



Thyroid Federation International

Thyroid Patients Worldwide

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Thyroid Federation International

Established in September 1995 in Toronto, Canada

Founder

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

Mentor & First President

Lawrence C Wood, MD FACP (USA)



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Member Organizations

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

Editor's Message

TFI is delighted, in the year of its 20th anniversary, to be present at the 15th International Thyroid Congress in Orlando.



Beate Bartès

This conference has a long history. The first International Conference on Goiter was held on August 24, 1927, in Bern, Switzerland. It was followed by the second International Conference on Goiter in 1933, also in Bern, and then by International Goiter conferences in Washington, DC and in London, in 1938 and in 1960. Goiter gave way to Thyroid in 1965, for the 5th International Thyroid Conference in Rome, Italy (the European Thyroid Association (ETA) was founded at this occasion). The following conferences took place in Vienna, Austria and Boston, US, in 1970 and 1975. The word Congress was first used in 1980, for the 8th International Thyroid Congress in Sydney, Australia. Then came conferences or congresses in Sao Paulo, Brazil, 1985, The Hague, Netherlands, 1991, Toronto, Canada, 1995 and Kyoto, Japan, in 2000. The 13th International Thyroid Congress took place in Buenos Aires, Argentina, in 2005, and the 14th in Paris, France, in 2010.

Thyroid Federation International was founded at the occasion of the 1995 ITC in Toronto, Canada – and has attended the congress ever since, in Japan, Argentina, Paris and now Florida.

The international ITC is a unique occasion to meet thyroid specialists from all around the world, from ATA, ETA, LATS and AOTA, to learn about news in the thyroid field and to discuss ways to increase and improve cooperation and interaction between patient groups and the medical profession, for the benefit of both patients and doctors.

We wish you a successful meeting!

BEATE BARTÈS, EDITOR

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President's Message

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

Dear Readers,

It is a milestone year for Thyroid Federation International (TFI) as we celebrate 20 years of our operation, spanning from Japan and Australia in the East, Europe in the centre, and to the far West in Canada, Brazil and the USA. It is not surprising to hear from many patients that they only become aware of their thyroid gland when they visit their physician and are diagnosed with a thyroid related issue. How has TFI and its country foundations helped patients that suffer from thyroid-related issues over the years?

- Awareness is a key element in understanding any disease or issues, and TFI members have been instrumental in spreading it.
- Education is key when it comes to managing your thyroid health; both TFI and its member countries have done a great job on this front.
- Patient information in the language they understand has been important in each country.
- In this communication age, the website efforts by TFI members have played an important role in reaching out to thyroid patients looking for credible information on thyroid issues and management.
- Global reach of International Thyroid Awareness Week and World Thyroid Day.
- Credibility and partnership with ETA, AOTA, LATS, ATA and many endocrine societies.

Twenty years is 1/5th of a century and a significant milestone in an organization's history. The question that some of you may ask is "What does it take to keep an organization viable and growing for the past 20 years"?

- People are one of the most important elements in the make-up of an organization. What makes an organization good or great has much to do with the people associated with it. TFI has been fortunate to have very committed people who have contributed to its growth and success. Passion and hard work were key ingredients in the people behind the success of our organization.



Ashok Bhaseen

- TFI has also been fortunate to have good organizations supporting and providing grants over the years.
- Some of the common factors that I find in each thyroid foundation are leadership with high energy individuals, passion for the cause, perseverance, hard work and selfless volunteer efforts.
- Strategic thinking and establishing achievable goals for each year with input from its members.

- Cultivating ongoing new leadership in organizations.

Website and information alone are not the only factors that can meet the needs of thyroid patients; they also need 1:1 communication and learning from fellow patients and educational programs that are provided throughout the year in different parts of the world. Personal touch, involvement, and volunteering still remain important for the people and the need becomes more acute when they suffer from thyroid issues which have a profound effect on their day to day functioning.

For TFI, this is just a beginning as more countries are finding the need for their own patient organization. Thyroid patients can greatly benefit from local foundations in countries from Asia, Africa and South America; the key remains to find the right leadership in these geographical areas. Our member organizations are mostly made of volunteers and some of them are physicians who put in many hours to add value to the lives of thyroid patients. TFI looks forward to helping patients and physicians from these areas of the world so that they can help set up organizations that will help in education and awareness of thyroid-related issues for early diagnosis and treatment. We look forward to hearing from you and helping you in setting up an organization in your country that can help thyroid patients.

We live in a communication age which provides patients an opportunity to access information with just a few clicks on the device they choose.

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TFI AGM and ETA Congress 2014

Santiago de Compostela, Spain

AUTHOR: BEATE BARTÈS
SECRETARY, THYROID FEDERATION
INTERNATIONAL

As every year, TFI held its Annual General Meeting in the days before the ETA congress, in the beautiful city of Santiago de Compostela in Galicia, in the North West of Spain.

Many TFI members participated in the last day and the solemn occasion of the walk on the "camino", the St James Way, organized by the Spanish organization AECAT (35 patients walked more than 100 km from Sarria to Santiago de Compostela in 5 days, to raise awareness for thyroid cancer). Video of the walk: <https://www.youtube.com/watch?v=E0YC7CGh70s>



TFI participated in the TFI/ AECAT patient forum with round tables on "Thyroid related diseases and health information": During the ETA congress, we had a booth in the exhibition area and attended various lectures and symposia. We

were very glad to see that "quality of life" gets increasing attention at these medical conferences: there were several lectures about this subject! TFI President Ashok Bhaseen was invited to address the audience during the ETA gala dinner.



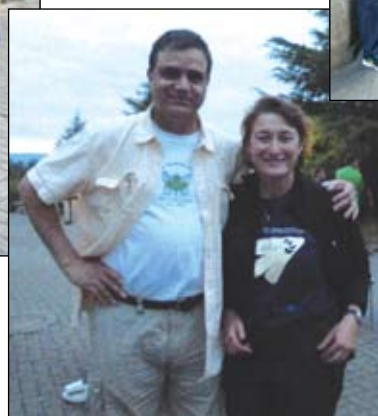
TFI booth at the 38th ETA congress



TFI members (Ashok Bhaseen, Bente Lasserre, Ulla Slama, Beverley Garside, Dag Lund-Fallinggen) joining the AECAT group for the last day of the "Camino"



Ashok and Cristina with the group of pilgrims on their arrival in Santiago



TFI president Ashok Bhaseen and AECAT president Cristina Chamorro

President's Message (continued from page 3)

TFI and its member organizations work responsibly, providing accurate information; we make sure to engage and involve all key healthcare stakeholders.

As we celebrate the 20th Anniversary of TFI, the following goals still remain important for the future:

- Iodine in salt remains at the top of the list for many countries. ICCDI members are doing a great job to accomplish this goal; we would like to support this in countries where it is most needed.
- Fukushima, Japan and the Chernobyl leaks have impacted the thyroid functioning of their populations. What proactive measures should be taken for people living within a 20 mile radius of such locations?
- In the UK the importance of iodine in the diet needs renewed awareness for the new generation.
- Deploying thyroid collars prior to taking X-rays in diagnostic, dental and hospital settings.
- There has been a rise of thyroid cancer in North America and some European countries - why? We need to know more about what is responsible for this rise.

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

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

May 25th, 2016 World Thyroid Day



Upcoming Events

March 16-19, 2017

12th Asia and Oceania Thyroid Association Congress (AOTA)
BEXCO, Pusan, S. Korea
www.aotacongress2014.com



March 2017

15th Latin American Thyroid Congress of the LATS, Latin-American Thyroid Society (TBD at ITC, Orlando during LATS Annual meeting)
www.lats.org



September 21-25, 2016

86th Annual Meeting of the ATA
Sheraton Denver Downtown Hotel
Denver, Colorado
www.thyroid.org



September 3-6, 2016

39th ETA Congress
Copenhagen, Denmark



May 23 to 30, 2016

6th International Thyroid Awareness Week
Topic "Thyroid disorders in children"
www.thyroidweek.com
www.thyroidweek.org



October 18 to 23, 2015

15th International Thyroid Congress (ITC)
Orlando, Florida, USA
www.itc2015.thyroid.org



September 2, 2016

22nd Annual General Meeting of Thyroid Federation International
Copenhagen, Denmark



Thank You!

Thank you to everybody who made this issue possible, most particularly Katherine Keen, who corrected the language of all non-native speakers among our authors, and Lynda Wegner who diligently took care of the layout.

A twenty year journey with TFI – Thyroid Federation International

YVONNE ANDERSSON LAKWIJK
PAST PRESIDENT OF TFI

In 1995 in Toronto, Canada, TFI was founded during the annual meeting of the Thyroid Foundation of Canada and the first president was chosen, Dr. Lawrence (Larry) Wood, from the Thyroid Foundation of America. It was decided the next meeting would be in 1996 in Amsterdam in The Netherlands.

In 1997 the annual meeting of TFI was scheduled to be held on the days before the Congress of the European Thyroid Association, ETA, in Munich, Germany. That year was the first time I participated as the newly chosen president of “Västsvenska Patientföreningen för Sköldörtelsjuka”, and as one of the representatives from Sweden, I didn’t know what to expect, but the doctor who I collaborated with in Sweden, Professor Ernst Nyström, told me that it would be a great meeting and we prepared a presentation. When I entered the room of the meeting there were about ten people in the room and Dr. Fumito Akasu from Japan was about to give his presentation. We had some three intensive days of work with reports from all the delegates, not to forget the huge job with the bylaws of the TFI. In Munich, Professor Peter Pfannenstiel helped us to arrange our first Patient Forum. A lot of patients attended and it was highly appreciated because nothing like this had been done before. However, at this stage we did not have any further cooperation with the ETA.

In 1998 the ETA Congress was planned to be in Greece. It was a meeting in two parts; first a meeting about Thyroid Eye Disease up in Pireea and then in Athens. During the first day’s meeting we had a little booth for our TFI material and we were all warmly welcomed to participate in both the lectures and the social events. At one of these lectures I was listening to Professor Wilmar Wiersinga from The Netherlands and during his talk, with a lot of doctors attending, he spoke about the importance of doctors working in cooperation with the patient organizations, about the mutual benefit that it could bring and the time saving factor by giving information to bigger patient groups and also having the help from the patient organization to answer many common

questions and sharing experiences. I have carried these words from Dr. Wiersinga ever since, in all my work with patient organizations and also told repeatedly at later presentations on behalf of TFI.

In 1999, the ETA meeting was held at the University of Milan. Here I also met a doctor, in fact a Swedish doctor, who could not understand at all the use of having patient organizations attending the ETA meeting. I tried to explain to him and slowly he realized the possible benefits. Since then we have had the best cooperation. At the TFI annual meeting, we were visited by the Italian patient organization, AIBAT, and their collaborating doctors.

In the year 2000 the International Thyroid Congress, ITC, was held in Kyoto, Japan and the TFI meeting was held in conjunction with the ITC. In Japan we had a very interesting presentation by one of their thyroid specialists about how they take care of the thyroid patient from the first visit and tests to the diagnosis and actual treatment, all done in the same clinic during the same day. We were all quite impressed by the way it was done, without any extra waiting time for the patients. During the days in Kyoto we were given a very special guided tour, just for the TFI delegates, by Professor Hashimoto. This was a wonderful day together with one of the most lovely and humble persons I’ve met.

