

THYROID WORLD



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Thyroid Federation International

Established in September 1995 in Toronto, Canada

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Katherine Keen

Member Organizations

Our member organizations now number 22, representing 17 countries. The names of the organizations and their current addresses are given on pages 11-12.

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From the Editors' Notebook



JRB, Editor

As you may have gathered from the above placement of the apostrophe, there has been more than one editor at work on this issue, namely Beate Barte and myself. As it is the last one that I expect to be working on, it seemed like a good idea to mark the transition in some way and share the responsibilities; one editor to invite articles, gather and sort material while the other did a general layout and edited the copy. As often happens in new ventures, there have been problems especially in gathering the material, but Beate Bartès can tell you about those! And I can tell you that you can't edit what you don't have.

This issue marks an anniversary—it's been ten years since we held our conference in Greece in the spring of 1998. The roads were fragrant with wild flowers. Our hotel was at the foot of Mount Olympus and we could walk through the fields or along the shore to a charming little country inn where we ate, drank and generally made merry.

Sadly some of our colleagues who were there that spring will not be there this time. I think particularly of Dr. Robert Volpé who contributed so much to TFI in its formative years. Some stalwarts, however, are still with us, I'm happy to say. Larry Wood, our first president and mentor, has always been ready to step into the breach and shoulder more than his share of the load, including contributing many articles and acting as interm president when needed. Kudos Larry.

As always, the Greeks have a word for it! [JRB]
And now here's Beate ...

For me, putting this issue of ThyroWorld to bed has been a real learning experience—at times a very frustrating one when nothing seemed to go right. I never before realized nor appreciated how much detail or time was involved.

This issue has truly been an international one: the editors in France and Canada, articles coming in from UK, USA, the Netherlands, Sweden and Finland, printing and delivery of the finished product to Greece in time (we hope) for the ETA conference. Having had my baptism by fire in this issue, I can only hope that I can put my "lessons learned" from this issue to good use in the next one! [BB]



BB, Editor

President's Message

Once again it is time to write the president's message. I remember the first time that I did so. I was honoured, proud and full of energy to put my thoughts, regarding thyroid problems and the role of the patient organisations, on paper. The important issue was to establish good co-operation with the professionals for a mutual benefit.

I am still very proud to again write the message but this year I really want it to be an opportunity to work together in an effective way for the future on behalf of the patients.

There is so much unexplored ground within the thyroid area and still so many unanswered questions.

There are many patients who feel still miserable even after treatment and who never feel as they used to. There are so many people who lack a good quality of life.

We cannot just standby and accept this situation. Life is far too short and valuable for all human beings. Everyone is worth a life as healthy and as good as possible.

One of the most frequent questions is "What should the TSH level be?". The GP's and internists tell patients that the TSH value is their guideline. If the TSH is within the established limits, then the patient is cured. I, myself, have participated in eight ETA conferences and four ATA meetings and



*Yvonne Andersson,
President*

at every occasion this issue has been discussed backwards and forwards. And yes the answers regarding the optimal or desired value have differed. In this way it is hard to get the patients to feel well and certainly the ones who have sensitivity for dose changes of their thyroxin.

Some time ago I read a Danish study of TSH in healthy people. The results really gave me something to think about. It gave us an idea of the need for a major study of the TSH levels in a good co-operation between the specialists and the patient organisations. We have to use all of our resources to make a difference for the patients. That is our joint responsibility, of the patient organisations and the specialists.

I would look forward to and appreciate a joint discussion and brain-storming session to identify important issues where we really can work together for the benefit of the patients.

Ten years ago we had a lovely meeting in Greece. I am sure that this year's meeting, also arranged by Professor Krassas, will be as nice as last time. I hope that we can help Greece start a patient organisation and I would really like to see this year's meetings of TFI and ETA as a "kick-off" for a new way of working together for a positive result.

Looking forward to seeing you all in Greece. 🍷

Yvonne Andersson, President of TFI

Message from the Board of Directors

The Thyroid Federation International is becoming stronger and more active in our efforts to expand and refine programs which educate and support thyroid patients.

