



Thyroid Federation International

Thyroid Patients Worldwide

In this Issue

Editorial	2
FROM THE BOARD	
President's Message.....	3
Personal memories of 4 stars in the Thyroid World.....	4
Echoes from the 18th TFI AGM and the 36th ETA congress, Pisa	5-6
Upcoming Events	6
TFI Participation at Bali, AOTA and LATS Florionopolis, Brazil	7-8
Meeting of the American Thyroid Association in Quebec, September 2012	9
TFI at the 2nd World Congress on Thyroid Cancer, Toronto	9-10
INTERNATIONAL THYROID AWARENESS WEEK	
International Thyroid Awareness Week in Bulgaria	10
Neonatal Screening Program in Brazil	11-12
Get Smart – Protect Your Baby's Brain	12, 15
Finland – World Thyroid Day.....	13
ACTIVITIES OF THE NATIONAL ORGANIZATIONS	
GDATF Hosts 19th Annual Patient and Family Conference.....	14-15
The Italian Association of Graves' and Thyroid Patients.....	16
Activities of the Thyroid Foundation of Canada.....	17
“My Africa”	18-19
Thyroid Association of Finland.....	20
PROMOTION OF PATIENT INTEREST	
Notable increase in T4 use in the Netherlands.....	21
Salt Reduction and Iodine Fortification Strategies in Public Health.....	22
Success at Court for the reimbursement of Thyrogen	23
TFI Member Organizations.....	24

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 2012 – 2013

Executive Committee

Ashok Bhaseen (Canada), President

Peter Lakwijk (Sweden), Treasurer

Beate Bartès (France), Secretary

Members-at-large

Nancy Patterson (USA)

Harald Rimmel (Germany)

Honorary Member

Lawrence C Wood, MD FACP (USA)

June Rose-Beaty (Canada)

Yvonne Andersson-Lakwijk (Sweden)

Editors, ThyroWorld

Beate Bartès (France)

Ineke Bink (the Netherlands)

Medical Advisors

Dr. Elina Gasparyan (Russia)

Pr. George J. Kahaly (Germany)

Pr. Martin Schlumberger (France)

Pr. Wilmar Wiersinga (the Netherlands)

Conference Coordinators

Beate Bartès (France)

Ineke Bink (the Netherlands)

Administrative Coordinator

Katherine Keen (Canada)

Website Coordinators

Katherine Keen (Canada)

Harald Rimmel (Germany)

Member Organizations

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

ThyroWorld is the official newsletter of the
Thyroid Federation International.

ISSN 1488-223X

Email: tfi@thyroid-fed.org

Internet: www.thyroid-fed.org

Website Coordinator: info@thyroid-fed.org

Layout & design by Fresh Image (Canada) – www.freshimage.ca

Editorial

Once again, we, the editors of ThyroWorld Magazine are proud to present this new edition of ThyroWorld. The mission of the Magazine is to inform its readers – the representatives of national patient organizations and the medical practitioners in the thyroid field – about the activities undertaken by TFI and several national members over the last year, how they provided patients with the most up-to-date information on their thyroid disorder and in what way the organizations have been defending patient interests. You'll read about it in the sections on the Activities of the National Organizations and the International Thyroid Awareness Week. Within this framework we especially draw your attention to a very creative and ingenious way to provide parents with information about the necessity of having their new born babies screened. You'll find this in the article on the neonatal screening program in Brazil.

In the section Promotion of Patient Interests, you will be interested to read that the Dutch national organization announces its success at court for the reimbursement of Thyrogen and that the Australian organization represented thyroid patient interests at the conference on Salt Reduction and Iodine Fortification Strategies in Public Health in Sydney.

The opening section is reserved for TFI News. Our president, Mr. Ashok Bhaseen, in his President's Message, will fill you in on what TFI, as a worldwide umbrella organization of 21 patient organizations, accomplished over the last year for thyroid patients all over the world and of all sorts: hypo – as well as hyper patients, patients with Graves' Eye disease, and patients with cancer. He emphasizes the importance of the presence of TFI not only at the ETA conference but also at other major international conferences for thyroid specialists.

We very much hope that you will find these articles interesting and useful: that they will be of help when you are planning activities for your own local organization or that they encourage you to start your own patient organization if it is still lacking in your country.



Beate Bartès



Ineke Bink

Beate Bartès & Ineke Bink, editors

President's Message

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

Dear Readers,

Thyroid Federation International (TFI) is a true Global organization. During the 2012-13 period, TFI partnered and was present at: ETA (Pisa, Italy), AOTA (Bali, Indonesia), ATA (Quebec City, Canada), LATS (Florianopolis, Brazil), and more recently, the World Congress on Thyroid Cancer (Toronto, Canada). Most of you met us, heard me speak and came to our booth during these conferences. It is heartwarming to see your interest in TFI and your dedication to your patients where some of you take the time to serve as volunteers in your local patient driven thyroid organization in your individual country.

In my last year's message I talked about the world 'being flat today' i.e. there is a level playing field due to the communication age. This was very visible when I participated at the above conferences, you can hardly see the difference from one geographical area to another when it comes to passion, hunger for knowledge and the desire to make a difference in thyroid patients' lives. The new communication age provides access to the latest developments in Thyroid disease across the globe. Physicians all over agree that patient participation, knowledge and partnership with their doctors results in superior medical outcomes. But to achieve that we must equip patients with some basic tools:

- patient handouts on thyroid disease in their native language that are easy to understand,
- the information should be available in both electronic and paper based handout forms,
- these materials should be unbiased and developed in partnership with TFI and its members' organizations in individual countries.

From my meetings with Endocrinologists from more than 50 different countries, I do realize that different countries have different priorities when it comes to thyroid related issues:

- In much of Asia, Eastern Europe, Africa and Latin America, Iodine supplementation is still an important need that food and salt manufacturers should adhere to. I am



Ashok Bhaseen

reminded of the late Dr. Aldo Penchera who devoted a lot of time at ICCDI to accomplish this goal; we would like to build upon his work and realize his dream.

- In Eastern Europe the Chernobyl leak has impacted the thyroid functioning of the population
- In the UK, iodine in the diet needs renewed awareness where

a new generation may be totally unaware of its importance

- In the developed world we need to ensure that Thyroid collars are being deployed before taking X-rays at the diagnostic, dentist and hospital settings
- In a world that is glued to the internet for information, we need to make sure that we provide professional and credible information as it is becoming harder to distinguish between self-interest groups and those that really care for the patients.

Therefore, TFI is doing its best to work closely with organizations and its members like ETA, ATA, AOTA and LATS to provide evidence-based information to Thyroid patients and alleviate their condition.

TFI will continue to focus on getting better access to more precise LT4 and LT3 dosages across the globe, having better diagnostic imaging and tests for thyroid, having better access to Thyroid Cancer medications that are more patient-centric and are of value to the patients.

During the past year, several countries have approached TFI to become members; we are in the process of looking into their requests and making sure that these organizations have a credible presence in their countries of origin and can truly make a positive contribution to thyroid patients.

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

Personal memories of 4 stars in the Thyroid World

AUTHOR: YVONNE ANDERSON-LAKWIJK (SWEDEN), PAST
PRESIDENT OF THYROID FEDERATION INTERNATIONAL

Since the last Annual General Meeting of TFI in Pisa the thyroid world has lost four great personalities. Four amazing specialists from four different continents, Professor Hugo Niepomnisczce, Latin America, Professor Aldo Pinchera, Europe, Professor Ernest Mazzaferri, the United States and Professor Jim Stockigt, Australia.

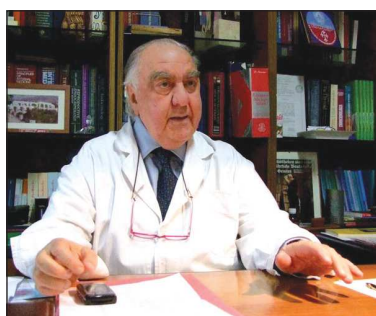
They, each in their own way, supported TFI over the years in their task to bring about knowledge and raise awareness of thyroid diseases, not just to the public, but also to the general medical professionals.

In 2005 the ITC took place in Buenos Aires. Prof Niepomnisczce's warm welcome made TFI's participation a successful one. This is something TFI will never forget, a true mutual respect. One especially nice memory is when Prof Niepomnisczce went to the airport in person to help one of our board members enter Argentina when she had lost her passport. It was "true friends" after that.



