



# 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*

### Patrons

Patricia Bradley (USA)

Dr. Kazuo Hashimoto (Japan)

Prof/Dr med Peter Pfannenstiel (Germany)

### Mentor & First President

Lawrence C Wood, MD FACP (USA)



## Officers of the Association 2011 – 2012

### Executive Committee

Ashok Bhaseen (Canada), President

Ulla Slama (Finland), Vice-President

Yvonne Andersson-Lakwijk (Sweden), Treasurer

Beate Bartès (France), Secretary

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Geraldo Medeiros (Brazil)

Nancy Patterson (USA)

Harald Rimmele (Germany)

### Honorary Member

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June Rose-Beaty (Canada)

### Editors, ThyroWorld

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Ineke Bink (Netherlands)

### Medical Advisers

Dr. Elina Gasparyan (Russia)

Dr. Martin Schlumberger (France)

Professor Wilmar Wiersinga (The Netherlands)

### Conference Coordinators

Beate Bartès (France)

### Administrative Coordinator

Katherine Keen (Canada)

### Website Coordinators

Katherine Keen (Canada)

Harald Rimmele (Germany)

### Member Organizations

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

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Email: [tfi@thyroid-fed.org](mailto:tfi@thyroid-fed.org)

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

Website Coordinator: [info@thyroid-fed.org](mailto:info@thyroid-fed.org)

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## Editorial

Once more the scene of our annual TFI meeting has changed. After interesting Krakow we find ourselves based this year in beautiful Pisa. The editorial team that is happy to present this next issue of ThyroWorld also underwent change. Beate Bartès stayed on the team but Ulla Slama had to step down because of her pressing duties as a doctor in Finland. Ineke Bink from the Netherlands and member of the TFI Board since last year is replacing her. We thank Ulla for all the work she did as an editor the previous two years and her continuing efforts to lend a helping hand when needed.



*Beate Bartès*



*Ineke Bink*

ThyroWorld is there for our members, but not exclusively! We also want to reach the thyroid specialists in order to let them know what we are doing and what we are trying to achieve as TFI and as national thyroid organizations.

We therefore decided that ThyroWorld would alter its focus slightly. More so than before, the magazine concentrates on articles about the way TFI is promoting patient interests and representing the patient's perspective. It also zooms in on the activities of our member organizations such as how they chose to celebrate Thyroid Day and organize International Thyroid Awareness Week.

In addition we decided not to select articles on medical research any longer since medical specialists have their own sources for scientific information. For most of our members it is the same situation. They have access to medical information, but knowledge about the workings and activities of other member organizations is much harder to find.

Nevertheless, we may report on scientific research in some cases, such as when TFI became part of the advisory team in the TRUST study and when the research is about quality criteria from a patient's perspective. Both are good examples of representing patients' interests.

We, the editors, hope you'll find the adaptation of the format of ThyroWorld interesting and useful.

*Beate Bartès & Ineke Bink, editors*

## President's Message

Dear readers,

It has been one year since I was elected as the President of Thyroid Federation International; it has been a busy period with ETA in Krakow, Poland, followed by ATA at Indian Wells, CA, USA and several meetings and activities that lead us to 2012. I would like to pay tribute to both our Past President Yvonne Andersson-Lakwijk and founding President Dr Larry Wood and their teams for their dedicated service to TFI for a span of 8 years each.



Ashok Bhaseen

The 'world is flat today': the communication age has brought several countries to a level playing field. Today the information is available at your finger tips by clicking a few keys on your computer or phone device. In this era of electronic communication, we have to keep up with the pace and the insatiable need for information. However, it is the correct and professional information that needs to be provided as there is too much misinformation out there. This is something that TFI takes seriously and ensures that the right information is provided to the patients. TFI therefore keeps close contact with the professional bodies like ETA, AOTA, LATS and ATA who strive for the same values. As part of this endeavor, one of my mandates as the new President of TFI is to ensure that we provide better, quicker and accurate information to our member organizations and keep our website communication up to date.

From a broader perspective and reader's interest, the following are some priorities for TFI:

- Broaden our reach to patients in countries with no thyroid forums or organizations
- Iodine deficiency awareness
- Strengthen professional relationships with organizations like ETA, AOTA, LATS and ATA
- International Thyroid Awareness Week and recognition of World Thyroid Day
- Remain a credible international body for thyroid foundations across the globe
- Support and collaborate on professional programs on thyroid related initiatives for patients
- Strengthen our individual country organizations that are bona fide TFI members

- Support and advocate 'best practices' that are preventative to thyroid related issues

As a pharmacist by education and with managing a thyroid portfolio in the pharmaceutical field, I have been exposed to thyroid education in great depth; at the same time I have met many patients over the years. I have heard the personal sagas of numerous patients, some of them very unique. Some patients who have multiple issues along with their thyroid conditions can

be difficult to treat. Many are so inundated with information and promises of solutions on various websites that they depart from the professional path and turn to holistic options, which only worsens their condition. In my experience, our member organizations play a significant role in providing professional patient material that is useful to patients and that helps them get back to the professional and proven path of managing their thyroid issues.

Physicians and patients working together is important for successful outcomes. It is rare that endocrinologists and/or general practice physicians have personal thyroid issues and firsthand experience of the disease. Hence, listening to patients and consistently having a methodic way of going over all symptoms is crucial to providing the best care.

We have a very hardworking board at TFI whose members you have come to know over the years. We strive to make a difference in a person's life that is diagnosed with any thyroid related issues. Some of the readers may not be aware that we have several endocrinology professionals throughout the world that work with our member organizations and provide volunteer time for patients. TFI is made up of thyroid patients, thyroid specialized physicians and also family members who suffer from thyroid issues.

I would like to thank all of you who support and recognize TFI's efforts and look forward to seeing you again at the TFI AGM and ETA meeting at Pisa, ATA meeting in Québec, AOTA meeting in Bali ...

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

# TFI 17th Annual Meeting

AUTHOR: INEKE BINK  
NETHERLANDS, BOARD MEMBER TFI

## Krakow, Poland 2011

The 17th annual general TFI meeting took place in Krakow, Poland, September 9th last year. It preceded the next days' annual meeting of the European thyroid specialists, ETA. Eleven TFI members, including Board members and one honorary member, convened in the old part of the town in Hotel Polonia, where the majority of the members were lodged.

On the agenda were reports on past activities as well as on future plans. For one, the membership situation was discussed. The new Italian member (Atta-Lazio) was welcomed and members got an update on possible prospective members. The strategy regarding ThyroWorld was adjusted. Up to now, the magazine has been focussing on the TFI membership predominantly. In future, the medical practitioners will be an equally important target group. The Board reported on its promising fundraising activities, and on the ways TFI represented patient interests: organisation of the International Thyroid Week, TFI participation in the advisory committee of the TRUST study and in the steering committee of the Amsterdam Declaration about Graves Eye Disease. Members also agreed to increase TFI attendance at future ATA, LATS and AOTA meetings. The decision on the internal rules of the organisation, however, was postponed to the next annual meeting.



TFI booth at the ETA congress: Beate Bartès, Nancy Patterson, Ashok Bhaseen, Jytte Flamsholt, Larry Wood.

At the election of the new Board, Yvonne Andersson-Lakwijk from Sweden, having served as TFI president for 8 dedicated years, stepped down. She was succeeded by Ashok Bhaseen from Canada. In recognition of everything the TFI presidency achieved over the last years, the new president presented a commemorative plaque to her and to her predecessor and first president of TFI, Larry Wood.

The ETA congress next day continued up to and including September 14th. Like previous years it was very interesting, with many inspiring lectures on various thyroid topics, from Graves' disease and Hashimoto's to nodules, surgery, cancer and the consequences of the Fukushima accident. The now former TFI president Yvonne Andersson-Lakwijk gave a speech at the opening ceremony. TFI presented itself with a nice booth in the exposition area, which attracted a lot of visitors. The TFI magazine ThyroWorld was packed in every delegate's bag.

A patient meeting was organized by TFI with the support of ETA. There were two speakers: Professor Martin Schlumberger from the Institute Gustave Roussy, France, and a Polish psychologist, Anna Syska-Bielak from the Nuclear Medicine and



Plaques: left to right, Larry Wood (past president), Beate Bartès (secretary), Ashok Bhaseen (president), Yvonne Andersson-Lakwijk (past president), Ulla Slama (vice president)

(continued on page 5)

## TFI 17th Annual Meeting (continued from page 4)



AGM group picture: Left to right, sitting – Beate Bartès, Yvonne Andersson-Lakwijk, Ashok Bhaseen; standing: Jytte Flamsholt, Dominique Van Doorne, Nancy Patterson, Peter Lakwijk, Ulla Slama, Harald Rimmele, Ineke Bink, Larry Wood.

Endocrine Oncology Department in Gliwice, Poland. Professor Schlumberger spoke about thyroid cancer. Mrs. Syska-Bielak gave a talk on the psychological consequences of thyroid disease and thyroid cancer (with simultaneous English/Polish translation).

Next to good talks, interesting lectures and new contacts, there were nice walks through the beautiful and fascinating town of Krakow!



