informed about potential adverse effects of treatment options.

People who remain symptomatic on thyroid hormone replacement are an important and medically challenging group who deserve to be taken seriously and managed holistically. Within this group there are individuals with other medical diagnoses or who have never achieved optimal thyroid hormone replacement with levothyroxine; alternative means of thyroid hormone replacement may provide temporary subjective improvement in symptoms, at the expense of long-term harm to their health and may delay the diagnoses of other conditions. Many symptomatic patients who have tried different thyroid hormone replacements fail to improve, which is indicative of the fact that this approach is not a panacea for people who are in that unfortunate category. For some people a trial of combination of T4 and T3 may prove to be beneficial. Thyroid Federation International endorses the European Thyroid Association guidelines on this topic which provide a sound,

responsible, safe and holistic framework (see Appendix 1).

Some people choose to take high doses of thyroid hormones or desiccated pig thyroid. This choice should be respected – in such cases we believe that they should have access to medical supervision and monitoring for potential development of adverse effects.

We believe that engagement between patients, scientists, doctors, patient and medical professional organizations with an open mind is the best way of improving patient outcomes and their quality of life. Our knowledge and understanding of thyroid hormone replacement in people with hypothyroidism needs to be broadened. Thyroid Federation International believes that more research is required using robust scientific methodology.

ASHOK BHASEEN, TFI PRESIDENT

DR PETROS PERROS, TFI MEDICAL ADVISORY BOARD

### Appendix 1

#### Background and practical information about combination of T4 and T3 based on the European Thyroid Association guidelines

Patients and doctors should have confidence and trust in each other, and have a dialogue about the risks and benefits of the various treatment options.

Before embarking on a treatment plan including T4 and T3 in combination, the following steps should be taken:

1. The patient should have the benefit of optimal levothyroxine replacement for a period of time, usually 6 months
2. The patient should have a thorough physical assessment to exclude other medical diagnoses, and an assessment of risk for osteoporosis and heart disease
3. An evaluation of cognition and memory (“brain fog” etc.) should be considered.

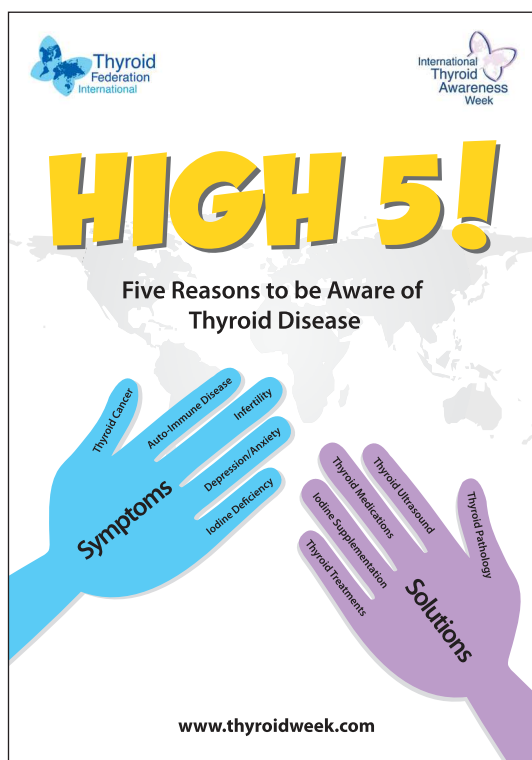
These examinations will provide a “baseline” of information. Once started on this regime, it will require more frequent blood tests.

*(continued on page 7)*

# ITAW Activities 2014 Around the World

The 6th International Thyroid Awareness Week was held from May 25th to 31st, 2014, presented by TFI and Merck Serono. ITAW is endorsed by the European Thyroid Association, Latin American Thyroid Society, American Thyroid Association, Chinese Society of Endocrinology, Chinese Medical Association, and Asia & Oceania Thyroid Association. Around the world more than 40 countries participated, including: Brazil, Central America, Chile, China, Czech Republic, Ecuador, Indonesia, Iran, Italy, Malaysia, Peru, Romania, Tunisia, and Turkey.

This year, ITAW's theme was **"High 5! Five Reasons to be Aware of Thyroid Disease"**. The theme's focus was the symptoms and solutions for 5 thyroid disorders consisting of: Thyroid Cancer, Auto-immune Disease, Infertility, Depression/ Anxiety, and Iodine Deficiency.



The organizers held press conferences with approx. 160 journalists from around the world. The ITAW activities were reported by 23 TV and radio stations, and print coverage reached millions of readers. The website [www.thyroidweek.com](http://www.thyroidweek.com) was visited by approx. 160,000 people. Ultrasounds and TSH tests were performed by medical professionals.

Remember to **High 5!** and pass it on. We look forward to next year's 7th International Thyroid Awareness Week, May 25-31, 2015.



Chile: Activity for patients in private clinic.



Indonesia: High 5! Sharing session with Merck Serono staff.



Malaysia: Creative "Blitz Competition"

## Thyroid hormone substitution (continued from page 6)

The following suggestions are made:

1. If you begin this treatment and feel "hyper", talk to your doctor immediately. It may be necessary to stop the treatment.
2. If you feel NO benefit, talk to your doctor, who will most likely recommend to stop the combination treatment (risks may be higher than the benefits)

3. If you have no hyper symptoms and feel better, continue. Stay in close contact with your doctor and be diligent about lab work to avoid toxicity.

### Reference:

2012 ETA Guidelines: The Use of L-T4 + L-T3 in the Treatment of Hypothyroidism  
 Eur Thyroid J 2012;1:55-71 (DOI:10.1159/000339444)  
<http://www.karger.com/Article/Pdf/339444>



# World Thyroid Day in Brazil

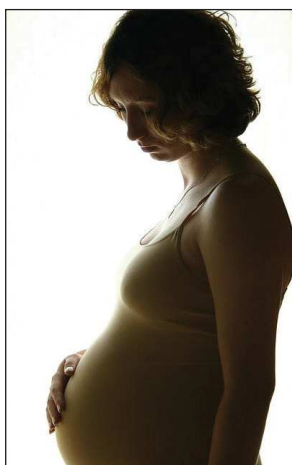
GERALDO MEDEIROS-NETO  
INSTITUTO DA TIROÍDE, SÃO PAULO

**W**orld Thyroid Day was celebrated in Brazil by informing the general population about the many faces of little known thyroid problems.

Dr. Medeiros-Neto was invited to appear in a show aired on one of Brazil's prime open TV channels. He spoke about several thyroid problems following studies on global control of iodine deficiency and concluded that, according to recent data from the ICC IDD (International Council for Control of Iodine Deficiency Disorders), these deficiencies seem to be as well-controlled in Brazil as in most other countries worldwide. This is amply demonstrated by the results obtained from Latin America.

Another major problem is neonatal screening for thyroid deficiency. For example, although neonatal screening for the problem is highly organized and apparently efficient, closer examination of the numbers reveals the major problem in around half of Brazil's States is that infants are brought to centers for neonatal screening only several weeks after birth. This likely results in late diagnosis and delayed treatment, with consequent risk of central nervous system damage. The Thyroid Institute has conducted a number of campaigns to raise awareness of the need to bring newborns to the medical center as soon as possible after birth. Approximately 900,000 simple leaflets were distributed to the whole population of one State (Bahia State), reaching 20 million inhabitants. Details on this campaign were published in ThyroWorld in 2013.