We are increasing public awareness of thyroid disorders so that patients with a thyroid problem recognize it and get appropriate information and treatment.

This year we will begin our project of designing thyroid web sites for different countries in Europe. This will be done in association with physicians of the European Thyroid Association. Each web site will be developed with the help of a thyroid specialist in that country so that we are sure that we are coordinating our recommendations with the current thyroid practices in the country. We will provide information about thyroid disorders and

thyroid related conditions including a number of other autoimmune disorders which occur with increased frequency in individuals who have hyper and hypothyroidism.

We will also be providing information about the use of new medications such as thyrogen (Genzyme Corporation) which is becoming increasingly helpful in the treatment of thyroid cancer but also in shrinking large goiters in many parts of the world.

We at TFI are anxious to help anyone, patient or physician, develop a new TFI chapter in your country. If you are interested in getting help to create such an organization, please contact our TFI Headquarters at: TFI@on.aibncom

We would welcome the opportunity to help you help thyroid patients and their families in your country. 🍷

Women of Means

Hypothyroidism is common among women and especially common in older women. Routine screening of women over the age of 50 shows that 10% are hypothyroid and would benefit from thyroid treatment.

In recent years, simple kits have been developed through which a physician or nurse (or the patient) can perform a simple blood test, which tells whether the TSH level is greater than 5 uU/ml. This level is understood by most physicians to be the cutoff point between normal thyroid function (below 5 uU/ml) and hypothyroidism (above 5uU/ml).

Dr. Roseanna Means is a member of Harvard's Medical School Faculty and a successful physician with a practice in the affluent Boston suburbs. She sees privilege everyday. But she also sees the lives of downtrodden, battered, and homeless women with no privilege and no health insurance.

... her life's mission [is] to bring free medicine, healthcare, and hope to these women.

She has made it her life's mission to bring free medicine, healthcare, and hope to these women. Five years ago, Dr. Means started *Women of Means* taking her expertise and that of more than a dozen doctors and nurses to ten homeless shelters in Boston. Last year the program provided service to 5,000 women and children that would have cost more than \$400,000.

Dr. Means is, of course, aware that hypothyroidism is common and when Dr. Larry Wood contacted her on behalf of the Thyroid Foundation of America, and offered her 100 free TSH testing kits (thyroid tests), she readily accepted and their cooperative venture began to develop.

"I contacted Jim Small, a longtime friend, who is an executive at ThyroTest and asked if it would be possible to get 100 of his TSH kits to donate to Women of Means. He responded immediately and positively," said Dr. Wood.

"We delivered the kits to Dr. Means, and within a day she had already begun thyroid screening for women with symptoms of hypothyroidism, thyroid enlargement, or other

evidence of a risk for thyroid dysfunction. We know that women with a personal or family history of juvenile diabetes, thyroid dysfunction, other autoimmune conditions, or certain traits, like prematurely gray hair beginning before age 30, are at increased risk for thyroid dysfunction," said Dr. Wood.

"These are the types of patients that Dr. Means' group is screening now. Anyone with a positive test indicating a TSH greater than 5uU/ml will have a standard TSH test and thyroid hormone levels checked in the laboratory of one of the 5 medical centers in Boston that support the Women of Means project. These tests are done at no charge.

It is likely that most, if not all of these women, should be confirmed to be hypothyroid, and the TSH blood levels will tell us how severe the hypothyroidism is. Thyroid hormone treatment will be started and evaluated periodically by the nurses and health professionals in the Women of Means Program." 🐼

TFC Poster

Thyroid Disease . . .

is
not
black
and
white.

To Get The Full Colour Picture . . .

Thyroid Foundation of Canada
La Fondation canadienne de la Thyroïde

www.thyroid.ca

A new poster from Thyroid Foundation of Canada.

The Search for Dr. Carl von Basedow

Carl Adolf von Basedow, 1799-1854

In the 1970's when I was studying medicine in Kiel and in Vienna, the emphasis was on knowing as many names as possible of doctors, who had discovered something important or some syndrome in medical history. This was especially true if the person was of German or Austrian origin like Freud, Frankl, Landsteiner (discovered the ABO and rhesus blood system), Billroth (stomach operation) etc. Famous teachers of my own were Professor Victor E Frankl in psychiatry, Professor Wolfgang Bargmann in histology, he discovered the thyrotropin releasing factor in hypothalamus and Professor Lennert who discovered the T- and B-lymphocytes.