Yvonne Andersson-Lakwijk and Pr Martin Schlumberger during the patient conference

## Thank You!

We would like to thank everybody who made this year's issue of ThyroWorld possible, most particularly Katherine Keen, who corrected the language of all the non-native speakers among our authors, and Lynda Wegner who diligently and patiently took care of the layout.

## Upcoming Events

### September 19-23, 2012

82nd Annual Meeting of the ATA  
Québec, Canada  
[www.thyroid.org/ann\\_mtg/2012\\_82nd](http://www.thyroid.org/ann_mtg/2012_82nd)



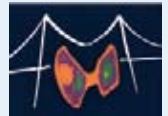
### October 21-24, 2012

10th Asia and Oceania Thyroid Association Congress  
Bali, Indonesia  
<http://aota2012.com>



### March 20-23, 2013

15th Latin American Thyroid Congress of the LATS, Latin American Thyroid Society  
Florianopolis, Brazil  
<http://www.lats2013.com.br/>



### May 20-26, 2013

5th International Thyroid Awareness Week  
[www.thyroidweek.com](http://www.thyroidweek.com)



### May 25th, 2013

World Thyroid Day



### July 10 - 14, 2013

2nd World Congress on Thyroid Cancer  
Toronto, Canada  
<http://thyroidworldcongress.com>



### September 7 to 11, 2013

37th annual meeting of the European Thyroid Association  
Leiden, Netherlands  
[www.eurothyroid.com](http://www.eurothyroid.com)  
TFI – 19th Annual Meeting



### September 6, 2013

19th Annual Meeting of Thyroid Federation International  
Leiden, Netherlands



*in conjunction with the 37th ETA Congress*

# The History of World Thyroid Day and International Thyroid Awareness Week

AUTHOR: BÉATE BARTÈS  
FRANCE, TFI SECRETARY

During their AGM prior to the ETA congress in Leipzig, Germany, in September 2007, the members of Thyroid Federation International decided to create a “World Thyroid Day”. They chose the date of May 25th (where there is already a national thyroid awareness day in some Scandinavian countries). During the ETA congress, they put a poster on their booth: “May 25th is World Thyroid Day”. Shortly afterwards, they created a logo, and decided that the first WTD would be celebrated in 2008.



It was also decided to send an application to the UN, to have May 25th put on the list of “World... days” – but due to administrative problems regarding the registration of TFI in Canada, this request was not accepted.

In their newsletter published in March 2008, the ETA announced the first “European Thyroid Day” on May 25th, 2008. At the same time, the date of May 25th celebrates the creation of the ETA (created on May 25th, 1965, who celebrated it’s 40th anniversary on May 25th, 2005).

## European THYROID DAY – May 25th

*May 25th has been designated as the anniversary of the European Thyroid Association, founded in Rome, May 25th, 1965, and in 2005 the ETA celebrated at the Jubilee Meeting in Athens, 40 years of excellence in clinical and experimental research.*

*We therefore propose the designation of May 25th as European Thyroid Day in the context of a number of several international efforts to implement a World Thyroid Day.*

*We strongly encourage all nationally or regionally based thyroid groups and networks in Europe to*

*organise meetings on May 25th with the public, patients and media, in order to draw attention to thyroid-related problems and increase the visibility of the ETA.*

*The ETA Public Affairs Board, March 2008*

In 2009, the ETA created a special logo:



## The Logo of the European Thyroid Day – 25th May

*On the occasion of the European Thyroid Day, the Public Affairs Board of the ETA has produced in Athens a logo with the aim of increasing visibility and requesting the active participation of all who are involved in clinical and experimental thyroidology, sure of their continued commitment and dedication to all our thyroid patients.*

*We sincerely hope that the logo is to your liking and trust that it will offer additional inspiration to us for the celebration of this special day, one that hopefully will further stimulate both political and public interest in thyroid disease, the most common endocrine disease worldwide, while simultaneously promoting the ETA.*

*Leonidas Duntas, on behalf of the Public Affairs Board*

ETA and ATA then decided to name the event “World Thyroid Day”, instead of “European Thyroid Day”.

*ATA press statement, 2010: <http://www.newswise.com/articles/american-thyroid-association-supports-world-thyroid-day>*

*“Newswise – The American Thyroid Association, in cooperation with its sister associations the world over, supports World Thyroid Day, May 25, 2010, marking it as a day to promote awareness and understanding of thyroid health and the advances made in treating thyroid diseases.*

*(continued on page 7)*

## History (continued from page 6)

World Thyroid Day was established in 2008 as part of a campaign led by the European Thyroid Association ([www.eurothyroid.com](http://www.eurothyroid.com)) and the American Thyroid Association ([www.thyroid.org](http://www.thyroid.org)) to emphasize the prevalence of thyroid diseases, to focus on the urgent need for education and prevention programs and to increase awareness of new treatment modalities."

ATA press statement, 2011: <http://www.worldthyroidday.com/about.htm>

### "ABOUT WORLD THYROID DAY

(Press release from the American Thyroid Association) – The American Thyroid Association, in cooperation with sister international thyroid societies, the European Thyroid Association, the Asia & Oceania Thyroid Association, and the Latin American Thyroid Society recognizes the 4th Annual World Thyroid Day, May 25, 2011.

Established in 2008, World Thyroid Day highlights five major goals to:

- Increase awareness of thyroid health
- Promote understanding of advances made in treating thyroid diseases,
- Emphasize the prevalence of thyroid diseases,
- Focus on the urgent need for education and prevention programs, and
- Expand awareness of new treatment modalities.

ETA press statement, 2010: [http://www.eurothyroid.com/admin/dc\\_media/WTD\\_2010doc\\_2\\_.pdf](http://www.eurothyroid.com/admin/dc_media/WTD_2010doc_2_.pdf)

ETA press statement, 2011: [http://www.eurothyroid.com/admin/dc\\_media/WTD\\_\\_2011.pdf](http://www.eurothyroid.com/admin/dc_media/WTD__2011.pdf)

The ETA press statements mention the International Thyroid Awareness Week, created by TFI.



WTD at indoor market place in Vasa, Finland



## Creation of the ITAW

In 2008, TFI started to discuss with Merck-Serono, about the creation of an entire "International Thyroid Awareness Week" – it was decided to have this in May, during the week around World Thyroid Day.

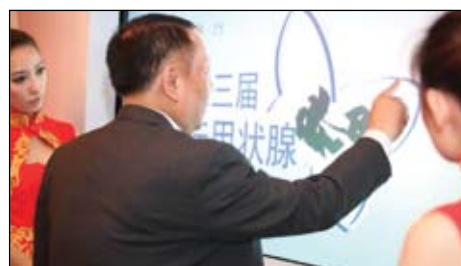
This was announced during a press conference at the 11th European Congress of Endocrinology Istanbul in March 2009.

The first International Thyroid Awareness Week took place in May 2009 (25th to 31st).

A website in 7 languages (Arabic, English, French, German, Greek, Portuguese, Spanish; Chinese, Russian and Turkish were added later) was created, [www.thyroidweek.com](http://www.thyroidweek.com) – each year, a special thyroid issue is put forward (in 2010, "Pregnancy/ children", in 2011 "Nodules and goiter"), with downloadable brochures, posters, videos etc, and all documents remain visible on the website (updated every year).

The campaign is endorsed by the European Thyroid Association (ETA), the American Thyroid Association (ATA), the Asia and Oceania Association (AOTA), the Latin-American Thyroid Society (LATS), the Chinese Society of Endocrinology (CSE), the Chinese Society of Nuclear Medicine (CSNM) and the World Thyroid Association

In 2012, the ITAW took place from May 21st to 27th, and the subjects were "Iodine deficiency" and "Thyroid and heart". 27 countries participated, and the website had visitors from more than 200 different countries".



World Thyroid Day in China

# Italian Thyroid Patients' organizations join together in a World Thyroid Awareness Week Committee

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

**F**or the first time in Italy, 10 Thyroid Patients' Organizations joined together in a Italian World Thyroid Awareness Week committee with President, Paola Polano and Vice President Anna Maria Biancifiori. Both were invited to join the central organizing committee together with Prof. Aldo Pinchera and the representatives of all the scientific societies involved.

"Thyroid is female- Thyroid and pregnancy" was the Italian 2012 Awareness Week theme, where endocrinologists and gynecologists worked together, emphasizing the importance of thyroid function during pregnancy. A questionnaire and a brochure were distributed in all participating endocrinology and gynaecology outpatients clinics to inform women and evaluate their knowledge on the topic.

135 different events were organized all over Italy (this number doubled from 2011). Patient forums, thyroid screenings in pregnant women with risk factors for thyroid disease, and several information points in major cities were set up to expand public opinion and increase the awareness of thyroid diseases.

On May 23rd a meeting was held at the Ministry of Health in Rome which included all the scientific societies involved in the Thyroid Awareness Week, together with prestigious health authorities and the Patients' Organizations representative, Paola Polano. Italy's Health Minister Mr. Balduzzi declared his intention to adopt further measures to decrease Italian iodine deficiency and underlined the importance of the Patients' Organizations campaigns for iodine deficiency. The iodized salt sales increase each year but Italy is far from its goal. Presently, only 60% of Italians are buying iodized salt .