Pregnant women usually are recommended to lower their salt intake. This may be associated to low iodine intake. Therefore, all pregnant women should receive. Henceforth need for a supplement of iodine that will be beneficial for pregnant women but essential for the child in gestation.



*Iodine supplement during pregnancy: Just do it!*

The main focus of World Thyroid Day in 2014 was the need for appropriate iodine supplementation among pregnant women. As salt in Brazil is iodinated (15-45 mg of potassium iodate/kg of salt), all pregnant women are assumed to ingest sufficient iodine during the 40-week gestation. However, the attending doctor often reduces salt intake during pregnancy because of the risk of hypertension or water retention. Most obstetricians prescribe multivitamins and minerals, including 150 mcg of iodine daily. This is probably adequate for the mother and more importantly for the infant. However, pregnant women with a lower socioeconomic status probably do not receive this iodine supplement. During the TV appearance, Dr. Medeiros-Neto stressed that all women should take iodine supplements during pregnancy. This program and subsequently, another morning TV show on which this same recommendation was repeated, were probably seen by close to 10 million viewers. The TV station received numerous calls asking for further details. A few questions were taken and the subject was probably made clearer to the audience.

To summarize, the main subject of World Thyroid Day in Brazil centered on the need for iodine supplementation during pregnancy. Subsequently, the Thyroid Institute proposed that any questions or queries regarding this need should be emailed to our Questions and Answers forum.

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

**May 25 to 31, 2015**

**7th International  
Thyroid Awareness Week**

**Topic –  
Hypothyroidism:  
Causes and  
Treatments**

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



## ITAW Activities in Bulgaria

SCIENTIFIC CENTER OF MEDICINE TO BULGARIAN ACADEMY OF SCIENCES AND ARTS, DIRECTOR: ACADEMICIAN PROF. BOJAN LOZANOV

Activities organized by the Bulgarian Academy of Sciences and Arts (BASA) in International Thyroid Awareness Week 2014:

- Postgraduate courses for physicians with main topics: IDD, thyroid carcinomas, hypothyroidism, Hashimoto's disease subclinical hyperthyroidism, Thyroid Eye Disease, Depressions. All of these were presented by some prominent university professors and specialists in the field
- Press conferences and many interviews for the national mass-media – several TV national channels, Bulgarian National Radio, many newspapers and magazines
- Free consultations and thyroid ultrasound diagnostics for patients in risk or suspected for thyroid disorders, which were organized



Acad. prof. Bojan Lozanov, DM, PhD

by some hospitals and outpatient departments in the city of Sofia and city of Varna

- A leaflet for patients was issued in 100,000 circulations (sponsored by MERCK-Bulgaria), containing sufficient information on 5 main topics of the ITAW-2014 campaign

The most activities were undertaken in collaboration with a non profit, non government organization (NGO VIOM) which has

been registered by patients with thyroid chronic diseases and set up a new site [www.thyroidbg.com](http://www.thyroidbg.com)

We believe these activities will enhance the awareness of the Bulgarian people and institutions in the problems and medico-social significance of thyroid disease.

We would like to express our great appreciation and gratitude for the encouragement through TFI/ ETA for the organization of the ITAW campaign in Bulgaria in the last three years which contributed to our efforts in this respect.

## Thyroid Awareness Week in Denmark

THYREOIDEA LANDSFORENINGEN, DENMARK  
[WWW.THYREOIDEA.DK](http://WWW.THYREOIDEA.DK)

To celebrate TAW this year we decided to make a Patients Forum on Thyroid Associated Orbitopathy. It is a special subject and luckily not many patients suffer from it. But when they do, it can be a devastating disease. Information and contact with other patients in the same situation is important.

We were very happy when not less than 70 patients and relatives showed up to spend a couple of hours together at Copenhagen University Hospital.

*Bente Julie Lasserre, Vicepresident at Thyreoidea Landsforeningen*



They had excellent information from the four doctors present: two ophthalmologists, Nicolai Søe and Peter Toft, and two endocrinologists, Aase Krogh Rasmussen and Birte Nygaard.

There were a lot of good questions from the audience and, of course, very good answers from the doctors.

*(continued on page 11)*

# 1st Spanish Thyroid Awareness Week

## From Give Your Voice to Voices on the Way

**A**ECAT, the only Spanish association of thyroid cancer patients as well as the only one related to the thyroid at all, has joined the TFI and embraced the challenge of spreading International Thyroid Awareness Week (ITAW). Particularly, this year's focus is on the "Thyroid High Five" and the related issues and problems.

Our first action was to assess the knowledge and awareness among Spanish society regarding thyroid cancer and thyroid in general. This has been carried out through a survey and research about the social impact and the level of knowledge about thyroid diseases, made public on September, 2013 and May, 2014 respectively.

Being the association of thyroid cancer (TC) patients, we already knew about the lack of media and social recognition we are facing whenever we try to explain anything about thyroid cancer. We understand the absence of such knowledge to be largely due to the lack of understanding of the major role the thyroid plays in our everyday life.



We experienced a great achievement we had not counted on. Our campaign, Give Your Voice, the first campaign ever in Spain to raise awareness about cancer of the thyroid, has been accredited with the 2012 Albert Jovell award for the most significant public awareness campaign regarding cancer, 2012.

The campaign aimed to collect supporting messages from patients, specialists, friends and celebrities, who helped us reach the media with their support and popularity. This campaign, created to last, has launched a microsite, [www.donatuvoz.org](http://www.donatuvoz.org), gathering several clips that made the round on the internet together with some ads from 2013 where diverse public figures dubbed

patients' voices "to help their voices get farther". The spots were broadcasted in September through the main television and radio stations.

So in 2013, on the occasion of National TC Day, we launched the spots as part of the campaign "Take a minute against silence".

On the one hand, we evidenced the silence we had been denouncing to the media. A survey and a forum on Social Perception about Thyroid Cancer in Spain showed that 55% of the Spanish people know little to nothing about TC, 54% didn't know the role of the endocrinologist in their treatment and 77% didn't know about radioiodine.

In addition, for the whole day, our logo was shown on TV, our spots broadcasted and a guerrilla war organized, with TV and radio interviews, conference participation, talks at schools, presence on blogs and a classical music concert in order to raise awareness about TC. With other good causes, we observe a minute's silence. For the II National Day of Thyroid Cancer, we wanted to break the information gap on the subject and asked the media, patients and anybody else who might want to help us to observe a minute against silence, giving their voices to talk about such an unknown type of cancer.

Yet in 2014 further action was required. Given voices that really helped us to get known were no longer enough. Our stories are important and we need to tell them first hand, directly. These stories are born from facing the word cancer, then moved away from the stereotypes following a different way, the one marked by the specific features of a gland: the thyroid. Essential to the human organism, the thyroid gland is very little-known and tends to be associated simply to its impact on weight. Giving voice and visibility to its disorders and implications on physical and mental well being is going to help early detection and spread better knowledge of the thyroid cancer experience, to ease the process for new patients.