In 2001 the ETA congress was in Warsaw and I did not have the possibility to participate. However this was the year that, for the first time, the TFI meeting was announced in the ETA program. We had made pens and brochures to be put into the congress bags and, as it turned out, these were the only pens in the bags, so it happened that all the doctors were taking notes with our blue TFI pens!

In the year 2002 it was Sweden’s turn to organize the ETA meeting, in Gothenburg, and of course the TFI meeting. Professor Ernst Nyström was responsible for organizing the ETA meeting and I looked after the TFI meeting. As one of the board members, I wrote to Professor John Lazarus to ask for permission to speak to the participants of the ETA and to give a presentation about TFI

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A 20 year journey with TFI (continued from page 6)

and our work and aims. With the support of Prof Nyström, it turned out to be a short presentation at the opening ceremony and a proper one later that week. We were provided with a beautiful, professional booth and we started to feel that the cooperation between the patient organizations and the medical professionals was building. We were welcome to attend all the lectures as well as the social events.

In 2003 in Edinburgh, the ETA meeting was organized by Professor Anthony Toft. Also here we were welcomed in a lovely way and we were invited to give a presentation before the Merck lecture prize. This was the first time I spoke as the President of TFI, since I had been elected at the TFI meeting in Edinburgh to take over the presidency from Dr. Larry Wood, my mentor and very special friend since 1997.

The year 2004, Istanbul was hosting the ETA congress and the TFI meeting was as usual held on the days before. As president I was invited by Professor Erdogan to speak at the annual meeting of the Turkish Endocrine Society. It was a big honour. The vice president and I were also invited for an interview by the Turkish Television Company, about the work of TFI. We were also provided with a meeting room at the same venue as the ETA congress.

In 2005 it was again time for the International Thyroid Congress, this time in Buenos Aires. Professor Hugo Niponitsche was head of the organizing committee of the ITC, but he took care of all the participants of TFI as well. Unfortunately I could not participate this year myself due to the loss of my youngest daughter Lisa, however I followed the activities from a distance and I certainly received all the news about the friendliness and helpfulness from the Argentinean organizers. Also a patient forum was organized together with the local patient organization.

In Naples, Italy, 2006, Professor Giancarlo Veccio, who was in charge of organizing the ETA meeting that year, invited TFI to a press conference together with some Italian Thyroid specialists. We had a booth, TFI material in the conference bags and we were part of all the activities.

In 2007 the ETA meeting was in Leipzig, organized by Professor Ralph Paschke. We held a patient forum, had a booth and had access to all lectures and events. This year at the annual meeting of TFI we made a decision to celebrate

a "World Thyroid Day" on the 25th of May. We announced this decision at our booth during the ETA meeting, and the board of ETA, as well as the board of TFI, made a joint decision. Since then World Thyroid Day is celebrated on May 25th.

In 2008 the ETA congress was again arranged in Greece, this time in the region of Thessaloniki. I remember it as the most rainy week I have experienced in Greece but the Greek people were happy because it had been so dry for a very long time. However, despite the weather, the conference went very well.

Also in 2008, the first ideas about a Thyroid Awareness Week began to grow in cooperation between Merck Serono and TFI. Merck wanted to support TFI in raising awareness about thyroid diseases all over the World without any demands on TFI. The work started that autumn.

In 2009 the first ever International Thyroid Awareness Week, ITAW, was launched in Istanbul during the Endocrine Society meeting in the middle of May and was to take place from May 25 until May 31. Speaking at this occasion were Professor Murat Erdogan and myself. A lot of journalists were invited and the idea of a Thyroid Awareness Week was highly appreciated and well received. Information films were produced with thyroid patients and these, together with written information, were put on a special website for this particular week. Since then this week is an ongoing awareness week every year around World Thyroid Day with different subjects within the thyroid area and all in cooperation with Merck Pharmaceuticals. The week was first acknowledged by the ETA but in the coming years was also acknowledged by the LATS, AOTA and ATA, all the medical professional thyroid organizations worldwide.

In 2009 the ETA as well as the TFI meeting took place in Lisbon. TFI by now had 18 member organizations and, through the chair of the organizing committee in Lisbon, we got in contact with a group of patients who wanted to start up a patient organization.

In 2010 in Paris it was again time for the ITC. During this meeting the TFI board was invited by Merck Serono to a meeting with the presidents from the different doctors' organizations, ETA, ATA, LATS and AOTA, to discuss how we could improve the ITAW to have it take place in all parts of the world. This was a great step for

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Thyroid cancer: 5 years of progress

MARTIN SCHLUMBERGER AND SOPHIE LEBOLLEUX
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Major progress has been achieved in the field of thyroid cancer since the 14th International Thyroid Congress (ITC-14) which was held in Paris in September 2010, and most of these advances have been taken into account in the updated American Thyroid Association 2015 guidelines. Unfortunately, most clinical data have been obtained in small retrospective studies which have inherent flaws, no matter how they are collected and prospective large trials are needed to provide high quality, convincing data.

It is now clear that the increasing incidence of thyroid cancers is mostly related to more extensive screening with neck ultrasonography and fine needle aspiration biopsy. A larger number of low risk thyroid cancers are found and these patients should not be overtreated. Therefore, FNA should be performed only in patients with isolated thyroid nodules larger than 1cm in diameter. When papillary cells are found in an isolated nodule smaller than 1cm and with no evidence of lymph node involvement and of extension beyond the thyroid capsule, the term "papillary tumor" should be used instead of "papillary cancer". A follow-up strategy may be offered to these patients who are aware of the (small) risk of progression and who agree to be followed up. For larger thyroid nodules, the indication of fine needle aspiration biopsy is based on the size of the nodule and on its characteristics at ultrasonography.

Fine needle aspiration biopsy results in malignancy in 4-5% of cases who should be sent to surgery and, in benign findings, in about two thirds of patients. Its performances are improved with US guidance, when performed by the cytologist and with on site quality control of the sampling. However, there is still a significant proportion of patients for whom the diagnosis is indeterminate: those with suspicious papillary carcinoma should be operated on because the risk of malignancy is above 66%, but in patients with atypia of undetermined significance or with follicular or oncocytic neoplasm, two techniques may be relevant: a transcriptomic signature may exclude malignancy and gene mutation screening may demonstrate malignancy. These techniques are expensive and still need to be validated. If not operated on, thyroid nodules are followed up

with neck ultrasonography every 12-24 months.

The prognosis of thyroid cancer is based on the risk of death according to the TNM scoring system and to the risk of recurrence according to the ATA risk stratification. The risk of recurrence does not take into account the age of the patient, but relies on the histologic type, the presence of mutation (BRAF and TERT) and the extent of disease including vascular invasion and extracapsular extension, and increases with an increased number and larger size of lymph node metastases and with the presence of extension beyond the lymph node capsule. These classifications may guide the extent of initial treatment.

The mainstay of therapy for differentiated thyroid cancer is surgery. A neck ultrasonography (thyroid gland and lymph node areas) should be performed prior to surgery. For many patients, total thyroidectomy is the treatment of choice. Morbidity is low in expert hands and? may be significant with low volume surgeons. It facilitates RAI ablation and allows optimal follow up using thyroglobulin as a tumor marker. Thyroid lobectomy offers equal oncological outcomes in appropriately selected patients (patients with low risk thyroid cancer with a normal contralateral lobe), but with a much lower morbidity rate, there is no risk of hypoparathyroidism and the risk of vocal cord palsy is unilateral and it is often only transient. In addition, although the use of thyroglobulin in follow up is less accurate, it can still be used effectively.

Therapeutic compartment-oriented lymph node dissection is performed in patients with known lymph node metastases. The indication of prophylactic central neck dissection in patients with no evidence of lymph node involvement is still debated and is mostly advocated in those with high risk papillary thyroid cancer (large thyroid tumor or extension beyond the thyroid capsule). Treatment with levothyroxine is given post-operatively to all thyroid cancer patients with the goal of a serum TSH level between 0.5 and 2.5mU/L in low and intermediate risk patients.

The use of post-operative radioiodine should be selective: it is clearly not indicated in patients with very low risk cancer (small tumor without

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lymph node involvement); two recent randomized trials have shown that low radioiodine (30 mCi) administered following injections of rhTSH to patients with low or intermediate risk tumor provides similar ablation rate to larger doses, but its benefits in terms of outcome are still not demonstrated in these patients; in high risk patients a higher dose (100 mCi) is administered following either injections of rhTSH or a prolonged withdrawal of thyroid hormone treatment.

Follow-up is performed on levothyroxine treatment and includes at 3 months the determination of serum TSH to control the adequacy of levothyroxine daily dose and then at one year to control the disease status with neck ultrasonography and serum thyroglobulin (Tg) determination preferably with a sensitive method. This strategy is also applied to patients who have been treated with lobectomy or total thyroidectomy but without any radioiodine administration. The use of injections of rhTSH may be restricted to patients treated with total thyroidectomy and radioiodine with detectable low serum Tg levels or with any suspicious finding, and the level of post-injections serum Tg may help to individualize those patients with residual disease. According to the dynamic classification, 4 subgroups of patients are individualized:

1. Excellent response (no evidence of disease with undetectable serum Tg in the absence of anti-Tg antibodies and a normal neck ultrasonography). These patients represent the large majority of patients and have a very low risk of recurrence (< 2% at 20 years): they are followed on levothyroxine treatment once a year with serum TSH and Tg determination.
2. Biochemical incomplete (detectable serum Tg but no structural abnormalities). The majority of these patients will have a decreasing trend in their serum Tg level with time and will reach an excellent response in the absence of any further treatment.
3. Structurally incomplete with structural abnormalities. These patients may need further treatment.
4. Indeterminate response: non-specific biochemical or structural findings which cannot be confidently classified as either benign or malignant. The majority of these patients will reach an excellent response with time.

This classification is updated at each subsequent step of the follow-up.

In patients with either structurally persistent disease or with increasing serum Tg levels with time, a complete work up is performed to localize the disease and to assess its extent, which may include neck ultrasonography, neck and chest CT scan with injection of contrast medium, and FDG PET scanning. The administration of a large dose of radioiodine (100 mCi following withdrawal of thyroid hormone treatment) with a whole body scan performed 2-5 days later may be indicated in selected patients, and in particular in those with no FDG uptake on PET/CT.

Patients with small lymph node metastases with uptake can be treated with RAI. However, larger lymph nodes are rarely eradicated with RAI alone, and lymph node metastases that are larger than 8 mm in their smallest diameter are submitted to fine needle aspiration and then to surgical resection.

Distant metastases occur mostly in lungs and bones. They may benefit from a combination of focal treatment modalities, including thermal ablation (radiofrequency or cryotherapy), external beam radiation therapy or surgery and of radioiodine administration when uptake is present in the tumor foci. Radioiodine treatment with high activities (100 mCi following thyroid hormone withdrawal) are administered every 6-12 months up to a cumulative activity of 600 mCi or more. Favorable predictive indicators for response and survival include younger age at the discovery of the metastases (<40 years), well differentiated tumor histotype, and small metastases and absence of FDG uptake in the metastases on PET/CT. More than 80% of younger patients with small metastases in lungs from a papillary carcinoma are cured, but cure is achieved in less than 10% of older patients with large metastases.