In thyroid history, Basedow and Hashimoto were well known names in German medical literature. Dr. Carl von Basedow was German himself and Professor Hakaru Hashimoto wrote his work about the thyroiditis lymphomatosa in the German language. He discovered as first in the world the histology of autoimmune thyroiditis using a Zeiss microscope from Göttingen in Germany.

Leipzig was an enchanting city with a lot of historic personalities like Johann Sebastian Bach, Mendelsson and Johann Wolfgang von Goethe. I would have liked to hear a little more also about Dr. von Basedow at the conference, although Dr. Robert Graves seems to be better known nowadays when we talk about hyperthyroid disease. In Germany and Austria we heard only about Morbus Basedow, the same was the case in Finland, maybe because of the political close connections to Germany in the 20th century.

So after the TFI and ETA conference in Leipzig, I decided to take the bus to Merseburg, and look up the traces of Dr. von Basedow. It was only a one- hour trip to the city that is known because of Merseburger Zauber Sprüche (a fairy tale healing rhyme) and the Merseburger Trias, the syndrome named by Dr. von Basedow. In Merseburger Trias we find the cardinal symptoms of Graves' or von Basedow's disease: "Struma, Tachycardie und Exophthalmus" (goiter, tachycardia and exophthalmus). From the beginning von Basedow called the disease "Glotzaugenkachexie", this was written in the recension about him in the Basedow Clinic in Merseburg.



Carl von Basedow, 1799-1854

Merseburg was a charming little town. I had seen on the internet that there was a small statue there of Dr. von Basedow, so I was sure to find it in the Basedow clinic. I went from the bus station with the tramway directly to the clinic. However, in the Basedow Clinic of Merseburg nobody knew about any statue or the grave of Basedow. The woman in the reception thought that the statue might be in Halle, the town where Basedow was born. But I reckoned that the grave of Dr. Basedow should be in Merseburg in the old main cemetery, not in the one close to the clinic. So, I had to go in the other direction with the tramway, my ticket was still valid. Unhappily enough just before I arrived at the main cemetery, the hour of my tram ticket was up. At that very moment, a control agent appeared. And I even got a fine of 40 euros.

At the entrance of the cemetery was an attendant but he had never heard about any Mr. Basedow. My hope of finding the grave of Dr. Basedow was rapidly going downwards. Suddenly, as I still was talking with the attendant, a lady at age over 80 walking with some difficulty, came closer as she heard our conversation: "I know of Dr. Carl von Basedow. His grave is close to a small chapel in that direction", and she showed me where to go. I went in that direction. Outside the chapel there was a map with the names of families buried at the cemetery there were also numbers, but the numbers were not written upon the graves. It was already darkening and I was a little bit anxious walking alone there in the cemetery, especially as I saw three motorcyclists of the group Hell's Angels in black leather suits sitting and drinking something from a bottle. They were quite close to the place where the grave should be. They seemed to take in their liquids in a place safe from the eyes of the police and happily enough they did not seem to show any interest in me. Finally, I dared to go closer. And at last I found it! On a high narrow lonely stone there was written in the German language the following text. It was not easy to read, because the letters were covered by vegetation:

"Here rests Dr. Carl von Basedow, district physician of Merseburg, who discovered the disease that bears his name".

There seemed to be no family members. And thus ended my search for the elusive doctor. 🍷

Ulla Slama, TFI Finland

Ultrasound Imaging

Over the last decade, ultrasound imaging, rather than a physician's fingers, has been used to detect an increasing number of thyroid nodules. So, what is ultrasound? And what is the connection with thyroid nodules?