*(continued on page 11)*



## 1st Spanish TAW (continued from page 10)

This is the origin of Voices on the Way. With the occasion of the 38th Annual Meeting of the European Thyroid Association, held in Spain, we organized five stages of the Way of Saint James – our Camino de Santiago – with thyroid cancer patients that will raise their voices to the specialists gathering in Santiago de Compostela, through a real and symbolic Way, the “Camino” of the trials we have gone through as patients. And at the end of the day, we will start bringing together:



1st Stage: Why are we Pilgrims? The impact of the word “Cancer”

2nd Stage: A New Way, the Camino. Understanding treatment and the health system

3rd Stage: Tiredness on the Camino. Hardness of the treatment itself

4th Stage: End of the Camino? New “normal”, fear and side effects

5th Stage: One Step Forward, Fly your dreams. You are not alone, make your efforts be of use for others.

And the best start for this campaign is to make the most of May and the ITAW and present the data released by the forum on the Social Impact of Thyroid Diseases. Data which showed, among other aspects, that despite the 20% of the Spanish people suffering from a thyroid related disease, the respondents declare they fail when evaluated on the knowledge about thyroid diseases and yet they do not seem to seek a lot of information, given the slight 2.4% that acknowledges doing so over the last year. At the same time, it evidences the large social costs of these diseases, which largely presented with general tiredness (65.8%), lack of attention (20.4%), mood swings (42.7%), depression (41.6%) and also interfered family and social life of 24,2% of the polled patients.

These non-specific factors are not always



sufficiently associated to the thyroid; and it make us reevaluate the urge to spread the ITAW 2014 topic, “Thyroid High Five” 5 Reasons to be aware of Thyroid Disease – Thyroid Cancer, Auto-Immune Disease, Infertility, Anxiety / Depression and Iodine Deficiency. Particularly when the survey highlights the fact that satisfaction is fairly broad regarding the final treatment, but it comes connected to an emotional, physical and cognitive exhaustion along the period of detection and dosage; hence the importance of the early detection.

That is why we have decided to stand up for an educational model based on the group of persons and moments when thyroid hormones should be tested. Besides which, we blog an article a week: nodules and TC, thyroid hormones, TSH and depression, TSH and pregnancy. All of this represents the groundwork of our shared path with other thyroid diseases.

Finally, we would like to invite all those who share this path to join us in September for our TC patients of Camino de Santiago.

If you cannot come to Spain we hope you will visit [www.vocesnelcamino.org](http://www.vocesnelcamino.org) and join the journey there.

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## TAW in Denmark (continued from page 9)

A very successful afternoon in Thyreoidea Landsforeningen in Denmark.



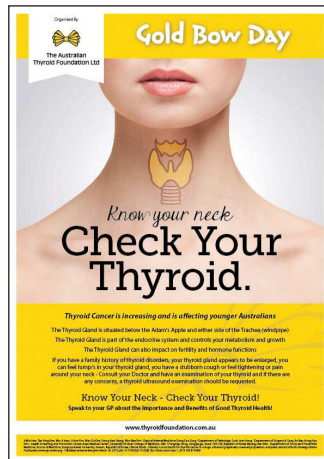
The Danish doctors – Aase Krogh Rasmussen, Birte Nygaard and Peter Toft.

# Gold Bow Day in Australia

## September 1st

The Australian Thyroid Foundation Ltd. (ATF) Gold Bow Day on 1st September promotes awareness of Thyroid Cancer. Thyroid Cancer is increasing in Australia and affecting younger Australians.

The ATF has developed a thyroid cancer campaign – Know Your Neck – Check Your Thyroid!



This campaign aims to bring awareness to the importance of diagnosis through an ultrasound.

Although thyroid cancer is well treated, in most cases once diagnosed, cancer is still cancer and early detection is essential to ensure minimal treatment is possible.



The Australian Thyroid Foundation Ltd

# ITAW Patient Forum in Canada

DONNA MINIELY, PRESIDENT  
THYROID FOUNDATION OF CANADA

This spring, as International Thyroid Awareness Week led into Canadian Thyroid Month (June), the Thyroid Foundation of Canada held a Patient Forum in North York, Ontario, featuring Dr. George Awad, Professor Emeritus of Psychiatry from the University of Toronto.

Dr. Awad spoke about “Thyroid Function in Health and Psychiatric Disorders”, covering the spectrum of thyroid disorders from hypothyroidism to thyroid cancer. He described the many body functions that thyroid hormone impacts and factors that can lead to abnormal thyroid states. He then focused on hyperthyroidism, hypothyroidism and subclinical hypothyroidism.

After this overview of the general considerations, the attendees were invited to submit questions to Dr. Awad in writing. He graciously took the time to read and respond to each question. As a result of this personal touch, the attendees were quite satisfied with the outcome of the Forum. The attendees received a handout of Dr. Awad’s slide presentation, which has now been posted on the website: [www.thyroid.ca](http://www.thyroid.ca)



Dr. A. George Awad, Chief of Psychiatry, Humber River Hospital and Frances Salvaggio, TFC Board Member

The psychiatric disorders that accompany thyroid conditions can be quite challenging for patients and their families. The Thyroid Foundation of Canada is very grateful to Dr. Awad for the insights he provided at the Patient Forum on May 31, 2014.



Thyroid Foundation of Canada

La Fondation canadienne de la Thyroïde

## Denmark: Congenital Hypothyroidism

THYREOIDEA LANDSFORENINGEN, DENMARK  
WWW.THYREOIDEA.DK

**H**aving a baby is a very special event and all parents can imagine how hard it is to hear that your newborn has a congenital disease that will probably be present for the rest of the baby's life.

Two Danish mothers – both with babies with congenital hypothyroidism – found each other and created a group on Facebook for those parents. Thyreoidea Landsforeningen got in contact with them and arranged a meeting for the group members in July 2013.

It was a sunny Sunday in Odense in the center of Denmark and 10 families came from all over Denmark to participate. The children were from 5 months old up till 10 years. Seeing the ten "big boys" of 10 and 7 years playing Nintendo and acting just like any other child of their age was especially good for the parents with small children.

Pediatrician Dorte Hansen from Odense University Hospital came and spent a couple of hours together with the families. She gave a speech about the disease and the parents had the chance to ask all the questions they had.

The Facebook group is growing and currently there are 68 members. It is a very positive group and they are so good at helping each other,



*Rasmus, Tobias and Adrian were born with congenital hypothyroidism.*

especially when parents with newly diagnosed children join the group.

Another meeting is planned for September 28th 2014 in Odense and again pediatrician Dorte Hansen will come and answer questions. In Thyreoidea Landsforeningen we are looking forward to meeting them all again.



