

# THYROID WORLD



## Thyroid Federation International

### Thyroid Patients Worldwide

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## Thyroid Federation International

*Established in September 1995 in Toronto, Canada*

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

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*The names of the organizations and their current addresses are given on page 20.*

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## Message from the Editors

This is the second issue of ThyroWorld which Ulla Slama and I put together (after having taken over from June Rose Beatty, whose talent is unequalled!), with contributions from TFI members all over the world! Many thanks to Lynda Wegner, Fresh Image, for her reactivity in adapting layout and design to our various last-minute changes!



*Beate Bartès*

ThyroWorld is the annual newsletter of Thyroid Federation International, umbrella organization of more than 20 patient and patient-oriented organizations from all over the world.

This year, it is distributed during the ETA congress held in the beautiful city of Krakow, founded over a thousand years ago, hosting much of Poland's rich historical, cultural and intellectual panoply.

We would like to thank the printer, Anders Juthman in Närpes, Finland, and his friends in Singsby, for printing the newsletter at an affordable price and forwarding the packages to the conference in time.

We are very happy to see the continuous growth and improvement of the cooperation and mutual understanding between patients and doctors, from year to year – there is so much to learn from each other, for the benefit of all!

*Beate Bartès, co-editor*

It is again a great pleasure to present our newsletter to you, now the ThyroWorld Volume 14. The patient organisations, as well as the doctor organisations, go on spreading information around the world about thyroid disease. The awareness of thyroid disease should be of great public interest, because it is the question of a widespread disease group. For example, in Finland in 2010, according to the statistics of the social security, instances of 240,000 people receiving financially supported thyroid medication – that is 4,4 % of the population.



*Ulla Slama*

*(continued on page 9)*

## President's Message

This will be a different message to you all. First, however, I want to tell you about the past year. Due to my health, it has again been a year of consolidation.

The International Thyroid Awareness Week, this year about "Thyroid nodules and goitre", was a success. All over the world patient meetings were organised by patient organisations (nearly 40 in the Netherlands), but also by hospitals, individual doctors or representatives of the pharmaceutical industry. Our cooperation with Merck Serono gives us a much further reach to patients all over the world.

New is our participation in an international research study. (see article on page 11)

This message will be my last as president of TFI. During my eight years as president I experienced a lot of highs and lows. The highs were mainly within my activities as president, and the lows were personal to me.

What stands out is the death of my daughter in 2005. The support that I got from my colleagues within TFI, the warm sympathy from many individual doctors within ETA, ATA, AOTA and LATS were highs.

All the people I met at the annual meetings of the ETA and ATA and at all the different meetings for the International Thyroid Day and the International Thyroid Awareness Week are individual highs for me. I will miss the networking with all the people so determined to make a change for people they don't know, patients as well as doctors.

My health causes me now to stop with all my volunteer activities. After more than 20 years in diabetes and thyroid patient organisations I cannot give enough of me to achieve the steps that I think, are necessary for TFI to take.

Recognition of the World Thyroid Day by the United Nations, acceptance of iodine related and other thyroid diseases as one of the key diseases in developing countries by the World Health Organisation, more member organisations of TFI in Asia and Africa. Goals



Yvonne Andersson,  
President

that I see for the coming years. They can be achieved in cooperation with doctor associations and the pharmaceutical industry, but the patient organisation has to take the lead in order to make the extra step.

I will try to introduce the new president, to be chosen during the Krakow Annual Meeting of TFI, to as many people as possible. He will find a different organisation from what it was 8 years ago. Before, the board of TFI was composed by board members of national organisations. TFI is now if possible changing into an organisation lead by dedicated people with not too many activities for their national patient organisations.

What I wish with all my heart is that the recognition of TFI, the achieved mutual respect and co-operation between the professionals and TFI will continue and grow. We do need each other. The meeting between the Presidents of ETA, ATA, LATS AOTA and TFI last year in Paris was a high which confirmed that.

I would like to thank you all on behalf of TFI and myself for all support and friendliness I have experienced during my time with TFI.

I look forward to seeing you all in Krakow what will make it another high. My very best wishes for the future for the benefit for thyroid patients worldwide. 🍀

YVONNE ANDERSSON

PRESIDENT OF THYROID FEDERATION INTERNATIONAL

**TFI 18th Annual Meeting**

**September 7, 2012**

**Pisa, Italy**

# ATF New Web Site Launch

The Australian Thyroid Foundation has launched a **NEW WEB SITE!!**

[www.thyroidfoundation.com.au](http://www.thyroidfoundation.com.au)

The new site includes a comprehensive Member's Section, which includes all ATF Member Information; newsletters, articles, thyroid disorder information, member meeting information, telephone support contacts and all ATF documents, members may require. ATF Newsletters, "Thyroid News" can now be viewed and downloaded from the website which will reduce mailing costs for the organisation.



The Australian Thyroid Foundation Ltd

The new site includes a Children's Section, ATF Awareness Events and all you need to know about the ATF.