It is important and interesting that this was the first time a patients' organizations representative participated at a meeting at the

Ministry of Health with all the authorities and endocrinologists. Ms. Paola Polano's presence to the debate was highly appreciated by all the speakers present.

We hope that the 2012 Patients' Organizations Committee will be the first step towards an Italian Thyroid Federation. It is our strong belief that the Federation is essential for its representative central role before Health Authorities.

A thought for next year: May 25 is not the best date for the Italian Awareness Week due to the nice and warm weather attraction (and the call to the beaches). But more so, because there is an overlapping of other disease awareness events which does not place enough press attention to thyroid problems. Next Committee/Federation may want to change this date.



**Among Italian Patients Organizations, ATTA-Lazio ONLUS is rather young (created in 2006) and joined TFI in 2011.**

**AIBAT is one of the oldest organizations (born before 2000) and the first Italian organization to join TFI.**

**We welcome the newborn ATTA3Veneto and hope to see new organizations in Italian regions still missing patients organizations.**



# Greetings from The Australian Thyroid Foundation



The Australian Thyroid Foundation Ltd

AUTHOR: BEVERLEY GARSIDE

PRESIDENT – THE AUSTRALIAN THYROID FOUNDATION

2012 has been a very interesting year for The Australian Thyroid Foundation (ATF). Existing sponsors of the organisation have continued to be loyal, which has enabled awareness messaging to be promoted in the community and the profile of the organisation continued to be raised. It has also enabled the ATF to improve member services, with more opportunities for members to connect and receive education.

The new ATF website [www.thyroidfoundation.com.au](http://www.thyroidfoundation.com.au) attracts most of our new members and provides a full Member Section which includes all ATF educational material. It allows visitors to join online, make purchases from our online shop and learn about the benefits of membership of the organisation.

The ATF Awareness Campaigns for 2012 have changed slightly from previous organised dates and events:

Mother's Day - 13th May, awareness for mothers to be. This message promotes the importance to have their thyroid tested to protect themselves from developing an unsuspected thyroid disorder during pregnancy which therefore will protect the foetus' brain development. Without enough thyroid hormone, the safety of the pregnancy and the brain development of the newborn can be impaired. Future generations of young Australians should be given the opportunity to reach their intended IQ without it being compromised due to lack of awareness.

The ATF's Thyroid Awareness Week date has been changed from 1 – 7 June, to align with the International Thyroid Awareness Week 21 – 26 May. This week will also focus on the importance of the newborn. The ATF message for this week - Iodine Deficiency in Australia: Are we winning the battle against it? At least 50-70% of Australian pregnant women are iodine deficient, which is alarming, and awareness of this statistic will be promoted to ensure this silent epidemic is addressed through a pregnancy supplement including 150 mcgs of iodine.

World Thyroid Day - 25th May will be recognised in Australia through the ATF.

Promotion of the importance of national awareness of recognising thyroid disorders, through testing, diagnosis and treatments, will ensure a strong message is developed for this day, to ensure Australians enjoy Good Thyroid Health.

Gold Bow Day - 1st September promotes the importance of awareness of thyroid cancer. As thyroid cancer research in Australia states 84% more women and 40% more men are diagnosed with thyroid cancer, this messaging is highly important. The ATF sell Gold Bow badges, the symbol of the organisation. All money raised from the sale of Gold Bows goes directly to improving Radio Active Iodine Treatment Rooms in public hospitals around Australia. The improvements consist of entertainment units, new furniture and inclusions that make the confinement and isolation more bearable for patients, during their stay, whilst undergoing radiation treatment. The ATF has completed two rooms and is currently organising another two rooms to be completed.

The ATF Big Breakfast/Brunch - 23rd October, is a day when the community, workplaces and families can get together and learn about the importance of Good Thyroid Health. It gives Australians the opportunities to enjoy a breakfast or brunch, made with iodine enriched food and also enjoy each other's company. Money raised from raffles, door prizes etc. on the day, is donated to the ATF to support the work of the organisation.

As an organisation, the ATF is gaining strength throughout Australia, with sponsors, thyroid education and awareness and, slowly, GP's and endocrinologists becoming aware of the benefits for patients to belong to the ATF.

The ATF Medical Advisors give their time to support the ATF, speak at events and on the organisation's behalf. Medical Advisors also write articles for the ATF newsletter 'Thyroid News' which is a quarterly newsletter for members and supporters of the organisation.

Very recently, a State Politician, Mr. Bryan Doyle gave his support to his local ATF Member's Meeting Group and also organised a morning tea at Parliament House in Sydney, for the ATF to be presented to other state politicians.

*(continued on page 10)*

## Greetings from The Australian Thyroid Foundation (continued from page 9)

This was a wonderful opportunity for the organisation to gain government recognition. From this day, Bryan believes, a pebble and ripple effect will begin with politicians, with the organisation and its public messaging being recognised and supported by governments. Mr. Doyle has accepted an invitation to be nominated as an Ambassador for the ATF.

As thyroxine brands in Australia, Oroxine and Eutroxig have to be kept refrigerated at all times, the Australian manufacture of the medications, Sigma Pharmaceuticals/Aspen sponsor ATF Medication Travel Packs. These packs give Australian thyroid patients the confidence of travelling with their medication and knowing it

will stay cool while they are away from home and a refrigerator. The ATF sell these packs via the ATF website and also through the organisation.

The ATF will be represented at the AOTA Meeting in Bali – October 2012. As President, I will join other Thyroid Federation International (TFI) members from around the world to promote the benefits of this worldwide organisation and encourage AOTA members and others to work with their patients and communities to begin their own thyroid patient organisation, with the support of Thyroid Federation International.

The ATF look forward to continuing its support, education and awareness programs throughout the coming year.

## INTERNATIONAL THYROID AWARENESS WEEK

# Denmark: more than 2000 hours of Thyroid Information



**THYREOIDEA**  
LANDSFORENINGEN  
FORENINGEN FOR  
STOFKIFTEPATIENTER

AUTHOR: BENTE JULIE LASSERRE  
DENMARK, TFI REPRESENTATIVE

**D**uring the International Thyroid Awareness Week in May 2012 the Danish patients organization, Thyreoidea Landsforeningen, arranged a "Thyroid Day" with a big whole-day conference at Aarhus University Hospital.

As usual we had very good cooperation with the Danish thyroid doctors and they were excellent speakers during a very interesting program. Professor dr. med. Laszlo Hegedüs had agreed to be the compere and he guided the more than 300 patients during about 7 hours with 6 different specialists speaking about different aspects of thyroid disease. That is more than 2000 hours of thyroid information to patients! The subjects were as different as iodine, weight problems, pregnancy, quality of life, T4 effects and side effects and news from the future. Very interesting subject that also lead to many questions from the patients.

For a relatively small organization as Thyreoidea Landsforeningen consisting of only volunteers as board members, such a day includes a lot of work but we wanted to do something special to emphasize the importance of thyroid disease and to give as much information to patients as possible.

Afterwards we had very positive feedback both from the patients and the doctors and we hope that it will be possible to do something similar again.



### HAR DU STYR PÅ DIT STOFKIFTE?

Torsdag på Aarhus Universitetshospital, Skejby Auditorium A, indgang 6, stuen  
Bredstrømsgade 100, 8000 Aarhus N  
Onsdag den 23. maj 2012 kl. 9.30-17.00

**PROGRAM**

9.30-10.30 **REGISTRERING**  
Kaffe og croissant

10.30-10.45 **ÅBNING AF KONFERENCEN**  
Thyreoidea Landsforeningen - Foreningen for stofskiftepatienter

10.30-10.45 **DAGENS PROGRAM**  
Overblik over de forskellige sygdomme, deres årsager og behandling. Efter hvert indlæg er der væk åbent for spørgsmål til oplægsholderne

10.45-11.00 **SALT OG STOFKIFTE**  
Svend Erik Jensen, Thyreoidea Landsforeningen, Odense Universitetshospital  
Hvad er salt, hvad er jod og hvad har med sagen at gøre?

11.00-11.15 **THYREOIDEAFUNKTION OG VÆGT**  
Henrik Høegh, Thyreoidea Landsforeningen, Odense Universitetshospital  
Hvordan kan jeg være for tyk eller for tynd?

11.15-11.30 **PROGNOSE**  
Forebyggelse med et eller værd

11.30-11.45 **THYREOIDEAFUNKTION OG GRAVITÆT**  
Overblik over de forskellige sygdomme, deres årsager og behandling. Efter hvert indlæg er der væk åbent for spørgsmål til oplægsholderne

11.45-12.00 **STOFKIFTE OG LIVSKVALITETEN**  
Overblik over de forskellige sygdomme, deres årsager og behandling. Efter hvert indlæg er der væk åbent for spørgsmål til oplægsholderne

12.00-12.15 **STOFKIFTEINFORMATION OG SVØRNINGEN**  
Overblik over de forskellige sygdomme, deres årsager og behandling. Efter hvert indlæg er der væk åbent for spørgsmål til oplægsholderne

12.15-12.30 **PAUSE**  
Kaffe og kage

12.30-12.45 **HVORDI BRINGER FREMTIDEN**  
Overblik over de forskellige sygdomme, deres årsager og behandling. Efter hvert indlæg er der væk åbent for spørgsmål til oplægsholderne

12.45-13.00 **PANDELEDET**  
De vigtigste symptomer og tegn på et opkommende problem

Konferencen er gratis for medlemmer i alle lande samt pårørende og andre interesserede.