Refractory thyroid cancer is defined as patients with advanced disease who either have no uptake in at least one metastatic lesion or who progress after radioiodine treatment despite the presence of uptake in all metastatic lesions. It is a rare disease that represents 4-5 cases per million population. In such patients with significant tumor burden and when tumor progression occurs, systemic treatment may be indicated. In recent years, major advances have been achieved, and prospective trials using kinase inhibitors with an anti-angiogenic effects have shown high tumor

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Thyroid cancer ... (continued from page 9)

response rates. Two tyrosine kinase inhibitors (sorafenib and lenvatinib) induced benefits in PFS and were labeled for the treatment of thyroid cancer patients with advanced disease and large tumor burden that is refractory to radioiodine and in whom progression has been demonstrated by imaging. Unfortunately, these medications induce significant toxicities, and have only transient effects. Another treatment method used redifferentiation with BRAF or MEK inhibitors that induce uptake of radioiodine in metastases and then treatment with radioiodine following rhTSH injections and provided encouraging results. Immunotherapy with antibodies directed against checkpoints is promising but unfortunately no data are so far available.

In conclusion, major progress has been achieved that should modify the therapeutic strategy of many thyroid cancer patients.

Implementation of guidelines may be facilitated by the availability of high quality data obtained in prospective trials. Randomised controlled trials of therapy using a superiority design (designed to show that the new treatment provides better results than an active control) have not been considered feasible because of the low mortality and recurrence rates, particularly in the most controversial low risk groups. The lack of prospective trials leads clinicians to rely on retrospective data which has inherent flaws, no matter how it is collected. However, recently, two prospective randomized trials have been achieved using a non-inferiority framework (designed to show that the new treatment is not unacceptably worse (or 'non-inferior') to an active control), demonstrating their feasibility and this design should be used in low risk patients.

A 20 year journey with TFI (continued from page 7)

mutual dialogue and cooperation for the benefit of thyroid patients for the future.

In 2011 the time had come for Krakow, Poland to arrange the ETA meeting and of course the TFI meeting followed. At the annual meeting of TFI, I stepped down as President and handed the responsibility over to Askok Bhaseen from the Thyroid Foundation of Canada. During the ETA meeting I tried to do my best to introduce our new President to as many as possible of my good contacts and friends within the area of Thyroid Specialists to provide good future cooperation and support, as well as mutual respect for many years to come. This year Ashok Bhaseen also attended the annual meeting of the AOTA, a new step within the thyroid world for TFI.

In 2012 the ETA meeting took place for the third time (in my presence) in Italy and this time, in the beautiful city of Pisa. The TFI members stayed in a convent where we also had our meeting. For the first time in many years I did not have the responsibility, I was still on the board as the treasurer and I was chairing our meeting, but there was a different feeling to it. Ashok Bhaseen was growing more and more into his role as President and getting to know all the people.

In 2013 the ETA meeting took place in Leiden, The Netherlands, as well as the TFI meeting. TFI had grown to 21 member organizations and there

were contacts going on with more countries. At the welcome reception in Leiden our president was invited to speak on behalf of TFI. The accomplishments of a booth, information material and our magazine ThyroWorld in the conference bags, patient forums and dialogue between the professionals and the patient organizations were achieved - but we have to keep on working to make it grow.

Last year, 2014, the ETA conference was in Santiago di Campostella, Spain, but due to health issues I could not attend. I would have loved to be there to meet the new organization from Spain but I do know it was a great meeting. We now have an organization in Mexico and in India, so we are now 24 organizations all over the World.

This year, 2015, it is again the ITC and the location is Orlando, Florida. For sure I would have liked to be there but, due to personal issues, we are not able to attend. This year Thyroid Federation International has existed for 20 years. A lot has happened in those years and we have taken huge steps forward, both the patient organizations and all the organizations of the medical professionals within the thyroid area - huge steps for humankind, even if it is just on the earth and not on the moon! I do hope, from the bottom of my heart, that this dialogue and cooperation will go on for the future to come.

Improving Outcomes for Patients with TED

Improving outcomes for patients with thyroid eye disease (TED) through prevention, early diagnosis and early intervention

DR PETROS PERROS, ON BEHALF OF TEAMED (COLIN DAYAN, JANIS HICKEY, DAN EZRA PETER FOLEY P, JOHN LAZARUS, CARRIE MACEWEN, JULIE MCLAREN, ANNA MITCHELL, GEOFFREY ROSE, JIMMY UDDIN, BIJAY VAIDYA)

Introduction

Approximately 0.25% of the population in the developed world suffers from TED. In rare cases TED causes blindness. TED impacts on physical and psychosocial wellbeing and direct and indirect costs are significant (1). Data indicate long delays from symptoms to starting treatment (2). Cheap, safe interventions can prevent mild TED from progressing to more severe forms (3). There is therefore an unmet need for early diagnosis, referral to specialist centres and treatment.

TEAMeD (Thyroid Eye Disease Amsterdam Declaration Implementation Group)

TEAMeD (4) was formed in 2010 aiming to implement the Amsterdam Declaration in the UK. The Amsterdam Declaration (signed in 2009 by 84 international patient/medical organisations, including the TFI) pledged to improve care for TED (5).

TEAMeD has focused on promoting preventive measures, early diagnosis and treatment for patients with TED in the UK. TEAMeD comprises 12 representatives of the stakeholders, a mix of professional organisations from the specialties of Endocrinology (Society for Endocrinology, British Thyroid Association), Internal Medicine (Royal College of Physicians), Ophthalmology (Royal College of Ophthalmologists, British Oculoplastic Surgery Society, Scottish Ophthalmologists Club) and patient-led organisations (British Thyroid Foundation, Thyroid Eye Disease Charitable Trust).

Over the past 5 years TEAMeD has held regular teleconferences and its members worked hard to bring change within the UK, inspired by the pledges of the Amsterdam Declaration.

Achievements

One of our early objectives was to explore variances in delivery of care for patients with TED. We focused on data collected by the National Health Service on orbital decompression in England. This is an operation that requires considerable expertise and is usually performed to improve the appearance of patients with TED and reduce the bulging of the eyeballs. Orbital decompression improves some of the chronic, troublesome symptoms of TED (for instance pain behind the eye) and the quality of life of patients with TED is known to change for the better after the operation. We identified a 30-fold variance in the rates of orbital decompression performed per unit population, by geographical area (6). Patients that lived close to major centres were far more likely to be offered orbital decompression than those who resided further away. The likely explanation was that this reflected referral habits among doctors rather than patient choice, and confirmed that there was work to be done.

We developed and piloted a simple diagnostic tool which identified previously undiagnosed patients with TED in Endocrine Clinics (DiAGO – DiAgnoSIng Graves' Orbitopathy). We found that about a third of patients attending endocrine clinics with previously undiagnosed TED, were identified using DiAGO and half of these when referred to a specialist clinic required specific treatment for TED. We presented our findings in the International Congress of Endocrinology in 2014 and published our findings to a widely read endocrine journal (7, <http://www.clinmed.rcpjournal.org/content/15/2/173.full.pdf+html>).

Smoking is very strongly associated with TED and there is evidence that quitting improves outcomes. We consulted closely with patients with TED who were smokers and designed a web-based Anti-Smoking Tool specifically for patients with TED (8).

Research funding organisations are increasingly interested in patient and public involvement (PPI) in research proposals and evidence of meaningful PPI in grant applications is an important selection criterion. In 2014 we organised a unique international patient and public event on research priorities in TED (2014)

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(9). The contribution of patients with TED in this meeting had a remarkably positive influence in placing emphasis on future studies that meet patient needs. As a result six potential studies were prioritised and are now available to researchers to use as a resource to support their pursuit for funding TED-related research.

We were invited to act in an advisory role to the commissioning group for specialised ophthalmology services relating to TED in England (2013-15) and we hope we have influenced national policy positively.

We compiled and published national guidelines on initial assessment, management outside specialised centres and referral pathways for patients with TED (2015), promoting the principles of the Amsterdam Declaration (10, free full text of the guidelines can be found in: <http://www.clinmed.rcpjjournal.org/content/15/2/173.full.pdf+html>).

Conclusions

TEAMeD is an example of how a small group of enthusiastic individuals driven by the same beliefs, can collaborate productively, without external funding. Keeping the group small made TEAMeD cohesive, flexible, and easy to steer. The enthusiasm of its members got jobs done. Sharing the same vision made putting aside small differences of opinion easy. But the most important catalyst for TEAMeD's achievements was having patients with TED within the group working alongside professionals as equal

partners. The success of TEAMeD or otherwise is yet to be judged, but for all of us it has been a worthy and greatly satisfying experience.

References

1. Ponto KA, Merkesdal S, Hommel G, Pitz S, Pfeiffer N, Kahaly GJ. Public health relevance of Graves' orbitopathy. *J Clin Endocrinol Metab.* 2013;98:145-52.
2. Estcourt S, Hickey J, Perros P, Dayan C, Vaidya B. The patient experience of services for thyroid eye disease in the United Kingdom: results of a nationwide survey. *Eur J Endocrinol.* 2009;161:483-7.
3. Marcocci C, Altea MA, Leo M. Treatment options for Graves' orbitopathy. *Expert Opin Pharmacother.* 2012;13:795-806.
4. <http://www.btf-thyroid.org/index.php/campaigns/teamed>
5. Perros P, Wiersinga WM. The Amsterdam Declaration for people with thyroid eye disease. *Thyroid.* 2010;20:245-6.
6. Perros P, Chandler T, Dayan CM, Dickinson AJ, Foley P, Hickey J, MacEwen CJ, Lazarus JH, McLaren J, Rose GE, Uddin JM, Vaidya B. Orbital decompression for Graves' orbitopathy in England. *Eye (Lond).* 2012;26:434-7.
7. Mitchell AL, Goss L, Mathiopoulou L, Morris M, Vaidya B, Dickinson AJ, Quinn A, Dayan C, McLaren J, Hickey JL, Lazarus JH, Rose GE, Foley P, MacEwen CJ, Perros P. Diagnosis of Graves' orbitopathy (DiaGO): results of a pilot study to assess the utility of an office tool for practicing endocrinologists. *J Clin Endocrinol Metab.* 2015;100:E458-62. (<http://press.endocrine.org/doi/full/10.1210/jc.2014-3146>)
8. <http://www.btf-thyroid.org/index.php/campaigns/teamed/ted-and-smoking-information-for-patients>
9. Perros P, Dayan C, Dickinson AJ, Ezra DG, Hickey JL, Hintschisch C, Kahaly GJ, Lazarus J, Ludgate M, Bartès B, MacEwen C, Mitchell AL, Morris D, O' Connor N, Pearce SH, Rose G, Salvi M, Wiersinga WM, Williamson A. Future research in Graves' orbitopathy: from priority setting to trial design through patient and public involvement. *Thyroid* 2015 (in press).
10. Perros P, Dayan CM, Dickinson AJ, Ezra D, Estcourt S, Foley P, Hickey J, Lazarus JH, MacEwen CJ, McLaren J, Rose GE, Uddin J, Vaidya B. Management of patients with Graves' orbitopathy: initial assessment, management outside specialised centres and referral pathways. *Clin Med.* 2015;15:173-8. (<http://www.clinmed.rcpjjournal.org/content/15/2/173.full.pdf+html>)

Historical Photo



Group picture at the annual meeting of the TFC in Toronto, Canada, 1995, where TFI was founded

Inquiry: Standardization of Thyroid Tests

The future standardization of FT4 and harmonization of TSH measurements in serum

LINDA M. THIENPONT, JAMES D. FAIX, GRAHAM H BEASTALL
– IFCC C-STFT

A request for input on benefits and risks from Thyroid Foundations

The timely diagnosis and treatment of thyroid dysfunction is essential given the prevalence and severity of the disease. It requires reliance on adequate first-line laboratory testing of serum thyroid stimulating hormone (TSH) and free thyroxine (FT4). The laboratory and clinical community have long recognized the need for standardization of thyroid function tests to achieve comparability of measurement results between the methods available from different manufacturers.

