

THYROID WORLD



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Thyroid Federation International

Established in September 1995 in Toronto, Canada

Founder

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

Patrons

Sir Richard Bayliss, KCVO MD FRCP (UK) 1917-2006
Patricia Bradley (USA)
Dr. Kazuo Hashimoto (Japan)
Prof/Dr med Peter Pfannenstiel (Germany)

Mentor & First President

Lawrence C Wood, MD FACP (USA)



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Katherine Keen (Canada)

Website Coordinator

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Member Organizations

Our member organizations now number 21, representing 16 countries. The names of the organizations and their current addresses are given on page 16.

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From the Editor's Notebook



JRB, Editor

Putting this issue of ThyroWorld together has been a real puzzle let alone a challenge. First, there was no material; then there was too much. There were excellent articles “reprinted with permission” from other sources but not as much information as I would have liked from our own TFI authors. Deadlines came and went and emails were returned or went astray. Then vacation intervened. Devoted as I am to the production of our newsletter, my dedication was not great enough for me to forego a trip to Italy with my husband in mid-May. So the designer and I did what we could, collected what we had and put it into a rough format.

While I was waiting, I decided that I might as well work on my own article for this issue. Julie Bente Lassere from Denmark had asked me some time ago to write something about TFI history — how it got started and who was involved. She reasoned that many member organizations did not know this information and that it would be a good idea to get it down on paper before it disappears from living memory. And indeed memory had a great deal to do with the assignment. Going back ten years and trying to remember names, dates and places was indeed challenging.

I called on as many people (as I could remember) who were around in those early days. But not everyone's recollections agreed. Ellen Garfield of Toronto who introduced the computer to TFI was particularly helpful. She and I must be natural pack rats since we both found a paper trail of programs, minutes and the like to flesh out my skeleton draft.

Since it was not a scientific treatise, I took a light-hearted approach in describing TFI's short history. At any rate, it was fun for me to discover and I hope it will be agreeable for you to read. I apologize for any and all inaccuracies and I would be happy to stand corrected on these. Let's consider it a work in progress.

So there we are — the puzzle and challenge of Issue No. 9. Read on! 🍷

*June Rose-Beaty
jrb.edit@rogers.com*

President's Message

This year you will receive a different kind of president's message, a very personal one. When life strikes you in the worst possible way, your daily life turns upside down. Your well planned time loses value and your priorities are totally changed.

Last year, May 17, 2005, I lost my daughter Lisa. She was only thirteen years old. She was on the wait list for a heart transplant, but her heart could not wait any longer. Lisa was so full of hope and confidence. Her dream was to be healthy or at least to feel what it was like to be healthy, as she used to say. She wished so much to be able to do the same things as her friends. But in spite of the restrictions of her life, she was always positive and happy.

Many of you have known me since the TFI and ETA conferences in Munich 1997. I was a woman from Sweden with a husband and four children, two daughters and two sons. I was also president of the thyroid organization for the western part of Sweden. To attend these meetings, to be able to work for and with an international organization was a possibility that I appreciated very much. When in October 2003, in Edinburgh, I was elected as President of Thyroid Federation International I was very proud. I was and still am very grateful for all the support I have received then and now. I was full of energy and ideas for the future. Open dialogue and good co-operation with the medical profession were and still are among my main goals. Yet, in a second, goals and plans can be swept away and happiness can change to deepest sorrow.

Losing a child, is the worst blow that life can deal. The helplessness tears you apart. Not being able to help and protect your child as a parent is meant to do is shattering. No parent should outlive their child. Suddenly you realize that work, career, money are no longer important. The only thing that really matters is the health and happiness of your family.

Trying to be in control and pretending to go on with your life as before is to fool yourself and those around you. It is just not possible. You lose energy and stumble through from one day to the next. Where once you could do many different things during a day with energy to spare, now you can hardly manage to crawl out of bed in the morning and accomplish one simple task. It is important to accept these signals from your body because this

lethargy is not something that you can push away or control yourself.

Why do I then, as President of TFI, write about this instead of thyroid related issues?

Some people think it is important to remain professional, in control in every situation. I think, however, that it is important to show that you are a human being with many emotions, to acknowledge and accept the fact that some things in life influence your professional life and these have first priority. Sorrow and grief have no agenda and no timetable. You are the only one who knows when it is time to return to normal life again.

When life turns the way it did for my family and me, you start to think about what's important in life. Your criteria have changed. Most of us have too much stress and too many "musts". I urge you to stop for a moment and think what is important and what your priorities are. Life is too short to waste. So take care of your life and your nearest and dearest, because that is the most important task in life.

By now I am sure you all understand that my priorities have totally changed since May 17 last year. But my interest in thyroid questions is still there and the energy is slowly coming back step by step. If all goes well, I hope to be back with you in Naples in September. I will not promise, however, because I have learned that you can never plan your life, you may only wish and hope about the future.

I want to thank the Board of TFI for the support and help that I received during the past year and still am receiving. You have done amazing work. The thyroid family is still together.