Professor Hugo Niepomnisczce

I met Prof Aldo Pinchera for the first time at the conference of the ETA in 1999 at the University of Milan. We greeted and I tried some of the Italian I know. Since that day my dearest Aldo always greeted me with "mia cara bambina" when we met at the different thyroid events – a dear friend. But there was so much more to it. Through Prof Pinchera TFI was introduced to the issues of iodine deficiency and thyroid diseases.



Professor Aldo Pinchera

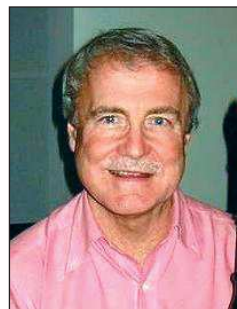
We were invited to participate in the meetings and work of ICCIDD. This created a good mutual dialogue. For me, this incredible Italian man always will have a place in my heart.

Unfortunately I never had the possibility to get to know Prof Ernest Mazzaferri in the same way but I met him often enough to know that he respected and supported the work of patient organizations, and he encouraged the ATA to fully accept TFI within a worldwide co-operation of efforts.



Professor Ernest Mazzaferri

Prof Jim Stockigt has been a good friend to me since we met for the first time in Munich, 1997, at the annual meeting of TFI. Jim was representing Australia and I was at my first TFI meeting representing the West Swedish thyroid patient organization. One very important issue that Prof Stockigt brought up early within TFI was how to improve the education about thyroid disorders at medical schools in order to increase the knowledge of these diseases among GPs. The possibility of getting early diagnoses, saving patients from having to endure long-term suffering and not



Professor Jim Stockigt

feeling well, was and still is an important goal for TFI. For Prof Stockigt, good quality of life for patients was extremely important, and from the start he supported the work of the patient organizations in Australia as well as internationally.

These are just some of the many beautiful memories I have of these special men.

On behalf of Thyroid Federation International I would like to send grateful thoughts and a sincere thank you to these four "big stars" in the Thyroid World, for their dedicated work and achievements for those affected by thyroid disorders throughout the world and for the respectful dialogue shared between us.

Four chairs will be empty in Leiden but will always be seated in the thyroid world.

With sorrow in my heart, yours

Yvonne Andersson Lakwijk

Echoes from the 18th TFI AGM and the 36th ETA congress, Pisa

TFI AGM: September 7th

ETA Congress: September 8-12th, 2012

AUTHOR : BEATE BARTÈS

SECRETARY, THYROID FEDERATION INTERNATIONAL

As in previous years, TFI held its Annual General Meeting in the days preceding the ETA congress, in the wonderful location of Santa Croce di Fossabanda.

During the ETA congress, we had a booth in the exhibition area, with a video screen showing pictures of the International Thyroid Awareness Week, and stands with newsletters and brochures. We had a lot of interesting talks and contacts at our booth.

Our newsletter ThyroWorld had 24 pages, and was packed into the delegates' bags of the approximately 1200 attendees of the congress, as well as available at the booth.



Patients and doctors attending the patient forum on thyroid nodules and thyroid cancer.

internal meeting, to talk about the project to have the various regional Italian patient organizations work closer together and to create an Italian federation.



TFI AGM: Béate Bartès, Yvonne Andersson and Ashok Bhaseen.

On Saturday, September 8th, TFI, together with the local organizing committee, organized a lecture for Italian thyroid patients, with 2 doctors speaking:

- Rossella Elisei, Pisa: Thyroid hormone replacement therapy and quality of life
- Laura Fugazzola, Milan: Thyroid nodules: an epidemic disease

There were more than 50 patients and doctors attending, very interested by the lectures – in the afternoon, the patients continued with an



Participants of the 18th TFI AGM, Pisa: rear, left to right – Harald Rimmele, Ulla Slama, Peter Lakwijk, Bente-Julie Lasserre, Larry Wood; front, left to right – Asta Tirronen, Elina Gasparyan, Nancy Patterson, Yvonne Andersson-Lakwijk, Ashok Bhaseen, Beate Bartès, Ineke Bink.

(continued on page 6)

TFI 18th Annual Meeting

(continued from page 5)



The TFI booth: Nancy Patterson, Béate Bartès, Peter Lakwijk and Ulla Slama.

During the ETA congress, we attended many instructive conferences – the subjects, among others, were “autoimmune thyroid disease”, “guidelines for combined T4/T3 treatment”, “anaplastic cancer”, “follow-up of low risk thyroid cancer”. We were particularly interested by the presentation of the very first “guidelines for combined T4/T3 treatment”, which will help us to answer questions frequently asked by patients. These guidelines (Eur Thyroid J 2012;1:55–71) can be found online at <http://www.karger.com/Article/Pdf/339444>



Some attendees of the TFI AGM. Front, left to right: Nancy Patterson, Bente-Julie Lasserre. Rear: Ineke Bink, Peter Lakwijk.

Upcoming Events

October 16 to 20, 2013

83rd Annual Meeting of the American Thyroid Association
San Juan, Puerto Rico
www.thyroid.org

May 19 to 25, 2014

5th International Thyroid Awareness Week
www.thyroidweek.com
www.thyroidweek.org

May 25th, 2014

World Thyroid Day

September 6 to 10, 2014

38th Annual Meeting of the European Thyroid Association (ETA)
Santiago de Compostela, Spain
www.eurothyroid.com

September 25 to 28, 2014

11th Asia and Oceania Thyroid Association Congress (AOTA)
Kochi, Kerala, India
<http://moneyopener.com/aota/>

October 29 to November 2, 2014

84rd Annual Meeting of the ATA
Coronado, California, USA
www.thyroid.org

October 18 to 23, 2015

15th International Thyroid Congress (ITC)
Orlando, Florida, USA

2015

15th Latin American Thyroid Congress of the LATS, Latin-American Thyroid Society
Location to be confirmed

September 5, 2014

20th Annual Meeting of Thyroid Federation International
Santiago de Compostela, Spain

in conjunction with the 38th ETA Congress



www.thyroid-fed.org

TFI Participation at Bali, AOTA and LATS Florionopolis, Brazil

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



Oct 2012, AOTA, Bali, Indonesia

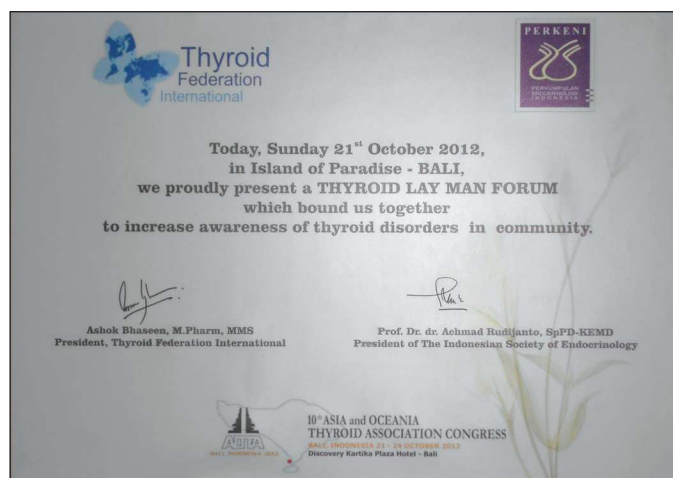
Travelling to the far Eastern part of the globe from Canada and arriving in the evening of the 3rd day of travel can take its toll. But the hospitality of the East helped me forget my tiredness so I could get down to work immediately. As soon as I got up the next day, I was busy with a very well organized patient group meeting (the best patient meeting that I have ever witnessed). It was planned over the months with patient interviews and videos produced ahead of time that were presented. There seemed to be a national effort with strong local influence in the success of this forum. The forum ran from 9:00 am in the morning till 2:00 pm in the afternoon. Patients with Thyroid Cancer, Hypothyroidism, Goiter, etc. were present at this forum, sharing their experience and fully participating in the meeting. TFI is thankful to Prof. Dr. Johan Masjhur and his colleagues Dr. Achmad Rudjianto, Dr. Made Ratna Saraswati, Prof. Dr. Sri Hartini K.S. Kariadi, Dr. Pande Dwipayana and Dr. Tjokord Gde Pelayun. TFI was represented by Beverly (ATF Australia) and myself.



(left to right) Dr. Made Ratna Saraswati; Beverly Garside, TFI, Australia; Dr. Achmad Rudjianto; Ashok Bhaseen, President TFI; Dr. Teofilo San Luis, Philippines; Professor Dr. Sri Hartini Kariadi and colleague.