## Finland: Patient/Physician Cooperation

### Cooperation is necessary between patients, physicians and patient organizations in management of thyroid diseases

ESA SOPPI, MD, PHD, ADJUNCT PROFESSOR IN INTERNAL MEDICINE, BOARD MEMBER, THE FINNISH THYROID ASSOCIATION



**G**lobally thyroid diseases are very common. In Finland close to 290 000 (about 5.4% of the population, 2013) patients were using levothyroxine medication. Out of them some 200 000 patients are not obliged to special reimbursement meaning that they most probably have subclinical hypothyreosis. The size of this group is now increasing rapidly; from 2012 to 2013 close to 20 000 new patients started levothyroxine medication. This trend is apparently a result of increased awareness of the high prevalence of thyroid diseases, their symptoms and easy access to low cost laboratory diagnostics for both patients and physicians. Thyroid tests are regularly requested as a part of health checks and to evaluate multitudes of symptoms, such as weight gain, tiredness and mood changes. Borderline thyroid values are often detected which create confusion both among patients and general practitioners since the diagnosis of subclinical hypothyreosis is often a great challenge even to an experienced specialist. A specialist considers possible alternative diagnoses, for example subclinical iron deficiency which among menstruating women as a cause of tiredness is much more prevalent than thyroid diseases.

The internet is today the main source of health related information for patients. Unfortunately it is impossible for patients to

judge which information is medically correct and helpful for an individual and which information needs to be considered misleading. Reviewing the internet pages and discussion forums it seems to be common for many patients to seek help and advice and even interpret their laboratory results based on information from the internet or on opinions of fellow patients. This creates a great challenge to many patients, general practitioners and patient organizations to create and exchange sound knowledge during collaborative discussions. To offer an alternative for bias of internet based information I used a few years to compile a book in Finnish "Thyroid Gland and Thyroid Diseases – A Book for Patients". Even medical students and many general practitioners could benefit from reviewing its content and its numerous patient cases.

Official patient organizations, like The Finnish Thyroid Association bear a great responsibility to offer undisputed, biologically sound information. I am grateful that The Finnish Thyroid Association has regarded the book as beneficial in their work as a responsible patient organization. I am also privileged to cooperate with the devoted people in the Association. In the current information overload continuous effort is needed between the patient organization, physicians and patients so that all parties can reach a trustworthy relationship.



**May 25th, 2015**  
**World Thyroid Day**

## Germany: Open Questions about High-Sensitive TG Assays

HARALD RIMMELE, DIRECTOR OF THE GERMAN ASSOCIATION FOR THYROID CANCER PATIENTS

(TRANSLATION OF AN ARTICLE PUBLISHED IN THEIR TRIMESTRAL "OFFLINE" NEWSLETTER)

*Comments after the publication of the review "Thyroglobulin measurement using highly sensitive assays in patients with differentiated thyroid cancer: a clinical position paper." (Luca Giovanella et al.), European Journal of Endocrinology, 2014, 171, R33-R46.*

*Statements and open questions from patients: how high is the risk of recurrence in case of a measurable thyroglobulin (TG) value? What is the impact on my life and on my quality of life?*

**D**ifferentiated thyroid carcinoma has a peculiarity: it can recur even decades after successful treatment.

Therefore patients diagnosed with papillary and follicular thyroid cancer, after surgery and successful radioiodine ablation, need long-term follow-up; in most cases, this follow-up consists in TG measurement and neck ultrasound, performed at least once per year by a physician experienced with the care of DTC patients.

Due to the fact that the value of the thyroglobulin depends on the TSH value and on the amount of TG antibodies, these two factors must always be assessed together with the TG. The TSH suppression during the follow-up of thyroid cancer patients does not only slow down the growth of thyroid cancer cells (in case there are still some left), but also the production of thyroglobulin – therefore the TG values measured with the current "old" TG assays (functional sensitivity 1-2 µg/l) are not very sensitive in detecting recurrences.

It is possible to increase the sensitivity by measuring the TG value while the patient is hypothyroid, with a high TSH level, or after stimulation with recombinant human TSH (72 hours after the last of the 2 Thyrotropin alfa injections). However, both stimulation methods involve more or less physical impairments for us, the patients. Furthermore, the existing guidelines

give no indications as to the periodicity of these stimulated TG measurements during follow-up.

The new highly sensitive TG assays (hsTG) make it now possible, under certain conditions, to follow patients without the need for a stimulated TG value. Our association had already begun to discuss this alternative – measuring the unstimulated TG value with highly sensitive or ultra-sensitive TG assays during the follow-up of DTC patients – back in 2011 (during the month-lasting supply problems for rhTSH), based on the studies made by the group led by Rossella Elisei, endocrinologist at the university of Pisa, Italy.

Under the direction of Prof. Luca Giovanella, nuclear medicine hospital in Bellinzona, Switzerland, some leading European thyroid cancer specialists (including Rossella Elisei) created a work group and produced a voluminous clinical position paper (1) with a total of 24 recommendations concerning the use of highly sensitive TG assays (hsTG) during the follow-up of thyroid cancer patients (Giovanella – European Journal of Endocrinology 2014, 171). In addition to the elaboration of the clinical position paper about the measurement of thyroid antibodies (2) (Verburg et al.; Thyroid. October 2013, 23(10): 1211-1225), our director Harald Rimmele participated in these discussions as patient advocate, bringing the patients' point of view.

Many of the recommendations elaborated by this workgroup are important mainly for doctors and for further research. The statement doesn't recommend the TG assay of any particular manufacturer – this is the reason why the term "highly sensitive" is used, instead of "ultra-sensitive" (term correlated with the assays of particular manufacturers).

Several of the recommendations published in this clinical position paper have been graded "I", i.e. "neither for nor against": there is not sufficient evidence; some of the authors are for a recommendation, others against.

(continued on page 16)

The most important – and uncontroversial – recommendation for the follow-up of DTC is that for low-risk patients with an undetectable hsTG ( $<0.1 \mu\text{g/l}$ ), no further TSH stimulated TG measurements are necessary.

If the hsTG value is higher than  $1.0 \mu\text{g/l}$ , further proceeding is as indicated in the existing guidelines.

Some other recommendations are based only on "expert opinion": for example, the first hsTG measurement shall be performed not earlier than 3 months after  $^{131}\text{I}$  remnant ablation. Prior measurements should be interpreted with extreme caution, as TG levels often continue to decrease up to 6 to 12 months.

Depending on the risk group of the patient, the measurements should be repeated every 3 to 12 months. If the hsTG value is situated between  $0.1$  and  $1.0 \mu\text{g/l}$ , measuring the TG at least once after TSH stimulation – possibly together with a whole body scan – should be considered.

### Patients' Comments and Questions

From the patients' point of view, the recommendation that with an undetectable hsTG measurement, no further diagnostic whole body scans are necessary, is a huge progress.

But is this also true for the recommendation that for patients with an hsTG between  $0.1$  and  $1.0 \mu\text{g/l}$ , an rhTSH stimulated TG measurement – optionally together with a whole body scan – shall be considered?

If we want to achieve a common cooperative risk assessment between the health professional and the patient (shared decision making), we need further information about how high the risk of recurrence is with such a low TG level (= positive predictive value). Most likely, the risk for recurrence with an hsTG between  $0.1$  and  $1.0 \mu\text{g/l}$  is between 15% and less than 1%, depending on the time since the successful ablation. Is the recommendation to perform a stimulated TG measurement only because of this low detectable hsTG value really less arbitrary than the recommendation to perform a stimulated TG measurement after 1, 3 and 5 years?