Finally I want to thank all of you, members of TFI, people among the medical profession, people from the pharmacy companies and many, many others, friends from all over the world, who have sent your sympathy and greetings to my family and me at the loss of our beloved daughter Lisa. 🌹



Lisa



Yvonne Andersson,
President

TFI: A Little History

The thyroid gathering held in Buenos Aires last October was indeed a special one, the 13th meeting of the International Thyroid Congress. It also marked the 10th anniversary of the founding of the Thyroid Federation International in Toronto Canada in 1995 at the 11th International Thyroid Congress. To mark the occasion, perhaps it is time to look back at how TFI came into being and what we have accomplished in a modest way in our first ten years.

It was a warm sunny morning in mid-September when a small group of people crowded into a downtown Toronto hotel room to discuss the possibility of an international patient-oriented thyroid organization. It was a quiet Sunday morning; the Congress was winding down after a highly successful meeting. Saturday afternoon had seen a very popular open public forum with an expert panel answering questions from the floor — a veritable who's who of thyroid specialists. We all had quantities of thyroid information, literature and souvenirs to take back to our home organizations.

Just one more meeting to attend. But those who responded to the informal invitation to attend that meeting had a vested interest – whether personal or professional – in being there. Dr. Larry Wood, President of TFA, chaired the meeting with Diana Abramsky, Founder of the Thyroid Foundation of Canada, by his side to give him an occasional nudge. High on Diana's wish list was to have an international thyroid organization run by and for patients.

Nine thyroid organizations from six countries were present at that 1995 inaugural meeting: Canada, Italy, Germany, The Netherlands, UK and the USA. Among the notables were Dr. Peter Pfannenstiel from Germany; Emma Bernini and Giovanna Laborio from Italy; Janis Hickey and Betty Nevens from the UK, Sally Mitchell and Ann Rigby-Jones also from the UK; there were double contingents from The Netherlands, the UK and the USA. Nancy Patterson represented NGDF and Larry Wood TFA. Canada had a strong showing: Joe and Rhoda Boyce, Lottie and Ellen Garfield, Dr. Jody Ginsberg, Rita and Roger Wales Sara Rosenthal, Katherine Keen and myself. As the first patient-oriented organization in the world, the Thyroid Foundation of Canada was to serve as a model for TFI, with Canadians well represented at the launching of this fledgling organization.

There was unanimous and enthusiastic support for the idea. It was very appealing to think of an international thyroid group, of sharing information with other organizations and of helping thyroid sufferers around the world. We couldn't refuse, especially when children were among those sufferers.

On that day and on the days to come, a great deal of necessary business was done and important decisions made. One was to hold future meetings in conjunction with those of the major thyroid organizations to benefit from their publicity and to make the new organization better known. Another was that we would freely and gladly exchange information and ideas. And with those basic agreements, TFI was underway, full speed ahead for Amsterdam in 1996. Indeed, if Toronto was the spirit of the project, then Amsterdam was the working force behind it.

So what have we accomplished in our first decade. We have grown from the initial nine members to the current twenty-one. We have been accepted by the medical profession as a bona fide organization ready and willing to help. As with most new groups, a fair amount of time was spent on its organization and governance, defining our mission and possible projects. Here are some of the highlights of our first ten years.

1995 – 2005

1995: Toronto, Canada

- * Inaugural meeting of the Thyroid Federation International
- * Countries represented: Canada, Germany, Italy, The Netherlands, UK, USA

1996: Amsterdam, The Netherlands

- * New Members: Australia (ATF) and The Netherlands
- * Twenty-one delegates from six countries were present.
- * A mission statement and goals were drafted, legal advice was sought, steering committees set up and officers elected.
- * Executive: Dr. Larry Wood, President; Dr. Peter Pfannenstiel, Vice-President; Rhoda Boyce, Secretary; John Borthwick, Treasurer.

... continued on page 5

TFI: A Little History (continued from page 4)

- * Honorary Founder: Diana Abramsky
- * Honorary Patrons: Sir Richard Bayliss, Pat Bradley, Dr. K. Hashimoto
- * Medical Adviser: Dr. Robert Volpé

1997: Munich, Germany

- * New Members: Denmark and Sweden
- * Successful Patient and Physician Forum organized by the German Thyroid League.
- * Newsletter is planned, information gathered and reviewed, draft compiled.
- * Help in equipment and medication given to Dr. Alexander Kurtev for the Pediatric Hospital in Sofia Bulgaria. Thanks to Dr. Larry Wood and Dr. Annette Grütters-Kieslich for organizing this effort.
- * *We did the polka.*

1998: Pieria and Athens, Greece

- * New Members: Japan and Sweden (Stockholm)
- * TFI and TED were invited to participate in the International Symposium on Thyroid Eye Disease. We shared an excellent booth to display our literature with considerable physician interest.
- * First issue of ThyroWorld published.
- * *We danced à la Zorba.*

1999: Milan, Italy

- * New members: France, Japan, Republic of Georgia, Thyroid Australia, United Kingdom (BTF)
- * Design and publication of TFI brochure — organized by Arliss Beardmore.
- * *A musical soirée with Shann Wood and friends.*