The measurement of these two hormones in serum is challenging. They are both present in extremely low concentrations. The measurement of FT4 has to be performed in the presence of very much higher concentrations of thyroxine, which is bound to serum proteins. TSH exists in serum in several different forms, which means that it is not possible to define a single standard preparation, which is representative of all patients and conditions.

In response to this need, the International Federation of Clinical Chemistry and Laboratory Medicine (IFCC) formed a Working Group (now a Committee) for Standardization of Thyroid Function Tests (C-STFT), which has worked towards the goal of recommending practical options for the standardization of TSH and FT4 testing. The membership of C-STFT comprises a mix of academics, laboratory people, proficiency testing organizers and the global companies that manufacture the TSH and FT4 methods.

The C-STFT established and validated a high level, definitive method for the measurement of serum FT4 (known as a reference measurement system). This method complies with international standards of practice and gives the correct results, but it is complex and expensive to perform and so unsuitable for routine use (1-3). The existence of the FT4 reference measurement procedure allows for comparison of routine methods against a true standard (hence standardization). The C-

STFT also defined a basis for the comparison of TSH assays (4). In the absence of a true standard this process is known as harmonization. Method comparison studies were performed in a number of phases to investigate and confirm the feasibility of the standardization of FT4 and harmonization of TSH tests, with attention to fit-for-the-purpose analytical quality (5-7).

For FT4, the between method variation is substantial and all currently available FT4 methods are different from the reference measurement procedure used for standardization. The FT4 methods used in clinical practice give results lower than the reference measurement procedure, with some methods yielding results <50% of the measurement procedure. Re-standardization of the available FT4 assays is feasible so that all methods can be modified to give very similar results. However, re-standardization will require method related changes in the lower and upper limits of current reference intervals for normal subjects. For example, the method that differs most from the reference measurement procedure will see the reference interval change from $-6.1 - 11.2$ pg/mL ($7.9 - 14.4$ pmol/L) to $9.5 - 20.3$ pg/mL ($12.2 - 26.1$ pmol/L).

The variability between TSH methods is significant but less dramatic than for FT4, being of the order of ~20%. It is possible to harmonize methods to produce very similar results but this will lead as well to method related changes to the reference interval for normal subjects. These will mostly affect the upper limit of normal, i.e., for the most negatively biased assay the current upper limit of -3.7 mIU/L will increase to 4.5 mIU/L, while for the most positively biased method it will decrease from -5.3 mIU/L to 4.5 mIU/L.

It follows from these findings that the standardization of FT4 methods and the harmonization of TSH methods will result in a change in the reference intervals for all FT4 methods and some TSH methods. In addition both FT4 and TSH results will shift after standardization/ harmonization and this will affect the interpretation of cumulative patient results.

(continued on page 14)

The C-STFT has discussed these data with the Food and Drug Administration, Division of Chemistry and Toxicology Devices (FDA), which is responsible for the regulation of TSH and FT4 assays. A dedicated meeting held in 2014 confirmed that the scientifically supported approach of the C-STFT was fully acceptable to the FDA and that everything was in place for performing the technical standardization of FT4 and harmonization of TSH assays. However, the FDA identified the need for a risk analysis to be performed before implementation.

To this end, the C-STFT is contacting a range of stakeholders to seek views on the benefits and risks arising from FT4 standardization and TSH harmonization. This short paper seeks the views of patient based Thyroid Foundations in three areas:

1. **Benefits:** We wish to learn of the benefits that you think would be achieved if all FT4 methods and all TSH methods give comparable results on patient samples.
2. **Risks:** We wish to learn of the risks to patient safety and clinical outcomes that you think may arise as a consequence of a change in reference intervals and cumulative results for patient samples.
3. **Implementation:** We wish to hear your views on the educational roles that could be played by the Thyroid Foundations in minimizing the identified risks to patients from FT4 method standardization and TSH method harmonization.

This call is being launched in parallel to several clinical journals and to professional organizations for doctors and laboratory specialists.

Please summarize your comments in a Word document and send them as an email attachment to the following three authors of this short article:

1. Linda M. Thienpont, PhD, is director of a Mass Spectrometry Reference Laboratory at Ghent University and a member of the Faculty of Pharmaceutical Sciences, Gent, Belgium. She is chair of the IFCC C-STFT. Email: linda.thienpont@ugent.be
2. James D. Faix, MD, is director of Clinical Chemistry and Immunology at Montefiore Medical Center and Clinical Professor of Pathology at the Albert Einstein School of Medicine in New York, USA. He is also a

member of the IFCC C-STFT. Email: jfaix@montefiore.org

3. Graham H Beastall, PhD, is a retired laboratory director from Glasgow, UK and former Treasurer of the British Thyroid Association. He is the Past President of IFCC. Email: gbeastall@googlemail.com

References

1. Thienpont LM et al. International Federation of Clinical Chemistry and Laboratory Medicine (IFCC), Scientific Division Working Group for Standardization of Thyroid Function Tests (WG-STFT). Measurement of free thyroxine in laboratory medicine-- proposal of measurand definition. *Clin Chem Lab Med* 2007; 45:563-564.
2. Thienpont LM et al. IFCC Scientific Division Working Group for Standardization of Thyroid Function Tests (WG-STFT). Proposal of a candidate international conventional reference measurement procedure for free thyroxine in serum. *Clin Chem Lab Med* 2007; 45:934-936.
3. Van Houcke SK et al. International Federation of Clinical C, Laboratory Medicine Working Group for Standardization of Thyroid Function Tests: IFCC international conventional reference procedure for the measurement of free thyroxine in serum: International federation of clinical chemistry and laboratory medicine (IFCC) working group for standardization of thyroid function tests (WG-STFT). *Clin Chem Lab Med* 2011; 49:1275-1281.
4. Stöckl D et al. A statistical basis for harmonization of thyroid stimulating hormone immunoassays using a robust factor analysis model. *Clin Chem Lab Med* 2014; 52:965-72.
5. Thienpont LM et al. Report of the IFCC working group for standardization of thyroid function tests, part 1: Thyroid-stimulating hormone. *Clin Chem* 2010; 56:902-911.
6. Thienpont LM et al. Report of the IFCC working group for standardization of thyroid function tests, part 2: Free thyroxine and free triiodothyronine. *Clin Chem* 2010; 56:912-920.
7. Thienpont LM et al. A progress report of the IFCC Committee for Standardization of Thyroid Function Tests. *Eur Thyroid J* 2014; 3:109-116.

Levothyroxine formulation change – who suffers? Thyroid patients!!

ASHOK BHASEEN, M.PHARM, MMS

Levothyroxine is a narrow therapeutic index drug and a small change in its formulation has an impact on patients who have been stable on an older formulation. Controversy exists over the true therapeutic equivalence of branded and generic levothyroxine—the drug of choice for treating hypothyroidism—hence professional and patient society's e.g. Thyroid Federation international recommend against switching between different formulations of the drug and suggest that patients who do switch (due to unavoidable reason) be monitored. Switching between formulations of different companies is just one issue for thyroid patients. The other issues is when manufacturers simply change the levothyroxine formulation (what makes a full bulk of a pill including other non-active ingredients, excipients and color) without informing the patients. This sudden change of formulation by manufacturers has caused problems for thyroid patients in New Zealand, Australia, Denmark, Belgium and Israel are just a few examples. In Australia the tablet has to be kept in a freezer and the problem gets compounded for these patients when they have to travel in other places in the world.

At Thyroid Federation International and local country thyroid foundation we face this issue as patients call and we are witness to the deteriorating health of the patients because of these changes which are done without their knowledge. The manufacturer, physicians and pharmacists fail to inform the patients. The very companies that pledge and have a credo for patients wellbeing fail them with these sudden unannounced changes in levothyroxine formulation.

The patients whose life and wellbeing depend on taking their thyroid hormones every day, for their entire life, are very willing to be serious and “compliant”, we know that this is important - but what can we do when the manufacturer decides to change the formula? The sad part in some in many countries is that, there isn't even an alternative, just one company making the levothyroxine formulation!!

Any slight formulation change in a generic or branded levothyroxine product can affect the bioequivalence of a medicine. While

bioequivalence is assessed using international standards before a product or formulation is approved, it is feasible that approximately 5% of patients may experience either an increased or decreased therapeutic effect, even when the product has been approved to be bioequivalent with the product previously available. Due to this very reason the manufacturer should issue an advice to all healthcare professionals describing the change in formulation, prior to its distribution to pharmacies and that advice should be passed on to thyroid patients. The changes in excipients of a formulation in practice as witnessed by thyroid patient organisations is also profound.

Various studies have proven that the savings in prescription drug costs after switching from branded to generic levothyroxine are offset by increases in costs for other healthcare services, such that switching is actually associated with an increase, not a decrease, in total healthcare costs. The same cost go up when sudden change in levothyroxine formulation are undertaken i.e. cost of hospitalization, cost of work day lost, loss of productivity, etc.

In conclusion countries with smaller population have to think of solutions e.g. Pan European approval of 1 or 2 levothyroxine products as it is not a big revenue generator for small volume manufacturers. Similar options should be looked at for other regions of the world where populations are limited. Thyroid patients whose life depends upon daily intake of levothyroxine pills need solutions and companies that can provide the best to our patients. This is definitely not an area where companies come and go, as patients depend on these products for a life time.

Historical Photo



Munich 1997:
Giovanna
Liborio, Larry
Wood, Nancy
Patterson,
Emma Bernini

International Thyroid Awareness Week 2015

A Thyroid Camp was organized by Thyroid Help India on behalf of Thyroid Federation of India at the village of Manamai, near Mamallapuram, Tamilnadu, India. International student volunteers from different parts of the world participated and helped in conducting this camp which was presided by Mr. Henry. On the final day a Thyroid Cancer awareness



Dr Senthil Kumar, President, Thyroid Federation of India at the thyroid camp.



lecture was given by Dr. M. S. Senthil Kumar followed by Q& A. On this occasion the guest of honour was Mr. C. Raj Kumar, a well known film star in South India. Thanks to Mr. Lakshminarayanan, the hotel owner who hosted a dinner for the volunteers involved in the Thyroid Camp. Thyroid Federation of India honored the international volunteers with a certificate of service to the Thyroid Camp.

AECAT Launches the “It Could Be Your Thyroid” Campaign

On the occasion of International Thyroid Week, the Spanish Thyroid Cancer Association (AECAT), with the support of the Spanish Endocrinology and Nutrition Society (SEEN), launched a public awareness campaign called “It could be your thyroid” on the health effects of thyroid dysfunction and the importance of an early diagnosis.

In view of the results of an 800 participant study by AECAT, the campaign sought to remedy the general population’s lack of knowledge regarding thyroid function, as well as a more effective way to inform of the thyroid gland’s

health role, 37.9% of the population declared they knew nothing or close to nothing about the thyroid gland, and 54% knew very little, associating it only with weight fluctuations.

The general population does not associate certain symptoms or diseases with the thyroid gland, which is resulting in delayed diagnoses and a significant percentage of undiagnosed diseases. When presenting the campaign, Dr. Miguel Angel Rubio, Secretary of SEEN, stated that the general population does not know when to visit an endocrinologist. “Only obesity is associated with this specialty, and in the best case to diabetes. For other hormonal problems (thyroid, adrenal, ovaries, etc.), most people are unaware that they are studied by the endocrine, delaying the diagnosis of many diseases.”