How shall we proceed in cases of detectable TG values which – often over many years or even lifelong – have no consequence for the patients'

health, and which most likely are produced by remaining benign thyroid cells or thymus cells (3) (Zanotti-Fregonara 2010)?

Sometimes these TG values are called "biochemical disease". Why is the simple probability to have a recurrence within a defined period of time designated as a "disease"?

In cases of recurrence, is the treatment really more difficult if it starts only with an hsTG value higher than  $1.0 \mu\text{g/l}$ ?

What are the impacts of the different therapeutic strategies for the overall survival and for the quality of life?

### Literature

- (1) Giovanella, L. et al.: Thyroglobulin measurement using highly sensitive assays in patients with differentiated thyroid cancer: a clinical position paper. In: European Journal of Endocrinology, 2014, 171, R33-R46  
<http://www.eje-online.org/content/early/2014/04/16/EJE-14-0148.full.pdf>
- (2) Verburg, Frederik A. et al.: Implications of Thyroglobulin Antibody Positivity in Patients with Differentiated Thyroid Cancer: A Clinical Position Statement. In: Thyroid. October 2013, 23(10): 1211-1225.
- (3) Zanotti-Fregonara P, et al.: Increased serum thyroglobulin levels and negative imaging in thyroid cancer patients: are there sources of benign secretion? A speculative short review. in: Nucl Med Commun. 2010 Dec;31(12)

*This article is translated from the printed German newsletter "[www.sd-krebs.de](http://www.sd-krebs.de) – OFFLINE" nr. 12, 2014.*

*The printed newsletter "[www.sd-krebs.de](http://www.sd-krebs.de) – OFFLINE" is published twice per year, with 25.000 copies. It is edited by the German thyroid cancer patient organization "Bundesverband Schilddrüsenkrebs – Ohne Schilddrüse leben e.V."*

*This organization is the biggest European patient group specially dedicated to thyroid cancer patients. Its website & online forum [www.sd-krebs.de](http://www.sd-krebs.de) has 2 to 3.000 visitors per day.*



**Bundesverband Schilddrüsenkrebs**  
**Ohne Schilddrüse leben e.V.**  
[www.sd-krebs.de](http://www.sd-krebs.de)



# Italy: AIBAT Projects

**A**IBAT, the Italian Association of Graves' Disease and Thyroid Patients, was founded by two patients, Emma Bernini and Donatella Aimi. With the contribution of volunteers, members and endocrinologists, AIBAT has organized lectures by specialists and conversations with patients, published a newsletter and several brochures on issues related to thyroid diseases, and promoted awareness and prevention campaigns with free ultrasound examination.

AIBAT has two important projects to carry out in 2014:

The first, "Conversations with patients", is meant to give patients the opportunity to ask all the questions about thyroid disease and treatment that they would like to ask specialists. Specialists, mainly for lack of time, cannot always satisfy the patient desire to know in full detail the therapeutic pathways, the effects of treatment, and the problems that may arise. We thought that the informal character of the conversations would make it easier for patients to participate.

The conversations take place once a month in the Endocrinology Unit of Santa Maria Nuova Hospital in the town of Reggio Emilia. Many patients have already attended the meetings and have expressed their appreciation for the detailed, easy to understand and scientifically based information. Furthermore, during the conversations patients often find the way to interact, telling their own experience.



Associazione Italiana Basedowiani e Tiroidei

AIBAT has succeeded in involving three Hospital Units in this project: Endocrinology, Radiology and Surgery. Beside specialists from the three Units, nurses and our volunteers are present at the meetings, which last two hours.

This project is also aimed at improving relations between patients, doctors and Hospital staff.

The second project, "Difficult Pathways: a psychologist to support patients", was created to meet a specific need expressed by those patients who have to undergo long and complex treatment (especially Graves' and oncology patients or patients who have to be treated with radioiodine in the radiotherapy rooms). Our association has thus decided to invest our economic resources to hire a psychologist, to provide professional support to patients who request it.

Sixty meetings will take place in the Endocrinology Unit with an experienced psychologist who is willing to do serious study and research in order to determine the best and more effective pathways for those patients.

AIBAT is actually committed to define health care projects that can become patrimony of the community of volunteer organizations. The association has found also in this case the support of the Santa Maria Nuova Hospital, recently promoted as IRCS (a title of excellence, meaning that the Hospital is a high standard Care center and is also a center for advanced technology and scientific research). Our projects will be analyzed, improved and then released.

**UN INCONTRO PER I PAZIENTI**  
per saperne di più

Un endocrinologo, un infermiere e le volontarie dell'AIBAT rispondono alle vostre domande

**un mercoledì al mese, alle ore 12.00**  
presso il Reparto di Endocrinologia

*Cosa dovrò aspettarmi dopo l'intervento?  
Quanti giorni per riprendere la vita normale?  
Cosa accadrà se mi viene somministrato lo iodio radioattivo?  
Cosa devo portare nelle stanze protette?  
Quali effetti dopo la terapia che devo affrontare?  
E la dieta? Cosa dovrò mangiare?  
Il laser è doloroso?  
La radiofrequenza è un intervento complicato?*

Queste e molte altre le domande che potrete rivolgere durante l'incontro del mercoledì.  
L'Associazione dei Pazienti (AIBAT), con la collaborazione della Struttura Complessa di Endocrinologia e del Servizio di Radiometabolica, organizza un incontro per tutti i pazienti affetti da patologie tiroidee che vogliono saperne di più.  
Tutto quello che gli specialisti non riescono a dire, per mancanza di tempo, potrete chiedervi direttamente alla figura che gestiscono l'incontro.  
Domande importanti, ma anche richieste sulle cose minime (tra assistenza case private per i pazienti?) potranno essere poste in un clima amichevole e disteso.

Per informazioni: 0522 296641 - 0522 296075 - 348 8282407

**PERCORSI DIFFICILI:**  
uno psicologo per accompagnare i pazienti

L'Associazione AIBAT da anni presta il suo servizio di volontariato presso la **Struttura Complessa di Endocrinologia** organizzando diverse iniziative a favore dei pazienti tiroidei.

Da quest'anno ha ritenuto di proporre e finanziare l'intervento di una figura professionale che accompagni e sostenga i pazienti che devono affrontare percorsi particolarmente complessi.

I Medici dei reparti di **Endocrinologia e del Servizio di Terapia Radiometabolica** individueranno di volta in volta i casi più problematici e li segnalano alla psicologa.

Le sedute si terranno presso la Struttura Complessa di Endocrinologia diretta dal **Dott. Roberto Valcavi**.

Per informazioni Segreteria: Benedetta Ricci Tel. 0522 295175  
E-mail: ricci.benedetta@asmn.re.it

## Italy: ATTA-Lazio ONLUS

AUTHORS: PAOLA POLANO AND DOMINIQUE VAN DOORNE MD, ITALY, ATTA-LAZIO ONLUS PRESIDENT AND SCIENTIFIC SECRETARY



**A**TTA-Lazio ONLUS is at it this year not only to prepare the Thyroid Awareness Week but to promote knowledge on Thyroid Diseases among people and the institutions, and to promote patient advocate education.