Ultrasound imaging relies on the transmission of sound waves through the body. When an ultrasound is performed, a transducer is placed on the skin above the body organ to be imaged. The transducer is usually rectangular and some gel is applied to the skin under the transducer. The gel helps facilitate the transmission of the sound waves: without it, an ultrasound cannot be done. After sound waves leave the transducer, they travel through the body tissues below it. The sound waves encounter resistance when they enter a different type of tissue. Some are bounced back to the skin surface while others continue to travel deeper. Different types of tissues provide different degrees of resistance. The computer can record and analyze the sound waves that return to the surface transducer, thus providing the composition of the picture displayed on the ultrasound monitor.

Because the thyroid is so close to the skin surface, ultrasound imaging provides abundant information about the thyroid. The ultrasound appearance of an underactive or overactive thyroid is very different from that of a normal thyroid. However, the main diagnostic application of ultrasound to thyroid disorders is to both identify and characterize thyroid nodules. This information is helpful in deciding whether a nodule should be biopsied. Subsequently, ultrasound may be used during the fine-needle aspiration biopsy of a nodule to visualize the needle and help the physician guide the needle into the nodule.

When should the physician order this test?

When should the physician order this test? Several clinical situations lead to the decision to do a diagnostic thyroid ultrasound. First, if the thyroid gland feels abnormal to the physician's "hands on" physical examination, or if the physician thinks that s/he feels a distinct thyroid nodule, the thyroid should be imaged by ultrasound. The ultrasound picture will show the presence or absence of nodules. Then the physician must decide if fine-needle aspiration

(FNA) biopsy is called for. In fact, recent guidelines published by the American Thyroid Association and the American Association of Clinical Endocrinologists recommends that thyroid ultrasound should be done for all patients who have a palpable thyroid nodule provided that the patient is not hyperthyroid.

Some research studies have shown that even when a physician finds what feels like a thyroid nodule, the ultrasound shows that there are no corresponding nodules in about 1 in 7 patients. Thus a biopsy is not required. In addition, although a nodule may be confirmed on ultrasound, the ultrasound procedure may find a second nodule that was not discovered by physical exam and is large enough to consider for biopsy. Second, thyroid nodules may be incidentally found on CT or MRI scans that are performed for other medical reasons. For example, after a car accident, a neck MRI or CT may be ordered to assess the spine and a thyroid nodule is found coincidentally. Or, a patient may be having a carotid ultrasound to look for atherosclerosis and a thyroid nodule is seen. A dedicated thyroid ultrasound is then required to provide important diagnostic information that is needed before any decision about FNA biopsy is made.

Information from a thyroid ultrasound will also alert the physician, during the nodule biopsy procedure as to whether ultrasound is needed. If the nodule is solid and easily felt on physical exam, then the FNA biopsy can be done without the use of ultrasound and simply by feeling the nodule and placing the needle into it. However, if the nodule is small, predominantly fluid filled, or in the middle or back of the thyroid, or if a patient cannot position his/her neck optimally, then ultrasound imaging should be used during the FNA biopsy. In these situations, the ultrasound probe is placed on the skin above the nodule before the biopsy and the nodule picture appears on the ultrasound screen. Once the biopsy needle is inserted into the skin, it can be seen on the ultrasound picture and the physician can move the needle to guide it into the nodule while, at the same time, continuously monitoring the needle's movement. Therefore, if a nodule has both fluid and solid parts, the needle can be accurately targeted to the solid portion where the material needed for the biopsy is located.

It turns out that not all nodules look the same on the ultrasound picture. In fact, the nodule's appearance may alert a physician as to whether

Ultrasound Imaging (continued from page 6)

it is more or less likely to be cancerous. Thyroid cancers may contain small calcifications, called microcalcifications, which often appear to be a darker gray color than the surrounding normal thyroid. As well, some cancers have very irregular borders that may indicate growth of the cancer into the thyroid tissue whereas others have a round shape but are surrounded by a thick dark line that is the tumor capsule. Lastly, many cancers contain lots of small blood vessels that can be seen with a special feature of ultrasound called either color flow or power Doppler.