The main conference was held at the Discovery Kartika Plaza Hotel, Bali, Indonesia. The Press was well represented at this patient forum and it was a pleasure to be part of the press conference that was covered in the national dailies the next morning. This patient forum and its publicity in the news definitely contributed to thyroid awareness in Indonesia.

At the end of the meeting a declaration was signed between TFI (Ashok) and the AOTA patient forum in Indonesia (Dr. Achmad Rudjianto), setting a foundation stone for the development of a patient-based thyroid organization. I am very hopeful and optimistic that we will see a flourishing patient organization in Indonesia. I am thankful to AOTA for providing me the time to address the congress at their gala dinner and acquaint them better with TFI's mission and vision.



March 2013, LATS, Florianopolis, Brazil

Coming from snowy Canada to summer in Florianopolis was a welcome change in the month of March 2013. Florianopolis is the perfect place to host an international event and its people

(continued on page 8)

TFI Participation (continued from page 7)

TFI booth at the 15th LATS Conference, Florianopolis, Brazil – LATS President Dr Marcos Abalovich and TFI President Ashok Bhaseen.



well suited to help out the tourist despite having difficulty with a language like English, totally alien to the majority of Brazilians. They are hospitable, helpful and go out of their way to accommodate your needs.

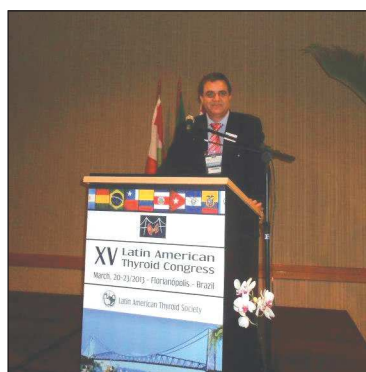
Once I reached the conference center I was welcomed by the local organization Chair, Marcia Neto de Campos da Silva who was extremely helpful to TFI in establishing a foothold at the congress. LATS was a well-run congress and I was pleased to see that perhaps 50% or more of the participants were female Endocrinologists;



TFI booth at the 15th LATS Conference, Florianopolis, Brazil – Ashok with Argentinian Endocrinologists.

appropriate since the majority of thyroid patients are women. LATS, like AOTA and ETA, provided a free booth for TFI. On the 3 days of the congress I was overwhelmed with the response of the physicians who came and met me at the TFI booth and wanted to know how they could establish Thyroid Patient Organizations in their own country.

I am thankful to the efforts of Dr. Geraldo Medeiros, Dr. Paul Cesar, Dr. Marcos Abalovich (President, LATS), Dr. Marcia Neto de Campos da Silva and Dr. Eduardo Tomimori for their help with TFI's participation at the LATS meeting and for ensuring that TFI's message is heard by providing me a forum to speak to the participants.



Ashok Bhaseen addressing the audience at the LATS welcome reception.

ThyroWorld

Deadline for the next issue: June 20, 2014

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

Internet: www.thyroid-fed.org

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.

Meeting of the American Thyroid Association in Quebec, September 2012

AUTHOR : BEATE BARTÈS
SECRETARY, THYROID FEDERATION INTERNATIONAL

From September 19th to 23th, 2012, TFI attended the annual meeting of the ATA in Quebec City. We had a booth in the exhibition hall, and attended various lectures. There were many interesting subjects, in particular the presentation of the ATA guidelines for the management of anaplastic carcinoma : <http://thyroidguidelines.net/anaplastic>.

Another interesting feature was the new clinical practice guidelines for the management of hypothyroidism, elaborated by the ATA and the AACE: <http://thyroidguidelines.net/hypothyroidism> – even if we, as patients, found these new guidelines a little frustrating, with not as many changes as we had expected, leaving a lot of unanswered questions.



ATA/Thyroid Alliance patient forum.



TFI booth at ATA Quebec, 2012: Ashok Bhaseen and Dr. Rossella Elisei.

During the congress, Thyroid Alliance and the ATA organized a patient forum, with several doctors from Quebec – there was no presentation, but discussions in small groups, one about thyroid cancer, the other one about thyroid disease in general. The patients asked lots of questions and were very satisfied to be able to discuss directly and frankly with several well-known thyroid specialists.

<http://www.thyroid.org/>

TFI at the 2nd WCTC, Toronto

AUTHOR : BEATE BARTÈS
SECRETARY, THYROID FEDERATION INTERNATIONAL

On July 10-14, Thyroid Federation attended the 2nd World Congress on Thyroid Cancer (WCTC) in Toronto – a global multi-disciplinary meeting of all specialists involved in the field of Thyroid Cancer: surgeons, endocrinologists, nuclear doctors, oncologists... from all over the world. This second edition (the congress takes place every 4 years) had more than 1000 participants from 61 countries. TFI had a booth (shared with the Thyroid Foundation of Canada) in the exhibition hall, where we presented our organization and activities to the doctors, and attended many captivating lectures about the management of thyroid cancer and the

newest research worldwide.

Some of the keynote lectures and panel discussions were particularly interesting for us as patient representatives, e.g. the symposium about “optimizing patient care”, and we were very happy to see that individual patient needs are more and more taken into account,

tailoring the treatment and follow-up individually for each patient, to adapt them to the extent of the disease and its risk of recurrence.

Research is progressing, we heard interesting talks about how molecular markers, in the future, will modify the diagnostic, prognostic and therapeutic implications for thyroid tumors, to better distinguish between benign nodules and



WCTC 2013: booth of TFI/TFC (Melanie Solmon, Harald Rimmele).



(continued on page 10)

International Thyroid Awareness Week in Bulgaria

AUTHOR: PROF. BOJAN LOZANOV
SCIENTIFIC CENTER OF MEDICINE

It is my great pleasure to inform you about the activities and events during the International Thyroid Awareness Weeks which have been organized by the Bulgarian Academy and Arts (BASA) since 2011. The main topic in ITAW-2013 was "Thyroid and Infertility" organized on the recommendation of TFI and ETA.

In all events undertaken together with the Bulgarian patient organizations, there took part specialists from the Scientific Center of Medicine, BASA, Clinical Center of Endocrinology, Medical University Sofia, Dept. of Endocrinology, "Tokuda Hospital, Sofia", and several endocrine units and institutions in the country. The main events were:

- A meeting on the current problems of thyroid diseases and related disturbances such as autoimmune thyroid diseases, IDD, infertility, pregnancy, vitamin "D" deficiency, in respect to diagnosing, prevention and management. Taking part in this event were 200 physicians, responsible persons of patient organizations, and institutions engaged in same problems.
- A press conference and interviews with prominent Bulgarian specialists for the mass media – Bulgarian National Radio, TV and

newspapers – were followed by a number of emissions and correspondences regarding the significance of thyroid disturbances and infertility.

- The original communications and reviews concerning the iodine status of pregnant women in Bulgaria and factors of goitrogens were published in the journal "Endocrinologia", the official issue of the Bulgarian Society of Endocrinology (No 1, 2013).
- The leaflet "May 25, World Thyroid Day" was issued with a circulation of 10,000 and contained sufficient information on thyroid diseases for people and patients at risk.
- "Open doors" for screening of women aged 16 to 46 for thyroid problems were organized by many outpatient departments in the country.

My colleagues and myself hope the activities undertaken in the Bulgarian ITAW-2013 enhance the awareness of people, and medical and governmental authorities in the field of thyroid and infertility.

We would like to express our great appreciation and gratitude for the encouragement received through TFI/ETA for the organization of the ITAW-2013 campaign.

TFI at the 2nd World Congress of Thyroid Cancer *(continued from page 9)*

carcinoma, avoid unnecessary thyroidectomies and adapt the extend of surgery. More and more targeted therapies are available for advanced thyroid cancer.

It was also very interesting to see the shift in paradigm over the past years – from "one treatment for all" to "personalized care" with less aggressive



Attendees captivated by the lectures.



"Morning with the Masters": Jeremy Freeman, Brian McIver, Clive Grant, Sebastiano Filetti, Michael Tuttle, Ezra Cohen, Henning Dralle.

treatment, less radioiodine, in some cases "wait and watch"... Important: be less aggressive, but identify those who need aggressive care, and ensure a serious follow-up. We as patient representatives were very happy to see that "quality of life" becomes a more and more important criteria in the management of thyroid cancer.