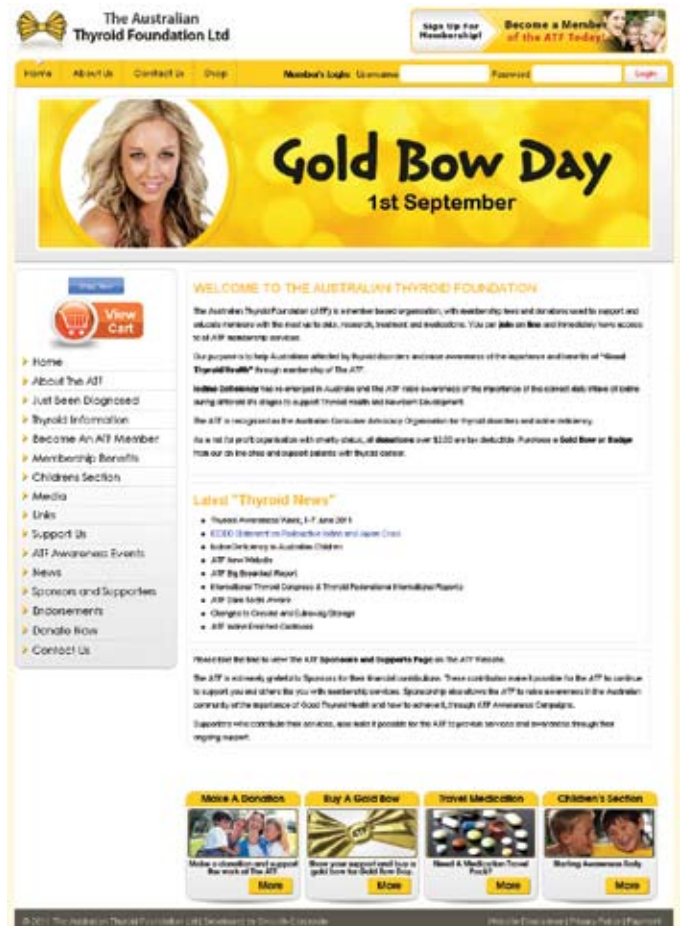
The site also includes an On-line shop where ATF Gold Bows and Green Badges in support of the ATF Gold Bow Day – for thyroid cancer patients can be purchased and other ATF Merchandise.

Member Registration can now be done online, ie; full membership, concession, lifetime membership and professional. Donations can also be made online.

The ATF are extremely grateful to Smooth Corporate, the web site designers who have made this new site possible.

Please take a look at the new website.

TFI current member organisations who wish to view the Member's Section and receive the ATF "Thyroid News" online, can do so by obtaining Login Details by emailing: [membership@thyroidfoundation.com.au](mailto:membership@thyroidfoundation.com.au)



# Turning around your Thyroid Organization

## Turning around your Thyroid Organization to a path of sustained growth - sharing a personal journey

ASHOK BHASEEN  
PRESIDENT, THYROID FOUNDATION OF CANADA

**T**he Thyroid Foundation of Canada is the first thyroid patient organization in the world; it began in Canada in 1980 and has played a lead role in establishing other such organizations around the globe. Today, the Thyroid Foundation of Canada is a thriving and a growing organization with many of its members busy with programs going on in different parts of Canada. However, like other organizations it has seen its ups and downs. I think it is always beneficial to share both the positive and not so positive experiences of an organization with fellow TFI member organizations so that best practices can be developed. Best practices should then become an integral part of the strategic deployment for sustained growth. I would like to share some of the things that I have lived by while managing TFC.



Ashok Bhaseen

organization to a path of success. As a leader you have to make sure that you give due credit to your team members when it is due; choose appropriate occasions to recognise their contributions.

It is crucial that as President you continuously develop other members on the board as part of an efficient succession planning. Frequently, the leadership in an organization becomes stale; often, families or close friends are part of the group and emotions may rule over judgement. This can discourage new members who come on board and do not find anything interesting

or appealing to them; they lose interest and move on to places where they can use their time and skills to contribute and be valued. Restricting the terms of Board members to 3-5 years will ensure a regular turnover and introduction of new ideas.

### Fiscal Fitness

As volunteers we should undertake our responsibilities seriously, and be very prudent with investments and expenses on each activity that we undertake. We cannot spend \$1,000 on a fundraising activity and generate only \$100, as this will evaporate your finances in no time at all. Fiscal fitness for an organization remains the key to its continued success and growth, but leadership and teams are needed to put a strategic plan in place to take the organization to a growth path. Some organizations have generated revenues but have no clue of how to make the best use of these funds. Hence, generating charitable revenues is just half the battle, making the best use of these revenues and adhering to charitable guidelines on investment are going to be the key for a sustained growth of your foundations.

We cannot deviate from our mission and vision of an organization. We can all pat ourselves on the back for generating funds, but cannot forgive ourselves for not being accountable for the purpose it was collected. Therefore, if research in thyroid disease is part of your mandate, you must find genuine, credible researchers to fund. Investing in bogus research with no strategic breakthrough is detrimental to the entire effort of generating funds. It is therefore essential to

*(continued on page 6)*

### Signs of an organization in distress

The following are some symptoms of distress in an organization:

- Lack of financial records or communication on the subject
- Total lack of communication - no newsletter or publications of the organization's activities
- Lack of transparency and accountability

These are some clear symptoms of an organization in distress, and if readers in their own organizations see any of these symptoms they should take immediate action and demand answers and accountability. However, demanding answers is not a solution in itself; it is merely the first step in the diagnosis of an issue that impacts an organization.

### Leadership

The second step is to install proper leadership. Taking prudent and calculated risks are part of good leadership skills, but it cannot be done without the involvement of a good team that will help in creating a viable plan to move the

## Turning around your Thyroid Organization *(continued from page 5)*

have physicians on your committee that can evaluate each research project on its merit.

### The Risks

What happens when an organization is not functioning and has totally deviated from its intended path?

- Loss of credibility both within and outside the organization
- Lack of support from the industry and members of the organization
- Risk of losing your charitable status
- The organization goes back to zero, hence a tremendous amount of effort to rebuild it

These scenarios are a nightmare for those who inherit a dysfunctional organization. The amount of work that goes in rebuilding is 10 times more than you would expect to put in a normal running organization. Those who succeed in turning around such organizations gain tremendously in experience and that is extremely satisfying and rewarding for all those who are involved in the process.

### Rebuilding

So, what does it take to rebuild an organization and bring it back to a path of growth?