2000: Kyoto, Japan

- * Death of Founder Diana Abramsky
- * New Members: Finland and Russia
- * TFI is invited to attend lectures and all conference activities.
- * Discussions with interested doctors on how to start a patient's thyroid association.
- * Special presentation to TFI by Dr. Kazuo Hashimoto, son of the renowned Dr. Hakaru Hashimoto.
- * *The tea ceremony in the Kyoto gardens and the excursion to Nara were memorable.*

2001: Warsaw, Poland

- * New Member: Brazil
- * TFI recognized in the official program as a satellite organization.
- * Publicity promotion: our unique blue and white pens were put into the kitbags of all the conference participants – a great hit.
- * Larry Wood steps down as President, Yvonne Andersson steps up.
- * *We enjoyed a fabulous Chopin concert at Ostrogski Castle.*

2002: Gothenburg, Sweden

- * TFI President-elect Yvonne Andersson is invited to speak to the conference on the mission of TFI, a tremendous breakthrough in recognition of our work.
- * *We scaled the walls of the Carlsten fortress for our Viking dinner.*

2003: Edinburgh, Scotland

- * Review of By-laws and concepts of governance. TFI is now defined as an Association of like-minded organizations, not a Foundation.
- * *We had a fling at the Highland Fling*

2004: Istanbul, Turkey

- * The President and Vice-President were interviewed by Istanbul TV.
- * New Member: Beate Bartes, France and her Bulletin Board Forum.
- * *Our magic carpet was for some a hot air balloon.*

2005: Buenos Aires, Argentina

- * Rules of membership were reviewed.
- * Many new contacts were made with potential new members.
- * TFI brochure translated into Spanish – an initiative of Dr. Ulla Slama.
- * Current Executive: Yvonne Andersson, President; Peter Lakwijk, Vice-President; Beate Bartès, Secretary; Janis Hickey, Treasurer
- * *We tried to tango but ...*

Onwards and upwards to Naples, Italy 2006 🐼

JRB, Editor

Sir Richard Bayliss kcvO: A Meeting

BTF Director, Janis Hickey, had the opportunity in January to meet with and interview Patron Sir Richard Bayliss over tea and biscuits. Sir Richard has been a staunch supporter of the BTF from the very early days when he was first approached by Janis with the idea of forming a national patient-led organization providing information and support for thyroid sufferers. The support and guidance he provided enabled the BTF to be established and launched. We are grateful for his continued support.



*Sir Richard Bayliss
1917-2006*

Here are Sir Richard's answers to the questions Janis asked him about his life and times.

When and where were you born?

I was born on 2nd January 1917 in Tettenhall, West Midlands.

Why did you decide to study medicine?

I decided to study medicine when I was six years old and suffering from whooping cough. Dr. Dent our GP, visited me daily during the first week or so. One morning he arrived and watched me. 'Poor boy', he said, 'he's just about to whoop'. And I did, making an uncontrollable whooping cough. His perception impressed me!

Who was your major inspiration in becoming a doctor and why?

My two sisters and I knew that my mother was devoted to Dr Dent who had delivered her at home of her three children. He was a qualified surgeon and worked at our local hospital as well as being a GP. It was his inspiration that led me to be a doctor and shortly after I had recovered from whooping cough, he showed me how to dissect a frog that I had caught in our garden and killed by anaesthetising it with chloroform. There were also doctors in our family. A great-uncle, Professor Sir William Bayliss, was a distinguished physiologist at University College Hospital in London in the first quarter of the nineteenth century and coined the word 'hormone' to describe the substance (secretin) secreted by the stomach and upper small intestine, which activated the secretions from the pancreas.

From the age of six I was single-minded in wishing to become a doctor.

When and where did you first qualify as a doctor?

After three years at Cambridge reading the Natural Sciences Tripos, I moved to St. Thomas's Hospital in London for my clinical training in medicine. I qualified in 1942.

Why did you decide to specialise in endocrinology?

My interest in endocrinology came from being a house-physician and then registrar to Dr Harold Gardener-Hill, who was one of the earliest

physicians in this country to specialize in diseases of the endocrine glands. The thyroid gland was the most frequently affected organ and initially most endocrine patients had some thyroid disorder. Only later with increasing knowledge did we begin to recognise disorders of the pituitary gland, and ovarian and testicular disorders came within the realm of endocrinology. Although I specialize in all endocrine disorders, thyroid disease is the most common and hence one sees more patients with thyroid disease than with any other.

What break-through, in your opinion, is the major achievement in the field of endocrinology that you have seen in your time as an endocrinologist?

The development of chemical tests that measure the various hormones in the blood stream. Not until the mid-1930s was it possible to measure accurately the hormone levels in the blood and in those early days only a very few of these hormones could be measured.

What break-through in the field of thyroidology would you like to see in the near future?

One hopes that one day we will be able to understand why patients develop endocrine diseases. We understand the mechanisms involved but have no good idea why some patients and not others develop endocrine disorders. In some there is a genetic disposition but we do not know how this predisposition is inherited or how it operates.