The ultrasound appearance of a thyroid nodule may help your doctor in two ways. First, if the nodule is quite small, <1-1.5cm, and does have the suspicious features for thyroid cancer, your doctor may decide not to biopsy the nodule now, but only if it grows. Second, if your thyroid has many nodules, your doctor will first biopsy the ones that look like they could be cancerous. However, it is important to realize that the

ultrasound picture alone cannot tell if the nodule is a thyroid cancer, but it can help your doctor make important decisions about the timing of the biopsy.

The use of ultrasound to examine the thyroid gland is increasing. Unfortunately, not all those who perform thyroid ultrasounds are familiar with the significance of the ultrasound features that may be associated with thyroid cancer. Therefore, it is important that the final written ultrasound report should describe not only the location and size of thyroid nodules, but also the appearance of these nodules including a description of calcifications if present, borders, blood flow, and the nodule's shade of gray (darker or not than the surrounding thyroid). Because of the central role of ultrasound in the diagnosis and management of thyroid nodules, many endocrinologists are now performing thyroid ultrasound examinations and FNA biopsies with ultrasound machines in their offices. ❁

Exit: TFA



After 22 years of service, the Thyroid Foundation of America closed its doors in March 2008. Founder and Medical Director Dr. Lawrence Wood announced the closure of TFA in a letter to members and on TFA's web site. Here are some of his thoughts on the closure.

In the early 1980's there seemed little thyroid information for thyroid patients that was up-to-date, accurate, and understandable. That led my colleagues David Cooper, E. Chester Ridgway and I to write *Your Thyroid: A Home Reference*. It became a success and has since been updated and republished, the most recent edition being in 2006 (Balantine Books).

Subsequently we realized that there was a need to respond to patients who had questions about a particular thyroid issue, to regularly update information, and to provide thyroid information to those who relied on the internet for medical guidance. This led to the creation of the Thyroid Foundation of America and our web site as well as having a staff member who could speak directly on our free 800 telephone line and help answer questions from patients who could not use the internet.

TFA became a part of a growing group of wonderful patient organizations including the Thyroid Foundation of Canada, the British Thyroid Foundation, the National Graves Disease Foundation and the Thyroid Cancer Survivors Association, and finally to the creation of the Thyroid Federation International. We are pleased that many physician thyroid organizations have supported and worked with us for the benefit of thyroid patients and look forward to meeting with the members of the European Thyroid Association later this month at their annual meeting.

We appreciate all the encouragement and cooperation of these groups and the continuing growth and development of free medical information and support for thyroid patients everywhere.

I have been asked by the American Thyroid Association to help them further develop their patient and public educational programs, so I will be able to help in new ways, and remain a part of future educational efforts on behalf of thyroid patients. ❁

Dr. Larry Wood

Conference and Congress Highlights

The TFI conference took place in Leipzig, Germany. Twelve members from 11 organizations attended the annual meeting and were present at our booth at the ETA. Leipzig is a town with a rich cultural history: Johann Sebastian Bach lived and worked there for 27 years, Johann Wolfgang von Goethe studied there and Felix Mendelssohn was "Kapellmeister" of the Gewandhaus.

Common Concerns

The TFI meeting opened with members giving short reports on their organization and on their most important activities of the past year: revising their existing literature, taking care of their web sites and bulletin boards, answering calls on busy telephone help lines, issuing newsletters. All groups had held various information meetings for patients. All say that working together in the "network" of TFI is very important in recognizing common problems and in receiving support and information from each other. The exchanges with patient organizations in other countries gives them new input, a sense of connection and the incentive to carry on with their work. Furthermore, our presence at important events like the ETA helps to create good relations with the medical community.

Improvements

The TFI web site will soon be totally modernized. Among other features, it will contain a "forum" (bulletin board or "closed user section") where TFI members can discuss with each other, in various groups ("all members", "board members", etc.), much more easily than by exchanging lots of emails, making it easier to find information. In the future, we intend to create web sites with information on thyroid disease in several languages, so that they can be used everywhere in the world.