We hope to be back for the third edition, in 2017! <http://thyroidworldcongress.com/>



A Practical Approach to Increase the Efficiency of the Neonatal Screening Program in Brazil

AUTHOR: GERALDO MEDEIROS-NETO, MD,
MACP
PRESIDENT, INSTITUTO DA TIROIDE
(THYROID INSTITUTE)



Brazil is a large country with marked differences across regions. Some believe Brazil should be considered a continent comprising the North Region together with the large Amazon River basin, the semi-arid Northeast, the fertile Mid-West, the industrial South East and the mostly European-like countryside of the Southern states. A National Program for Neonatal Screening was created in 2001 covering Brazil's 26 states plus the Federal District of Brasilia, each having its own Neonatal Screening Program team reporting to the Ministry of Health.

Every four years since 2004, the Instituto da Tiroide (Thyroid Institute), a nonprofit social organization with state recognition registered at the Ministry of Justice, has promoted a meeting that brings together all representatives of the state services for Neonatal Screening.

Since the first meeting in 2004, it became clear that the Southern States (n=3) and South Eastern regions (n=4) were testing 60 - 70% of the live newborn population while other states were achieving test rates of only 30 - 50%. In subsequent years (2008, 2012) the program in the seven Southern states reached all live newborns, successfully performing the tests, diagnosing diseases, and providing treatments for these infants. This article focuses only on screening for Neonatal Congenital Hypothyroidism, a condition present in about 1/2000 newborns, based on a cut-off for spot (paper) TSH of above 10mUI/L.

During this 10-year period (2002-2012), it became clear that the Mid-Western States and the Federal District were also improving the search, testing and diagnosis, with treatment provided to 80-90% of all affected newborns. Results, however, were less encouraging in the Northern (Amazon Basin) and Northeast regions where the efficiency of the program was below 70% of all live newborns. In other words, > 30% of these newborns were NOT being tested for

Congenital Hypothyroidism and other diseases. It transpires that communication and transport in the Amazon River Basin are carried out mainly via the river system by boat. Pregnant women need to travel for 3-4 days before reaching the Hospital facilities for medical care. If the baby tests positive for Congenital Hypothyroidism, re-testing and adequate treatment can take 10-20 days. The solution for the Northern Region is relatively simple, calling for organizing of a trained team (medical doctor, nurses and social workers) to have a presence in the villages. The team will collect blood specimens from newborns and mail them to the major cities for analysis. If testing positive, a second blood specimen will be similarly tested and the infant started on the appropriate treatment (L-Thyroxine). The team will undergo annual retraining at a major city to improve efficiency and to debate local difficulties.

For the Northeastern States (n=9), the local conditions render it more difficult to implement a successful Neonatal Screening Program. These states are located in the semi-arid region of Brazil with periods of severe drought. The villages face enormous difficulties to survive, where water is scarce and agricultural yields below average. Thus, newborn babies seldom receive all the medical care needed, including Neonatal Screening. One of the main reasons why newborns are not screened for neonatal diseases is the total lack of the necessary information. We have proposed a new method of reaching most (if not all) households in the Northeastern villages.

Bottled cooking gas is supplied monthly by trucks that reach all the villages in a given state. Trucks deliver full gas bottles and collect the empties. Our proposal is to provide truck drivers with leaflets to be distributed to all inhabitants (Figure 1) in every household. Briefly, the leaflet will explain the need for newborn testing in the first week of life. Moreover, all trucks will bear a banner (Figure 2) explaining the "Teste do Pezinho", or "Little Foot (Heelstick) Test".

One million leaflets were printed for distributing to one million households. Half of the leaflets will be distributed in early May and the

(continued on page 12)



Figure 1. The leaflet (in Portuguese) to be distributed to one million households. Top line: Little foot (heelstick) test. Immediately below: Mothers: take your newborn baby to the Basic Health Unit in your village between the 3rd and 7th day of life to be screened for newborn diseases.

other half in early June 2013. This project will be conducted during “International Thyroid Day” on May 25th 2013.

It is envisaged that this strategy will result in better information for the local population. The plan is to start with the state of Bahia and proceed to include other states in the Northeast region.

Enthusiastic cooperation has been shown by the Gas Company, local teams implementing the Newborn Screening Program and local Medical Authorities.

The Instituto da Tiroide are convinced that, through this campaign, close to 100% of all live newborns in the Northeast region of Brazil can be tested. Therefore, it is hoped that in the near future, all 2.7 million Brazilian newborns can be tested for Congenital Hypothyroidism and other diseases every year.



Figure 2. Bottled gas delivery truck. A banner on the rear of the truck recommends mothers to take their

neonates to the Basic Health Unit from the 3rd to 7th day of life for neonatal screening. One million households will get the message.

Get Smart – Protect Your Baby’s Brain

The Australian Thyroid Foundation has updated its messaging for the women of childbearing years. This update is to ensure women during this life stage know the importance of ingesting a daily pregnancy supplement including 150 mcgs of iodine.

Australian research shows that 50% of pregnant women are iodine deficient, which can affect the development of the foetal brain and lead to lower intelligence and learning difficulties in the newborn.

(continued on page 15)

AUTHOR: ULLA SLAMA DR MED, BOARD MEMBER OF THYROID ASSOCIATION IN FINLAND, PRESIDENT OF THYROID ASSOCIATION IN VAASA REGION

May 25th, 2013

On World Thyroid Day 2013 Finland represented this day with events from previous years, beginning with the year 2009 when a small presentation was made at a Global Village event, a yearly multinational occasion for different associations held in a large park in Helsinki at the end of May.

Since 2011 the Thyroid Association of Finland has succeeded in marketing World Thyroid Day and Thyroid Awareness Week throughout the country. Nearly all the 15 regional associations participate with events in the main cities of Finland. The radio broadcasts about the day, and people are interviewed by national and local television. Daily newspapers are informed and journalists write articles, also women's magazines publish stories about thyroid patients. During the Thyroid Awareness Week there are lectures given throughout the country by thyroid specialists or other persons connected to the field. For the past three years, Director Asta Tirronen of the Thyroid Association of Finland has sent out a pamphlet to the regional associations informing them what the focus of that year will be and they in turn distribute it in their regions.

Also, in the areas of Finland with Swedish speaking populations, we had more information this year. The President of the Thyroid Association of Finland, Kirsti Hänninen, has emphasized for a long time that the association in the Vaasa region should take care of the whole Swedish speaking population in Finland, because the association of Vaasa region is already bilingual. The Swedish speaking population in Finland lives in the coastal regions in Western and Southern Finland and in the Åland islands between Sweden and Finland. During the Thyroid Awareness Week two representatives from Vaasa, Secretary Dorrit Högbacka and President Ulla Slama visited the Åland islands. A lecture about thyroid disease was held in the lecture hall of the Central Hospital of Mariehamn. The discussions about cooperation showed that there is a great interest in the thyroid group of Åland to have more contact with the thyroid associations on the Finnish continent, especially for publishing more information material



WTD event in Finland – thyroid booth in Vaasa Rewell Centre on the World Thyroid Day. From left: Sirkka-Liisa Tamminen, Hilka Heikkilä and Anneli Tervasmäki, board members of the Thyroid Association of Vaasa, Finland.

about thyroid disease in Swedish.

The world is changing towards globality in all countries; the travelling is easier than a hundred years ago, and people move and live in states with other languages than their own. There are a lot of these people who do not know any of the world's main languages and need information material about their disorders in their own language.

Sending out that information about thyroid problems over the internet in different languages during the Thyroid Awareness Week and World Thyroid Day is an essential task of the international doctors and patient thyroid organizations. It is nice to work together and see Finland become part of the world community during World Thyroid Day and Thyroid Awareness Week.

www.thyroidweek.org

May 19 to 25, 2014

6th International
Thyroid Awareness Week

www.thyroidweek.com

GDATF Hosts 19th Annual Patient and Family Conference

AUTHOR: KIMBERLY DORIS, EXECUTIVE DIRECTOR
 GRAVES' DISEASE AND THYROID FOUNDATION

The Graves' Disease and Thyroid Foundation (GDATF) is a U.S.-based non-profit organization dedicated to providing education and support to those impacted by Graves' disease, thyroid eye disease, Hashimoto's thyroiditis, and other related disorders.

Programs and services include a web site (gdatf.org) with free informational publications, an online support forum for patient questions, a network of local patient support groups, patient support via phone or e-mail, and a print and e-newsletter.

The GDATF's patient & family conference is an annual tradition, giving attendees the opportunity to connect with fellow patients and family members and to hear the latest on treatment options from internationally recognized experts.