Educational Video

To reach a larger scope of people, the centrepiece of the campaign is an educational video with impactful drawings charged with meaning, seeking to simplify the message by highlighting the essential: keeping a healthy thyroid gland will help you live more and better.

<https://youtu.be/tyBc864fLYo>

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Poster for the “It could be your thyroid” Campaign
See the video, go to: <https://youtu.be/tyBc864fLYo>

<p>Hipotiroidismo, hipertiroidismo y salud. Aspectos prácticos de la acción de las hormonas tiroideas.</p> <p>Dr. Sánchez Franco Endocrinólogo</p> <p>Miércoles 3 de junio 13:00hrs</p>	<p>Depresión, ansiedad y tiroides.</p> <p>Dr. Corona Psiquiatra y médico general</p> <p>Martes 9 de junio 19:00hrs</p>
<p>Aspectos prácticos del tratamiento con hormona tiroidea.</p> <p>Dr. Sánchez Franco Endocrinólogo</p> <p>Viernes 19 de junio 18:00hrs</p>	<p>Hormonas tiroideas durante el embarazo. Cáncer de tiroides y embarazo.</p> <p>Dr. Juan Carlos Galofré Endocrinólogo</p> <p>Miércoles 24 de junio 18:00hrs</p>

As it is not always easy to recognize the symptoms of thyroid dysfunction (often confused with other ailments such as stress, anxiety, depression or loss of abilities due to age), it often takes some time to request the test that confirms this disease: TSH (Thyroid Stimulating Hormone). Therefore, and facing the impossibility of testing the entire population, this campaign focuses on raising awareness and monitoring certain risk groups, specifically:

- Those with a family history of thyroid related diseases
- When planning a pregnancy, in cases of infertility, abortions, postpartum depression, etc.
- All kinds of depressive disorders
- Cardiac disorders
- +65 years of age
- Cases of obesity
- Diagnosed hypercholesterolemia
- Risk of Osteoporosis

Webinars

Concurrently, for those seeking more information, AECAT organized webinars by the best specialists, interactive online courses for patients available here: <http://www.aecat.net/podria-ser-tu-tiroides/>. With this initiative, AECAT wagers on an informed patient and health education as the best preventive measure.

Said presentations and specialists are on: "Thyroid and mental health", "Hypothyroidism, hyperthyroidism and health", "Thyroid hormones during pregnancy, thyroid cancer and pregnancy" and "Practical aspects of thyroid hormone treatment".

30 second advertisement

A short version of the educational video was sent to all major television networks, being broadcast for two weeks on national, regional and local channels, among which we highlight La Sexta, Telemadrid, and TeleExtremadura.

IMAGEN DEL SPOT

The advertisement aims to shine a light on the importance of the thyroid gland on health; thyroid dysfunction can be related to diseases such as depressive disorders, hypertension, infertility, high cholesterol, osteoporosis, cognitive impairments, and seriously impair a successful pregnancy and the baby's health. In order to act on this, AECAT also wants to emphasize *the lack of a clear commitment towards the welfare of the population and prevention policies. In both respects, the thyroid gland is key; however, it is the most overlooked in health education.*

Proof of this is that according to a meta-analysis recently published by Garmendia et al, from the Group of Dr. Galofré of the University of Navarra, the average prevalence of Europeans with thyroid dysfunction is close to 11%, and only half are aware of the illness. That is, the prevalence of undiagnosed thyroid dysfunction (people who do not know they suffer from it) is 6.71%; the prevalence of undiagnosed hypothyroidism is 4.94% and 1.72% for hyperthyroidism. Unfortunately, a similar study at a national level does not exist in Spain.

Hopefully, with this campaign over ... impacts will contribute to show the founding role of the thyroid gland on health.

You can download material from the campaign from this dropbox file (*Includes an educational video 1:25 long and the campaign's 0:30 advertisement, as well as 180x198 and 369x249 posters*)

<https://www.dropbox.com/home/Podr%C3%ADa%20ser%20tu%20tiroides>

Historical Photo



Athens 1998:
Prof. Robert Volpe (Canada),
Dr Alexander Kurtev ("Sasha",
Bulgaria),
Rhonda Boyce
and Joe Boyce
(Canada)

International Thyroid Awareness Week 2015

JANIS HICKEY

DIRECTOR AND FOUNDER, BTF

We started working on our hypothyroidism project in 2013 and we marked World Thyroid Day by raising awareness of the development of our 'Hypothyroid Care Strategy Project'. In 2012 the BTF had partnered with Sense about Science to take part in an online clinic hosted by NHS Choices and TalkHealth. The record numbers of people who logged in to take part gave us access to large amount of data about the concerns that affect patients with hypothyroidism, which helped to shape up our project.

The Hypothyroid Care strategy is designed to support people in the UK diagnosed with, and treated for hypothyroidism. It focuses on improving communication between hypothyroidism patients and their healthcare professionals, including GPs, endocrine specialists, nurses and pharmacists. In addition it will support the development of research to improve patient care. The BTF is in a uniquely advantageous position in being able to act as a catalyst in the UK as it has access to thyroid experts in the UK and a long track record of collaboration with them. So far, BTF has undertaken various components of the project, which are described below.

During 2013-14 the BTF ran a hypothyroidism awareness campaign with a specially created poster and leaflet, listing hypothyroid symptoms, which was displayed in more than 1,250 GP surgeries across the UK. This resulted in an increase in calls to BTF HQ and an increase in membership from the parts of the country where the poster/leaflets were displayed, plus requests from GP practices for further information from BTF. There was also a 250% increase in hits to the BTF hypothyroidism webpage in this period compared with the same period the previous year.

In 2014 patient representatives from the BTF met representatives from a pharmaceutical company to discuss patients' experiences of hypothyroidism and in particular the challenges some have with their medication.

The BTF also worked with a GP who wanted to update a GP training module that appeared in PULSE Learning (the most widely used training module amongst GPs) about hypothyroidism including how to manage subclinical hypothyroidism and managing hypothyroidism in pregnancy. This has been published and appears to be well received and used by GPs.

The BTF is now involved a study to investigate the Clinical And genetic determinants of Thyroid Hormone Replacement In geNeral practicE (CATHRINE). The study is supported by AMCo Ltd and will be run by investigators from the Universities of Sunderland, Newcastle and Cardiff. The project will explore patient and professional attitudes and perceptions of symptom control in hypothyroidism, genetic associations with thyroid control and the association of thyroid specific genetic abnormalities and psychological symptoms.

The BTF created four short films in which people talk about hypothyroidism and how it affects them – available to view on the BTF website: <http://www.btf-thyroid.org/index.php/campaigns/hypothyroidism-care-strategy/hypothyroidism-films-patient-journeys>.

The BTF Research Award 2015 of £20,000 was set aside to fund research specifically into hypothyroidism, and was awarded to Dr. Carla Moran, Consultant Endocrinologist at Addenbrooke's Hospital, Cambridge for a research study entitled: Diagnosis and management of RTH – a disorder characterised by tissue-specific hypothyroidism associated with near-normal thyroid function tests. <http://www.btf-thyroid.org/index.php/awards/research-awards/current-awards/2015>.

The BTF has been invited to play a key role in an endocrine network, which is in the process of being established under the name of THYRONET. The aim of the network is to compliment the activities of the Society for Endocrinology and the British Thyroid Association (BTA), and also engage with people with a diverse professional background (surgeons, ophthalmologists, oncologists, nuclear medicine specialists) as well as patient groups and members of the public with an interest in thyroid disorders.

The BTF has worked with the British Thyroid Association by providing feedback on the revised BTA statement on the Management of Primary Hypothyroidism, which is posted on the BTF website and is accompanied by frequently asked questions and answers for patients: www.btf-thyroid.org/index.php/thyroid/statements/30-general-btf-articles/general-pages/462-bta-statement-on-the-management-of-primary-hypothyroidism.

With all these activities in place, and with plans to develop them further, the BTF was delighted to have been able to promote its Hypothyroidism Care Strategy Project in ITAW.

The Australian Thyroid Foundation Celebrates 20 Years!

BEVERLEY GARSIDE

2015 is The Australian Thyroid Foundation's (ATF) celebration of 20 years supporting and educating its members.

The ATF Founder, Gail Ballantyne, who suffered from thyroid cancer, began the organisation in 1995 after her battle to find information about thyroid cancer and treatments. With 3 other thyroid patients and the support of her endocrinologist, Professor Steven Boyages, The ATF was born.

The first Thyroid Information Patient Conference was held in 1996 with a packed auditorium in Westmead Hospital, Sydney. Committee Meetings were held in member's homes. Telephone support, Member Newsletters and Member Meetings in local areas were the way the ATF supported and educated its members in the early days.

In 1995, Gail reached out to the Thyroid Foundation of Canada, who kindly sent her thyroid information brochures for the ATF to use to educate members about different aspects of thyroid disease which were very helpful and much appreciated.

The ATF was one of the first member organisations of Thyroid Federation International (TFI), which again gave the ATF support in the early days and, still today, provides international awareness messaging.

Professor Creswell Eastman provided office space for the ATF in Westmead Hospital for our first office. Professor Eastman was very generous with his support, which gave the ATF the opportunity for meetings to be held in a meeting room and the use of office equipment and services.

From those early days, The ATF has grown to where we are today. Sponsors and Supporters have helped the ATF to expand and improve member services and awareness campaigns. Our Medical

Advisory Team, who are thyroid specialists and other connected health specialists, have written articles for the ATF Newsletter 'Thyroid News', spoken on the ATF's behalf and represented the ATF when asked for media interviews and on other occasions.

The ATF office is well equipped and situated in Macarthur House, a beautiful heritage building in Parramatta in Sydney. The ATF has changed to meet member requirements and needs over the years, with online information the way members want to receive their education rather than meeting for a day conference. Member Meetings are held in several areas around Australia by volunteer members.

2015 is our celebration year of the past, present and future of the organisation. The ATF recently launched a brand new website, which is a great improvement on our last, www.thyroidfoundation.org.au. The ATF will hold its inaugural 'Touch of Gold' Gala Ball in September, celebrating 20 years of providing support and education to our members and raising much needed awareness of thyroid disorders throughout Australia. It is estimated there are 1 million Australians undiagnosed with some form of thyroid disease, so our organisation and work must continue. The Gala Ball will be our first official fundraiser of this type and we are very pleased to have the support of the community

in organising this event. Westpac Banking Corporation will "match" every dollar made on the night with a donation in support of the ATF work.

From a very humble beginning to where the ATF is today, I am very proud to represent the organisation as President and have worked with some amazing volunteer members, medical advisors and sponsors over the years who have helped the ATF grow and continue to support thyroid patients throughout Australia.



THE AUSTRALIAN
THYROID
FOUNDATION LTD

Thyroid Institute – a non-profitable institution which helps and advices people with thyroid disease



GERALDO MEDEIROS-NETO, PRESIDENT AND EDUARDO TOMIMORI, SECRETARY-TREASURER

Introduction

The Thyroid Institute was chartered in December 2001, in São Paulo, Brazil, as a non-profitable organization, dedicated to studies on thyroid disease and free information and support for patients either by printed information or individualized online support.