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— and a Parting

It was with great sadness that TFI members learned of the death of Sir Richard Bayliss in April of this year. His passing was especially felt by members of the BTF as he had been their Patron and adviser since its beginning. He was as well Patron to TFI whose members also feel the loss.

Janis Hickey, BTF Director, was fortunate to have had the opportunity to meet with Sir Richard just a few months before his death. "I am so pleased that I spent those few hours with him, talking to him, telling him what was happening in BTF and TFI and about the increase in patient organizations. He was the first person that I contacted when I was thinking of setting up BTF. He was our first chair and later our Patron. He was always very supportive and truly believed in patient support groups. I'm glad that I had the chance to thank him."

Sir Richard was an eminent physician, in attendance to the Queen and her household for many years as well as to many notables in government and public life. He had a special interest in thyroid function. His publications included *Thyroid Disease: the Facts*. The book which went into three editions became the cornerstone of

thyroid literature for patients. It was a book they could read and understand. His distinctions, including his knighthood (KCVO) in 1978, are many: Honorary Fellow of the Royal College of Pathologists and President of the Association of Physicians and of the endocrinology section of the Royal Society of Medicine.

He was an excellent teacher, one who did not shy away from innovative or controversial ideas. He was often in the news with his medical opinions and didn't hesitate to call his own profession to task. He once remarked in a lecture on the unproven powers of a healthy diet to prevent heart attacks, "The problem is half of what we teach today is wrong and we don't know which half it is."

His third marriage of twenty-seven years to Marina Rankin was a happy one. She said of his passing that he loved life and left it at the age of 89 "reluctantly."

Although Sir Richard moved in high circles, he never forgot his West Midlands roots.

His warmth, humanity and sense of humour earned him great affection from his patients and appreciation from us all. 🍷

Sir Richard Bayliss (cont'd from page 6)

Would you name three people whom you would like to have to dinner and why?

The three people I would most like to have to dinner would all have to be resurrected! To begin, Fuller Albright an American endocrinologist (1900 – 1969) who first described 'Albright's syndrome' a rare genetic disorder affecting the bones and skin pigmentation). Then, my great uncle the distinguished physiologist Sir William Bayliss (1860 – 1924) and the renowned pioneer of scientific endocrinology in the UK. Finally, Russell Fraser (1908 – 1994) who incidentally was a New Zealander by birth. They were all great men and good conversationalists. 🍷

*As indeed was Sir Richard himself, KCVO
KNIGHT COMMANDER OF THE VICTORIAN ORDER.*



*TFI Family:
Australia, Canada, Denmark, Finland, France, Russia, The
Netherlands, United Kingdom, United States*

Frequent Miscarriages —

Professor W.M. Wiersinga is with the Department of Endocrinology and Metabolism, Academic Medical Centre in Amsterdam. In 2004, he carried out a study with the late Dr. M. F. Prummel on the relationship between thyroid autoimmunity (TPO antibodies) and frequent miscarriages.



Dr. Prummel

Jenny Pannekoek a member of Schildklierstichting, Nederland interviewed Dr. Wiersinga on the subject, in which she has a personal interest – the safe arrival of a healthy baby girl.



Professor Wiersinga

First, what is TPO and what is its function?

TPO is the abbreviation for Thyroid Peroxidase, a very important enzyme in the production of thyroid hormone. A TPO test (TPOAb) can be done to detect autoantibodies directed against the thyroid gland itself.

How did you and Dr. Prummel come up with the idea of doing a study into repeated miscarriages in women with thyroid autoimmune diseases?

Both Dr. Prummel and I regularly saw in our clinic female thyroid patients with repeated miscarriages. The current scientific literature could not give us a clear answer on whether this was due to autoimmune disease of the thyroid gland. So, we carried out a meta-analysis. We put all the results from the studies together so that we could draw a clear conclusion.

How did you set about doing the study?

In two ways. We looked at 'case control' studies. The female patients with TPO antibodies formed the 'case' group and the patients without TPO antibodies formed the 'control' group. In both these groups of women we determined the risk of a miscarriage (defined as rejection of the foetus before the 12th week of pregnancy).

We also analysed the prospective studies that have been carried out. In the course of time, 1000 women have been followed and we looked at their pregnancies. Of these women, 500 had TPO antibodies, and 500 did not.

What important conclusion emerged from your scientific study?

The first study showed that women with TPO antibodies had a 27% risk of a miscarriage if they become pregnant, while women without TPO antibodies had an 11% risk. The average risk of a woman with TPO antibodies having a miscarriage proved to be 2.73 times greater than that of a woman without TPO antibodies (the 95% confidence interval of this risk was between 2.2 and 3.4 times greater).

The prospective study confirmed this conclusion: 23% of the women with TPO antibodies had had a miscarriage compared with 11% of the women without the TPO antibodies. This study showed that a woman with TPO antibodies had on average a 2.3 times increased risk of having a miscarriage compared with a woman without these TPO antibodies.

What causes the presence of TPO antibodies in the body?