- A dedicated and passionate team
- Do every activity through volunteers instead of spending money that you do not have
- Take baby steps to rebuild the organization, it helps to strengthen the weakened foundation
- Establish ongoing communication and ask for help from whoever is ready to give
- Establish clear priorities



*TFC Fashion show in London, ON Canada, April 2011*

- Talk passionately to people about your organization, you will be surprised how many more hands will come to your aid
- Answer every call and dig into your archives to reach those who may have left the organization due to poor leadership
- Rely on those who promise less and deliver more, be careful of those with vested interest; if people on your team have defaulted using lame excuses, you must seriously consider replacing them with those who are dependable
- Demand monthly financial updates; if you suspect any financial wrongdoing, address it immediately

### Summary

The past three years were some of the most crucial years for the foundation. It took many hours and personal time from Board Members to resurrect the organization and bring it to where it stands today. The first year of my mandate, 2008-2009, was the toughest one, and collectively board members had to put in a lot more time and effort than in any normal year in order to move the organization forward and also take care of what was committed and not done in the previous four years. I applaud the TFC board members and chapters across the country that have worked hard to keep the organization moving ahead and organizing various awareness and education programs across Canada. Their efforts paid off and the Canadian organization has become an organization in line with 21st



*TFC Meeting held by Mabel Miller in Gander, NFL, Canada*

*(continued on page 7)*

## Turning around your Thyroid Organization *(continued from page 6)*

century expectations. There will always be a lot to do, but the past three years have laid down a solid foundation to make TFC a stronger organization.

Reflecting back on the past three years, I am happy to see the following:

- Today, TFC is comprised of an honest group of volunteers that have patients' interests foremost in their plans
- A toll free 1-800 number for thyroid patients and members of the public
- A new Thyroid website, radio talk shows, print media and education programs
- TFC Fashion show, TFC Art Show, Education program on new treatments for thyroid cancer
- High tea, Farmers market, Drama and other activities on thyroid awareness programs in Canada
- Ongoing communication with physicians and the industry



*Dr Jack Wall being recognized as 'Star of TFC', Ottawa, ON (TFC 30th anniversary, 2010)*



*A play by Donna-Lynne Larson, Writer and Actress on Thyroid, Vancouver, BC*

- Timely financial reporting
- Ongoing publication of Thyrobulletin and Health guides
- Monthly board meetings, minutes and reports
- Continuing efforts to fund genuine research in Thyroid disease

In summary, I believe that the greatest risk is not taking one. Never hesitate to make tough decisions when you encounter issues or problems; sometimes people within your organization

are the ones who may be counterproductive and barriers to growth. As leader it becomes your responsibility to address the issue with your team and come to collective resolution.

There will be times in leadership roles where issues dominate and the future looks bleak, but remember, tough times never last, but tough people do. Your role as a leader is to deal with the issues and come up with solutions with the help of your team.

Finally, the most valuable thing that one can give in life is 'a few hours of your personal time for the benefit of others as a volunteer', thus making this world a more beautiful place.

I am looking forward to passing on the baton to the new President at the June AGM who will bring in new ideas to take the organization to the next level. 🍁



# The Netherlands Thyroid Foundation maintains its relationships!

In the meantime the Dutch Thyroid Awareness Week has come and gone. However, the theme of the week we chose 'Living and working with your thyroid disorder' applies throughout the whole year. Whilst writing this, our June 2011 Thyroid Magazine has just been published. The magazine is entirely dedicated to 'family and relationships', the second theme of the Thyroid week. Relationships exist in various forms. People enter into friendships, go out together, they get married or live together, they have children, they do paid or unpaid work, they provide voluntary aid, are neighbours, fellow students or share a hobby. What is my approach to this topic? Needless to say: from a managerial perspective.

Which relationships does the Netherlands Thyroid Foundation management have? We have just started dating, so it seems, with the Netherlands Graves Disease Foundation (NVGP) and with 'Hypo maar niet Happy' (Hypo but not Happy ((HmH)). Together we form a coordinated management partnership which in time should lead to one strong unit. Meanwhile it has been established that we will continue together as the Netherlands Association for Thyroid Organisations (SON). We are open to more partners who would like to join us. Together we are starting to synchronise things more and more. So yes, our relationship has more and more signs of a serious date.

Which other relationships will we be entering into? As from last year we have been participating actively again in the TFI annual meetings. And this year we registered ourselves with the Thyroid Cancer Alliance, the international non-profit organisation that would like to unite thyroid cancer organisations. This mainly concerns the exchange of knowledge. Our Thyroid cancer work group will play an important role there. Moreover we would like to tell you that the Netherlands Thyroid Foundation will make a donation from its science fund to Dutch research which aims to register patients with medullary Thyroid carcinoma. Fortunately some disorders are rare, but as a result they are often not monitored enough. Here, too, the characteristics of a social relationship apply: one hears and sees each other and transforms involvement into help and support.

The [www.schildklier.nl](http://www.schildklier.nl) website is visited a lot and the social media are used frequently.



Information spreads fast because it is easier to find one-another. Nowadays, The Netherlands Thyroid Foundation is also on Facebook and Twitter. A group of volunteers would like to organise a day for youngsters. Perhaps this is the way to

reach more people: our target group is many times larger than the number of donators. We would like to build up a good relationship with all thyroid patients. Youths recognize themselves in each other, in the same way as older people. In a relationship one tunes things together. We hope that regarding the youths we will be able to grow in terms of using modern methods and possibilities.

It is the year of the volunteer. Without volunteers, an organisation with patients does not mean anything socially. Therefore we are continuously working on our relationship with our volunteers. We want to find more volunteers, but also to bind and interest the existing volunteers. This requires professional attention and maintenance. As of 1 April we were able to strengthen the organisation with a paid volunteer coordinator.

By deploying volunteers from the Netherlands Thyroid Foundation, the Netherlands Graves Disease Foundation and Hypo but not Happy, the Thyroid Awareness Week (21 to 28 May) was a success. That week, there were about 40 information stands throughout all the regions. The joint website, [www.weekvandeschildklier.nl](http://www.weekvandeschildklier.nl) was visited a lot and the leaflet 'Leven en werken met een schildklieraandoening' (Living and working with a thyroid disorder) was published. We are very proud of this.

Finally, we, of course, are also working on our relationship with our donators. We like working on all matters that are necessary in the interests of thyroid patients. Love and affection is an essential basis for a good relationship. I am convinced that that basis is very strong. Very many people with a thyroid disorder come in contact with each other during meetings, on the website and during research programmes.