For the 3rd consecutive year, ATTA-Lazio has been working with an increasing number of Italian thyroid patient organizations which joined together in a national committee, C.A.P.E. – Comitato Associazioni Pazienti Endocrini (the Committee of Endocrine Patients Association).

Organizing regular meetings is not an easy task in a big and geographically long country but all the patients' representatives have been making a big effort. The motivation is high, being conscious of the increasing patient organizations' role today as Italy is going through an important political and economical change, accelerated by the 2008 long lasting economic crisis and the following spending review which is having a heavy impact on the Italian health system.

Unfortunately Italy is still a "mild iodine deficiency country" and according to data presented by the ISS (the Italian Superior Health Institute), the percentage of iodized salt used by Italian families in 2013 was just 54%, far from the 95% recommended by WHO and followed up by several European countries. A law was passed a few years ago in Italy recommending iodized salt, and recently the law was being reinforced stating that there would be sanctions for not applying this. Prof Aldo Pinchera, who sadly passed away 2 years ago, played a major role in the last 2 decades, urging the Ministry of Health and the Italian government to promote iodine prophylaxis.

CAPE, together with the three Endocrinology Scientific Associations, looks forward to working together to educate the younger population on the importance of iodized salt. They asked the Italian Ministry of Education, University and Research, MIUR, to extend a hand. A protocol was recently signed between MIUR, CAPE, and the three Italian Scientific Associations (AIT, AME, SIE) to promote Iodine Prophylaxis in Italian schools.



*from the left: Paola Polano, Dominique Van Doorne, Helenia Di Lorenzo and Marie Anne Van Doorne*

This protocol proposes that AIT, AME and SIE prepare the didactic material for teachers and children and that MIUR places on their website the on-line syllabus.

In the last 3 years AIT, AME and SIE have been giving strong support to CAPE and they had helped in preparing the scientific leaflet that has varied every year, depending on the theme of Thyroid Awareness Week. This year, the theme chosen focuses on the high neurological impact of thyroid diseases and its social impact: "Tiroide problema sociale – dal corpo alla mente" ("Thyroid is a social problem- from the body to the mind").

The different themes in the last years have always aimed at involving other specialties like pediatricians, gynecologists, neurologists to increase thyroid awareness among physicians and Hospital managers.

Last but not least ATTA-Lazio is actively participating in the EUPATI project, a 5 year project (2012-2017) that aims to educate patients and patients' advocates on the long and complicated process of Medicines Research and Development (R&D). EUPATI will provide scientifically reliable, objective and comprehensible information on medicines R&D to patients in 12 countries and 7 languages. Well informed patients will be effective advocates and will then be able to collaborate with regulatory authorities, with ethics committees and doctors in clinical trials.

## Netherlands: New Project to Assess the Burden of Disease

DR. VANESSE PLATTEEL, MPH,  
RESEARCHER AT SON (DUTCH  
THYROID ASSOCIATION)



After several successful projects carried out by the Dutch thyroid association (SON) a new project started in 2013 named 'How are you REALLY doing? The aim of the project is to adapt the validated Nijmegen Clinical Screening Instrument (NCSI) questionnaire in which the burden of disease is assessed and combined with medical outcomes as thyroid blood values.

Originally the NCSI was developed for patients with chronic lung diseases (e.g. COPD, asthma, lung cancer) by Dr. Jan Vercoulen. The NCSI combines questions specific for symptoms in lung diseases, but contains over 70% questions that are generic for chronic diseases in general, such as fatigue and various subscales on functional impairments in daily life, anxiety and depression, quality of life, and the grieving process. The answers given by the patient are then combined with his health status e.g. results from lung function tests, BMI and blood work in a visual Patient Profile Chart. It works like a traffic light: answers are grouped by a specific area and come out (depending on the answers given by the patient) in a red box when severe problems are existing, green if there is no problem and in an orange box when it's mild. The test results are then discussed together with the patient and his doctor (or nurse) and helps to address issues that otherwise may have stayed undetected. For example, when asked, a patient may say he is doing fine but the test shows he doesn't get out the house anymore because of fear of exacerbation (episode or flare up of difficulty breathing causing sickness). The NCSI helps to address issues which the doctor or nurse can act upon with the patient. This way the patient is involved and more motivated to change his behavior.

In a previous study by SON 11 focus group discussions were held with patients all over The Netherlands. Patients stated despite having 'normal' T4 blood values (substituted by



*Researcher in action*

medication) they were not feeling well. 'The doctor says my T4 values are good but I'm not feeling good at all', many patients confided. Others said their social life was suffering due to lack of energy. Nowadays life is complicated: we want a nice social life, a family, a clean house and we need (or want) to work. This is often too much for a thyroid patient to handle, as shown by the study. 'Sometimes I go to bed really early', one woman explained, 'and when I'm still tired the next morning my husband doesn't get it. He asks me: "but you went to bed early, why aren't you rested?" It makes me sad he still doesn't get it. But on the other hand I can't blame him because I don't understand it myself either.' Issues like these may be detected by the redeveloped NCSI and offers patients and the doctor the chance to address them easier.

The NCSI for thyroid patients will include questions on these and other aspects. At the moment of this writing the questions are being developed. When the NCSI is adapted for thyroid patients it will be tested and validated. The NCSI has already been successfully adapted and validated for patients with various cardiac diseases and Q-fever as well. In this project SON works together with 5 other patient organizations to redevelop the NCSI for their specific patient population. These populations consists of patients with Marfan, MPN, Klinefelter, dyslexia and pelvic pain problems. The project runs at least until 2015.



*SON researchers, Cecilia Kalsbeek and Vanessa Platteel.*

# Netherlands: Thyroid and Pregnancy

## Dutch thyroid association gives a voice to mothers with thyroid disease

DR. VANESSE PLATTEEL, MPH,  
RESEARCHER AT SON (DUTCH THYROID ASSOCIATION)



In 2014 the Dutch thyroid association (SON) started the project 'thyroid and pregnancy'. The aim of the project is to collect the experiences of women regarding pregnancy and thyroid disease on a scientific level. In order to accomplish this, four focus group discussions were held with mothers who have thyroid disease. Being the researcher, these women shared their experiences with me and I would like to share some of them with you.

One woman had suffered five miscarriages. Once she got treated for hypothyroidism she gave birth to a healthy baby. One might wonder, what had caused the miscarriages? 'There is no way to prove it but I believe it was because of my thyroid', the woman said. Another woman shared with us that when she found out she was pregnant she consulted her general practitioner about raising her Levothyroxine medication, as she had read of this in the SON magazine. The doctor in question had no knowledge on the matter. As the woman said: 'It really felt like I had to convince the doctor to raise my medication. He called me back later, saying that he had consulted a specialist and that it was important to take more Levothyroxine medication at once.' Sadly, this experience was heard in more focus groups. One can't help but wonder, what would have happened if these women weren't informed? Other women developed thyroid disease after giving birth. As one mother tells us: 'It was my first baby and everyone kept telling me it's normal to feel tired and depressed. No one told me my thyroid could become affected by the pregnancy. So it took a while before I went to the doctor and it became clear I had hypothyroidism.' One woman wonders: 'When you are pregnant you receive so much nonsense information, like all sorts of recipes. Why wasn't there anything on pregnancy and thyroid disease?'