That is still not clear. It is partly due to genetics. But something still has to happen to make the antibodies develop. Women do not have them before their first menstrual period. When the menstrual cycle starts, antibodies develop in a number of women and they increase as the years go by. Part of the explanation may lie in the hormonal changes in the female body.

Do you have an explanation why miscarriages occur so frequently in women with TPO antibodies?

We arrived at three possible explanations for the fact that women with TPO antibodies have a 2.73 increased risk of a miscarriage. First, we know that TPO antibodies attack the patient's own tissue, including the thyroid gland. The women with TPO antibodies who have miscarriages could be an 'auto-immune type'. Other antibodies may also be present in these women and these may turn against the foetus since, for the mother, the foetus is for 50% a foreign body, namely the part from the father.

Next, we considered the age factor. The average age of the women with TPO antibodies in the study was 31 years, while for those without TPO antibodies this was 30.3 years. The older a woman

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Is TPO, the possible culprit?

is, the greater the risk of a miscarriage, so it is possible that this age difference goes a small way to explaining the differences seen. But this could not be the whole cause of the differences.

If TPO antibodies are present in a woman's body, she has a higher risk of becoming hypothyroid. The women with antibodies had a slightly higher TSH level, so it is possible that they became a bit short of thyroid hormones and that could also be the culprit. The women in the study were not taking thyroid hormones.

How can frequent miscarriages in women with TPO antibodies be prevented?

We cannot do anything about the age factor. At best, we could select women who are exactly the same age in a following study. If the cause is an as yet unknown autoimmune disorder in the women with TPO antibodies as in explanation 1, then there is unfortunately no solution to offer these women. We could consider giving them a high dose of corticosteroids (such as prednisone), but that brings with it an increased risk for the foetus. If explanation 3 causes the higher incidence of miscarriage, then there is certainly something we can do. We can give them thyroid hormones. This treatment is not damaging to the foetus. We had hoped to continue our study further but, sadly, Dr. Prummel passed away.

In Italy, there has recently been further investigation on this subject. It confirmed our finding that women with TPO antibodies have a more than twofold increased risk of a miscarriage. The Italian conclusion on administering extra thyroid hormone is that this would not have any effect. I would like to point out, however, here that the Italian study included women who had undergone IVF treatment. They were given hormone injections (oestrogen) that could have counteracted the effect of the extra thyroid hormone. What I would like to do is repeat the Italian study, but only give the extra thyroid hormone without the hormone injections used in the IVF treatment.

What scientific research is still needed to gain more clarity about the cause or to find a solution?

The administration of selenium needs to be studied further. In that context, it is interesting to mention that women with repeated miscarriages

have a lower level of selenium in their hair than women who have not had miscarriages. A certain dose of selenium (about 200 microgram daily) decreases the number of antibodies in the blood, according to a number of studies. This is, however, still experimental and cannot yet be used as treatment.

Why has so little research been done on thyroid diseases? Aren't doctors interested in this subject?

No, this is certainly not due to the doctors, they are very interested in this subject. The problem lies with the pharmaceutical industry. A great deal of money is needed to carry out a scientific study, and that sort of money is not available for thyroid research. Thyroid hormone is a very inexpensive medicine to produce while drugs for cardiovascular diseases are much more expensive. This means that the pharmaceutical industry is keen to do research in that area, while studies on thyroid diseases are not considered financially interesting.

Up until now, we have been talking about women with TPO antibodies, what about the women with TSI antibodies (Graves patients)?

In my practice, I see that Graves patients have less trouble getting pregnant and have fewer miscarriages than women with TPO antibodies. It is much more difficult to study these TSI antibodies, because they are rarer, and they sometimes disappear and then suddenly pop up again. To date no studies at all have been carried out on this subject. However, a number of Graves patients do have TPO antibodies as well as TSI antibodies, and therefore also have a greater risk of miscarriages.

What should women with TPO antibodies do to prepare themselves as well as possible for a future pregnancy?

They should make sure that their blood level of thyroid hormone is as good as possible. So, a TSH level above 0.4 with a maximum of 2.5 for patients with Hashimoto's disease.

Could these women benefit from animal thyroid hormone, as some homeopathic doctors contend?

No, there is no evidence at all to support that. Animal thyroid hormone can even be dangerous because it may cause T3 levels to increase too much. It is in fact T4 that the brain of the foetus needs.

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TPO, the possible culprit (continued from page 9)

Could you also conclude that women with thyroid autoimmune diseases find it more difficult to become pregnant and more often seek medical help in getting pregnant at IVF clinics?

In the IVF population there is probably a relatively large number of women with TPO antibodies.

Many women hear from their internist, gynaecologist or family doctor that their repeated miscarriages and infertility cannot be associated with the thyroid gland. What is your opinion on this?

Our study has proved that the TPO antibodies in a thyroid patient really may be the culprit. There is a clear relationship.

Why then don't these internists, gynaecologists and family doctors know this yet?

The relationship between thyroid disorders and miscarriages or infertility is now gradually appearing in the literature, but it is a slow process. It is the doctor's own responsibility to keep up to date with the medical literature.