Background

It was obtained from the Brazilian Ministry of Justice, the title of non-profitable organization linked with the support of patients with thyroid disease. During those 15 years, the Thyroid Institute, using mostly digital information resources, spread over Brazil and neighboring countries a lot of data about the physiology, genetics and diseases of thyroid gland, its short and long term treatment and follow-up.

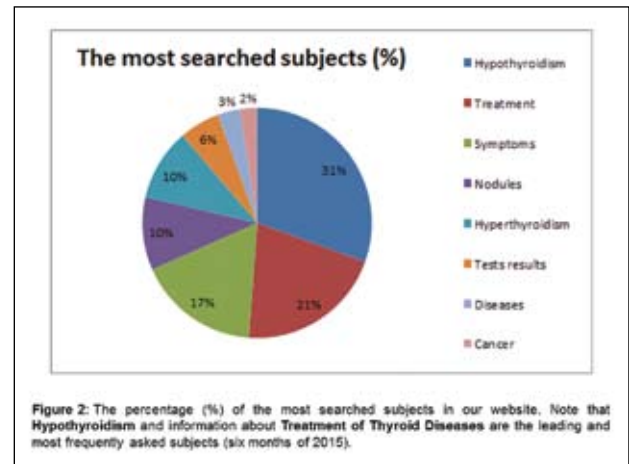
The Thyroid Institute maintains an open channel for the Brazilian population by online answers to the general public concerning all aspects of thyroid disease management and general aspects of treatment. Indeed, the institution answers about a mean of 150 monthly questions received by e.mail , giving explanations, corrections and details about most of the thyroid pathologies.

Vital statistics

The number of viewers of our site (www.indatir.org.br) increased rapidly to 42,000 accesses every month as demonstrated in Figure 1.



It is also shown in Figure 2, that hypothyroidism, and all aspects of medical and surgical treatment of thyroid diseases are the most frequently asked questions and details about diagnostic, side effects and results of medical intervention.



Other commonly asked subjects are doubts about symptoms, presence of nodules, hyperthyroidism, test result, and associated diseases. Surprisingly cancer of thyroid is not often a subject that people want to know more or have doubts about this relatively common thyroid condition.

The Thyroid Institute is also involved in public health and, its Officials have frequently participated into the TV shows in order to explain the need for permanent iodination of salt consumed by the Brazilian population. Moreover, recently, the Thyroid Institute was involved in a campaign to induce pregnant women to add iodine daily in their respective medication. Another field which it has been deeply involved concerns the need of all newborns to be tested for hypothyroidism during the first few weeks of life. Indeed, this campaign first started when it was noticed that many children were only tested for thyroid dysfunction relatively late after birth. Probably the newborns that received medication later in post-natal life would have a variable degree of mental retardation or present a neurological damage or both pathologies.

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Thyroid Foundation of Canada – 35th Anniversary

DONNA MINIELY, PRESIDENT

Congratulations to the Thyroid Federation International on its 20th anniversary! At our AGM in June 2015, the Thyroid Foundation of Canada (TFC) celebrated its 35th anniversary and as part of looking back over our history, we viewed pictures from the 1995 AGM where the TFI was launched.



Several members at the 2015 AGM had attended the 'birth' of the TFI, which was the realization of one of Diana Meltzer Abramsky's wishes: "I wish for a world Thyroid Foundation with Chapters in every corner of the globe, where the universal problems of thyroid patients may be addressed."

Diana founded the Thyroid Foundation in Canada, the first thyroid foundation in the world. Her wishes, which can be viewed at http://www.thyroid.ca/diana's_wishes.php, continue to provide direction for TFC's efforts and perhaps resonate for other member organizations of TFI.



What a delight to see that TFI is thriving and growing bigger each year, demonstrating that word is getting out around the world about the symptoms and challenges of thyroid disease and the treatments for various conditions.

This past year, TFC partnered with Abbott Pharmaceuticals (now Mylan) to undertake two initiatives. The first was to host accredited training for pharmacists on the www.thyroid.ca website. Entitled "Thyroid Disorders – A Pharmacy Approach to Managing Patients' Thyroid Health", more than 200 pharmacists had completed the training within the first 6 months.

The second was to hold Thyroid Health Days in pharmacies across the country where a nurse was available to discuss a thyroid assessment questionnaire with thyroid patients. These Health Days were held in over 80 pharmacies during the first 6 months.

TFC is funding research at the London Health Science Centre in London Ontario into the Detection of Circulating Tumour DNA in Thyroid Disease. We hope that one day, the number of indeterminate results for thyroid nodule biopsies can be reduced with the help of a simple blood test. More information about this research is available in our Spring 2015 Thyrobuletin.



*Pharma Choice Gabriel Drugs in Nepean Ontario hosted the first of Thyroid Health Days
LT to RT: Ricki Samuels (patient referred to nurse by pharmacist), Carolyn Goodfellow (TFC Ottawa Chapter), Tina Perkins (nurse)*

The TFC's website continues to be very popular, attracting 120,000 visitors each month from around the world. Watch for enhancements to this website over the coming year!

Once again, we send our congratulations to TFI on its 20th anniversary. May TFI and its member organizations continue to flourish in order to reach out and help all thyroid patients around the world.



Thyroid Foundation of Canada

La Fondation canadienne de la Thyroïde

New interesting studies in Denmark

Researchers from several Danish Hospitals have been working on new interesting studies on hypothyroidism the last years. Therefore the Danish patient organization, Thyreoidea Landsforeningen, took the opportunity of International Thyroid Awareness Week to hold a meeting for patients in order to give an update of the latest scientific research on the subject.

The meeting was held in the city of Odense and the main speaker was Chief Physician Steen Bonnema from Odense University Hospital. He gave the attending 120 patients and relatives a brief lecture on "What you need to know, Facts and Myths about Hypothyroidism". Afterwards he took the audience through a handful of new interesting studies on the subject. One study he found particularly interesting, was the Danish study on symptoms of hypothyroidism by Allan Carlé of Aalborg University Hospital and Silkeborg Regional Hospital.

Feeling tired?

The study shows that 75 percent of women with an underactive thyroid disease experience tiredness. This makes it the most recognizable symptom for doctors. Unfortunately, 40 percent of the group of women without thyroid disease report that they too experience tiredness. According to Chief Physician Steen Bonnema this means that doctors



Chief Physician Steen Bonnema from Odense University Hospital told the audience about the basics as well as the myths of hypothyroidism.



cannot diagnose thyroid patients based on symptoms alone because they are so indistinct and can occur in many other illnesses and diseases.

Future studies

In his concluding remarks Steen Bonnema gave an interesting insight into the future and to the questions he would like to answer. From his point of view, one of the major unknowns is our immune system. He argues that if we are to cure autoimmune thyroid disease, for example Hashimoto's thyroiditis, we need to know more about its interaction with the immune system rather than only about the thyroid gland. And then, perhaps, it would be possible to repair and cure autoimmune thyroid diseases by way of stem cell technologies.

Also Chief Physician Steen Bonnema looks forward to see new studies on T3 treatment and its effect on larger groups of patients, as well as studies on thyroid patients' quality of life and the effect of thyroid hormones on brain function.

These are studies that we in the Danish patient organization also would like to see. The more we can chart effects on thyroid disease, the better the quality of life for thyroid patients.



Left, Chief Physician Steen Bonnema from Odense University Hospital teamed up with Vice President Bente Lasserre of the Danish patient organization, Thyreoidea Landsforeningen (right) and answered questions from the audience.

As a part of the International Thyroid Awareness Week, the Danish patient organization Thyreoidea Landsforeningen, had designed new postcards to hand out at an information meeting in Odense and in waiting rooms of general practitioners.

Covert iron deficiency simulates symptoms of hypothyreosis

ESA SOPPI, MD, PHD, ADJUNCT PROFESSOR OF MEDICINE
EIRA HOSPITAL. LAIVURINKATU 29, FI-00150 HELSINKI, FINLAND

During the recent years the number of levothyroxine users has increased rapidly, probably because many patients seek medical advice for symptoms resembling hypothyreosis (Pearce et al 2013, Taylor et al 2014). Some 5-10 % of treated hypothyroid patients have symptoms even if they have euthyroid blood values (Wiersing et al 2012). In both situations exclusion of other diseases and a correct diagnosis are important for appropriate and correct treatment.

Iron deficiency is as common as hypothyreosis (Hallberg 1995, Johnson-Wimbley and Graham 2011). To separate these two entities carries at least three challenges. Firstly, symptoms of iron deficiency resemble or may be identical with those of hypothyreosis. Secondly, anemia appears late in iron deficiency: iron stores are consumed first and only after this, when iron stores are depleted, anemia ensues. Thirdly, patients with depleted iron stores can have numerous and even severe symptoms before any changes in the blood count emerges.

The serum ferritin concentration correlates with the volume of the body's iron stores (Worwood 2007). Recently, the serum ferritin reference values in clinical use have been questioned (Garcia-Casa et al 2014), also supported also by previous literature (Punnonen et al 1997, Koulaouzidis et al 2009). A ferritin concentration >50 microg/l is frequently consistent with iron deficiency.

Covert iron deficiency should be suspected in patients, especially young females, with symptoms resembling hypothyreosis if their TSH value is below 10 mU/l and they are TPO-antibody negative. Similarly, if a patient is not feeling well during levothyroxine treatment, iron deficiency, vitamin B12- and vitamin D deficiency and celiac disease should be considered and appropriate tests taken.

I am presenting a paper in the 15th International Thyroid Congress describing a preliminary series of 25 patients with covert iron deficiency, as indicated by a low serum

ferritin concentration, who were not feeling well on their optimized levothyroxine regimen.

Iron supplementation accompanied by an increase in the serum ferritin concentration to a value above 100 µg/l cleared the symptoms of two thirds of the patients. The reason why not all patients respond is currently unclear.

Covert iron deficiency should be considered for all patients with suspected subclinical hypothyreosis and for patients with hypothyroid symptoms despite adequate levothyroxine treatment.

Literature

- Garcia-Casa MN, Peña-Rosas JP, Pasricha S-R. Rethinking ferritin cutoffs for iron deficiency and overload. *The Lancet Haematology* 2014; 1: e92-e94.
- Hallberg L. Results of surveys to assess iron status in Europe. *Nutrition Reviews* 1995;53:314-322.
- Johnson-Wimbley TD, Graham DY. Diagnosis and management of iron deficiency anemia in the 21st century. *Therap Adv Gastroenterol* 2011;4:177-184.
- Pearce SHS, Brabant G, Duntas LH, Monzani F, Peeters RP, Razvi S, Wemeau J-L. 2013 ETA Guideline: Management of subclinical hypothyroidism. *Eur Thyroid J* 2013; 2:215-228.
- Punnonen K, Irjala K, Rajamäki A. Serum transferrin receptor and its ratio to serum ferritin in the diagnosis of iron deficiency. *Blood* 1997; 89:1052-57.
- Taylor PN, Iqbal A, Minassian C, Sayers A, Draman MS, Greenwood R, Hamilton W, Okosieme O, Panicker V, Thomas SL, Dayan C. Falling threshold for treatment of borderline elevated thyrotropin levels—balancing benefits and risks. Evidence from a large community-based study. *JAMA Intern Med* 2014;174(1):32-39.
- Worwood M. Indicators of the iron status of populations: ferritin. In: WHO, CDC. *Assessing the iron status of populations: report of a joint World Health Organization/Centers for Disease Control and Prevention technical consultation on the assessment of iron status at the population level*, 2nd ed. Geneva, World Health Organization, 2007;35-74. available: http://www.who.int/nutrition/publications/micronutrients/anaemia_iron_deficiency/9789241596107.pdf
- Wiersinga WM, Duntas L, Fadeyev V, Nygaard B, Vanderpump MPJ. 2012 ETA Guidelines: The use of L-T4 + L-T3 in the treatment of hypothyroidism. *Eur Thyroid J* 2012; 1:55-71.