Luckily, not all the stories told by the mothers were heartbreaking. We learned about some good practices as well. For instance one hospital provides a combined session with an

endocrinologist and gynecologist for pregnant women with thyroid disease. This way the pregnancy and thyroid are monitored together at the same consultation. In one region in The Netherlands midwives screen pregnant women on their thyroid function. This started as a pilot in which many women with abnormal thyroid values were detected and referred to a specialist. Because of the high number of women who were detected, the midwives in this region decided to continue screening (and referring) pregnant women once the pilot ended.

Based on the outcomes of the focus groups a research report was written. The report was then reflected and discussed by doctors (endocrinologists, gynecologists, midwives and general practitioners) in an evening session organized by SON. The doctors were shocked by some of the stories. The session made it clear that despite medical guidelines not all doctors are aware of the thyroid affecting pregnancy and how to treat these women. It is important to raise awareness of thyroid disease and pregnancy among health professionals in mother and child care. Therefore, in the second part of 2014 SON will publish a book based on the research report and the reflection session held by the health care professionals. With the book, SON provides the patient perspective in order to help the discussion on thyroid function and pregnancy. Hopefully, the discussion will raise awareness and bring changes in health care policy so the stories collected become something of the past. In the meantime SON will keep informing women as much as possible on the matter.



*Not all doctors are aware of the thyroid affecting pregnancy.*

# Spain: Five Voices to Understand Medullary Thyroid Cancer



## Asociación Española de Cáncer de Tiroides (AECAT)

The Spanish Association of Thyroid Cancer (aecat) is a non-profit organization that was born out of the lack of information or support that both thyroid cancer patients and their families suffered in our country. Founded in 2004, our association rose first around a forum, completed, later on, with a helpline and a solidarity chain of buddies with the same aim of helping, guiding and supporting people affected by this illness.

Being the only association of patients with thyroid cancer in Spain, we try to represent the patients' interests and be the thyroid cancer voice in front of medical professionals, society and sanitary authorities. Our main goal is to provide the patients with all the information and orientation they may need to have an active role in their treatment and, after it, during their lives.

With this same goal and with all the medical societies backing, we generated the first materials of thyroid cancer from patient to patient in Spain that can be found in our website [www.aecat.net](http://www.aecat.net). Last year we completed it with an active profile in social networks (Facebook, Twitter and Youtube) and especially with a blog that we update weekly with investigation or opinion articles as well as with the latest news that may interest patients with thyroid cancer.

In 2013, all this effort obtained an increase of the readers' fidelity and a total of 562,133 pages visited to a website exclusively focused in thyroid cancer, 384% more than in 2013. Visitors came not only from Spain but also from both South and North America.

In 2014, however, we wanted to take one step forward. In Spain there was barely any information available regarding a very rare type of thyroid carcinoma: medullary thyroid cancer. In fact, until very recently, this kind of cancer (whose incidence runs from 5 to 10% of the total thyroid cancer) didn't even have any approved treatment options.

From the Spanish Association of Thyroid Cancer (aecat) we wanted to fill the gap, and, through a groundbreaking initiative, we launched the campaign Five Voices to Understand Medullary Thyroid Cancer.

This campaign, available at <http://www.aecat.net/5-vozes-cancer-medular-de-tiroides/>, consists of six professional 5- to- 10- minute- long videos, two of them coming from patients and four from specialists in medullary thyroid cancer (endocrine, oncologist, surgeon and geneticist). We try to answer the most frequently asked questions and to emphasize the importance of a multidisciplinary approach in such diseases.

Made in a friendly and didactic format, the videos expect that those who are suffering this type of cancer can get the information they need in each stage of their illness. In this way, we not only guarantee the quality of the information but also highlight the importance of the patients' knowledge of details about their illness to be able to take part and have a voice in important decisions about their health.

As Cristina Chamorro, chairman of aecat, stated: "The patients of MTC feel stranded and vulnerable when they are diagnosed, due to the general lack of knowledge about the disease and especially because of the lack of official reference centres. Counting on both the advice of these great professionals and the

experience of other patients will contribute to their empowerment".

Some of the greatest specialists on the subject took part in the videos, such as Dr. Mercedes Robledo, head of the Group of Endocrine Hereditary Cancer in the National Centre of Oncologic Research (CNIO), Dr. José Ángel Díaz, senior to Endocrinology and Nutrition Service in the Hospital Clínico San Carlos of Madrid; Dr. Pablo Moreno, head of the Endocrine Surgery Unit in Hospital Universitario Bellvitge of Barcelona, and Dr. Enrique Grande, in charge of Oncologic

*(continued on page 23)*





# United Kingdom: Thyroid Eye Disease in the 21st Century

JANIS L. HICKEY, DIRECTOR OF BTF – MEMBER OF TEAMED

Newcastle upon Tyne – a centre of excellence for thyroid eye disease (TED) – hosted a two-day event in May that brought together leading European and British experts on TED. The event provided a unique opportunity for patients with TED, their families and carers, and members of the public to meet with the experts to find out about the latest advances and together be involved in discussions about the priorities for future research into TED. Medical students, consultant endocrinologists and ophthalmologists, sixth formers interested in a career in medicine, nurse specialists, optometrists and scientists were also invited to take part. Six patient representatives with TED were involved, including Janis Hickey and Peter Foley from the BTF, Gillian Barron and Sue Devine from TEDct, Sian Gray – a GP, and Peter Howe, who had been treated in Newcastle for TED. It was particularly appreciated that two TFI members made the journey to be involved in the event: Beate Bartès, Founder/Director of Vivre sans Thyroïde, France, and Dr Nancy Hord Patterson, who developed TED in 1987 and is founder of The Graves' Disease Foundation in the USA.

On day one students heard talks explaining endocrinology presented by experts in the field. They were then joined by patients and the public. A welcome address by Sir Leonard Fenwick, Chief Executive, Newcastle upon Tyne Hospitals NHS Foundation Trust, preceded a presentation by Dr Petros Perros, the main organiser of the event, about thyroid eye disease. Four fascinating talks followed about the unmet needs of patients with thyroid eye disease in which the patient representatives talked about the struggles they had faced and highlighted the improvements needed: Gillian Barron – My journey from developing an overactive thyroid to living with TED; Sue Devine – Double vision as an early symptom of TED; Sian Gray – GPs get TED too! and Peter Foley – Feedback as a BTF telephone contact for TED.

This was followed by a lively discussion involving medical professionals and patients in the audience. Medical professionals acknowledged patients' contributions to the success of the event and expressed concern over many aspects of information shared by patients.

The event was an opportunity for TEAMeD (Thyroid Eye Disease Amsterdam Implementation Group UK), of which BTF and TEDct are members, to distribute its Executive Summary Report, highlighting the work it has undertaken on TED since 2010 (see [www.btf-thyroid.org/index.php/campaigns/teamed](http://www.btf-thyroid.org/index.php/campaigns/teamed)). One aspect of TEAMeD's work is involvement in discussions about Commissioning of Specialised Services for TED. A session on Commissioning took place for medical professionals, chaired by Professor Geoffrey E Rose, BTF Trustee, in which the challenges of commissioning were presented and discussed. TEAMeD members gave presentations, Professor Colin Dayan – "Critical mass makes best service" – how many tertiary care centres should there be?', Dr Petros Perros – 'Is there any point in Combined Eye/Endocrine clinics when local physicians/eye doctors choose to ignore advice?' and Janis Hickey – 'Would patients realistically prefer local care (with its convenience) or tertiary care (with its greater experience)?'.