I hope that a solution can be found for these patients. In this day and age it is terrible that people have a problem and the medical world is powerless to help them. 🐼

Postscript from Jenny Pannekoek

In the AMC scientific hospital in The Netherlands, a study under the name of 'ALIFE' is currently being carried out into the administration of anticoagulants in pregnant women who have had at least two miscarriages. This is to see if anticoagulants could offer a solution. Women with TPO antibodies who have had two or more miscarriages are also eligible for this study.

Unfortunately in The Netherlands, women are not automatically tested for TPO antibodies. If she is being examined in a fertility clinic, she must ask to be tested. We do not know what the situation in other countries is.

We regret the untimely death of Dr. Prummel and value his contribution to the study.

We are indebted to Professor Wiersinga for his work, his concern for patients and for this interview.

ETA – 31st Annual Meeting September 2 – 6, 2006 Naples, Italy



Welcome to Naples

Rooted in legend the origins of Naples are shrouded by mystery. It is believed that the city was founded on the spot where the siren Parthenope died, thus the origin of the city's ancient name. It is generally accepted though, that the earliest colonizers were of Greek origins (thus the name of Neapolis, the new city as opposed to Paleopolis, the old city) and that the earliest settlement was on the isle of Megaride (where, currently, Castel dell'Ovo stands) between the ninth and seventh centuries B.C.

Naples allure goes way beyond its history, culture and architectural masterpieces. Its lively atmosphere, its very special food and drinks its music and the very attitude of its people make the city a most special place that everybody should visit at least once in a lifetime!

Conference Secretariat:

e-mail: info@fasiweb.com
web site: www.fasiweb.com

Events:

- Opening Ceremony and Welcome Reception
- Scientific Sessions
- ETA General Assembly
- Excursion and Social Dinner in Pompeii
- Gala Dinner
- Closing Ceremony

On Line Registration:

www.eta2006.com (deadline August 20, 2006)

Thyroid Federation International

The Thyroid Federation International Conference will be held from August 31 – September 2, 2006. The venue: Room C - University Congress Centre, Via Partenope, 36, Naples.

For information please contact:
tmhawkins@sympatico.ca



TFI: 11th Annual Conference

Buenos Aires, Argentina

Conference Highlights

On stage at the Sheraton; Common Concerns

This year, the Congress started with a particularly interesting event: a satellite symposium on thyroid cancer. It was an information event for Argentinean patients. Organized by the Light of Life patient group with support from Genzyme, it featured lectures by Argentinean and American doctors, specialist surgeons, and endocrinologists. There were many patients, and many questions.

TFI was introduced and we had an excellent opportunity for interesting discussions with the patients and doctors. We had many good contacts, particularly with two Argentinean women, Maria Teresa Rojas and Maria Rosa Tacta, who are very interested in starting a patient group in Argentina. They attended part of the ITC meeting with us, and we have been in contact since, helping them with information and advice. During the Congress, at the TFI booth, we met several Argentinean doctors interested in helping to start a patient group. We will now try to put them in touch with the patients and get some new groups started.

The Congress was a very big event, with more than 1800 participants, hundreds of lectures, symposia and poster sessions. The main topics for 2005 were "thyroid problems and pregnancy" and "new guidelines for the follow-up of well differentiated thyroid cancer". Thanks to the chairman of the ITC local organizing committee, Dr Hugo Niepomnyszse, TFI was registered as a "non-profit organization" and we were able to attend all the lectures and social events without charge. TFI had a booth in the exhibition area in the entrance hall. It was very well situated near the



Manning the booth: Ted Hawkins and Peter Lakwijk.



Down to business.



Two new recruits with TFI old hands.

ATA and LATS booths and the travel agency. We had many visitors, lots of interesting contacts, and were extremely busy all throughout the week! The contacts with the doctors and the local organizers were very good and the people from Lothse and Barcelo Vergerwere very helpful.

... continued on page 12

Back Stage at the Golden Tulip: Home Business

While there was a great deal of activity and discussion at the Congress, there was also a lot going on behind the scenes at TFI's own conference, including revising our membership guidelines. To encourage membership in TFI, those joining will have associate member status for two years gratis. An application to join must be supported by a doctor who is member of a recognized thyroid organization. An application form and letter explaining the guidelines is being sent to applicants along with a warm welcome.

Newborn Screening project

Another topic in our discussions was to undertake a survey of how newborn screening is administered in the countries of our home organizations and in the countries of the major endocrine societies.

A questionnaire will be prepared and circulated. This simple heel blood test is crucial in detecting thyroid deficiency in the infant.

A Little Sightseeing

We had far too little time to visit Buenos Aires but managed to do some short tours, including a guided visit of that beautiful city as well as a tango dinner. Some of the participants had reserved a few extra days before or after the Congress to make private trips to some of Argentina's most spectacular sites: the Iguazu waterfalls, Peninsula Valdes with whales and penguins, Ushuaia, the Patagonian glaciers ... Argentina is a marvelous huge country, full of contrasting landscapes, and we really enjoyed the hospitality of the Argentinean people.



Everybody tangos.