The Foundation's 19th annual conference was held Oct. 26-28, 2012 at the Kona Kai Resort & Spa in San Diego, California. The event featured a stellar line-up of presenters on a wide range of topics. A few highlights follow:

- Dr. Noel Rose (Baltimore, Maryland) from the Johns Hopkins Autoimmune Disease Research Center kicked off the program with a discussion of autoimmunity. Dr. Rose noted that autoimmune diseases occur when the body's own immune system mistakenly attacks healthy tissue. Two of the most common autoimmune disease – Graves' disease and Hashimoto's thyroiditis – both affect the thyroid.
- Dr. Terry Smith from University of Michigan Kellogg Eye Center recommended that patients "find a doctor who evaluates and considers your whole body, not just your thyroid."
- Dr. Andrew Gianoukakis of Harbor-UCLA Medical Center shared that long-term use of Anti-Thyroid Drugs is more common in Europe than in the U.S.
- Dr. Kevin Brumund of University of California San Diego spoke about thyroid surgery as a treatment option and recommended that patients seek out surgeons who do at least 40-50 procedures per year.
- Dr. Carl Hoh of University of California San Diego noted that patients undergoing RAI as a treatment option should not stay in a hotel while under post-RAI safety restrictions, as the next guest could potentially be exposed. Dr. Hoh also shared that those travelling post-RAI should carry a patient card in case they set off airport radiation detectors.
- Dr. David Granet from University of California San Diego's Shiley Eye Center spoke about the emotional burden of living with thyroid eye disease: "Imagine you wake up in the morning & you don't look like yourself. That's devastating. Levels of depression & anxiety in thyroid eye disease patients rival that of patients with cancer and AIDS."
- Dr. Don Kikkawa from University of California San Diego's Shiley Eye Center explained that surgery for thyroid eye disease is reconstructive and restorative, not cosmetic! Many U.S.-based insurance companies will refuse payment if a procedure is coded as cosmetic.
- Dr. Raymond Douglas from University of Michigan Kellogg Eye Center noted that large medical centers need to ensure that the patient remains the center of focus, rather than creating "silos" where doctors don't communicate.
- Dr. Catherine Hwang from the University of California @ Los Angeles (UCLA) Jules Stein Eye Institute noted that thyroid eye disease can occur before, during, or after the onset of thyroid involvement. She shared that some of her patients had noted reduced inflammation by following an anti-inflammatory diet and advised participants to eat less "CRAP" (cheese, refined sugar, artificial anything, and processed foods).
- All of the presenters on thyroid eye disease stressed the importance of quitting smoking and avoiding exposure to second-hand smoke. Dr. Kimberly Cockerham of Cockerham Eye Consultants explained that nicotine is a direct stimulant of the autoimmune process.
- Volunteer Elias McQuade provided an update on the GDATF's "Greater Than Graves'" coast-to-coast bike ride, which raised \$13,000.

(continued on page 15)

19th Annual Patient & Family Conference (continued from page 14)

- Dr. Michael Gottschalk of University of California San Diego shared that Graves' disease in children can be misdiagnosed as ADHD and that deterioration in a child's handwriting can be an early warning sign of Graves'.
- Dr. Ira Lesser from the Geffen School of Medicine at University of California Los Angeles explained that thyroid abnormalities can directly affect emotions, but that psychiatric disorders can sometimes occur independently of Graves'. Getting a proper diagnosis can be a challenge, as symptoms of anxiety disorders, panic attacks, bipolar, and depression can mimic those associated with Graves' disease.
- Dr. Larry Wood (Boston, Massachusetts), founder of the Thyroid Foundation of America and a past president of the Thyroid Federation International noted that 17% of pregnant women in the U.S. are deficient in iodine and that 2.4 billion people worldwide are iodine deficient.

The event also featured some favorite traditions, including a Thursday night social reception and two "Ask the Doc" sessions during Saturday lunch and Sunday breakfast.

A new feature at the 2012 conference was a 5-member patient panel moderated by GDATF Founder and Chairman Emeritus Dr. Nancy H. Patterson (Hendersonville, North Carolina), where participants shared their insights on finding a "new normal", minimizing stress, and managing priorities.

One downside of the conference was its timing — Hurricane Sandy left many attendees from the East Coast stranded for several days due to cancelled flights. But as several participants quipped, "There are worse places to be stranded than California."

The GDATF will test a new format for 2013, with a series of one-day events around the U.S., rather than a single multi-day conference. "We receive very positive feedback from the attendees who travel to our multi-day conferences," stated GDATF Executive Director Kimberly Dorris. "But we also hear from many patients who are unable to pay for travel or take off work to attend a multi-day conference. At the end of 2013, our Board will evaluate this new format both in terms of number of patients reached and attendee satisfaction."

Get Smart – Protect Your Baby's Brain (continued from page 12)

The Australian Thyroid Foundation messaging also recommends the importance of testing and monitoring thyroid hormone function levels during pregnancy.

Without adequate thyroid hormone during foetal development this Silent Epidemic could not only put the foetus brain development at risk, but could also impact on sustaining pregnancy.

The Australian Thyroid Foundation will launch the updated version, "Get Smart – Protect Your Baby's Brain" campaign on Mother's Day 2014.

Get Smart. Protect your baby's brain.

If you are considering pregnancy, or if you are pregnant or breastfeeding, **your thyroid function and an adequate daily iodine intake** is essential for the brain development of your baby.

Australian research shows that **50% of pregnant women** are **iodine deficient**, which can affect the development of the foetal brain and lead to lower intelligence and learning difficulties.

The Australian Thyroid Foundation recommends you take a specifically-formulated daily **pregnancy supplement** containing at least **150 mcgs of iodine**. Also replace the salt you use with **iodised salt**, to ensure you get adequate iodine in your diet.

The Australian Thyroid Foundation also recommends ensuring you speak to your doctor about the importance of **testing and monitoring your thyroid hormone levels**. Thyroid hormone is essential for the development of the foetus and sustaining pregnancy.

Safeguard your baby's health and speak to your GP or obstetrician about the benefits of **Iodine Supplementation** and **Good Thyroid Health** or visit our website **www.thyroidfoundation.com.au** for more information.

ORGANISED BY



The Australian
Thyroid Foundation Ltd

Sarah C Bath PhD, Colin D Steer MSc, Prof. Jean Golding FMedSci, Pauline Emmett PhD, Prof. Margaret P Rayman DPhil, Effect of inadequate iodine status in UK pregnant women on cognitive outcomes in their children: results from the Avon Longitudinal Study of Parents Children (ALSPAC). *The Lancet, Early Online Publication, 22 May 2013* doi: 10.1016/S0140-6736(13)60436-5

Kristen L. Hynes, Petr Otahal, Ian Hay, and John R. Burgess. Menzies Research Institute Tasmania (K.L.H., P.O.), Faculty of Education (I.H.) and School of Medicine (J.R.B.), University of Tasmania, Sandy Bay, Tasmania 7005, Australia; and Department of Endocrinology (J.R.B.), Royal Hobart Hospital, Hobart, Tasmania 7000, Australia. *Jcem.endojournals.org J Clin Endocrinol Metab, May 2013 98(5):1954-1962* doi: 10.1210/jc.2012-4249

www.thyroidfoundation.com.au

The Italian Association of Graves' and Thyroid Patients (AIBAT)

AIBAT (Italian Association of Graves' and Thyroid Patients) was founded in 1996 by Emma Bernini and Donatella Aimi. Both of them were suffering from thyroid pathologies and wanted to help other patients. They were convinced that patients need the appropriate therapies prescribed by specialists, but could also be helped by sharing their experiences and by finding correct information on their pathology and the therapies available.

AIBAT's activities are supported by volunteers and members, with the important contribution of specialists for the publication of our informative booklets and participation in conferences and other events organized for patients and to raise public awareness. We are based in Parma and are active also in Reggio Emilia.



Medical Director Giorgio Bouquets, Dr. Roberto Valcavi director of the Service of Endocrinology, Dr. Stephen Savonitto, director of the Service of Cardiology, Emma Bernini national president of AIBAT.

Patients have shown appreciation especially for initiatives like "The Patients tell their Story", conversations with specialists who answered questions from the public; "Know your Thyroid: free for all ultrasound exams", thanks to which some people discovered what their thyroid was and others that it needed medical attention; "Art and Thyroid", a conference to know more about thyroid disorders and therapies, followed by guided visits to art exhibitions to learn how beauty can help by arousing emotions and giving comfort to those suffering.