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- Symptomerne kan være meget diffuse og misde om for såvel på stress
- Lægen kan kontrollere stofskiftet med en blodprøve
- Sygdommen rammer kvinder langt oftere end mænd

• Overblik over Thyreoidea og stof og betydning af jodforbruget. Det er den kirtel, som styrer stofskiftet

• Læs mere om stofskiftesygdomme på Stofskifteforeningen.dk

Der tages forbehold for ændringer.



# Thyroid Awareness Week in Brazil

AUTHOR: GERALDO MEDEIROS-NETO, MD  
PRESIDENT, INSTITUTO DA TIRÓIDE

*The "Instituto da Tiróide" organizes an International Meeting on May 25-27, 2012, in São Paulo, Brazil.*

**D**uring the Thyroid Awareness Week (May 25-27, 2012), an international meeting on Neonatal Screening for Congenital Hypothyroidism was organized by the "Instituto da Tiróide" at the Panamby Hotel, in São Paulo. Brazil has a centralized and well-organized national Screening Program for Neonatal Disorders (PNTN).



*A view of the Meeting main room with representatives of every State Regional Neonatal Center, as well as representatives of Argentina, Bolivia and Chile.*

In each of the 27 States and in the Federal District of Brasília, a multidisciplinary team is responsible for Neonatal Screening of all newborns alive. In a large and continental country like Brazil, the average number of live newborns is, approximately 2.8 million per year. In order to compare Brazil with other countries in South America, we invited Gustavo Borrajo and Ana Chiesa from Argentina, Virginia Perez from Chile and Alvaro Aguirre from Bolivia.

Dr. Borrajo delivered an excellent overview of Newborn Screening programs in South America, comparing the National Budget for Health expenditures and coverage for neonatal disorders. Dr. Chiesa

indicated that Neonatal Screening in Argentina is not centralized by a Federal Agency but every Province has its own Neonatal Program.

The situation is quite different in Chile, reported Virginia Perez, where a Central laboratory receives all local blood tests in filter paper and is responsible for the expedition of results and confirmatory tests as well. Most affected newborns are followed up in the large Hospital San Juan de Dios in Santiago de Chile.

The Neonatal Screening testing is barely performed in Bolivia according to Dr. Aguirre. Only since 2010, have some Provinces and Regional Hospitals been prepared for testing for Congenital Hypothyroidism. Thus, as far as South America is concerned, Neonatal Screening may be quite effective (as in Chile and Brazil), but lack of a Central Agency to coordinate the Regional programs for Neonatal Screening may affect the efficiency of the Program in Argentina.

Going back to Brazil, the country has been divided in five macro regions:

1. North: Amazon, Rondonia, Acre, Para, Roraima, Amapa, Tocantins
2. Northeast: Alagoas, Bahia, Ceará, Pernambuco, Maranhão, Paraíba, Piauí, Rio Grande do Norte, Sergipe.

*(continued on page 12)*



*Prof. Medeiros-Neto addressing the attendants to the Seminar on "Congenital Hypothyroidism Neonatal Screening in Brazil and south America (May 25-27, 2012)*

## Thyroid Awareness Week in Brazil (continued from page 11)

3. Southeast: Espírito Santo, Minas Gerais, Rio de Janeiro, São Paulo
4. Central west: Brasília, Goiás, Mato Grosso, Mato Grosso do Sul
5. South: Paraná, Santa Catarina, Rio Grande do Sul.

Two or more representatives from each State (as detailed above) were invited to participate in the Seminar, bringing their own experience concerning coverage of the newborn population for the first spot test (filter paper), here called “the little foot test” because of the puncture of the newborn heel between the 2nd and the 7th days after birth.

In most State centers, the cut-off for the TSH values is 10 mUI/L although there is a strong tendency to lower this cut-off value to 6 mUI/L (spot TSH value).

In three regions (South, Southeast, Central west) 89 to 100% of all newborns were screened for Congenital Hypothyroidism (CH) as well as for other disorders.

In the North and Northeast region, however, the coverage was below 80% due to many adverse factors. For example, in the Amazon State, the main transport system is solely by waterways (rivers) and most of the population lives at the margins of the many tributaries of the Amazon River. Pregnant women will travel by boat to a main Hospital near the State Capital and 48h after the baby is born, mother and child go up the river to join their families. To find a child tested positive of CH is a challenging job. Moreover, mother and child must travel back to the Hospital for confirmation of the diagnosis of CH and this may take 5-10 days down the Amazon River. Thus



*Prof. Geraldo Medeiros-Neto with Dr. Paulo Cesar Silva from the Reference Center for Neonatal Screening of Santa Catarina State.*

neonatal screening in the North of Brazil is quite difficult due to geographic conditions and worse during the rainy season.

In the Northeast, the situation is also quite challenging due to the fact that this region, periodically, has long periods of lack of rain and drought that could be as long as 5-10 months. Therefore, the population basically depends on familial agriculture for subsistence. Most people will migrate to larger cities where food and water will be provided. A number of newborns will never be tested at local village Health Centers. In the Meeting in São Paulo a solution for common problems of the North and Northeast regions of Brazil was proposed. The idea is to have in most villages of these regions a trained group of doctors, nurses and social workers to perform locally the neonatal screening testing, followed by a confirmation test if there is a suspicion for neonatal disease. If confirmed, for instance Congenital Hypothyroidism, L-Thyroxine could be started immediately, avoiding the well-known neurological damage of neonatal hypothyroidism. The local team would receive a week's brush-up training course every year to keep information and skills at the desired level.

The meeting in São Paulo was considered to be an excellent source of new ideas, new information, exchange of experience in the field and enthusiasm for conducting a better screening program. A document with several suggestions was prepared to be sent to the Health Authorities in Brasília, and signed by representatives of all Regions of Brazil.



*Professor Ricardo Meirelles, former President of the Brazilian Endocrine Society.*

# TRUST Study Update

AUTHOR: YVONNE ANDERSSON-LAKWIJK  
SWEDEN, HONORARY MEMBER TFI

**T**he TRUST study concerns Thyroid hormone Replacement for Untreated older adults with Subclinical hypothyroidism. Mrs. Yvonne Andersson-Lakwijk, who is reporting, is the TFI representative since last year.

I was never aware of all the paperwork that was involved in a scientific study. In order to write down what you want to study, how you want to do it and how to report about it, many pages must be written. For getting support of the EU even more paperwork has to be done.

Therefore I want to acknowledge and thank the people involved for their work that was done to:

1. get this study approved with all the paperwork involved and legal issues;
2. get the practicalities around logistics in four different countries;
3. solve the problems of all the country variations.

After the granting of support by the EU, the TRUST study started last year in November with a first general meeting in Glasgow.

This meeting was mainly aimed at getting to know each other and to put the basic structure together for the study. I gave a presentation about the goals of TFI and the activities of TFI and our members. It turned into a lively discussion on the purpose of the patient associations and how they can benefit the study. I felt the support from the others that TFI's involvement is important for the study.

In January the second meeting was in Cork (Ireland) where we discussed the setup of the study, many practical things and the supply of medication.

In June the meeting was in Leiden (Netherlands). We were introduced to the representative of the EU, who is responsible for the correct use of the support that is given by the EU: For this support the involvement of the patients by TFI was crucial.

We again had a discussion about the starting dosage. This issue already came up



in Glasgow and Cork, due to the worries and hesitations from the GPs and TFI to start patients on 50 mg. The original proposal for the study was to start with a dosage of 50 mg Levothyroxine for all patients.

Although there seems to be no evidence, we think that it is better for some to start more slowly. In the Dutch guidelines for GPs it says that the elderly should be started with 12.5 mg. For TFI this is one of the main issues that has to be solved in the best way for the patients. Following much further discussion by the study team it has been proposed to reduce the starting dose of levothyroxine to 25 mg for patients with low weight (<50 kg) or heart disease. This proposal will be subject to further ethical review.

TFI gave a lot of input for the patient information, but most of this cannot be used in the way it is given, in order to be able to follow the national rules of providing information to patients with medical studies.

It is expected that in September the recruiting of patients can start and the study itself in January. The next meeting will take place in October in Bern, Switzerland.

I will keep you all informed through these articles in ThyroWorld and on the TFI website.

The website of the TRUST trial is <http://www.trustthyroidtrial.com/>

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*TRUST is a new research project from five European universities investigating current treatment practices for people who suffer from a mildly underactive thyroid gland. The study is entitled Thyroid Hormone Replacement for Subclinical Hypo-Thyroidism Trial (TRUST).*

*Experts in ageing, thyroid problems and vascular disease from around Europe, work together in the TRUST project:*

*Leyden Academy on Vitality and Ageing, The Netherlands*

*Leiden University Medical Centre, The Netherlands*

*Universität Bern, Switzerland*

*University College Cork, Ireland*

*University of Glasgow, Scotland*

# Quality criteria from a patient's perspective

AUTHORS: JOKE VAN GALEN, NETHERLANDS  
THYROID FOUNDATION & NIKO DE JONG,  
DUTCH ASSOCIATION FOR GRAVES PATIENTS

**T**wo Dutch Thyroid organisations – Schildklierstichting Nederland (Netherlands Thyroid Foundation) (SN) and the Nederlandse Vereniging van Graves Patiënten (Dutch Association for Graves Patients) (NVGP) – started a project in 2009 called “Goud in Handen” (The Golden Nuggets of Knowledge). The project's objective was to develop quality criteria for the treatment of thyroid disorders from a patient's perspective. The results surpassed all expectations.