Currently, the financial situation is unfortunately not always certain. We try to keep the contribution fees as low as possible. But then we have to make sure that we are able to establish more relationships for and with each other. The more donators there

*(continued on page 9)*



## The Netherlands Thyroid Foundation (continued from page 8)



are the more certain the budget will be to be able to implement or continue implementing all our wishes and required activities. Considering the cuts our government is making, I feel it is necessary to really address the solidarity of the thyroid patients. We work with and for each other to improve the future for the generations after us, particularly when it concerns knowledge and know-how with regard to thyroid disorders. 🌱

JOKE VAN GALEN  
SECRETARY OF THE NETHERLANDS THYROID FOUNDATION  
MANAGEMENT BOARD

## Message from Editors (continued from page 2)

More people are followed up for thyroid disorder but are still without medicine, such as people with nodules, goiter, subclinical hypo- and hyperthyroidism, autoimmune thyroiditis, etc. There are, of course, people with undiagnosed thyroid disease. Similar numbers may be valid in other countries.

The celebration of the World Thyroid Day and Thyroid Awareness Week is already fairly developed with programmes and interviews on radio, tv and in newspapers. It contributes to an increase in the diagnose of thyroid disease.

The initiative of the Amsterdam Declaration in October 2009 has caused the creation activities in many different countries with the focus on the diagnose and treatment of thyroid eye disease. It has been on the programme at endocrinological meetings as well as at the national doctors' meetings in Finland.

ICCIDD works for the appropriate iodine supply worldwide. Members of ETA, ATA, AOTS, LATS (where is Africa?) and the Endocrine Society also do excellent research work. In spite of this, many people with the most common thyroid disorder, hypothyroidism, go a long time without diagnosis because of slowly increasing symptoms. Recently, a woman with TSH more than 400 IU/l, got pregnant. Another woman had TSH 250 IU/l, however, had no thyroid disease but heterophilic antibodies imitating TSH. Should money be invested in general TSH screening of pregnant women? There are still questions that need more, but urgent, studies. The best results we get are by cooperation between scientist, clinical doctor and patient. 🌱

*Ulla Slama, co-editor*



**4th edition**

**May 21 to 27, 2012**

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

The dedicated web site (in 7 languages) is aimed at providing helpful advice and information on living with thyroid conditions for all members of the family.

The International Thyroid Awareness Week is a campaign supported by:



and endorsed by:



# Targeted Therapy in Refractory Thyroid Cancer

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The large majority (>85%) of patients with differentiated thyroid carcinoma (DTC) and many (40%) patients with medullary thyroid carcinoma (MTC) can be cured, others may survive for decades despite persistent disease, and few patients with advanced disease may require novel therapeutic modalities (1,2). Very few patients with anaplastic carcinoma survive over one year. These refractory thyroid cancer patients are rare, with an estimated annual incidence in France of 350 cases that is stable with time, including 200 patients with DTC, 50 with MTC and 100 patients with anaplastic thyroid carcinoma. In most patients, an initiating carcinogenic event can be found and molecular targeted therapy can be given with a scientific rationale. Patients with progressive thyroid cancer should preferably be included in prospective trials, and even phase I trials that are testing the newest therapies should be considered for these patients, as these protocols may allow early identification of possibly effective drugs.

Although response criteria in these contemporary trials differ markedly from those evaluating cytotoxic chemotherapy, anti-tumour efficacy of these agents in MTC patients is likely to be much greater than that of earlier chemotherapies (ORR<20% with chemotherapy using 5FU-DTIC) (3). Tumour response rates are similar in lymph nodes, and lung, liver and bone metastases, and were similar in patients with smaller or larger tumour masses. Serum calcitonin and CEA levels decreased during treatment in most patients, and this indicates an inhibition of the RET kinase, but it may be not paralleled by a decrease in tumour volume.

Comparison of the outcome among these compounds is at the present time not possible.

Toxicity was significant. Benefits demonstrated with vandetanib in a randomised phase III trial on both ORR (44% with long lasting responses) and PFS (>30.5 months in the treatment arm (median not reached) versus 19.3 months in the placebo arm) counterbalance toxic effects and justify its use in MTC patients with progressive or symptomatic disease and those with large tumour burden (4). Vandetanib is available in France within the framework of an Autorisation Temporaire d'Utilisation (ATU) and has been labelled in the USA by the FDA.

Results of the ongoing phase III trial with XL-184 are expected to confirm promising results obtained in the phase I trial in which 29% of 35 patients had a confirmed partial tumour response. There is apparently no cross resistance between drugs. Drugs used up to now have similar mechanisms of action, all being anti-angiogenic and some (including vandetanib and XL-184) targeting the RET tyrosine kinase.

The relative role of the inhibition of each target or of their combined inhibition is currently unknown, but because axitinib and pazopanib are thought to be only anti-angiogenic drugs, responses suggest that the anti-angiogenic effects of these compounds might play an important role. Also, responses to vandetanib or XL-184 have been observed in patients without RET mutation.

Even among patients with an RET mutation, tumour responses were partial and were observed in only a fraction of patients. This may indicate that targeting RET may not be sufficient in all MTC patients. Future studies should explore the interest in effective inhibition of the MAPkinase pathway downstream of the RET kinase, and of other pathways such as the PI3K-AKT-mTOR pathway, and search for other relevant targets that may indicate the use of other drugs. Toxicities of the drugs used in these patients led to dose reduction in 11–73% of patients and to drug withdrawal in 7–25%. There were no unexpected toxicities with long-term treatment.

In DTC patients, refractory disease is defined by the presence of at least one tumour focus without any uptake of radioiodine, or by progressive disease following radioiodine treatment or by persistent disease after six treatments with radioiodine (5-7). Among these

*(continued on page 11)*

## Targeted Therapy (continued from page 10)

cancers, histology (papillary and variants, follicular and poorly differentiated) and genetic defects may differ. Anti-tumour efficacy of these agents is likely to be greater than that of earlier chemotherapies, with partial responses observed in 8–32% of patients and long-term stable disease in at least another half.

Comparison of the outcome among these compounds is at the present time not possible, but the response rates recently reported with pazopanib and E7080 (around 50%) seem higher than in previous reports. It also appears that efficacy may differ among histological subtypes, but further studies are needed to correlate drug efficacy with the genetic defect present in the tumour.