We have a telephone help line, and AIBAT's volunteers are present at the Centre for Thyroid of the Arcispedale Santa Maria Nuova in Reggio Emilia to give patients a warm welcome, to make them feel that they are not alone, to help relieve their anxiety about the exams or the therapy they are seeking.

To celebrate the new year 2013, AIBAT published a Calendar dedicated to patients: every month is illustrated by a portrait of a woman, painted by famous artists from Parmigianino to Picasso, followed by a quotation of words of a patient, or a volunteer, a doctor or a nurse. On the occasion of the World Thyroid Month AIBAT sponsored two events. The first was a Photography Exhibition, with photos of doctors, patients, volunteers and nurses taken by Nadir Bonazzi at the Arcispedale S. M. Nuova in Reggio Emilia: Bonazzi donated the photographs to the hospital because he felt that the medical staff took very good care of patients. The second was "Thyroid and the Heart", a conversation with Dr. R. Valcavi, Director of Endocrinology and AIBAT's scientific adviser, and Dr. S. Savonitto, Director of Cardiology at the Arcispedale S.M.Nuova in Reggio Emilia, who answered the questions from the public on this important subject.

To read patients' stories (including that of our founder Donatella Aimi) and see video clips on our activities, visit our web site www.aibat.it.



Activities of the Thyroid Foundation of Canada



AUTHOR: MABEL MILLER, NATIONAL PRESIDENT
THYROID FOUNDATION OF CANADA

Thyroid Foundation of Canada, the first organization in the world of its kind for Thyroid patients, continues with its mission. We are an enthusiastic group of people with interests in promoting the well being of all thyroid patients. As an organization, we continue on a journey upward and onward with Education & Awareness events, recruitment of Volunteers, and Fundraising.

In the past year we've seen some new developments in Education and Awareness through a couple of different approaches. A one day Workshop proved to be very successful and the start of something different in how we reach patients. Social Media is expanding and we are now on Facebook and Twitter. This gives those who have access to such sources a more versatile means of keeping in touch with us and the various items on the latest thyroid news. Some highlights of the year as follows:

Health Workshop

Gander, NL, Canada chapter saw a great partnership form with a team of Public Health Nurses employed by Central Community Health in Newfoundland. They assisted in putting together a program that would appeal to all thyroid patients. Presentations were as follows: Thyroid Disease, Active Living, Nutrition and Medications. *Health Guides on Thyroid Disease* and other educational materials were made available as well some other related Healthy Living information. Sixty-five participants attended the workshop who felt it was a very worthwhile day. All evaluations completed showed a very successful event. Plans are underway for more of this type of presentation in the future.



Other Education sessions in various areas across Canada continue to be a great source of needed information on thyroid disease.

Fundraising with Class

London, ON, Canada has become well known for their annual *A Touch of Spring* Fashion show featuring clothing from well renowned clothing designers.



It's always a delightful evening of dinner and modeling by friends of the Thyroid Foundation of Canada. This has become one of the biggest fundraisers for chapters.

Something new for TFC has been *Let's Light a Tree* campaign which is done prior to the Christmas season inviting members, friends and others to donate and add a star on our virtual Tree displayed on our website. We are now planning a virtual *Butterfly Garden* where we will accept donations for a butterfly in the garden. This will be on our website during the months of May and June and will bring more prominence to *June is Thyroid Month in Canada*.

June is Thyroid Month in Canada

In 2012 TFC started something new for our Annual General Meeting, signing a Proclamation and developing a theme. The theme of this year's "June is Thyroid Month in Canada" is *Thyroid Disease is a Family Affair*, in recognition of the genetic connection in thyroid disease. Helping families of thyroid patients become more aware that other family members could also develop a thyroid condition will lead to being better informed, to recognize the symptoms and, ultimately, to an earlier diagnosis.

Promoting Awareness took on a new twist this year. Electronic board displays in various medical centres across Canada will show a short message of what thyroid disease is and who we are, bringing awareness to a vast population that may not otherwise be reached.

The best possible care for thyroid patients is our concern. We will continue to maintain a slogan developed a few years ago —

We are the Voice and Face of Thyroid Disease in Canada

“My Africa”

AUTHOR: ULLA SLAMA DR MED, BOARD MEMBER OF THYROID ASSOCIATION IN FINLAND, PRESIDENT OF THYROID ASSOCIATION IN VAASA REGION

Africa is a fascinating continent with beautiful lands, animal diversity, poverty, diseases, rich music, and friendly people with a good social life rarely found in industrial countries. I went back to Ethiopia for the third time in November 2012 together with my friend Britt-Marie, who is leading a nursing school in Western Finland.

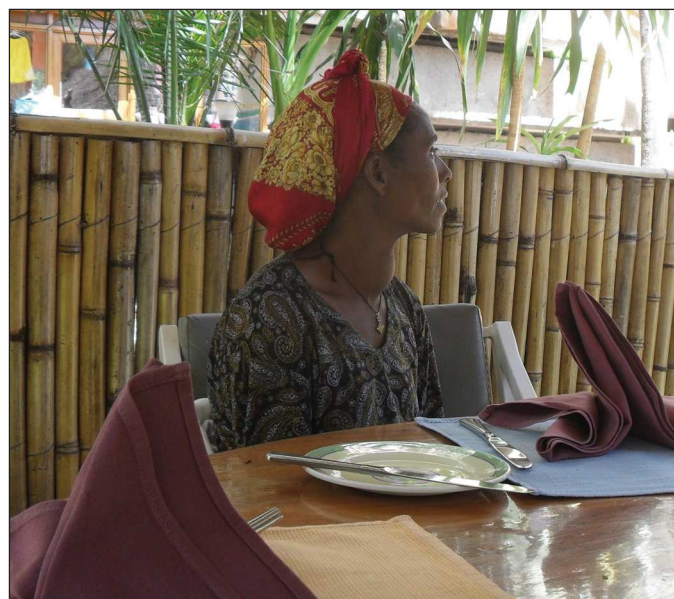
My first visit to Ethiopia was seven years ago when I worked together with a group of infection specialists from Sweden. We spent the practical part of our education in tropical diseases in Ethiopia. I became aware of how many people had goiter in Ethiopia, both young and elderly. It can be explained by iodine deficiency, in a mountainous landscape with a huge countryside and many different tribes with their own languages living in remote places without access to healthcare and education. However, although the time was relatively short since my first visit in Ethiopia, I noticed some change towards economic progress in the city picture. There were now more cars, at least three-wheeled ones, and more people wearing shoes. The main roads had been covered with asphalt due to Chinese companies. It was especially obvious in places where we'd had to drive the car in ditches three years ago; now we covered the same route in two days compared to three days last time. The climate in Ethiopia is pleasant for tourists from about November to March with sun every day, but in the European summer months, because of



Britt-Marie, Zemed and Ulla.

the high altitude it can be very cold with daytime temperatures around 17 degrees Celsius and nighttime temperatures down to 3-4 degrees. Dry spells and heavy rains can cause problems for agriculture, and famine often occurs in some areas of the country causing malnutrition. My friend, Dr. Shitaye from the Gondar university clinic, has described a third kind of diabetes, malnutrition diabetes, in which the pancreas gland cannot produce enough insulin because of protein deficiency.

During this trip, we also went to the holy city of Lalibela in Northern Ethiopia, 2-3 days by car from Addis Ababa, where I sponsor the schooling and food for some young people who have moved there from small villages in the countryside. One of them is Getawe, now 17 years old. He took us to the hut where he stays with his sister Zemed, a woman aged 30-35;



Zemed with goiter (at swimming pool in Addis).

she does not know exactly and cannot count either. Zemed was in poor health, and she had to prepare food for Getawe who went to school. She had breathing problems and had gradually become weaker. Before she moved to Lalibela she lived in a small village, or hut group, about 60 km away. She left her husband because of her illness and went to Lalibela, where she thought to find holy water, which could make her healthy again. So she stayed in the hut with her young brother and slept at the foot of his narrow

(continued on page 19)

“My Africa” (continued from page 18)

bed which they had built out of branches, and underneath it they kept 3-4 chickens (by now they will have eaten all these chickens).

I noticed that Zemed had a goiter, and she also had a nodule. Britt-Marie and I decided to take her with us to Addis Ababa to examine her. It was the first time Zemed had ever travelled by air. At the hotel, we were surprised to realize, as she looked at her face in the mirror in our room, that she was seeing herself for the very first time in her life. She looked up and down at her dress and again into the mirror several times and then she started laughing. We had some problems showing her how to use the bathroom; she climbed up on a chair and also sat down below the hand basin, but after some hand gesticulations she understood and soon learned many of the ways of our modern civilization. We had no common spoken language. A Finnish friend of ours living in Addis tried to talk Amharic with her, but they could not understand each other either. There are about ninety different languages in Ethiopia.