Day two comprised a seminar 'Of Eyes, Mice and Dice' sponsored by the Society for Endocrinology in which presentations took place from leading UK and European researchers on recent advances in: pathogenesis of TED; disease assessment; therapeutics; and, epidemiology, psychology and health economics, providing an insight into the fascinating studies that are taking place.

On both days break-out sessions took place. In 2012 priorities for TED research had been set in the Sight Loss and Vision Priority Setting Partnership, in which Janis Hickey, Peter Foley and Mr Dan Ezra, Consultant ophthalmic and oculoplastic surgeon at Moorfields Eye Hospital and member of TEAMeD had participated. These priorities were discussed in a breakout session on day one, the remit being to translate the priorities into specific research questions.

On day two the break-out sessions involved translating the research questions formulated on the previous day into study designs.

The meeting was a joint venture between the European Group on Graves' Orbitopathy (EUGOGO) and the Thyroid Eye Disease

*(continued on page 23)*



Patient testimonies at the Newcastle meeting (from left to right): Peter Foley, Gillian Barron, Sian Gray, Sue Devine.

Amsterdam Declaration Implementation Group UK (TEAMeD UK). The patient and public engagement component on the 16th May attracted 140 attendees of whom 54 were patients and public. The attendance on the 17th May was 132 and included delegates from a wide range of backgrounds (23 basic scientists, 78 consultants, 29 trainees and 8 patient representatives, managers, health service researchers, specialist nurses, orthoptists, psychologists, medical physicists), from 3 continents and 13 countries. One of the outcomes was the formulation of 6 major potential study proposals for basic and clinical research in this field, some of which will hopefully be taken further. There was a great sense of teamwork throughout the meeting and a desire for patients and professionals to build on the Newcastle experience and continue to work together. Feedback about the event has been positive with participants saying how helpful they had found the sharing of information to be.

In his closing remarks, Dr Perros thanked in particular the patient representatives for attending

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### Five Voices ... (continued from page 21)

Medical Service in Hospital Ramón y Cajal in Madrid; they are all professionals who have selflessly contributed in this project.

Through these interviews, the specialists explain not only the characteristics of this complex disease and the implications for the patient in each of its stages, but also the relevance of carrying out DNA screening to confirm or dismiss possible hereditary medular thyroid cancer cases, and the important role of surgery in this kind of tumor. Likewise, the important steps taken forward in the last years in thyroid cancer treatment can be seen. These advances go fundamentally through inhibitors of tyrosine kinase inhibitors, oral treatments which have entailed a revolution in the whole approach of this disease.

and said their involvement had greatly enhanced the quality of discussions.

Janis Hickey, a member of the event organising committee, said, 'We have Dr Perros to thank for his vision that patients with TED can make a positive contribution to such events. Working together with medical professionals and researchers to take matters forward and bring about improvements is a big step in the right direction. We are very grateful to Dr Perros for including us'.



*Barriers between health professionals and patients have always existed. Sometimes unfortunately they become impenetrable and a source of discontent, or even turn into a battleground. In most cases the culprit is poor communication. The optimistically predisposed will highlight a clear trend for more patient engagement, shared decision making encapsulated in the "no decision about me without me" moto, championed by the British National Health Service recently. However, beyond the rhetoric and political correctness, good examples of this philosophy are hard to come by.*

*The event in May 2014 in Newcastle was rather different from other meetings, because it set out to challenge the skeptics about the usefulness of engaging patients, their families and the public as equal partners. The outcome was the formulation of three proposals for clinical studies, an important foundation on which applications for funding can be built. At a personal level, the highlight was simply the presence of patients and their families in the proceedings, which inspired and motivated the audience. May 2014 was a landmark when a wall between patients with thyroid eye disease and professionals most emphatically came tumbling down, right here in Newcastle.*

PETROS PERROS  
CONSULTANT ENDOCRINOLOGIST, NEWCASTLE UPON TYNE UK  
PRESIDENT EUROPEAN GROUP ON GRAVES' ORBITOPATHY  
MEMBER OF TEAMeD

# TFI Member Organizations

## AUSTRALIA

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

## BELGIUM

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

## BRAZIL

*Instituto da Tiróide*  
Rua Artur Ramos, 96 – 5A  
01454-903 São Paulo, SP Brazil  
[medneto@uol.com.br](mailto:medneto@uol.com.br)  
[www.indatir.org.br](http://www.indatir.org.br)

## 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)

## DENMARK

*Thyreoidea Landsforeningen*  
Strandkrogen 4C  
3630 Jaegerspris, Denmark  
[www.thyreoidea.dk](http://www.thyreoidea.dk)  
[www.stofskifteforeningen.dk](http://www.stofskifteforeningen.dk)

## FINLAND

*Suomen Kilpirauhasliitto ry*  
Vilhonkatu 4 B  
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

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[thyroidhelp.in@gmail.com](mailto:thyroidhelp.in@gmail.com)  
[www.thyroidhelp.in](http://www.thyroidhelp.in)

## ITALY

*Associazione Italiana Basedowiani e Tiroidei*  
Borgo Felino, 3, 43100 Parma, Italy  
[www.aibat.it](http://www.aibat.it)

*ATTA-Lazio Onlus*  
Via Gregorio Ricci Curbastro n. 56  
00149 Roma, Italy  
[www.atta-lazio.it](http://www.atta-lazio.it)

## JAPAN

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## MEXICO

*Sociedad Mexicana de Nutricion*  
Zacatecas 230, Quinto Piso  
Colonia Roma, C.P. 06700  
México, D.F., México  
[www.tiroides.org](http://www.tiroides.org)

## THE NETHERLANDS

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

*Schildklier Organisaties Nederland*  
Stationsstraat 79G  
3811 MH Amersfoort  
The Netherlands  
[www.schildklier.nl](http://www.schildklier.nl)

## NORWAY

*Norsk Thyreoideaforbund*  
Fr. Nansens plass 9, NO-0160  
Oslo, Norway  
[post@stoffskifte.org](mailto:post@stoffskifte.org)  
[www.stoffskifte.org](http://www.stoffskifte.org)

## PORTUGAL

*Associação das Doenças da Tiróide*  
Rua Ricardo Jorge, 55 – 1º C  
4050-514 Porto  
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## RUSSIA

*Thyroid Foundation of St. Petersburg*  
“Professor” Medical Centre  
42 Chaykovsky Street  
St. Petersburg 191123, Russia  
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## SPAIN

*Asociación Española de Cáncer de Tiroides (AECAT)*  
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 KINGDOM

*British Thyroid Foundation*  
2nd floor, 3 Devonshire Place  
Harrogate HG1 4AA UK  
[www.btf-thyroid.org](http://www.btf-thyroid.org)

## UNITED STATES OF AMERICA

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



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