Only results of phase II trials have been reported; a phase III trial (sorafenib vs. placebo) is ongoing and at least two phase III trials (with either pazopanib or E7080 vs. placebo) will be activated in 2011, as well as several phase II trials. Also, the stability of response and patterns of relapse have not been well characterised.

Drugs used up to now have similar mechanisms of action, all being anti-angiogenic and some targeting the kinases in the MAPkinase pathway. Tumour responses were partial and transient and were observed in only a fraction of patients. This may indicate that future studies should use drugs targeted to already known abnormalities (such as an inhibitor of the BRAF kinase in patients with a papillary thyroid carcinoma harbouring the mutated BRAF), and search for other relevant targets. However, there was no significant unexpected toxicity, and the dose of l-thyroxine treatment had to be increased in the majority of patients.

Given the commercial availability of sorafenib and sunitinib, these agents have entered into clinical use for those patients with progressive, refractory disease who are not suitable candidates for clinical trials.

Finally, trials should be performed in patients with anaplastic thyroid carcinoma, using drugs directed against angiogenesis or other targets.

Further trials should also search in MTC and DTC patients for other treatment modalities, including combination or sequential treatment. Recent trials have shown that inclusion of the expected number of thyroid cancer patients to reach statistically significant conclusions is possible in a limited period of time, and this may

be further improved by networks such as the French TUTHYREF network and organisations such as the Endocrine taskforce of the EORTC.

### Conflict of Interest

Author has received grants and research funding from Amgen, Astra-Zeneca, Bayer, Esai, Exelixis and Genzyme. ❖

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### ThyroWorld

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

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# Iodine use in case of nuclear catastrophe?

**N**uclear accidents in small scale have happened a lot now and then since nuclear plants have been established. Serious events have been more rare, but more catastrophic. The IAEA (International Atomic Energy Agency) has made a scale for the seriousness of a nuclear accident, INES (International Nuclear Event Scale) 1-7. Serious events with scale 4-7 have been: Harrisburg 1979, Chernobyl 1986, Fukushima 2011. Chernobyl and Fukushima were on grade 7. Only Fukushima was depended on a natural catastrophe, most of the events at all scales have been caused by the human action, generally started up by a small mistake. Also when a nuclear plant would be built in a low risk area for natural dangerous events, we should consider the possibility of human action.

Guidelines for management with in case of nuclear disaster have been published, but simple guidelines for the common population would be welcome and inadequate acting could then be avoided. For example there were some pharmacy which had sold out all their iodine tabletes on the other side of the globe after the Fukushima accident. Iodine prophylaxis was not recommended in Europe after the event in Japan 2011.

Lack of information by the authorities directly after an accident cause mistrust and anxiety. However, when an accident has happened, it is not always easy neither for authorities nor to general people how to act in reality. Some workers maybe have to offer their lives for performing the immediate measures to stop the spreading

of radioactive material. The first step is the evacuation of the people in close neighbourhood of the accident. The first groups to be evacuate are young children and pregnant women. The people are recommendated to listen to the radio and the recommendations of the national health authorities.

The only established risk factor for thyroid cancer in humans, besides age and gender, is ionizing radiation

Most of the thyroid cancers that were noted after the Chernobyl were among children less than 6 years of age who lived within 100 km distance from the nuclear plant. Nearly 5000 children and adolescents up to 18 years at the time of the accident have been diagnostized with thyroid cancer in the neighbouring regions of the plant. Most of them have survived the disease, but they have to live without thyroid gland and have to be followed up for their whole life.

Even a short exposure to radioactive iodine can cause a mutation into the thyroid gland that remains as a lifelong increased risk of thyroid cancer.

Also an elevated risk of incidence of leucemia among highly exposed workers has been reported.

An increased rate of breast cancer in Belarus 2,2 times and Ukraine 1,4 times 10-15 years after the exposure of RI in women younger than 45 years with thyroid nodules was reported. The human breast gland takes up a small amount of iodine.

The risk of thyroid cancer is dependent of the dosis of radiation. The national health instancies evaluate the risk and recommend in which areas and when to take iodine tabletes to block the radioactive iodine from reaching the thyroid gland.

The recommendated dosis are the following:

Adults over 18 years age 100 mg (in some countries tabl size 130 mg) 1 tabl per day of exposure

3- 12 years ½ tabl

1 month – 3 years ¼ tabl

0-1 month 1/8 tabl

Pregnant women take the same dose as other adults. Pregnant women with hyperthyroidism should not take iodine. The iodine passes the

*(continued on page 13)*

## Candle Lighting Ceremony



*This photo was taken in Finland on August 6th, 2011, at a candle lighting in memory for Hiroshima. It is held every year in Finland.*

## Iodine use (continued from page 12)

placenta. In areas of iodine deficiency there is a risk of blocking the function of the fetal thyroid by prolonged use of stable iodine in the second and third trimester of pregnancy when the fetal thyroid already is developed.

Persons with iodine allergy, thyroid disease or dermatitis herpetiformis (skin celiac disease) and certain types of vasculitis (type of immunological blood vessel inflammatory disease) shall not use iodine prophylaxis.

Milk products should be avoided in contaminated areas.

It is necessary to take accurate steps for preventing thyroid cancer after a nuclear accident. It is to hope that the health authorities give appropriate information to the population without delay. Poland is a good example of immediate information and health recommendations after Chernobyl. In Finland, where actions by accidents generally happen speedy, we got this time the first information by the Swedish radio, it was after the radioactive fallout already had passed over Finland to Sweden.

In conclusion: First keep your common sense in every situation, then listen to the recommendations given by your national health authorities and act according to their advice.

Further it is to hope that the human brain will reach capacity of developing energy sources which are less dangerous than the nuclear energy is today, that we try to keep our important ground water clean and not contaminated by nuclear waste. And would it be possible to lower the need of economic growth? 🌱

ULLA SLAMA, MD

SUOMEN KILPIRAUHASLIITTO RY, FINLAND



*Chernobyl children rehab area*

### About the Author

My interest in the thyroid field started as I worked as general physician on the beautiful west coast archipelago of Finland, and we had 200 children from the Chernobyl region at rehabilitation camps after they had been operated for thyroid cancer.