While we were in Addis, I noticed that Zemed had a lot of relatively hard nodules in her axilla. Oh no, I thought, why did we do this, take her to the capital, give her hope and then have to take it away? If there were so many cancer distant



Zemed makes coffee.



Dr Digafe, outside Alert Leprosy and Tuberculosis Hospital in Addis Ababa.

metastases, she would have no chance to get any kind of treatment in her region except for some simple painkillers, and to move to the capital for months would be tragic for a woman from the wilderness like her. After a lot of visits between different labs in Addis and with the great help of Dr. Digafe, who is a university professor and specialist in infectious diseases and dermatology in the Alert Leprosy Hospital of Addis Ababa, we could finally find out the correct diagnosis for Zemed. The hard even lymph nodules in her axilla were due to an infectious disease. Her goiter was benign, and her TSH and free T4 were close to hyperthyroidism but still within normal levels!! With a certificate from Dr. Digafe she was able to get her treatment covered by the State, and after sufficient nutrition and half a year of treatment with drug combinations, she could finally finish her treatment in June. I talked with her brother by phone some days ago in August 2013, and he told me that his sister Zemed is very happy and in good health again.

Finally, it is to be hoped that African doctors will soon have the possibility to participate in thyroid conferences. And that sometime in the future, patient organizations can be started in sub-Saharan Africa.

May 25th, 2014
World Thyroid Day

Thyroid Association of Finland



AUTHOR: ULLA SLAMA DR MED, BOARD MEMBER OF THYROID ASSOCIATION IN FINLAND, PRESIDENT OF THYROID ASSOCIATION IN VAASA REGION

At our TFI meeting in Pisa 2012 we had a discussion about the contents of ThyroWorld. It was felt that we should write more about the organization and activities of the national patient organizations. I will briefly relate a little about what we are doing here in Finland, and our organization's leader Asta Tirronen will speak more about it and give a Power Point presentation at the TFI meeting in Leiden.

The thyroid organizations of Finland started as a small group of about 20 people in Helsinki in the year 1995. It was supported by Professor Bror-Axel Lamberg, who was one of the founding members of ETA, and by Professor Matti Välimäki; both are well known in Finland as medical school professors of endocrinology at the University of Helsinki.

As the membership of the thyroid group in Helsinki increased, the name was changed to the Thyroid Association of Finland. The name remains the same in English, but in Finnish and Swedish the association had to be changed to a "Federation" in 1999 because by then we had several regional associations. Today there are 15 regional thyroid associations in Finland belonging to the national Thyroid Association of Finland.

The membership has grown continuously and there are now about 7,000 members. The yearly membership fee is 19 euro; of this, half goes back to the regional associations. The rest of the budget is covered by the national lottery organization RAY. The membership records are held by the national organization and a professional accounting firm controls the finances.

The members receive the newsletter "Kilpi" (meaning shield, from the shield of the turtle, *tiroidos* in Greek). Kilpi has about 30 pages and complimentary copies are sent to members four times per year. There are also leaflets in Finnish and Swedish on hypothyroidism, hyperthyroidism, children's thyroid disorders and thyroid cancer. Recently a book for patients about thyroid disease was published in Finnish by Dr Esa Soppi.

The address of our website is www.kilpirauhasliitto.fi, in Finnish only at this time.

There is a telephone help line held every Thursday night.

The Thyroid Association of Finland has an office in Helsinki, with two full-time employees and one part-time. The activities of the employees are contributing to the growth of the membership numbers.

Each year three weekend training camps for thyroid patients are held in spa hotels in different regions of Finland. A special camp is arranged for young people. Two camps for thyroid patients and their families take place in July. A weekend meeting for the presidents of the 15 regional organizations takes place yearly in the autumn. A strategy weekend is held in spring.

The local associations hold events and arrange specialist lectures all over the country. The patient support groups in some associations, which come together once a month, are very important.

The annual meeting is held in June. The regional associations can send one voting person per 100 members to the annual meeting and the number of votes depends on the membership size of the association. For example, if an association has 900 members, it has 900 votes. If they send 9 representatives, each one has 100 votes. If the association sends only 2 representatives each of them have 450 votes. Activity and financial reports from the past year are presented in several printed booklets and the activity and financial plans for the next year are made. For example, at this year's annual meeting in June 2013, the whole plan for the year 2014 has been completed.

The representatives for the next year are elected at the annual meeting. The board members of the ongoing year continue until the 31st of December.

Finland is a member of TFI and a representative has been sent to the TFI meetings since the year 2000. In 2012 we had two representatives attend and again, for 2013, there will be two of us.

The statutes of the Thyroid Association of Finland are legalized by the Ministry of Law and the Register and Patent Directory of Finland.

It is essential for a big organization to have a good structure. In this way conflicts are better avoided and the organization can work and develop in a positive atmosphere. The goal is to give support and information for thyroid patients alongside of the doctors.

Notable increase in T4 use in the Netherlands

The number of thyroid patients using T4 has increased by more than 50% in the last six years.

AUTHOR: NIKO DE JONG, SECRETARY OF THE BOARD OF THE DUTCH THYROID ASSOCIATION (SON)

Information from Dutch pharmacies reveals that the number of thyroid patients in the Netherlands has increased markedly in recent years – a staggering increase of 53% in the last six years. If this increase continues, there will be over 500,000 thyroid patients using T4 (thyroxine) in March 2013.

A few years ago we thought there would be at least 300,000 thyroid patients. But we did not know for sure. We suspected that in reality the number of patients would be much higher, but were unable to prove it. A count in 2006 revealed that 320,000 patients were using T4 daily and that 3,200 patients were using T3 (trijodthyronin) daily, usually in combination with T4. The number of patients that are prescribed T3 together with T4 is increasing, but this is still no more than 1% of the T4 users.

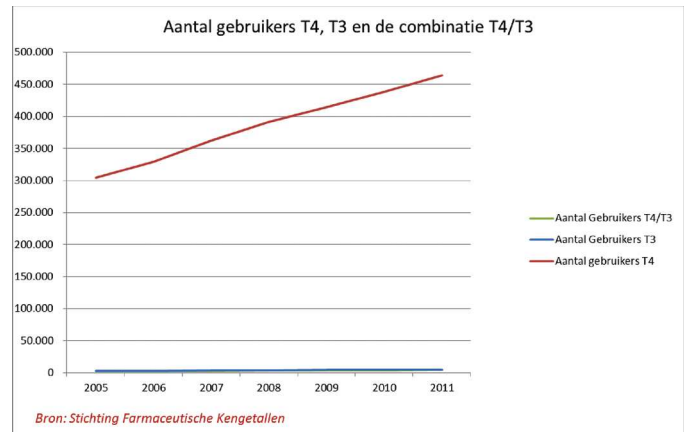
‘We suspected that in reality the number of patients is much higher, but were unable to prove it’

Intriguing

An annual increase of approximately 8.7% in the use of T4 is considerable and it intrigued me. Part of the increase can be explained by the population growth and the doubling of the ageing population. Over these past six years the population has grown by a total of 2.1%, an average therefore of 0.35% per year. By a twofold increase in the ageing population we mean that on average people live longer and hence there are more and more older people. The twofold rise in the ageing population could contribute to 1.2% of the annual increase. If we subtract the two annual increase percentages from 8.7% we are left with a rounded off figure of 7% which we are unable to explain directly. Where could that increase come from? There are three theories.

1. Sub-clinical hypothyroidism

A patient's blood tests often do not give the G.P. direct cause of concern regarding the thyroid. In retrospect it is often a thyroid problem.



In science this is referred to as sub-clinical hypothyroidism. As of 2006 G.P.'s have been more vigilant for sub-clinical hypothyroidism and they therefore diagnose it on time, more often.

2. New software

Specific software has been developed in recent years for G.P. practices for the request of blood tests. G.P.'s now take patient's blood more readily if the patient is complaining of fatigue and much to their surprise they are finding more hypos.

3. Using Google

People are "digi-doctoring" more and more. Those who Google vague symptoms are often given a link to a thyroid problem. Patients are asking G.P.'s. more and more specific questions during surgery hours with regard to the thyroid. G.P.'s are listening to the patients and when conducting further examinations they find a thyroid problem at an earlier stage, earlier than before.