A Chance Encounter

When we were in Buenos Aires last year at the TFI conference, Ricki Lakwijk and I happened to see the Mothers of the Plaza de Mayo making their regular Thursday walk — a practice that began to protest the military regime in Argentina 1973-83. The mothers of the missing sons and daughters started walking around Plaza de Mayo in front of the presidential palace. They did not say anything — they just walked every Thursday wearing their white scarves and holding pictures of their missing loved ones. Most are grandmothers today and some are in wheelchairs but they still come.



Mothers of the Plaza de Mayo — Thursday walk.

One mother went to fetch someone who spoke English. She came back followed by a lovely little lady wearing her white scarf. At 91 years old, her legs were not as good as they used to be but she was still walking at Plaza de Mayo every Thursday. When she found out where we came from, she remembered that a group from The Netherlands had helped so much by sending a donation in the 70's. It turned out to be the same one that Ricki had been a member of. Now some 30 years later, she could see living proof of the mothers' appreciation. A chance encounter became a very moving experience. 🌹

Bente Julie Lasserre
Denmark

Thyroid Cancer: A guide for patients and doctors

In September 2005, the “Instituto da Tiróide” of Brazil published a book entitled *Thyroid Cancer: A guide for patients and doctors* by Geraldo Medeiros, Eduardo Tomimori and Rosalinda Camargo.



Geraldo Medeiros (center), Eduardo Tomimori (left) and Rosalinda Camargo (right) launch their book.

This book, written in Portuguese, explains to the general public the thyroid function, nodules, fine needle aspiration biopsy, ultrasonography and other diagnostic tools. In other chapters, the authors comment on the pathology of differentiated thyroid cancer, types of surgery, radioactive ablation by radio iodine and other methods of controlling growth of recurrent cancer. A section of questions and answers and a glossary of terms close the volume.

This book is intended for the general public but could also be useful for general practitioners who need to brush up their knowledge about thyroid cancer. In Brazil, about 22,000 surgeries for malignant nodules are performed every year and it is estimated that more than 200,000 survivors of thyroid cancer are being followed up.

At our email address duvidas@indatir.org.br, we have received monthly about 100 requests for information about thyroid disease and many questions. The book has sold, so far, about 3,000 copies and a new edition is planned for next year. 🐾

*Geraldo Medeiros-Neto, MD
President, Instituto da Tireóide*

Thyroid Cancer: the Basics

Thyroid cancer is not a very common cancer, but for those who have nodules, it is something to be cautious of. Fortunately, it is among the few curable cancers. Thyroid cancer is a cancerous tumor found growing in the thyroid gland. It usually forms when thyroid cells experience abnormal growth and reproduce rapidly.

There are four types of thyroid cancer: papillary, follicular, medullary, and anaplastic. Papillary and follicular are the two most frequently diagnosed and successfully treated types.

The most common treatment for thyroid cancer involves surgery and radiation therapy. The surgery involves removing part or all of the thyroid gland.

Depending on what the physician recommends, surgery may be followed by radiation therapy. The procedure for radiation treatment is fairly simple. For the patient, it involves drinking or taking a capsule of radioactive iodine. The combination of

surgery and radiation together ensures that any cells that could contain cancer are cleared out of the body.

After the radiation treatment is complete, many patients are placed on thyroid hormone suppression therapy (THST). Its purpose is to replace the hormones (T3 and T4) that the thyroid gland produces.

Although thyroid cancer is curable, regular testing after treatment is required to make certain that the cancer has not returned. The advantage of this testing is that if the cancer does return, it will be caught at an early stage when it is easiest to treat.

It's a good idea to keep a personal health journal. It can be used to track doctor appointments, dates when injections or special treatments are received, dates when medication is started or stopped, dosage levels of medications, and to track any unusual health symptoms. 🐾

*Kristin Wood
Reprinted from Thyrobulletin, the newsletter of TFC.*

How many more lives will Chernobyl claim?

It is a certainty that the explosion at Chernobyl twenty years ago was the world's worst nuclear accident. What is less certain is agreement among expert scientists as to its aftermath — the number dead or who may die, the number suffering from thyroid and other cancers. The following article from New Scientist gives a sampling of opinion from both sides.

The cloud of radiation spewed out by the world's worst nuclear accident at Chernobyl 20 years ago could kill up to 60,000 people — 15 times as many as officially estimated. So say scientists who are accusing two UN organizations, the International Atomic Energy Agency (IAEA) and the World Health Organization (WHO), of downplaying the impact of the accident.

Chernobyl reactor number 4 in Ukraine was ripped apart by an explosion on 26 April 1986, and burned for 10 days. It disgorged a massive amount of radioactivity — up to 14 exabecquerels (14 × 10¹⁸ becquerels) — over Europe and the rest of the world.

“The IAEA/WHO report misrepresents reality by significantly underestimating the number of deaths”.

Last September, the IAEA and the WHO released a report which claimed to reveal “the true scale of the accident”. Its headline conclusion that radiation from the accident would kill a total of 4000 people was widely reported (*New Scientist*, 10 September 2005, p 14), but that figure is now being challenged. In a report this week for the Green group in the European Parliament, Ian Fairlie and David Sumner, two independent radiation scientists from the UK, say that the death toll from cancers caused by Chernobyl will in fact lie somewhere between 30,000 and 60,000.