Vivre sans Thyroïde: 15 years of online patient support



AUTHOR: BEATE BARTÈS

“Vivre sans Thyroïde” started in October 2000, as a small personal discussion forum created by a patient to share her experience and help others with all the information she found during her cancer journey.

The forum has been one of the first French online patient communities, and over the years has grown bigger: it now has categories for all kinds of thyroid disorders, a huge “Frequently asked questions” list and contains links to medical websites, official guidelines, and patient literature. There are approximately 5000 visits and more than 100 messages per day, from many different French-speaking countries: France, Belgium, Switzerland, Morocco, Algeria, Tunisia, Canada, African countries ...

In 2007, the forum became an official non-profit organization. It is financed by the fees of its members, and run by a small group of volunteers, all thyroid patients. The main activities are still “online”: the web forum, with 15.000 registered



users, a Facebook page, a Facebook group with more than 2500 members, a Twitter account and a YouTube account with educational videos. But the association also organizes or participates in patient information events, patient meetings and medical congresses, in order to raise awareness and spread information about thyroid disorders. It works with institutions and doctors for articles and patient literature, and carries out

patient surveys on subjects like “What a patient expects from his doctor” or “Quality of life after thyroidectomy”. At the international level, VST cooperates with thyroid and thyroid cancer patient organizations all over the world within the Thyroid Federation International and Thyroid Cancer Alliance.

www.forum-thyroïde.net

Thyroid Institute... (continued from page 20)

Conclusion

Today, the Thyroid Institute plays an important role in the Brazilian way of life concerning thyroid function and disease. In essence, it will provide up-to-date information about thyroid disease, the continuous use of iodine as included in common salt and the need for an extra iodine intake during pregnancy (among other subjects).

We believe that we are filling a gap between what is commonly provided by the Ministry of Health, and public health activities. Hopefully, we will continue to work in this direction as part of our daily work.

Join the Butterfly Effect



10 Years of AECAT The Spanish Thyroid Cancer Association

This year, AECAT also celebrates its anniversary, 10 years working as volunteers with and for patients, 10 years that have been possible thanks to joint efforts, through the butterfly effect of solidarity. AECAT has wanted to celebrate this with a campaign that aims to honour the volunteers who, over the years, have worked altruistically and motivated only by empathy, as well as further involve partners, volunteers, and society in general.

Their motto is: **Join the Butterfly Effect**, and their promotional video shows this supportive and empathetic chain, from patient to patient, from its foundation to the present.

A decade creating bonds of dialogue between patients

The Spanish Association of Thyroid Cancer was born in forums; it has evolved from a group of patients with similar concerns that decided to join their personal experience to form one big family.

It was born out of dialogue in forums, due to the absence of information and support suffered by patients with this tumour and their families. A small group of patients began sharing experiences and realizing what bound them. They were bound by the need of improving their quality of life in terms of knowledge of the disease and regarding diagnosis and treatment.

Spontaneously, a chain of solidarity arose where expert patients were supporting new patients in their process, resulting in the wonderful butterfly effect we celebrate this year.

The base of the only thyroid cancer patient association that currently exists in Spain emerged from the sharing of experiences. In 2004, it was founded under the name of Ibero-American Association Against Thyroid Cancer (AICCAT) reflecting, with this name, that the butterfly effect had no boundaries, and in September 2011, it changed its name to AECAT, with the objective of clarifying the field of committed and responsible action before the Spanish administration, but without sacrificing the feeling of brotherhood with Latin America.

Website of reference in Spanish

Over time, specifically in 2012, the forum was complemented by a website, a blog and participation in social networks. At present, only three years later, our digital platform has become a website of reference for Spanish speaking thyroid cancer patients, winning their loyalty with its videos and weekly articles. From June 2014 to June 2015, the web platform had 1,544,288 views by 590,324 users, 76.6% of which have been regular visitors. Spanish visitors are the most common (nearly 40%), followed by Latin American countries (Mexico, Argentina, Colombia, Chile, Venezuela, Peru, Ecuador and the Dominican Republic) as well as the U.S.A.

On the website, you can find detailed information on treatments and patient to patient practical advice, as well as video interviews with national and international experts, webinars, presentations, weekly research or opinion articles, audiovisual features, documentaries, patient testimonies, educational audiovisual material, awareness campaigns and advertisements.

Working in networks

Over a decade, this non-profit organization has also worked to position itself and participate among other social agents of interest at a national and international level, such as the federation of Spanish Cancer Patients Association (GEPAC) of which we are founding partners or the Spanish Federation of Rare Diseases (FEDER), the Thyroid Cancer Alliance (TCA) and the Thyroid Federation International (TFI). This responds to one of our objectives, consisting of taking the voice of patients and working in coordination with the networks that deal with thyroid cancer, from patient groups to government agencies and, above all, with the sections, commissions and working groups of the different scientific societies specialized in our disease.

AECAT's social responsibility

As the **voice of thyroid cancer patients**, AECAT took on the challenge of raising society's awareness of this rare disease, and educating people in an attempt to improve early diagnosis. With this goal, AECAT created the National Thyroid Cancer Day, on the 28th of September and

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launched the first thyroid cancer public awareness campaign in 2012: **Donate your voice**, winning the GEPAC award for the most relevant cancer advertising campaign that year.

The following year, its second campaign, *A Minute Against Silence*, was finalist in the Albert Jovell award for solidarity with cancer patients, by proposing and achieving a campaign of guerrilla actions against the silence faced by thyroid cancer patients. To this end, a “Social perception of thyroid cancer” report has been presented by AECAT on the occasion of the national thyroid cancer day on the 28th of September, 2013.

It is estimated that, each year, 46,000 new cases of thyroid nodules should be analyzed, adding them to those that are already in follow-up. The presence of malignancy stands at 5-15% of thyroid nodules. Although its incidence is low, in the last decade it has multiplied by two and, in fact, at this time, about 3,000 cases of thyroid cancer are diagnosed in Spain each year. Despite these figures and its increased incidence, it is one of the cancers less known by society.

In 2014, AECAT took the opportunity offered by the **38th Meeting of the European Thyroid Association** held in Santiago de Compostela, Spain, to organize and invite patients from around the world to a Camino de Santiago (route of pilgrimage to Santiago). 35 patients from 5 different countries completed 113 km, in 5 stages that represented the 5 challenges faced on the road of thyroid cancer, and taking the voice of patients collected in www.vocesencamino.org (in English and Spanish) to the European Congress. After each day, we held a special meeting to share the patients’ life lessons, following the parallelism created with the Way’s stages.

To everyone’s delight, the last day of pilgrimage, more patients and new members of the TCA and TFI Patients Association joined the group, totalling nearly 100 patients from 11 different countries. Upon our arrival to Santiago, we held a public outreach event, **Voices on the Way**, to kick off the Congress and tell society about our TC experience.

With the campaign “Voices on the Way”, the anonymous patients were encouraged to put a face to this disease and add their voice to it. Testimonies and scars were recorded on videos that are now part of the graphic documentation of www.aecat.net, as well as video interviews with the speakers and specialists that participated in the conference.

Most of all, the coexistence among thyroid

cancer patients creates deep ties of solidarity. As a result, the Association has grown in membership, volunteers, number of visits to the website from in and outside of Spain and participation in social networks. Moreover, the media coverage of the campaign was widespread with 6 TV interviews, as well as 17 announcements on radio and presence in daily press (71 in general press, 21 in medical press and 59 in other internet media). All this summed up to an estimated audience of over 29 million.

Poor social knowledge of the thyroid gland

2014 was also the year that AECAT joined the TFI team, whom we met sharing the experience in Santiago.

As thyroid cancer patients, we were aware of the Spanish population’s poor knowledge of thyroid diseases. In fact, AECAT is the only association related to thyroid patients in Spain. We also understand that, while the fundamental physical and mental role of the thyroid gland remains unrecognised and unacknowledged, the experience faced by thyroid cancer patients will not be comprehended.

Spanish thyroid weeks

Given this lack of information, AECAT has contributed to the International Thyroid Week in May with two campaigns:

- In 2014, along with Voices on the Way, we presented the study on the “**Social impact of thyroid pathologies**” in an effort to clarify information gaps that exist in our society concerning the thyroid gland. This deficit affects us as thyroid cancer patients, but also many other patients with thyroid diseases whose incidence is increasing in Spanish society.

The results of the survey were presented at the 38th Congress of the ETA in a roundtable with journalists, doctors and patients representing the TFI and the TCA.

The general population has scarce knowledge regarding the actual effects of the thyroid on general health and well-being. The results of this study conclude that 37.9% declare they know nothing, or almost nothing on the subject, and 54% know very little, considering that it is estimated that 6.71% of the population might suffer from thyroid dysfunction without being aware of it. According to recent clinical studies, 21% of the

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population admitted to being concerned about suffering from thyroid dysfunction or some type of nodule, goitre, or thyroid cancer.

The study was conducted based on an online survey by the agency for qualitative and quantitative research, Adhara Marketing Tools, involving 801 people aged between 18 and 65, all of them residing in Spain.

- On the occasion of the current 2015 International Thyroid Week, the Spanish Thyroid Cancer Association (AECAT), launched, with the support of the Spanish Endocrinology and Nutrition Society (SEEN), a public awareness campaign called "It Could Be Your Thyroid" on the health effects of thyroid dysfunction and the importance of an early diagnosis.

The general population does not associate certain symptoms (often confused with other ailments such as stress, anxiety, depression or loss of abilities due to age), or diseases (cardiac disorders, osteoporosis, hypercholesterolemia, infertility, abortions or postpartum depression) with the thyroid gland, which is resulting in delayed diagnoses and a significant percentage of undiagnosed diseases.

So as to reach a larger scope of people, the centrepiece of the campaign is an educational video and a shorter TV spot showing the impact that a thyroid disease may have on health. <https://youtu.be/tyBc864fLYo>

For those seeking more information, AECAT organized webinars by the best specialists, interactive online courses for patients available here: <http://www.aecat.net/podriaser-tu-tiroides/>, where expert endocrinologists are invited to respond to the questions posed directly by patients.

With this initiative, AECAT wagers on an informed patient and health education as the best preventive measure.

The Spanish Association of Thyroid Cancer, today

Well-informed patients can make more consistent decisions regarding their own health and quality of life; they become empowered patients who know what questions to ask their doctor. This is the direction that AECAT is taking.

With a growing number of members, the purpose is still to help, guide and support those who are fighting this disease. The goal is to make

their process easier and resolve any doubts that may arise, before, during and after this period, both for the patients who have suffered or are suffering from this condition, as well as for their families and other affected people.

In order to achieve this, AECAT has created and organized, during 2015, a **training school for volunteers and expert patients: the "Butterfly Effect"** and is promoting its local presence through senior members and zone groups, in an attempt to go beyond its virtual presence and get closer to the patient.

Also among our objectives, is detecting and responding to the needs that thyroid cancer patients may have; showing and defending before health institutions, and society in general, the needs that these patients have, and collaborating with practitioners, health authorities, scientific societies and medical services in order to attain an effective promotion of the best protocols, treatments and possible practices.