A booklet is now available describing eight quality criteria from a patient's perspective, and with specific statements about what patients consider to be good quality care. This booklet can be seen as the “golden nugget of knowledge” that the patient organisations now possess.

The criteria are as follows:

1. Diagnosis
  - a) All people with ‘vague symptoms’ are tested for a thyroid disorder.
  - b) All women who, after a pregnancy or in their menopause, consult their GP with ‘vague symptoms’ are tested for a thyroid disorder.
  - c) Awareness with regard to thyroid disorders is increased so that people can alert the GP at an earlier stage.
  - d) Primary care practitioners follow proven and regular refresher courses regarding thyroid disorders.
2. Treatment
  - a) The patient receives up-to-date information regarding his/her disorder and treatment options.
  - b) Not only the blood values, but also the perceived complaints play a central role in the treatment.
  - c) The patient and his or her quality of life play a central role and it is included in the treatment plan.
  - d) After the diagnosis, people with hyperthyroidism will be sent immediately



Board members and TFI representative receive booklet on Quality Criteria.

to the internist-endocrinologist for treatment.

- e) If there are any further complaints concerning hypothyroidism, the patient is referred to an internist-endocrinologist.
3. Easily accessible psychosocial assistance
    - a) Thyroid patients may benefit from easily accessible psychosocial assistance, for example through:
      - a specialised endocrinology nurse-practitioner or thyroid nurse
      - A (medical) clinical psychologist or health psychologist
    - b) Thyroid patients are reminded of the usefulness of companions in adversity in the accepting and coping.
    - c) Partners can be involved in the patient's (psychosocial) treatment, if requested.
  4. Pregnancy
    - a) Female thyroid patients with an active desire for children (or pregnancy) are referred to an internist-endocrinologist. The women are given the relevant information upon diagnosis.
    - b) The maternity team (gynaecologist or midwife) take on the responsibility during pregnancy and childbirth to monitor and help the thyroid patient and her (unborn) child, with the help of the internist or endocrinologist.
    - c) In the event of two successive spontaneous miscarriages, a woman's thyroid is examined by means of a blood test.
    - d) During the first year after giving birth, explicit questions are asked with regard to symptoms of fatigue and depression, and if these symptoms are present, the thyroid is checked by means of a blood test.
  5. Treatment with radioactive iodine
    - a) After having been informed, the patient is given the opportunity to consent to treatment with radioactive iodine, and the pros and cons of treatment or no treatment are pointed out by the practitioner.

(continued on page 15)

## Quality criteria from a patient's perspective (continued from page 14)

- b) Prior to treatment with radioactive iodine, the patient is informed about the course of events and the regimen.
  - c) The doctor or supervisor actively asks the patient how he/she will apply the regimen at home.
6. Thyroid cancer and surgery
- a) Thyroid surgery takes place in a specialised treatment centre with multi disciplinary collaboration.
  - b) In such cases, a volume control setting is established for thyroid surgery, the follow-up and Tg levels.
7. Graves' eye disease
- a) Patients with Graves' eye disease are given up-to-date information and advice on realistic expectations regarding recovery.
  - b) Patients with Graves' eye disease are treated in a specialised treatment centre whereby:
    - Various specialisms are synchronised during the consultations;
    - There is one leading practitioner and the patients know who it is;
    - The patient's time is taken into as much consideration as possible (as many examinations in one day as possible);
    - The quality of life plays a central role.
8. Companions in adversity
- a) The existence of patient organisations is pointed out to the patients, and what they can do to help.
  - b) Doctors and patient organisations can collaborate regionally to provide information.

The information was collected from nine focus groups that had been set up throughout the whole country. The reaction of the members and donators of the two organisations to the invitation to participate in the focus groups was massive; much more than required for the survey. It proved that there is a great need for the recognition of hands-on knowledge amongst thyroid patients. The information obtained by the focus groups resulted in a great report. Each experience told is a pearl on its own. These stories impressed the professionals greatly.

The feedback group (comprised of medical professionals) and the expert group (the hands-on experts from the patient organisations) derived the operational quality criteria under the inspiring supervision of the supporting agency, whereby, needless to say, the expert group had the last say.

It is worth mentioning the great effort made by the many patients who contributed towards the survey.

The contact that was experienced amongst the companions in adversity during the meetings resulted in the thyroid organisations' decision to introduce their regional volunteers to the way the meetings were held. This took place during a series of additional discussion group meetings that were organised to honour those patients whose application for participation in the regular focus groups had not been met. Thus, the way the meetings were held was passed on to the volunteers. In some regions, the existing contact between companions in adversity has transformed into "knowledge cafés". Thus, thyroid organisations continue to deploy the knowledge from experience gained effectively and they maintain the hands-on expertise of their volunteers in order to be able to utilise it in all contacts.

With the publication of this great booklet, the "digging for golden nuggets of knowledge" has not ceased, quite the contrary!

The next nugget is applying the criteria in daily practice, in collaboration with the medical professionals and the experts with hands-on experience. The idea is for the patient to start using the criteria for his/her self-management in order for the patient to regain control over his/her own life. The criteria can also be used to assess the plans for starting a thyroid outpatient clinic. The practitioners will be approached directly with this set of criteria. Newly diagnosed people will be informed about the criteria via our volunteers, and with it, the treatment options so that they know what to expect from the practitioners. They are also taught to provide the practitioner with feedback; this will result in treatment that is more effective. All in all, this will lead to the improvement of the quality of medical care in our country.

New research topics will arise: one thing sets something else in motion and in fact forms the beginning of a new perspective for practitioners, science and patients, together. The fact that the Netherlands Thyroid Foundation and the Association for Graves' Patients are celebrating their 25th anniversary in 2012 cannot be coincidence. Even if there were any doubts, the organisations have proven with this project the value of patient organisations, and they would like to face the future, in collaboration with other thyroid organisations, with even better quality for all thyroid patients.

# An Education Course of the European Thyroid Association

## Following the pathways of Hippocrates in Kos

AUTHOR: PROF. LEONIDAS DUNTAS

MEMBER OF THE EDUCATIONAL BOARD OF THE ETA

The Educational Course of the European Thyroid Association 2012 was held on 24 - 26 May 2012 on the Greek island of Kos, the island of the ancient Greek god Asclepius, of his daughter Hygeia (Hygeia), the goddess of good Health, and of Hippocrates the father of modern medicine. The meeting, which took place in the midst of an outstandingly beautiful environment, was a highly interesting and successful event, crowned by the commemoration of the centennial of Hashimoto's thyroiditis (1912-2012), and the celebration of 25th of May, World Thyroid Day.

Prof. Peter Smyth (Dublin), chairman of the Archives Board of the ETA, introduced Prof. Yuji Hiromatsu (Fukuoka) who offered a fascinating outline of the life and the scientific pathway of Prof. Hakaru Hashimoto who first described autoimmune thyroiditis (AIT). The presentation was backed by a film kindly provided by Dr Slama showing aspects of the private life of H. Hashimoto.

AIT has been attributed to a complex interaction between genetic and environmental factors whose precise mechanism remains to be fully elucidated.

The meeting started with informative presentations by Prof. Luca Chiovato (Pavia) and Prof. Jean Louis Wemeau (Lilles), who have extensively analyzed the pathogenesis of AIT, the most common thyroid disease in large parts of the world today: they emphasized that AIT may often be presented as part of the

polyglandular syndrome which is characterized by the association of two or more organ specific endocrinopathies and non-endocrine autoimmune diseases.

Prof. Josef Koehrlé (Berlin) very eloquently focused on the role of essential elements in the development of AIT. The diagnosis of AIT is based on cytological findings of which the spectrum was effectively presented by Prof. Sofia Tseleni, (Athens), with Prof. Murat Erdogan (Ankara) delivering an interesting talk on the characteristic ultrasonographic pattern. New imaging technology such as elastography, providing us with information regarding the stiffness of thyroid tissue, may be helpful in the future for the differential diagnosis and classification of the disease.

Prof. Paolo Vitti (Pisa) elegantly summarized the complexity of iodine in the development of AIT while pointing out the great importance of iodine for thyroid function.

Jacques Orgiazzi (Lyon) presented the issue of AIT and pregnancy and the challenges in diagnosis and treatment. Prof. Demetrios Goulis (Thessaloniki) interestingly spoke about the interactions of AIT with fertility, revealing a number of new aspects of this topic.