### Sources

WHO, [www.who.int/mediacentre/factsheets/fs303/en/index.html](http://www.who.int/mediacentre/factsheets/fs303/en/index.html)

NIH, US National Institutes of Health, [www.cancer.gov/newscenter/pressreleases/2011/ChernobylRadiation](http://www.cancer.gov/newscenter/pressreleases/2011/ChernobylRadiation)

[http://en.wikipedia.org/wiki/Nuclear\\_accident](http://en.wikipedia.org/wiki/Nuclear_accident)

# Thyroid Awareness Week, Denmark

## An extra effort was worthwhile

*The Danish Thyroid Patients' Organization had a short tv programme produced as part of a campaign during the International Thyroid Awareness Week.*

*This photo of Jytte Flamsholt appeared in several places, e.g. in an interview on DR's health site, [www.dr.dk/sundhed](http://www.dr.dk/sundhed).*

BY JYTTE FLAMSHOLT,  
JOURNALIST AND TFI DELEGATE  
(DENMARK)



Jytte Flamsholt PHOTO: LARS AAROE

**T**his year the Danish Thyroid Patients' Organization celebrated week 21 as International Thyroid Awareness Week. The results have been remarkable.

In 2010 Danish Thyroid Patients' Organization and the Danish Thyroid Organization (doctors' org.) agreed to make a common campaign during the International Thyroid Awareness Week in May 2011.

A working party of two members from the board of the Danish Thyroid Patients' Organization and two from Danish Thyroid Organization was set up, and after some discussion we decided to make an OBS feature for DR\* the central element of our campaign. This would be shown several times during the International Thyroid Awareness Week and could also be broadcasted on other occasions. For instance we have had the feature texted into English in order to be shown at ETAs (European Thyroid Association) annual meeting in Cracow in September 2011.

The Danish Thyroid Patients' Organization earmarked a sum of money for the campaign, but we also started to look for sponsorship - and ended up with almost enough to cover the costs.

At the same time, which was soon after the turn in the year 2010/2011, we began to cooperate with a freelance journalist who was competent in producing for both tv and print. We made a plan for the campaign which should also target other media such as radio, newspapers and magazines focusing in health.

The result of our effort was rather surprising.

### Electronic and digital media

Apart from the OBS feature which has been broadcasted during week 21 and will be shown again we succeeded in making Aftenshowet, DR's\* and Denmark's main news show, focus on thyroid diseases in a prime time live programme on May 24th.

The same day DR also had thyroid diseases as their main topic when it published an interview on their health site [dr.dk/sundhed](http://dr.dk/sundhed) - four weeks after its publication the article was still the second most read on the site, and the article can still be read on the site, which links directly to our homepage.

Furthermore, one of the big weekly magazines in Denmark, Ude og Hjemme, recommended this article to its readers in a later issue.



PHOTO: © OBS / DR / STOFKIFTEFORENINGEN.DK

### Print media

As for print media we had an article produced, which was offered for free to three different health magazines, and from one, RaskMagasinet, there was immediate response, when it printed the article in full in its May issue. Another magazine, Lægemagasinet, would print it later.

Also the five public regional health magazines have shown interest in focusing on thyroid diseases. One magazine, Sund i Syd, has, with our assistance, produced a theme on thyroid diseases for their August 2011 issue.

After some consideration we chose not to give high priority to the daily newspapers, because we had no special activities going on during the

*(continued on page 15)*



campaign. We did, however, send a press release - and had it published - to a regional newspaper where our organization partook in a health fair at the regional hospital.

We also suggested ideas for articles about thyroid cancer to Ekstra Bladet (national daily), Dagens Medicin (daily health magazine) and Kræftens Bekæmpelse (The Danish Cancer Society), but until now without effect.

### Conclusion

The overall conclusion afterwards is, that it was easier to make various media interested in the topic than we thought, so we do not hesitate to conclude, that the general awareness about

the existence of thyroid diseases was heightened substantially in Denmark during week 21.

In our organization we had a high rise in the number of visitors to our homepage, peaking with a 300 percent rise right after our appearance in Aftenshowet. Since then we have welcomed many more new members than we usually do.

Apart from these remarkable results we also learned, that it may have been convenient for us to concentrate a campaign for a certain period of time. In our organization we are, after all, working on a voluntary basis, but we realized that an effort outside a special awareness week or day would prove just as effectful. We have therefore decided to continue our cooperation with the journalist - and not only during campaign weeks.

This does not mean, however, that we shall not make a special effort in May 2012. Next year we plan to hold a whole day national meeting for patients, focusing exclusively on their needs and worries.

\* OBS are short programmes, broadcasted by DR (Danish Broadcasting Corporation/public service organisation), usually produced by NGOs. 🇩🇰

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## Potassium Iodide in the Age of Nuclear Reactors and Terrorism

*By the kind curtesy of the writer excerpt from my latest book, The Complete Thyroid Book, 2nd edition : Dr M. Sara Rosenthal, Ph.D., Associate Professor, Bioethics, Departments of Internal Medicine, Pediatrics, and Behavioral Science, Director, Program for Bioethics, Chair, Hospital Ethics Committee, University of Kentucky, USA*

**P**otassium iodide (KI) is the same form of iodine used to iodize table salt. Given in sufficient amounts, it floods the thyroid with stable (non-radioactive) iodine, thus preventing radioactive iodine from being taken into the thyroid gland in the event of a nuclear accident. If taken at the proper time, potassium iodide protects the thyroid from radioactive iodine from all sources - air, food, milk, and water. Potassium iodide is a non-prescription drug that can be bought over the internet and at some pharmacies. It's made in liquid or pill form. The two FDA-approved brands of full adult dose

130-mg pills are IOSAT® (Anbex, Inc.) and Thyro-Block® (Medpointe, Inc.). The FDA-approved brand of 65-mg pills is ThyroSafe® (Recip US). Properly packaged, the shelf life is at least 5 years and possibly as long as 11 years. If you accidentally take a very old pill, it may not work fully but it won't hurt you.