At least 10,000 individuals view the patients' support group websites a week. This substantiates the Google hypothesis and for the near future it is probably the most promising one. We do not know whether all these hypotheses are equally valid, neither do we know whether the increase will continue. In order to find a more conclusive explanation further investigation will be required.

Niko de Jong is Secretary of SON (Dutch Thyroid Association) and Chairman of NVGP (Dutch Association for Graves patients). He published articles on this topic in June 2012 in the European Thyroid Journal. For more information: dejongniko@planet.nl
T4, Thyroxine is distributed under various brand names: Thyrax, Euthyrox, Eltroxin and suchlike.
T3 is distributed as Cytomel.

Salt Reduction and Iodine Fortification Strategies in Public Health

AUTHOR: BEVERLEY GARSIDE
– PRESIDENT –THE AUSTRALIAN
THYROID FOUNDATION



The George Institute, Australia/WHO and the ICCIDD jointly convened an Information Exchange Forum on Salt Reduction and Iodine Fortification Strategies in Public Health, March 25, 2013 in Sydney Australia.

I was invited to attend this international meeting as a member organisation representative of Thyroid Federation International (TFI). I represented all member organisations, as the President of The Australian Thyroid Foundation.

The first day of the consultation was attended by representatives from WHO/The George Institute, ICCIDD, UNICEF, international and local medical researchers, government health officials, food industries, consumer organisations, patient organisations, non-government organisations, including the Food Standards of Australia and New Zealand. The following two days of the consultation involved medical experts discussing and designing strategies to reduce salt intake in the diet to prevent cardiovascular disorders while ensuring edible salt continues to be used as the most important vehicle for iodine fortification in the food supply.

The Australian Heart Foundation and The Australian Stroke Foundation were represented. The Heart Foundation gave a presentation on the importance of reducing salt in manufactured foods. Local and international medical researchers gave presentations on the effects of increasing salt in the diet and the results of heart disease and stroke.

World Iodine/Thyroid Researchers gave presentations on the importance of fortifying salt with iodine, as a vehicle to ensure the world population received an adequate daily iodine intake to reduce iodine deficiency and eventually eliminate this health issue.

There were presentations and discussions about the importance of ensuring pregnant women received an adequate daily intake of iodine (250 mcgs) to ensure the developing foetal brain was not impaired. Without enough daily iodine before and during pregnancy and while the mother is breastfeeding, can result in the reduction of the child's IQ and other significant brain developmental problems.



Dr Michael Zimmerman – ICCIDD Switzerland, Beverley Garside – ATF President, Professor Creswell Eastman – ICCIDD Australia and ATF Patron, Dr. Eduardo Pretell – ICCIDD Regional Co-ordinator Peru.

At the conclusion of the three day consultation, a Press Release, dated March 27th, stated that The George Institute and The WHO as a Collaborating Centre on Population Sodium Reduction will provide ongoing technical advice and support for low to middle income countries to implement salt reduction strategies, access evidence based research and advise on effective salt reduction strategies, be a forum for exchange of best practices in salt reduction and support countries in relation to measuring and monitoring progress of salt reduction.

The centre will launch April 1st, a Salt Reduction and Iodine Fortification Strategies in Public Health Consultation. This is part of the WHO's Non-Communicable Disease action plan implementation program, to begin the development of a Framework for Member States for salt reduction strategies to help them achieve the global targets.

The ATF as the TFI Representative at this meeting, realize salt reduction is necessary to improve the overall health of the world population. However as important as salt reduction is, the necessity to ensure the world addresses the importance of eliminating iodine deficiency to improve the outcomes of the future generation's brain development and thyroid health disorders, is just as important to world health outcomes and needs to be acknowledged to ensure both health issues are improved by all stake holders collaborating to continue to work together to reduce both heart/stroke disease and iodine deficiency worldwide.

Success at Court for the reimbursement of Thyrogen

AUTHOR: JOKE VAN GALEN, BOARD
MEMBER OF THE DUTCH THYROID
ASSOCIATION (SON), THE NETHERLANDS

In 2010, the Health Care Insurer, Menzis, restricted the use of Thyrogen®. It was only to be used in hospitals as part of a specialised treatment regime. At the time, patients were suddenly faced with changes in policy terms and conditions that were very disadvantageous because the financial budget for Thyrogen® use in hospitals was very limited. The Netherlands Thyroid Foundation presented this case to the Judge, on behalf of the patients together with the manufacturer Genzyme and the supplier ApotheekZorg.



Joke van Galen

What is Thyrogen®?

Thyrogen®, recombinant human TSH, can be used right from the start of the primary treatment with radioactive iodine and in blood tests and the body scan during the diagnostic follow-up of patients with thyroid cancer whose thyroid has been removed and require thyroid hormones.

What is the matter at hand?

In the Netherlands, medicinal reimbursement takes place via two systems: medicine that is used outside a hospital (pharmaceutical care) and medicine that is used for specialised treatment in hospital (medical care). The pharmaceutical care is regulated by the "Geneesmiddelen VergoedingsSysteem (GVS)" (Drugs Reimbursement System (DRS)). Some medicines, such as Thyrogen® are reimbursed by the DRS, but they can also be used *in* hospitals.

Insurers and the Regulatory body

Insurers can, to a certain degree, and within the framework of the Healthcare Insurance Act, determine additional terms and conditions for the reimbursement of medicines, in an effort to enhance an efficient health care system. In 2010,

Menzis had therefore included a condition that Menzis had to approve the use of Thyrogen® outside the hospital in that the reimbursement was limited to use *in* a hospital, unless it was outside the 30-kilometre radius of the insured person's place of residence. The use of Thyrogen® in a hospital was however met by financial constraints due to budget restrictions, as the use was being reimbursed by the DRS if used in a home situation.

The Dutch Healthcare Authority (NZA) monitors the policy conditions of healthcare insurers. It did not object to Menzis' terms and conditions for Thyrogen®. A number of parties felt that Menzis could not set such a condition and therefore requested the NZa to instruct Menzis to alter the policy terms and conditions. The NZa did not feel this was necessary.

The verdict

The case was presented to the Trade and Industry Appeals Tribunal (CBb). The Netherlands Thyroid Foundation was one of the parties during this court case against the NZa. The CBb has now decided that Menzis' terms and conditions for Thyrogen® are not in line with the Healthcare Insurance Act. Following this, the NZa requested Menzis to bring its Insurance regulations in line with the Healthcare Insurance Act and to duly inform its clients. In the meantime, Menzis has adjusted its terms and conditions. The limitation is therefore no longer applicable to the subsequent post-2010 insurance regulations.



TFI Member Organizations

AUSTRALIA

The Australian Thyroid Foundation Ltd.
Beverley 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
www.levenzonderschildklier.nl

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
Ashok Bhaseen (President)
PO Box 298
Bath ON K0H 1G0 Canada
www.thyroid.ca

DENMARK

Thyreoidea Landsforeningen
Jytte Flamsholt Christensen
(President)
Bente Julie Lasserre (TFI Representative)
Strandkrogen 4C
3630 Jaegerspris, Denmark
info@stofskifteforeningen.dk
www.stofskifteforeningen.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
(President)
Elena Shelestova (Contact)
National Centre for Diabetes
Research
1, Chachavha str, fl. 4
Tbilisi, 0159, Georgia
diabet@access.sanet.ge
e_shelestova@yahoo.ge

GERMANY

*Bundesverband Schilddrüsenkrebs
– Ohne Schilddrüse leben e. V.*
Harald Rimmele (Managing Director)
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 Tiroides
Carlos M Duncker, MD (President)
Zacatecas 230, Quinto Piso
Colonia Roma, C.P. 06700
México, D.F., México
amet@tiroides.org
www.tiroides.org

THE NETHERLANDS

Schildklier Organisaties Nederland
R.M. Bink-Leijh MA (International
Representative SON)
Stationsstraat 79G
3811 MH Amersfoort
the Netherlands
www.schildklier.nl

NORWAY

Norsk Thyroideaforbund
Solveig Sikkeland (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 – 1º 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

British Thyroid Foundation
Janis Hickey (Director)
2nd floor, 3 Devonshire Place,
Harrogate HG1 4AA UK
www.btf-thyroid.org

UNITED STATES OF AMERICA

Graves' Disease & Thyroid Foundation
Nancy Hord Patterson (Founder)
P. O. Box 2793
Rancho Santa Fe, California 92067
info@gdatf.org
www.gdatf.org

www.thyroid-fed.org