In the following session, dedicated to Prevention and Treatment of AIT, Prof. Peter Laurberg (Aalborg) gave an impressive talk on the possibilities of prevention of AIT by lifestyle changes and dietary intervention. Though large studies are lacking, there is significant evidence that nutrition influences the course of the disease. In this line, Prof. Leonidas Duntas (Athens) reported on the potential use of nutrigenetics and nutrigenomics, that is, the analysis of food and its influence on genes and vice versa, which can provide means of support for a personalized approach of treatment in patients with AIT.

Prof. Luigi Bartalena (Varese), the secretary of the ETA, dealt with the current treatment modalities of autoimmune hyperthyroidism, underlining the potential role of immunological drugs such as rituximab in Graves' Ophthalmopathy. The meeting proceeded with the lecture by Prof. Ekaterini Dacou (Athens) who presented

*(continued on page 17)*



*Participants of the conference in front of the ruins of Hippocrates' hospital*



## An Education Course (continued from page 16)

data concerning AIT in childhood and also referred to the pathogenesis of disease.

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***It was a fantastic opportunity for learning from one another and discussing the many aspects of AIT ...***

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Finally, the session dedicated to AIT and thyroid cancer was especially interesting: Prof. Mathias Schott (Duesseldorf) delivered a talk on the association of AIT and thyroid cancer, Prof. Peter Smyth (Dublin) spoke about the association between AIT and breast cancer and Prof. Ulla Feldt-Rasmussen analyzed the significance of positive anti-Tg in patients with differentiated thyroid cancer.

The participants visited the Asclepeion, the oldest healing sanctuary of the western World where we enjoyed a ceremonial re-enactment of the Hippocratic oath.

The meeting was a celebration of sciences and culture at an extremely elevated level and within sacred environs. It was a fantastic opportunity for learning from one another and discussing the many aspects of AIT, a disease that is now marking its 100 years of recognition and investigation!

### ***ThyroWorld***

Deadline for the next issue: June 20, 2013

For artwork, please send *high-resolution electronic files*. Send all submissions to:

The Editors, ThyroWorld  
**Thyroid Federation International**  
P.O. Box 471,  
Bath Ontario K0H 1G0 Canada

Email: [tfi@thyroid-fed.org](mailto:tfi@thyroid-fed.org)

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

## PROMOTION OF PATIENT INTEREST

# TFI for the first time at the AOTA Congress

AUTHOR: PETER LAKWIJK

**T**FI received an invitation to be present during the upcoming 10th Asia and Oceania Thyroid Association Congress (October 21-24, 2012) in Discovery Kartika Plaza Hotel, Bali, Indonesia.

For thyroid specialists, there are 4 thyroid associations representing their respective regions: the American Thyroid Association (ATA, established in 1923), the European Thyroid Association (ETA, 1965), the Latin American Thyroid Society (LATS, 1974) and the Asia & Oceania Thyroid Association (AOTA, 1975). The youngest of these siblings, AOTA, was established in 1975 in Boston at the time of the 7th International Thyroid Congress.

Their members come from all over the area, with countries like Australia, China, India, Indonesia, Iran, Japan, Korea, Philippines, Singapore, Taiwan and Thailand.

One of the major problems in the AOTA area is iodine deficiency. Many countries in this area have a very low iodine intake and no access to iodized salt. AOTA and TFI feel a shared responsibility to raise awareness of the need for iodine in the food.



More and more patients in the AOTA area turn to the internet for quick information. Cooperation between AOTA and TFI can provide them with evidence based information that will help them and their doctors to live with their disease in the best possible way.

During the congress TFI will organize, together with the congress organizing committee, a patient meeting with lectures in the local language and in English. There will also be a TFI booth at the exhibition in the congress hall.

TFI will be represented at the AOTA congress by its president and by the president of The Australian Thyroid Foundation Ltd. and booth staff.



**10<sup>th</sup> ASIA and OCEANIA  
THYROID ASSOCIATION CONGRESS  
21 to 24 October 2012.**

# The Case of Eltroxin in Israel

## “Narrow therapeutic range” and the Patient’s Well-being

AUTHOR: OFRA TOREN-COMMERE  
ISRAELI THYROID PATIENT

**I**n Israel about 250.000 patients are treated with In Israel about 250.000 thyroid patients are treated with levothyroxine. Most of them use the drug Eltroxin sold in Israel since 1981, available in two dosages: 50 µg or 100 µg.

Since 2001 the producing company –GlaxoSmithKline (hereafter GSK) - started to develop a new product, under the same name, by changing some of the non-active ingredients of the drug in order to improve its stability. Following the distribution of this drug in New-Zealand in 2007, and in Denmark in 2008 (in both countries, Eltroxin was the only available levothyroxine treatment at that time), hundreds of complaints by users were received concerning side-effects mostly associated with changes in hormonal equilibrium and with allergic reactions. Reports about these unwarranted effects were widely reported in the mass media.

On March 19, 2008 GSK started the process of registering the new Eltroxin formula in Israel. The company did not report the occurrences in other countries, since it claimed that the problems were mainly due to the mass media reports rather than to the composition of the product itself. The company nevertheless asked permission to change the recommended dosage because the new pill cannot be divided into two parts. These requests were approved in Israel in March 2010. In September 2009 the company transferred its production site to the Aspen Corporation in Germany, and the Perrigo company became the owner of its registration in Israel.

“In February 2011 a new formula of Eltroxin was introduced in Israel without any warning to patients, pharmacists, and physicians and without any visible external change of its package.”

*(Quote from the report of the investigation committee of the ministry of Health, January 2012).*

### Excipients

New formula:	Old formula:
microcrystalline cellulose	lactose
pre gelatinized starch	starch corn
talc	acacia powder
silica colloidal anhydrous	magnesium stearate
magnesium stearate	

It is well known that a change in excipients can change the absorption of the drug in the gastrointestinal tract - and that for a drug with a “narrow therapeutic range” like thyroid hormones, even a small change can have big repercussions on the patient’s well-being – this has been pointed out by the American Thyroid Association (ATA) and the American Association of Clinical Endocrinologists and Endocrine Society (AACE) since 2004.

“Patients should be maintained on the same brand name levothyroxine product. If the brand of levothyroxine medication is changed, either from one brand to another brand, from a brand to a generic product, or from a generic product to another generic product, patients should be retested by measuring serum TSH in six (6) weeks, and the drug reiterated as needed. Since small changes in levothyroxine administration can cause significant changes in TSH serum concentrations, precise and accurate TSH control is necessary to avoid potential adverse iatrogenic effects.”

[http://www.thyroid.org/professionals/advocacy/04\\_12\\_08\\_thyroxine.html](http://www.thyroid.org/professionals/advocacy/04_12_08_thyroxine.html)

As a consequence of the changes in the composition of the Eltroxin drug in Israel, thousands of patients suffered from symptoms of hormonal disequilibrium.

Since neither physicians nor pharmacists had been informed about the change in the drug’s composition, nobody knew the reason of the users’ complaints and problems, and how to handle them. Only half a year after the start of the new Eltroxin marketing, in August 2011, did the ministry of Health order the Perrigo company to add a warning “New formula ... close medical monitoring is required” on all the new drug’s packages. However, this warning appeared only in Hebrew.



*Translation of the red sticker: “New Formula distributed since February 2011, close medical monitoring is required”*

*(continued on page 19)*

## The Case of Eltroxin in Israel (continued from page 18)

From my personal experience as a patient (after a thyroidectomy) and as a user of Eltroxin for six years, I can honestly say that I received the information about the composition change of the drug from my pharmacist for the first time in November 2011, i.e. nine months after the change of the drug's ingredients. After a blood test, as thousands of patients, it appeared that I suffered from a hormonal disequilibrium.

According to the investigation committee and as reported by the importer, the Perrigo company, the declared side effects of the new formula are as follows: "72% of the complains were related to hypothyroidism with the following symptoms: fatigue, weakness, mood change, depression, performance difficulties, swelling of feet and hands, constipation, loss of hair, blood pressure, and enlargement of the thyroid gland.

57% of the complaints were connected to symptoms of hyperthyroidism; only 18.5% concern hypothyroidism. Typical symptoms are: trembling, nervousness, strong heartbeat, diarrhea, arrhythmia, insomnia.

3% of the complaints (24) report symptoms related to allergic reactions. There are no reports (except in one case) of the TSH value. Typical symptoms are: appearance of rash on different body parts, face redness and swelling, symptoms of asthma.

Fifteen of the side-effects are defined as serious. The criteria for classifying a symptom as serious are not noted therefore the detailed classification is based on the accepted criterion of "serious adverse effects."

*(From the investigation committee's report)*

These data do not represent the real situation accurately, since in Israel there is no official process of pharmacovigilance, and the data were reported by the importing company Perrigo itself.

### **How were the Israeli patients informed about the new Eltroxin formula?**

The Eltroxin new formula cases were exposed after a mother was told that she should no longer cut the pill that her young son used to take into halves. At that time, there were no warnings on the packages of the drug, indicating that the formula had been changed. She started to investigate the matter. But it took some time until the case was revealed by the press.

After the journalist Isaak Wolf revealed the scandal in October 2011, an Israeli Eltroxin patient

started a Facebook group as an open patient forum for the exchange of information and discussion: [www.facebook.com/groups/eltroxin/](http://www.facebook.com/groups/eltroxin/)

She was surprised that after a very short time there were dozens of subscriptions on the page. Today, more than 2000 people have joined and use this platform for free discussions on issues concerning Eltroxin and also for organizing themselves as a group fighting for their rights as thyroid patients.