TFI booth at the ETA 2007, Anne Nielsen, Elisabeth Rusdal, Beate Bartès, Bente Bakke
PHOTO TAKEN BY KIT

For the conference in Leipzig, we wanted to have some new PR material (doctors' leaflets, posters, roller banner), with a modern, colourful graphic design. We noticed that the present TFI logo, a globe with the words "Thyroid Federation International" and the byline on the web site "Thyroid disease in a global perspective", had two disadvantages: some countries were not represented on the globe (Australia/New Zealand) and the byline did not show that we are a *patients'* organisation. We have now chosen a butterfly, to symbolize the thyroid, with all countries shown and the byline "Thyroid patients worldwide".

The Future of TFI

We need to change our way of working more efficiently together. Our Memorandum of Association will soon be updated. We need "active" members and clear job descriptions.

International Thyroid Day

Following a proposal from Norway, TFI decided that May 25th should be *International Thyroid Day*. There are already some national initiatives: the ATA/ACE have "thyroid month" (January), Australia has a thyroid week (September), there are thyroid days or weeks in several countries.

Iodine Project (China)

Larry Wood explained the project: in China, there are huge regions where medication is difficult to obtain, and there is no newborn thyroid screening. An inexpensive "TSH self-made test" has been developed and is presently being tested (financed by the Gates Foundation, Ronald McDonald, etc). If this works, it would be possible to detect children with a high TSH at birth, and they could be cured by a unique administration of some drops of iodine.

ETA Congress

Thanks to our new material and design created by a British artist, our booth was very colourful and attractive. We had a huge roller banner, posters and notebooks and T-Shirts for those on duty at the booth to wear and display space for pamphlets and newsletters. We had a many visitors and answered many questions. When we were not on duty, we had the opportunity to

(continued on page 9)

Over the last year the Dutch Thyroid Foundation (Schildklierstichting Nederland) made two major innovations.

A complete overhaul of our web site resulted in the launching of a new web site – www.schildklier.nl – with a new look and a new logo in the beginning of April of this year. The work made high demands on those volunteers who committed themselves to the successful finishing of this strenuous and time-consuming job.

Somewhat earlier a new committee, the Scientific Data Committee (Kenniscommissie), was formed to support various parts of our organization with state of the art knowledge on current research. As well as gathering research data, the members of this committee, who have backgrounds in medical, paramedical and health education, represent the Foundation at relevant congresses and symposia. They broaden our network and to make contact with patients, researchers and medical doctors.

The Committee's set goal is to share knowledge based on evidence as well as knowledge based on patient experience with the individual target groups. This resulted, among others, in a private meeting with one of the top researchers on thyroid metabolism at the Erasmus University Medical Center (Erasmus MC) in Rotterdam for members of the Committee. The subject of this meeting was the latest insights in cell thyroid hormone transporters and the conversion of T4 into T3 with special emphasis on the importance of T4 for brain development of the foetus during pregnancy. It also brought about an interview with one of the specialists at the VU University Medical Center (VUmc) in Amsterdam on the quality and explanatory value of package leaflets of the various levothyroxine brands. These leaflets differ amongst themselves most notably in the information they give on the interaction with other drugs and in the importance of adjusting the dose in the treatment of pregnant women.

A new special activity is the arrangement of a pdf-selection of articles from our magazine on our web site. These articles are being filed under various headings, like auto-immune thyroid disease (AITD), medication, research and pregnancy and thyroid, to name a few. We

use these articles for distribution at symposia. At the moment special attention is on Graves' disease and pregnancy, thyroid disease and pregnancy in the Dutch thyroid guidelines, the treatment with levothyroxine and the interactions between levothyroxine and other drugs.

As well as our own pdfs we hand out other appropriate pdfs of recent scientific reviews on research in the field of thyroid diseases. For example, last June one of our volunteers used part of the review on the *Clinical Significance of Subclinical Thyroid Dysfunction* (Endocrine Reviews, 2008) at the Dutch symposium on Young Pregnancy at the Erasmus MC (Rotterdam University Medical Centre). In this way, they were able to inform gynaecologists and midwives, who attended this symposium about the relation of AITD and recurrent miscarriages and preterm delivery.