"Basically, potassium iodide is a salt that is cheap to make, with an almost unlimited shelf life. It is highly valuable in the wake of a nuclear reactor accident, or a terrorist attack with a radioactive bomb. Potassium iodide's capacity to protect the healthy thyroid gland derives its ability to flood the thyroid gland with so much iodine that radioactive iodine isn't taken into the gland. As a public health measure, having households supplied with potassium iodide is a prudent guard against nuclear disasters.

"After the Chernobyl nuclear reactor accident in 1986, Poland successfully prevented its citizens

(continued on page 16)

## Potassium Iodide (continued from page 15)

from developing thyroid cancer by making sure everyone got adequate doses of potassium iodide as soon as the news hit of the reactor accident. This did not happen in the former Soviet Union, however, where 1,800 children in the fallout region developed highly aggressive thyroid cancer as a direct result of the accident, and thousands more developed it years after the accident because of their exposure.

“In the wake of September 11, 2001, The Department of Health and Human Services announced that it was buying millions of doses of potassium iodide to protect people from thyroid cancer caused by radioactive fallout. The Food and Drug Administration issued new guidelines calling for more rapid administration of the drug in radiation emergencies. Finally, the Nuclear Regulatory Commission advised states that free stockpiles of potassium iodide were available to them for the asking. Unfortunately, not all U.S. States believe this is important, and there is not yet a Federal mandate to force states into stockpiling and distributing potassium iodide.

### “When should potassium iodide be taken?”

Potassium iodide needs to be taken 6-12 hours before exposure to radioactive iodine, and is also protective if taken within the first few hours after exposure to radioactive iodine. People should take one dose a day, only while they are being exposed to radioactive iodine and one day afterward. Only health authorities can determine which radioactive isotopes are released during a nuclear event, and, if radioactive iodine is released, when to take potassium iodide and how long to keep taking potassium iodide it.

### “What about a “dirty bomb” attack?”

Not every radioactive release includes the radioactive iodine that can cause thyroid cancer. For example, a “dirty bomb” may not contain radioactive iodine because it has a short half-life. A “dirty bomb” is a conventional bomb mixed with radioactive material, and designed to explode spewing out the radioactive isotopes and contaminating a wide area.

### “What are the recommended doses?”

The U.S. Food and Drug Administration (FDA) has published general recommendations for minimum potassium iodide doses: a full 130-mg pill for adults, 65 mg for children 3 to 18 years

old, 32 mg for babies 1 month to 3 years old, and 16 mg for newborns up to 1 month old. In the U.S., potassium iodide pills are now sold in both 130-mg and 65-mg doses. The pills are scored to make it easier to cut them up for children’s doses. According to the FDA, children over 1 month old can safely be given a full-dose 130-mg pill on each of 2 consecutive days. However, newborns should be given only a 16-mg dose. The easiest way to prepare a 16-mg dose is to dissolve a 130-mg pill in 8 oz of a clear liquid and feed the newborn 1 oz of the liquid. Another alternative is to give the newborn 16 mg of the liquid form of a saturated solution of potassium iodide, which requires a doctor’s prescription. For FDA suggestions on preparing potassium doses for children, see <http://www.fda.gov/cder/drugprepare/potassiumiodideprep.htm> <<http://www.fda.gov/cder/drugprepare/kiprep.htm>> .

### “Who should not take potassium iodide?”

If you don’t have a thyroid gland, or you already had your thyroid gland ablated by radioactive iodine (as in Graves’ disease, see chapter 6), you don’t need to worry about taking potassium iodide. In our family, Sara wouldn’t need to worry about taking potassium iodide, nor her sister (who had Graves’ disease), but Ken and our two teenage boys would need to take it. I (Ken) have also taken potassium iodide to protect my thyroid gland during times when my laboratory research could have potentially exposed me to radioactive iodine used to label proteins in laboratory testing.

“ The Public Health Security and Bioterrorism Preparedness and Response Act of 2002, enacted by Congress in May 2002, created a mechanism to extend the radius of potassium iodide distribution to communities within 20 miles of nuclear plants, and directs the President to decide which agency or agencies will oversee stockpiling and distribution. The American Thyroid Association (ATA) has been urging potassium iodide stockpiling since 1984. Its members have been studying the Chernobyl nuclear accident and participating in studies and care for its victims. The Association’s recommendations are outlined in the public health statement on its website.” 🍀



# Fine-Needle Aspiration Biopsy in Thyroid Nodules

## Diagnostic Work-Up by Fine-Needle Aspiration Biopsy and Cytology

VISITING PROFESSOR (WROCLAW MU)  
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**N**odules of the thyroid gland often give rise for further work-up. The patient's history, clinical examination and ultrasound studies give valuable information concerning the classification of the nodules. The differentiation between "cold" and "hot" nodules is usually done by thyroid scintigraphy using [99mTc]-pertechnetate as a tracer.

From epidemiologic surveys it is well known that approx. 20-25% of the population harbour nodules in a normal sized or enlarged thyroid gland. There is an increase of the incidence of thyroid nodules with age. For instance, in people over 50 years of age thyroid nodules are detected in more than 50%.

Most of the thyroid nodules are benign. Malignant nodules are diagnosed in about 5-15% of all nodules.

Nodules larger than 1 cm in diameter are frequently observed by the patient himself or at clinical examination. Using ultrasound devices the size of the nodule can exactly be determined. In a number of patients ultrasound is also suitable to reveal further nodules which have not been aware to the patient himself. Using high resolution ultrasound probes nodules can be imaged which have not led to local (cervical) symptoms. A definite differentiation between benign or malignant nodules cannot be done by ultrasound alone.

However, some ultrasound appearances are well known which characterize either a benign or a malignant nodule. Malignant nodules often show one or more of the following criteria in ultrasound examinations:



- hypoechogenicity ("dark" nodule)
- calcification within the nodule
- irregular margin of the nodule
- no halo (e. g. dark rim around the nodule)
- rapid increase in size.