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***One of the main conclusions of the Eltroxin case in Israel is that ... Israel should establish a pharmacovigilance agency in the Ministry of Health.***

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Following the publication of articles in the press and the repeated demands from the patients, supported by TFI who also addressed an open letter to the government, the Israeli government mandated an inquiry commission, whose conclusions were published in January 2012. The case is at present still under investigation.

The Eltroxin case revealed several important facts:

- Until December 2011 in Israel there was only one thyroid replacement hormone. Since then another drug (Euthyrox manufactured by the Merck Serono laboratories) has been approved. Patients who cannot use Euthyrox may, with the approval of an endocrinologist, use Synthroid, manufactured by Abbott Laboratory.
- There are no low dosages of levothyroxine for babies and small children.
- There is no systematic procedure for the reporting of drug side-effects in Israel.

One of the main conclusions of the Eltroxin case in Israel is that - like in Japan, the United-States and Europe - Israel should establish a pharmacovigilance agency in the Ministry of Health. Only such an agency would be able to prevent problems like that of Eltroxin and prevent the possible dangers of adverse side-effects.

*Further information :*

[www.facebook.com/groups/eltroxin/](http://www.facebook.com/groups/eltroxin/)

<http://tfi.free-si.de/board/viewtopic.php?t=143>

## 'Greater than Graves' Ride

AUTHOR: KIMBERLY DORRIS  
USA, GRAVES DISEASE & THYROID  
FOUNDATION EXECUTIVE DIRECTOR

**W**hen Michaela Cui began organizing the 2011 "Greater Than Graves" ride, she had no idea the 3,200-mile bike trek from Anchorage, AK to San Francisco, CA would inspire an annual event. But in 2012, a new group of riders set out on a cross-country journey to raise funds and awareness for Graves' disease, thyroid eye disease, and other

thyroid-related disorders. On May 26th, at the conclusion of Thyroid Awareness Week, riders Elias McQuade, David Britton, and Keating Tufts dipped their bikes in the Atlantic Ocean at Christopher Columbus Waterfront Park in Boston, MA, and set out on a 4,100-mile cross-country journey, set to conclude on July 31st in San Francisco, CA.

McQuade has a personal connection to the project. "I drew the inspiration for the idea from my sister, who has had to deal with the challenges of Graves Disease," he explained. "I decided on a cross country bike ride because I feel that the ride would challenge me physically and mentally and could give me insight into the daily problems that face those who have diseases that affect their lives. I am really hoping to gain personal awareness of



*The riders kicked off the 2012 journey by dipping their bikes in the Atlantic Ocean at Christopher Columbus Waterfront Park in Boston, MA. At the conclusion of the journey in San Francisco, the team will dip their bikes in the Pacific Ocean!*

the disease, while drawing communities' and people's attention to this issue.»

University of Michigan Kellogg Eye Center hosted a special patient education event when the ride passed through Ann Arbor on June 9th. UM staff surprised the team with Michigan sunglasses and bike jerseys – and Dr. Raymond Douglas of UM Kellogg showed his support by riding with the team for the first 35 miles of the following day's journey!

At press time, the team had just left Cody, Wyoming and were headed to Yellowstone National Park. The riders were looking forward to crossing the finish line in San Francisco on July 31st and participating in another patient education event at University of California San Francisco co-sponsored by the Graves' Disease and Thyroid Foundation and the Let's Face It Together Foundation. For more information on the 2012 Greater Than Graves' ride, please visit [gdatf.org](http://gdatf.org) or [greaterthan Graves.com](http://greaterthan Graves.com).



*L-R: David Britton, Dr. Raymond Douglas, Keating Tufts, and Elias McQuade outside UM Kellogg Eye Center in Ann Arbor, MI*



*Greater Than Graves' founder Michaela Cui and team member Chris Doudna celebrate the conclusion of the 2011 GTG ride in San Francisco, CA*



*Meet the 2012 Team (l-r): Elias McQuade, Manchester, NH, Keating Tufts, Manchester, NH, and David Britton, Ashland, MA. The team is biking coast-to-coast to raise funds and awareness in honor of Elias McQuade's sister, who was diagnosed with Graves' disease.*

# National Graves' Disease Foundation *became* Graves' Disease and Thyroid Foundation

AUTHOR: KIMBERLY DORRIS  
USA, GRAVES' DISEASE & THYROID FOUNDATION EXECUTIVE DIRECTOR

The Graves' Disease & Thyroid Foundation (GDATF) is a U.S.-based 501(c)(3) tax-exempt, non-profit, international charitable organization. Our mission is to provide public and professional education, patient and family support services, and to fund medical research. The GDATF's Patient & Program Services include:

- Free online informational publications on specific topics of interest.
- An online community forum, hosted by trained facilitators.
- Educational meetings and conferences, featuring internationally recognized experts.
- A network of volunteer-led community support groups.
- A toll-free hotline for information and support.
- An e-newsletter and print newsletter featuring current news and information.
- An online physician registry, featuring U.S.-based specialists in treating Graves' disease and thyroid eye disease.



The organization was founded by Dr. Nancy Hord Patterson in 1990 as the "National Graves' Disease Foundation". Our focus has since expanded, with the addition of Dr. Lawrence C. Wood, founder of the Thyroid Foundation of America, to our Board of Directors. In 2011, the Foundation changed its name to the "Graves' Disease and Thyroid Foundation", reflecting our commitment to providing assistance to patients with thyroid eye disease as well as Graves' disease, Hashimoto's thyroiditis, thyroid nodules, and other conditions that affect thyroid hormone levels. We work to educate the public regarding signs, symptoms, and risk factors (including family medical history) for these disorders.\* We are the only U.S.-based 501 (c)(3) non-profit dedicated to providing one-on-one support for patients, family members, and caregivers impacted by these disorders.

The Foundation also participates in national conferences hosted by professional organizations for endocrinologists, ophthalmologists, endocrine surgeons, and other specialists to help these professionals understand the specific needs of patients.

We are one of the founding members of the Thyroid Federation International (TFI), an umbrella organization for thyroid patient groups all over the world. The GDATF is an active member of the National Coalition of Autoimmune Patient Groups (NCAPG). Facilitated by the American Autoimmune Related Diseases Association, the NCAPG is a coalition of national autoimmune disease organizations representing people with autoimmune diseases throughout the United States and the world.

\*The Foundation refers patients with Thyroid Cancer to ThyCa and Light of Life Foundation—two organizations with a long-standing tradition of providing support and expertise to individuals who have been impacted by this disease.



*Pictured: GDATF Executive Director Kimberly Dorris, Thyroid Federation International President Ashok Bhaseen, GDATF CEO and Board Co-Chair Steve Flynn, GDATF Board Co-Chair Kathleen Flynn, George Kahaly, M.D., Ph.D., of the Gutenberg University Medical Center, Mainz, Germany, and Paul Olivo, M.D., Ph.D.*

# A Notable Organisation for Thyroid patients in The Netherlands

AUTHOR: JOKE VAN GALEN, NETHERLANDS, BOARD MEMBER  
NETHERLAND THYROID ORGANIZATIONS (SON), NIENKE LAMSMA  
& GERARD MONSMA, NETHERLANDS, STAFF MEMBERS SON

## Organisational principles, diagnoses and categorization

The merger of the four patients organisations: Schildklierstichting Nederland (SN) (Netherlands Thyroid Foundation), Nederlandse Vereniging van Graves' Patienten (NVGP) (Dutch Association for Graves' Patients), Hypo maar niet Happy (HmnH) (Hypo but not Happy) and Stichting Schild ("Schild" Foundation), has resulted in Schildklier Organisaties Nederland (SON) (Netherlands Thyroid Organisations), creating a strong and easily manageable organisation in The Netherlands, with the following main objectives: information services, contact between fellow sufferers and representation of interests.

The four organisations remain easily recognisable within SON regarding the specific disorders from which they derive their existence. They have organised themselves in such a way that they are recognisable to their members and donors, all patients with a specific (thyroid) disorder. The first thing these patients want is information pertaining to that specific disorder and they want to identify with patients who are going through the same thing.

The diagnosis categories that were selected:

1. Hypothyroidism
2. Hyperthyroidism
3. Graves' eye disease
4. Thyroid cancer
5. Congenital thyroid disorders in children

Other aspects are also considered, such as the specific issues of thyroid disorders that come with the various stages in life, as well as current issues present in all the diagnostic categories.

Questions that arose when setting up the new organisation:

- How do we set the organisation up so that the different diagnoses continue to be recognisable and the patients feel they are receiving quality treatment?
- How do we involve volunteers when categorizing the diagnoses?

- How do we make the most of the combined organisation to approach/mobilise target groups within all the diagnosis categories?

It led to the following division of tasks with regard to the specific diagnostic categories

Each Board member is in charge of a diagnosis category. The SON expertise committee is organised in such a way that attention is paid to all diagnosis categories. All diagnoses receive the same attention when preparing information material and proposals that are used to improve and enhance knowledge. The various diagnosis categories were taken into consideration when organising the Medical Advisory Council.