Other symposia the members of the Scientific Data Committee recently attended were Dutch differentiated thyroid carcinoma at LUMC (Leiden University Medical Centre) and 100 years Dutch Pharmacology in Utrecht. 🇳🇱

TFI: 13th Annual Conference (continued from page 8)

visit other booths and attended some interesting lectures on various subjects.

It was a pleasure to meet old friends and to make new ones!

Leipzig - Cultural City with Charisma

Leipzig has a rich cultural history and many beautiful churches and museums. We were very busy, but also found some time to stroll along the town. The ETA welcome reception took place in the Museum of Fine Arts, in a very spectacular modern building. The ETA organised an excursion through the town, with local guides who gave us many interesting explanations about their town and its history, followed by an organ concerto in St. Thomas Church, on the organ used by Johann Sebastian Bach himself, followed by dinner in a youth and student club located three storeys underground, in impressive brick vaults. The gala dinner took place in the historical "Auerbachs Keller", immortalized by Goethe in his dramatic work *Faust*. 🇩🇪



In June 2000, Kate Farnell was diagnosed with thyroid cancer at Newcastle Upon Tyne hospital. Although initially devastated by the diagnosis, she decided to make something positive from her experience and founded the Butterfly Thyroid Cancer Trust.

At this time there was no support available locally for patients with this type of cancer other than from family and limited time during hospital appointments. Being diagnosed with cancer can be both a frightening and isolating experience especially if the cancer is rare, but talking to someone who has experienced similar surgery and the same treatment regime can help. Such support can be particularly helpful during periods of hypothyroidism [living without thyroid hormone] and during treatment in isolation. These are currently at most treatment centres in the UK the necessary elements in the treatment of Thyroid Cancer.

However, it appears that these periods of hypothyroidism may be negated with the increasing use of Recombinant Human TSH "Thyrogen" [a drug therapy].

To those seeking help during these difficult periods, Butterfly offers information, support and encouragement in various ways:

- a dedicated telephone help line,
- contact with other patients on the web site via telephone and e-mail.
- regular support group meetings and social outings.
- one to one Buddy System to support you through the stages of surgery, RAI Treatment and follow up.
- providing accurate reliable, up to date information about the disease.
- visiting all patients when in hospital.
- on site clinical support from a fellow patient in the Thyroid Cancer Clinic at NCCT in Newcastle.

The organisation has gone on to become the first registered charity in the UK dedicated solely to the support of people affected by the disease.

We work closely with and have the full support of the Multi Disciplinary Thyroid Care Team in Newcastle and work closely with other associated support organisations: BTF, A.M.E.N.D., Vivre Sans Thyroïde and TFI

By sharing knowledge and information with them and attending both National and International Conferences on Thyroid Cancer we can ensure that we are providing our members with accurate, up to date information.

The founder herself works in the Thyroid Cancer Clinic at the Northern Centre for Cancer Treatment in Newcastle and is available to fellow patients for support, information and advice.

She has been interviewed for both TV and Radio and given presentations at a number of Thyroid Cancer Conferences:

- Thyroid Cancer Masterclass London 2007
- Genzyme Thyroid Cancer Conference Lisbon 2008
- Thyroid Cancer Symposium Greece 2008

This innovative work and achievement has been rewarded by the receipt of the following awards:

- Winner of the Pfizer Excellence in Oncology Award 2006
- Winner of the NHS Bright Ideas Innovation Award 2007
- Winner of the NHS Hospital Doctor of the Year Ward 2007

All of the volunteers involved in the organisation have either had the disease or been closely involved in the care and support of someone who has.

Butterfly Thyroid Cancer Trust is not externally funded and relies entirely on donations to be able to continue its work. The butterfly of hope is an appropriate symbol for this worthy organization.

We welcome the Butterfly Thyroid Cancer Trust to TFI. 🦋

ThyroWorld

Deadline for the next issue: TBA

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

The Editor, ThyroWorld
Thyroid Federation International
797 Princess Street, Suite 304
Kingston, ON K7L 1G1 Canada

Email: tfi@on.aibn.com or thyroworld@rogers.com
Internet: www.thyroid-fed.org

Iodine Deficiency Projects

In previous issues of *ThyroWorld*, we have featured articles on the cause and consequences of thyroid deficiency. Here are two new projects being carried out on that subject, one in the United States and one in China.