Consensus has been made among the scientific community members that nodules larger than 1 cm in diameter should be further evaluated by scintigraphy. "Hot" nodules are 100% benign. Most of the "cold" nodules are also benign. However, 5-15% might be malignant. Therefore, further work-up is essential.

For this further work-up fine-needle aspiration biopsy (FNAB) has well been established. For this purpose needles with a diameter of 0.6-0.8 mm are used. Lokal anaesthesia is not necessary. The intensity of the prick of the needle in FNAB is comparable with that of an usual venous blood sample. Written consent of the patient should be given after careful information of the procedure and possible complications (bleeding, infection, pain). Care has to be taken in patients receiving anticoagulation (heparin, cumarines, clopidogrel or ASS). If there is a bleeding risk FNAB should be carried out only after stopping the anticoagulant therapy for an adequate period of time.

Usually, the FNAB is done in supine position of the patient with extended head under sonographic guidance. Using an aspiration technique, small tissue elements are taken by FNAB and a smear is made on a glass slide. The air-dried smear is then sent to a cytologist specialized to thyroid disorders.

The FNAB procedure takes only some minutes and is well tolerated by most patients. There is absolutely no evidence for any dissemination of malignant cells into normal tissue.

After appropriate drying the smear is microscopically evaluated by the cytologist. Special attention is made with respect to the formation of the cell cytoplasm, the cell nucleus and the smear background.

In most cases adequate smear allows differentiation of inflammatory, benign or

*(continued on page 18)*

# TRUST Study

## Thyroid hormone Replacement for Untreated older adults with Subclinical hypoThyroidism

Plans are well advanced for a 4-country study of subclinical hypothyroidism in older age. Expert groups in Scotland, Netherlands, Switzerland and Ireland are collaborating in this project. TFI is delighted to support the study, acting as the patient advocacy group for the project.

Subclinical hypothyroidism (SCH) is a common condition among European older men and women affecting between 8 and 18% of over-65s. Although by definition people with SCH have mild thyroid hormone deficiency without major symptoms, SCH is a possible contributor to multiple problems in older age.

Thyroid hormone has multiple actions on different parts of the body, including the circulation, heart, muscle and brain. Therefore, treatment with thyroxine has the potential to give a number of benefits to older people with SCH.

Small studies have reported less fatty lining in blood vessels (atherosclerosis) and improved heart function with thyroxine replacement, but no large clinical trials have been performed.

There are always concerns that indiscriminant over-replacement might have side effects such as irregular heart rhythms or bone thinning and fractures. Therefore the available evidence is limited, leading to major variations in guidelines and clinical practice, with uncertainty regarding the indications for screening and treatment.

The project has proposed a trial to assess the impact of thyroxine replacement in 3,000 older adults with persistent SCH. Half the subjects will be allocated to get thyroxine and half a dummy tablet (placebo). During the trial subjects will not know which they have been allocated to. In the project older men and women will be included with a wide age range and of varying health status.

The project will examine whether thyroxine reduces the risk of heart attacks and strokes, improves health-related quality of life (reducing symptoms such as tiredness), increases muscle strength and speed of thinking over an average of 3-years of follow-up.

Patients will be carefully monitored to ensure that they are not over-replaced with thyroxine; this is important to reduce the risk of any side effects. This clinical trial should clarify whether thyroxine treatment for SCH provides benefits that are relevant for patients, without causing problems such as irregular heart rhythms or fractures.

This trial will provide strong evidence with the potential to improve clinical practice, reduce healthcare costs and promote healthy ageing of European older adults.

It is anticipated that negotiations over details of the trial will be concluded in September, with the first subjects recruited in February 2012. 🍀

For further information, contact the representative of TFI for the project, Mrs. Yvonne Andersson Lakwijk – Yvonne.Andersson@thyroid-fed.org.

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### Fine-Needle Aspiration

*(continued from page 17)*

malignant lesions. If cytology renders a benign result, operation of the thyroid gland can be omitted. The accuracy of FNAB and cytology is reported to be 65-98%. However, some limitations of cytology have to be noted. The differentiation between a benign follicular adenoma and a malignant follicular carcinoma is not possible. In these cases only histologic evaluation after operation can yield the correct diagnosis.

An inadequate number of aspirated cells by FNAB is observed in up to 15-20% of samples. In these cases a second FNAB with sufficient aspiration of cells should be considered. 🍀

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# TFI 2010 Annual Meeting

Paris, France, September 9th, 2010

The 16th annual general assembly of Thyroid Federation International took place in Paris, the day before the International Thyroid Congress started. Patient organizations from Australia, Belgium, Canada, Finland, Germany, France, the Netherlands, Sweden and the USA were represented. We worked on the internal rules, on past activities and on future projects – in particular the yearly “International thyroid awareness week”, launched in 2009 and now a worldwide event, with a thyroidweek website in many different languages.



TFI booth at the ITC



A short break during the TFI annual meeting 2010, Paris.  
Left to right: [Top] Larry Wood (USA), Ashok Bhaseen (Canada)  
[Bottom] Peter Lakwijk (Belgium/Netherlands), Beverley Garside (Australia), Nancy Patterson (USA), Yvonne Andersson (Sweden), Ulla Slama (Finland), Ineke Bink (Netherlands), Harald Rimmele (Germany), Beate Bartès (France)

During the International Thyroid Congress, TFI had a booth, with posters, videos, information leaflets and newsletters, which attracted a lot of visitors. We also organized a patient information meeting, together with the French Ligue contre le cancer, and met the representatives of the 4 international doctors' organizations, ETA, ATA, LATS and AOTA, to talk about common projects. 🐼

TFI meets the ETA, ATA, LATS and AOTA

Left to right : Beate Bartès/Yvonne Andersson (TFI), Leonidas Duntas (ETA), Terry Davies (ATA), Junji Konishi (AOTA), Peter Laurberg (ETA), Hans Graf (LATS).



## TFI – 18th Annual Meeting September 7, 2012

The 18th annual meeting of Thyroid Federation International is planned on September 7, 2012, in conjunction with the 36th ETA congress (September 8 to 12) in Pisa, Italy.



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