The new magazine "Schild" has been arranged into distinct sections for the various diagnosis categories.

Other points of attention:

- Experienced specialists in various diagnosis categories are consulted when organising the regional work groups. This is in order to guarantee that appropriate activities can be organised regionally for all diagnosis categories.
- The website and/or Forum is arranged in such a way that donors or members are immediately enlightened and in direct contact with fellow sufferers regarding their personal diagnosis. A lot of effort is going into the SON website. Currently there is a temporary website with links to the websites of the individual organisations.
- Once the different diagnosis of all members / donors is available, we can offer an e-mail service by means of which they can be informed specifically about the developments in the areas pertaining to their own diagnosis, as well as about specific activities.
- It is important that people who speak a different language can choose between Dutch or English. The latter, of course, is also interesting for thyroid foundations abroad.

## Further professionalization of the organisation The Board's involvement with the organisation

Managing an organisation with approx. 15,000 members, five diagnostic fields, projects, etc., requires continuous attention. Operations must

*(continued on page 23)*

## A Notable Organisation for Thyroid patients (continued from page 22)

continue, even with a shifting administrative task force.

- A few key points here:
- Board members do not have executory tasks
- The Board is provided with optimal information
- The ongoing business is run by an operational organisation independent of the Board

The organisation is managed by a number of professionals who work for the organisation. They are stationed in the centre of the country with the Bureau that carries out the administrative functions for SON.

It concerns a:

Director, 28 hours a week:

- Prepares board meetings, which are synchronised with the Chair person
- Attends board meetings
- Is in charge of the organisation (in charge of the volunteer coordinator, the

secretary's office and the administrative department)

- Synchronises with the portfolio managers (diagnoses and other management tasks)
- Maintains external contacts
- Steers external support
- Supervises and supports central task forces (projects and assignments)

Volunteer coordinator, 16 hours per week, who coordinates all volunteer work. Volunteers are subdivided into work groups and committees, nationally per region or central.

Secretary, 12 hours per week, for reporting, filing and dealing with the post.

The other tasks, such as member and financial administration are carried out by the guidance services.

The SON Board is very confident that the new organisation will be able to further improve services to Dutch thyroid patients.

## SPECIAL EVENTS

# Even polar bears can have thyroid problems

AUTHOR: ULLA SLAMA

**T**he Thyroid Patient Association of Finland has taken the ice bear mother Venus living in the national park of Ranua in northern Finland as godchild bear.

One year ago the female ice bear Venus was diagnosed for insufficiency in her thyroid gland. This seems to have contributed to her reproductive problems. She had a miscarriage in 2009.

It is very rare for polar bears to give birth when they are in captivity, away from their natural freedom.

The well-being of Venus, the mother polar bear, was taken extra care of when she got pregnant again. She got the appropriate thyroid medication. In addition, we also ensured that Venus received the all-important fatty acids by giving her cod-liver oil.

The cub was born on Friday, November 18, and survived the most critical period of five days for polar bear cubs. The cub is growing and developing very well. The first polar bear cub

ever surviving its birth in Finland was the greatest Christmas present for all at the Ranua Wildlife Park.

At birth, the cub weighed half a kilogram and in three weeks time it more than doubled its weight. On February 23rd, it went outside with his mother for the very first time. At that moment, it weighed 7 kilograms. There has been a competition on the Ranua zoo web site to name the bear cub. The winning name will be announced on September 3rd.

The polar bear mother Venus has been adopted as godchild of the Thyroid Patient Association of Finland.



*Mother and Child in Ranua Zoo*

<http://www.kilpirauhasliitto.fi/>

<http://www.goodnewsfinland.com/archive/news/ranua-zoos-polar-bear-cub-stumbles-out-of-its-den/>

<http://www.ranuazoo.com>



# TFI Member Organizations

## AUSTRALIA

*The Australian Thyroid Foundation Ltd.*  
Beverly Garside (President)  
Suite 2, 8 Melville Street  
Parramatta, NSW 2150 Australia  
info@thyroidfoundation.com.au  
www.thyroidfoundation.com.au

## BELGIUM / NETHERLANDS

*Leven Zonder Schildklier*  
Peter Lakwijk (President)  
Belgium  
info@levenzonderschildklier.be  
www.levenzonderschildklier.be

## BRAZIL

*Instituto da Tiróide*  
Geraldo Medeiros-Neto, MD, MACP  
(President)  
Rua Artur Ramos, 96 - 5A  
01454-903 São paulo, SP Brazil  
medneto@uol.com.br  
www.indatir.org.br

## CANADA

*Thyroid Foundation of Canada*  
*La Fondation canadienne de la Thyroïde*  
Mabel Miller (President)  
Ashok Bhaseen (TFI Representative)  
PO Box 9  
Manotick ON K4M 1A2 Canada  
www.thyroid.ca

## DENMARK

*Thyreoidea Landsforeningen*  
Jytte Flamsholt Christensen  
(President)  
Bente Julie Lasserre (TFI Representative)  
Strandkrogen 4A  
3630 Jaegerspris, Denmark  
info@stofskifteforeningen.dk  
www.thyreoidea.dk

## FINLAND

*Thyroid Association of Finland*  
Kirsti Hänninen (President)  
Ulla Slama (TFI Representative)  
Vilhonkatu 4 B  
00010 Helsinki, Finland  
ulla.slama@gmail.com  
www.kilpirauhasliitto.fi

## FRANCE

*Association Vivre sans Thyroïde*  
Beate Bartès (President)  
2, av d'Expert  
Léguevin 31490, France  
info@forum-thyroïde.net  
www.forum-thyroïde.net

## GEORGIA (EU)

*Georgian Union of Diabetes and  
Endocrine Associations*  
Prof. Ramaz B. Kurashvili  
(Chairman)  
Elena Shelestova (Managerial  
Secretary)  
National Centre for Diabetes  
Research  
1, Chachavha str, fl. 4  
Tbilisi, 0159, Georgia  
diabet@access.sanet.ge  
e\_shelestova@yahoo.ge

## GERMANY

*Ohne Schilddrüse leben e. V.*  
Harald Rimmel (TFI Representative)  
Rungestrasse 12  
10 179 Berlin, Germany  
info@sd-krebs.de  
www.sd-krebs.de

*Schilddrüsen-Liga Deutschland e.V.*  
Barbara Schulte (President)  
Ev. Kliniken Bonn GmbH,  
Waldkrankenhaus  
Waldstrasse 73, 53177  
Bonn, Germany  
info@schilddruesenliga.de  
www.schilddruesenliga.de

## ITALY

*Associazione Italiana Basedowiani e  
Tiroidei*  
Emma Bernini (President)  
Borgo Felino,3, 43100 Parma, Italy  
www.aibat.it

*ATTA-Lazio Onlus*  
Paola Polano (President)  
Via Gregorio Ricci Curbastro n.56  
00149 Roma, Italy  
info@atta-lazio.it  
www.atta-lazio.it

## JAPAN

Dr Fumito Akasu (Contact)  
CBON Queen Building, 4th Floor  
Roppongi 7-18-12  
Minato-ku, Tokyo 106-0032 Japan  
akasu@akasu.com

## MEXICO

*La Asociación Mexicana de Tiroïdes*  
Carlos M Duncker, MD (President)  
Zacatecas 230, Quinto Piso  
Colonia Roma, C.P. 06700  
México, D.F., México  
amet@tiroïdes.org  
www.tiroïdes.org

## THE NETHERLANDS

*Schildklierstichting Nederland*  
Joke van Galen (Acting President)  
R.M. (Ineke) Bink-Leijh (TFI  
Representative)  
Stationsstraat 79G  
3811 MH Amersfoort  
The Netherlands  
info@schildklier.nl  
www.schildklier.nl

## NORWAY

*Norsk Thyroideaforbund*  
Kristin Kvalsnes (President)  
Fr. Nansens plass 9, NO-0160  
Oslo, Norway  
post@stoffskifte.org  
www.stoffskifte.org

## PORTUGAL

*Associação das Doenças da Tiróide*  
Celeste Campinho (President)  
Rua Ricardo Jorge, 55 – 1° C  
4050-514 Porto  
adtiroide@gmail.com  
www.adti.pt

## RUSSIA

*Thyroid Foundation of St. Petersburg*  
Prof. Elina G. Gasparyan (President)  
"Professor" Medical Centre  
42 Chaykovsky Street  
St. Petersburg 191123, Russia  
gasparyan@peterlink.ru

## SWEDEN

*Svenska Sköldkörtelföreningen*  
Peter Lakwijk (President)  
Postbox 10256  
SE-43423 Kungsbacka, Sweden  
info@skoldkortel.se  
www.skoldkortel.se

## UNITED KINGDOM

*The Thyroid Eye Disease Charitable  
Trust*  
Dr. Jimmy Uddin (Chair)  
P.O. Box 1928, Bristol  
BS37 0AX U.K.  
ted@tedct.co.uk  
www.tedct.co.uk

## UNITED STATES OF AMERICA

*Graves' Disease & Thyroid Foundation*  
Peter Filocamo (President)  
400 International Drive  
Williamsville, NY 14221 USA  
info@ngdf.org  
www.gdatf.org