They accuse the IAEA/WHO report of ignoring its own prediction of an extra 5000 cancer deaths in the less contaminated parts of Ukraine, Belarus and Russia, and of failing to take account of many thousands more deaths in other countries, where more than half of Chernobyl's fallout ended up. “It is poor scientific practice to issue figures which only reflect part of the real situation,” Fairlie says.

Zhanat Carr, a radiation scientist with the WHO in Geneva, says the 5000 deaths were omitted because the report was a “political communication tool”. “Scientifically, it may not be the best approach,” she admitted to *New Scientist*. She also

accepts that the WHO estimates did not include predicted cancers outside Ukraine, Belarus and Russia. The health impact in other countries will be “negligible”, she says, adding that there is no epidemiological research showing otherwise. The WHO “has no reasons to deliberately mislead anyone”, she insists. “WHO's position is independent, free from political issues, and based on scientific evidence of the highest quality.” The IAEA refused to comment.

Fairlie and Sumner's accusations are backed by other experts. The IAEA/WHO report “misrepresents reality by significantly underestimating the number of cancer deaths”, says Timothy Mousseau of the University of South Carolina in Columbia. A paper co-authored by Mousseau and published this week in *Trends in Ecology and Evolution* (DOI: 10.1016/j.tree.2006.01.008) points to studies suggesting that fallout from Chernobyl has already caused germline mutations in animals and plants.

Elizabeth Cardis, a radiation specialist from the WHO's International Agency for Research on Cancer in Lyon, France, says that 30,000 to 60,000 cancer deaths is “the right order of magnitude”. She is due to publish a study later this month that will estimate the number of excess cancers attributable to Chernobyl amongst 570 million Europeans. Though they will be difficult to detect, as they will only form a tiny proportion of the millions of cancer deaths from all causes, this doesn't mean that they should be ignored, Cardis says. “They are real people who suffer from the accident.” ♣

Rob Edwards

Issue 2546 of New Scientist magazine, 06 April 2006

Against advice, popular author Martin Cruz Smith visited Chernobyl some two years ago. That visit provides the background for his novel *Wolves Eat Dogs*. Although a work of fiction, the book describes with chilling detail the aftermath of the Chernobyl nuclear disaster. The description of the sarcophagus enclosing the number 4 reactor is haunting, the deserted villages ghost-like, evoking the enormity of the disaster and of the lives lost.

Moments of Memory: Dr. Bob

An address given by Ted Hawkins at the 13th International Thyroid Congress, Buenos Aires, Argentina, November 2, 2005

Ladies and Gentlemen, Friends all!

Thank you for the opportunity to share with you some moments to reflect on and celebrate the life of Dr. Robert Volpé. Dr. Volpé was a friend of ours, of patients, of the profession and of thyroid interested individuals around the world.

Dr. Volpé, Bob Volpé, also known as "Dr. Bob" was, to all those on the Canadian scene, one of the reasons that the Thyroid Foundation of Canada is celebrating 25 years of service to patients. Through his selfless support and as our Medical Adviser of many years, he fiercely safeguarded the publication of medical questions and issues relating to thyroid disorders.

Dr. Bob encouraged, guided, and promoted our efforts to develop a fund to support thyroid research. He then coordinated a dedicated group of professionals, some of whom are present today, to act as our review group for the allocation of those funds.

As a mentor, Dr. Bob nurtured, steered and listened. He spoke *to* the thyroid population as well as *for* them when the occasion required. Although the various segments of our Canadian patient population felt that they had kept Bob very busy, we have learned that he squeezed in chats and presentations to patient groups around the world. All this in addition to his contributions to the profession.

Scholars have described in detail his academic and professional accomplishments. His listed accomplishments, however, did not emphasize two major personal achievements. First, his joy, loving dedication and pride in his family and his role as husband, father and grandfather. Second, his skill



Dr. Robert Volpé

in making people laugh, whether at one of his old jokes or poking fun at himself. He had that ability to make each individual feel comfortable and important. Right now, if you take a moment, I'd bet that most of you could think of a humorous anecdote that you shared with him. Don't hold back, let the smile show and celebrate.

Most of you have had the opportunity to share in the life of Bob Volpé. To celebrate his life, we invite you to take a moment to record a memory to share with his family. This

memory booklet will be in the foyer for you to write your message. It is respectful to take a moment of silence. However, with your smiles, it will be more of a celebration to take a moment and sign the book.

In closing, a fund has been established to honour Dr. Volpé. The Robert Volpé Memorial Thyroid Research Fund has been created and will be an ongoing project of the Thyroid Foundation of Canada.

It was a pleasure and honour to know Robert Volpé. It is a pleasure and honour to share in the contributions of his life; it will be a pleasure and honour to develop this legacy in his memory.

Robert Volpé, March 6, 1926 to April 19, 2005. An Absent Friend. Thank you. 🍀

ThyroWorld

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