Internationally, iodine deficiency is the leading cause of mental deficiency in the world, affecting 2.2 billion people, or 38% of the world's population. Two cretins are born every minute worldwide, with up to 15 cretins born every minute in areas of severe iodine deficiency.

US Project

In the United States, Dr. Elizabeth Pearce at the Boston Medical Center, is evaluating various aspects of iodine deficiency in pregnancy. Mothers need iodine to make thyroid hormone and even mild iodine deficiency may have adverse effects on the cognitive function of offspring.

Her group will look for evidence of iodine deficiency in 1,000 pregnant women, and will also measure urinary thiocyanate and perchlorate, which are environmental toxins that may decrease thyroidal iodine uptake. They will measure thyroperoxidase (TPO) antibody levels since thyroid autoimmunity may modify the effects of perchlorate or thiocyanate on thyroid function in pregnancy. Finally, since only half the prenatal vitamins in the United States contain iodine, she will get information on how many women are actually taking the form of the vitamin that contains iodine.

China Project

In China, Dr. Michael Zimmermann from the International Council for the Control of Iodine Deficiency Disorders (ICCIDD) is screening for severe iodine deficiency to prevent cretinism in southern Xinjiang, China. In that province, recent studies by Professor Chen Zu-Pei

identified 16 cretins, less than 15 years of age the youngest being three years old. A follow-up team of physicians found an additional 36 cretins less than 10 years of age in villages where mainly non-iodized rock salt is used.

Cretinism can be prevented only if mothers with severe hypothyroidism due to iodine deficiency are identified before the end of the second trimester of pregnancy. Doctor Zimmermann and his colleagues in China will be screening these young women in two ways. There is now a reliable ten-minute TSH test kit. Two drops of a mother's blood, obtained by a finger prick, is placed on a test kit strip. After two minutes, eight drops of buffer are added. Within ten minutes, the kit tells whether a mother's TSH is normal or abnormally high. Mothers with a high TSH level will have a second blood sample sent for exact TSH measurement and serum thyroglobulin level to determine the severity of the hypothyroidism. At the same time, the mother will be given four potassium iodine tablets to take one daily for the next four days. This small amount of iodine is enough to supply the mother with all the iodine she needs to make thyroid hormone during the pregnancy, and will prevent cretinism from developing in her baby.

We invite other TFI groups and governmental organizations to support these wonderful efforts to prevent cretinism. 🐼

Lawrence C. Wood

TFI Member Organizations

(continued from page 12)

The Thyroid Eye Disease Charitable Trust
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UNITED STATES OF AMERICA

Graves' Disease Foundation
Peter Filocamo (President)
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ETA 34th Annual Congress

September 6-10, 2009
Lisbon, Portugal

TFI Member Organizations

AUSTRALIA

Australian Thyroid Foundation
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Thyroid Australia

Christopher McDermott (President)
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BRAZIL

Instituto da Tiróide
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(President)
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CANADA

Thyroid Foundation of Canada
La Fondation canadienne de la Thyroïde
Ashok Bhaseen (President)
1669 Jalna Blvd. Unit 803
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FINLAND

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www.kilpirauhasliitto.fi

FRANCE

Association des malades de la thyroïde
Chantal L'hoir Liesse (President)
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www.asso-malades-thyroïde.org

Association Vivre sans thyroïde
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www.forum-thyroïde.net

REPUBLIC OF GEORGIA (EU)

*Georgian Union of Diabetes and
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GERMANY

Ohne Schilddrüse Leben e. V.
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Schilddrüsen Liga Deutschland e.V.
Barbara Schulte (President)
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Germany
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ITALY

*Associazione Italiana Basedowiani e
Tiroidei*
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www.endocrinologia.re.it/aibat.htm

JAPAN

Thyroid Foundation of Japan
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Minato-ku, Tokyo 106-0032 Japan
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MEXICO

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THE NETHERLANDS

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NORWAY

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Thyroid Foundation of St. Petersburg
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SWEDEN

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