In 2015 and to this end, AECAT launched two campaigns, taking a step further in the path of Voices on the Way, to defend our interests as a collective in the eyes of Government institutions, at a time of budget cuts.

The **Time is Life** campaign, on the International Day of Rare Diseases (28th of February), denounced, through an awareness video and a manifesto with 10 proposals, the bureaucratic problems faced by medullary, refractory and anaplastic thyroid cancer patients.

Participation in the National Cancer Survivor's Day with the campaign and exhibition of photos and testimonies: **cancer makes a life-long mark**.

Finally, the **Loud and Clear** campaign, for the international thyroid cancer month (September 2015), also seeks to speak out against the injustices and inequities that are being generated in the Spanish health system, while providing proposals to improve treatments. Our main goal is always the same: making our experience useful to future patients.

To this end, the Loud and Clear Survey was designed to focus on discovering the needs, covered and not covered, of thyroid cancer patients and their treatment priorities. It served as a call for patients to add their voices to the struggle and evaluate their path through the health system. Simultaneously, a campaign on social and audiovisual media has been launched,

(continued on page 28)

based on patient testimonials and defending, with their experiences, the need for each of our proposals. 10 years of patients defending with their testimony the 10 measures to follow. For added visibility, the campaign has been accompanied by several events to raise awareness and patient education.

The butterfly effect

Actually, in addition to the 2015 campaigns, other local actions were carried out by the volunteer group of expert patients during the whole year and thanks to the "Butterfly Effect". This is another line of action, based on the flutter as an example of small actions that, when summed up, yield great results.

In addition to internal patient meetings and "thyroid coffees", and thanks to this butterfly effect by the volunteers, the following awareness acts were organized. AECAT believes that it is time to start on the creation of local action groups.

May-2015 International Thyroid Week:

Along with the media presentation of the educational video, the advertisement and the "It Could Be Your Thyroid" campaign, with its selection of webinars, the following awareness-raising events were held in:

- Valladolid, Charitable/sports day for awareness.
- Information stands during the local festivities of Meco and Vicálvaro, two villages close to Madrid.
- Information table in Cáceres.
- Awareness action in Cáceres: presentation, round table and projection of the documentary Voices on the Way.

September-2015 International Thyroid Cancer Month:

Along with the presentation of the Loud and Clear Survey data results and webinars, the following educational events were held:

- Santiago de Compostela: presentation on the Diagnosis and Treatment of Thyroid Cancer, round table and projection of the documentary Voices on the Way.
- Madrid, charitable/sports day for awareness.
- Madrid, in a square in the city centre, presentation of the Loud and Clear Survey data, as well as a karaoke involving supporters and celebrities to make our voices loud and clear.

From all of this, and among other successes, we achieved a network and won the friendship created between the volunteers; tightly woven with effort and enthusiasm and with great generosity, to the point of transforming a situation as tough as facing cancer, for many the worst of their life, into an example of brotherhood that speaks of the exceptional values of human beings and the quality of connections when they arise from sincere support and empathy. As we defend in the butterfly effect: a word said from the heart in Valencia can awaken a storm of emotions in Peru.

Historical Photos



Milan 1999: Larry, Dr Fumito Akasu (Japan), Dr A. Kurtev (Bulgaria), Yvonne Andersson. Front row: Emma Bernini (Italy), Giovanna Liborio (Italy), Katherine Keen (Canada), Prof Anette Gruthers (Germany), Arliss Beardmore (Canada)



Kyoto 2000: TFI family at Nara with Dr. Hashimoto – open to listen and receive. First row: Katherine Keen (Canada), Dr. Larry Wood (USA), Prof. Hashimoto (Japan), Bente Lasserre (Denmark), Ulla Slama (Finland); second row: Arliss Beardmore (Canada), Anne-Marie Kroon (The Netherlands), Catherine McNeill (Australia), June Rose-Beaty (Canada); third row: Yvonne Andersson (Sweden), Beverley Garside (Australia), Nancy Patterson (USA), Dr Fumito Akasu (Japan).

The British Thyroid Foundation

JANIS HICKEY
DIRECTOR AND FOUNDER, BTF

The British Thyroid Foundation (BTF) was granted charitable status in October 1991. We launched the BTF at the British Endocrine Societies (BES) meeting in Harrogate in March 1992. Equipped with a basic display board (card and Letraset!) the launch of the BTF was announced to an auditorium of endocrinologists.

Our first newsletter, four pages in black ink on white paper, was sent out to a few hundred people in summer 1992 [see photo].

In 1993 the first BTF local groups were established.

In 1995 we managed to acquire a room in a hospital in Leeds, which became the BTF HQ. Another key event in 1995 was attending the TFI launch in Toronto.

In 2002 we moved to bigger premises in Harrogate with BTF's three employees. In 2008 we took on more office space, employees and volunteers and were able to increase our support for patients: a website, groups to head up projects and campaigns, and a regular review of our information.

The BTF currently has five members of staff, around 50 volunteers who provide telephone support or run local groups, a whole host of fundraisers, a strong Board of Trustees and eight patrons including former members of the Board of Trustees and well-known and respected endocrinologists: Dr Michael Tunbridge and Professor John H Lazarus.

Over the years we have built on our foundations, and relationships with the medical profession are strong. We particularly enjoy a fruitful relationship with the British Thyroid Association and the British Association of Endocrine



Nancy Patterson & Janis Hickey, TFI 2003.


and Thyroid Surgeons, both of whom advise and support our work. We have increased the funds that we put in to research – we provide an annual research award of £20,000 - developed our projects, partnerships and campaigns.

The changes since 1991 have been enormous. No longer do we expect patients to be simply on the receiving end of healthcare; many want to be actively involved not only in decisions about their own


health care but also in research, in discussions (to shape the future of the National Health Service, for instance), giving feedback on guidelines, and fundraising.

Dialogues between medical/health professionals and patients take place more frequently, and patients are more aware of the bigger picture, how they can get involved, and the shared responsibility for healthcare. Patients question their doctors more readily, and the BTF endeavours to give them the tools to be able to ask the questions that will help them receive reliable answers.

For further information please visit our website: www.btf-thyroid.org



Supporting and informing patients



Our Campaigns

- Thyroid Cancer
- TED
- Iodine
- Pregnancy
- Hypothyroidism
- Children
- Elderly
- Hyperthyroidism
- Films
- Supporting research



The GDATF turns 25!

The Graves' Disease & Thyroid Foundation is celebrating its 25th anniversary! Founded in 1990 as the National Graves' Disease Foundation, the GDATF has been providing help and hope to patients and family members for two and a half decades!

GDATF Founder and Chair Emeritus Nancy Hord Patterson, Ph.D., recalls, "When I was initially diagnosed... I began to look for information, and for people to talk to that had faced the same concerns. When this proved impossible, I began an effort to start this Foundation. With the support of my Endocrinologist and Reconstructive surgeon, I was led to medical experts both nationally and internationally who were most willing to share their expertise."

Without access to email or Internet, the Foundation's early communications were accomplished primarily via phone and snail mail.

The Foundation partnered with patients and medical professionals around the world to provide free bulletins on a number of topics, including treatment options for hyperthyroidism, thyroid eye disease, psychosocial issues, and special concerns for students. An article about Graves' disease published in Reader's Digest generated 3,000 pieces of mail—all of which ended up in Nancy's living room!

In order to foster personal connections among patients and caregivers, the Foundation developed a model for local support groups and kicked off its first support group meeting in Jacksonville, FL in 1991. The Foundation also established an annual patient & family conference, branded "A Bridge to Wellness".

The Foundation hosted 19 annual multi-day conferences before switching to a free 1/2 day, multi-city format in 2013 in an effort to reach more patients and family members.

The advent of the Internet, smartphones, and social media has expanded the GDATF's reach. The Foundation now has a vibrant online support forum, our free informational literature is available on our gdadf.org web site, and presentations from many of our educational events have been posted on our YouTube site.



Dr. Nancy Patterson and Dr. Carol Greenlee, Member of Board of Advisors and Keynote Speaker at the first NGDF conference.

The Foundation currently has 11,000 "Likes" on Facebook and 2,100 Followers on Twitter, and our social media community continues to grow!

Thank you to all of our dedicated volunteers who have served over the years and to those who have taken the time to share their stories with us. Here's to another 25 years!



Representing the fact a person could re-build their life into something beautiful, even when it seemed things were completely shattered.

Historical Photo



Warsaw 2001: Dr David Cooper (US) & son, Larry Wood, Shann Wood

Graves' Disease & Thyroid Foundation

On Saturday, Nov. 22nd, the Graves' Disease & Thyroid Foundation hosted its first-ever event specifically for parents of children with Graves' disease. The event was co-hosted by the Pediatric Thyroid Center at The Children's Hospital of Philadelphia (CHOP), one of just a handful of centers in the U.S. dedicated solely to serving children and adolescents with thyroid disorders.

Andrew J. Bauer, MD, FAAP, medical director of the Thyroid Center at CHOP, kicked off the event with a presentation on "A Tailored Approach to Medical Management of Graves' Disease in Children and Adolescents." Dr. Bauer began by reassuring parents that "there is nothing you could have done to prevent Graves' disease", noting that the condition is a complex combination of genetics, biology, and environmental factors.

"This is a difficult, at times unpredictable and fluctuating disease," Dr. Bauer explained. Dr. Bauer's presentation went on to cover the risks and benefits of anti-thyroid medications and radioactive iodine therapy as treatment options for Graves' disease, noting that "treatment must be individualized."

Dr. Bauer also shared that CHOP is embarking on an exciting new research project to study the neurocognitive aspects of Graves' disease and whether stabilization of thyroid levels can provide symptom relief.

The next presenter was N. Scott Adzick, MD, MMM, FACS, FAAP, CHOP's Surgeon-in-Chief and the C. Everett Koop Professor of Pediatric Surgery at CHOP, discussed "The Surgical Approach for the Pediatric Patient". Dr. Adzick shared excerpts from a video produced by CHOP on thyroid surgery and discussed cases where surgery might be the best treatment option, as well as risks and benefits of the surgical approach. He also stressed that the multidisciplinary approach at CHOP is extremely important, with endocrinologists, ophthalmologists, surgeons, nurses, social workers, and pathologists all working together to provide seamless care.

William R. Katowitz, MD, Attending Surgeon at CHOP, closed out the formal presentations with a discussion of "Graves' ophthalmopathy in children and adolescents". Dr. Katowitz explained that fortunately, Graves' ophthalmopathy (also referred to by a number of other names, including thyroid eye disease) is usually less severe in children than adults. Because double vision and sight-threatening optic neuropathy are rare in children, eye surgery is generally optional in children with thyroid eye disease.

However, the emotional impact of changes to appearance should not be underestimated; Dr. Katowitz noted that it is important to ask young patients how they feel about their appearance.

The event wrapped up with a Question and Answer session, featuring all three presenters.

"It's our privilege to help care for children and adolescents with thyroid disease," Dr. Bauer noted. "We have a world-renowned thyroid team at CHOP and it was a wonderful opportunity to partner with the GDATF for a great day of education and collaboration."

For those who were unable to attend in person, video footage of the event is available on CHOP's YouTube channel at: <https://www.youtube.com/user/ChildrensHospPhila/videos>.

Historical Photo



Gothenburg 2002 : Nancy, Bente Lasserre, Carol Spencer (US), Shann Wood

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