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Thyroid Federation International

Established in September 1995 in Toronto, Canada

Founder

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

Patrons

Patricia Bradley (USA)
Dr. Kazuo Hashimoto (Japan)
Prof/Dr med Peter Pfannenstiel (Germany)

Mentor & First President

Lawrence C Wood, MD FACP (USA)



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Medical Advisers

Dr. Elina Gasparyan (Russia)
Dr. Martin Schlumberger (France)
Professor Wilmar Wiersinga (The Netherlands)

Conference Coordinators

Beate Bartès (France) – 2007

Administrative Coordinator

Katherine Keen (Canada)

Website Coordinator

Katherine Keen

Member Organizations

Our member organizations now number 23, representing 17 countries. The names of the organizations and their current addresses are given on pages 15-16.

ThyroWorld is the official newsletter of the Thyroid Federation International.

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From the Editor's Notebook

This issue of *ThyroWorld* will see changes and choices. At the TFI conference in Naples, the membership decided to try a change in distributing the newsletter to its readers. It will now be available electronically on TFI's web site in two formats, one "to read" from your computer screen for those electronically-minded; the other "to print" for those, like myself, who prefer to have a hard copy to carry with them on their travels. Our web site will undoubtedly need to be redesigned to accommodate these changes.



JRB, Editor

So why the change? Well, the bottom line is money. It costs a tidy sum to print and mail the newsletter. The cost is not so much in the actual printing but in the mailing. Postal rates are formidable. Since we are a grassroots organization with a limited budget, we need to spend our pennies wisely. So the decision was made to try the new system for at least a year and then review the situation.

But as *ThyroWorld* is still "our face to the world", we will have a special printing of hard copies to display at our conference booth in Leipzig and to introduce TFI to new delegates. I should point out, however, that there will be no change in the work that has to be done in the editing, layout and design to prepare the disk. That happy task remains the same. We hope that you will enjoy this issue whichever reading route you choose. Your comments on the new system would be much appreciated.

As you read through this issue, you will see new names and faces. TFI is steadily growing, so much so that we have had to spill over the list of member organizations from page 16 to page 15. A very encouraging sign. 🐼

June Rose-Beaty
jrb.edit@rogers.com

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President's Message: The Best Possible Light

The objectives of the Thyroid Federation International are Information, Education and Co-operation. It is vital for thyroid patients and those affected by thyroid disorders to understand and have information about their disease. It is also essential for them to work with a health professional educated and trained in these diseases. TFI organizations therefore need to present themselves in the best possible light to health professionals all over the world.

We co-operate closely with thyroid associations such as ETA, ATA and LATS. We arrange our annual meetings to coincide with theirs, so that we can attend their sessions, give presentations to their members and spread information about what a patient organization can do for the health professional. These are expensive activities. Travel, hotels and sometimes even entrance fees take a large share of the little money that TFI has available. These activities are, however, important and necessary to spread the word, to raise knowledge and awareness and to make personal contacts.

We are also invited to present ourselves and the activities of our patient organizations in different countries. Our membership is steadily growing. Our attention is increasingly drawn to parts of the world where patient participation in health care is less common than in western countries. Countries like China, India and South Africa together have

more thyroid patients than the rest of the world. TFI is now in contact with sponsors to reach thyroid patients and their health professionals. Sometimes a simple solution such as the right kind of salt can make a world of difference and change people's lives.

To achieve this, we must all realize, not just TFI but also the medical professionals, that we depend on each other. The patient needs the doctor and the doctor certainly needs the patient. A healthy dialogue and close co-operation is more than ever needed. In these days when, unfortunately, money rules, we have to use whatever resources are freely available.

Our common goal should be the best possible treatment and care for thyroid patients throughout the world. These patients include not only adults but children and newborn babies as well.

Working together we can achieve our goals for the benefit of all who are affected by a thyroid disorder. I look forward to seeing one and all in Leipzig. 🐼

*Yvonne Andersson, President
Thyroid Federation International*



*Yvonne Andersson,
President*

A Test Kit for the Future

Easy and accurate TSH kits that can tell reliably whether an individual's TSH is over 5 could have an increasing role for thyroid patients in the future. There are, of course, tests in every laboratory now, which can tell exactly what the TSH level is. Unfortunately such tests may cost over \$200. For this reason, several companies appear to be developing do-it-yourself TSH tests, which can be set to tell whether a TSH level is above normal. If the test kit shows the TSH to be above that level, these patients should see their personal physicians for standard TSH follow-up in a medical laboratory. The exact TSH level will determine the degree of hypothyroidism and guide physicians who will be treating the hypothyroidism.

One in 4500 babies (USA) is born without a thyroid gland. The condition is not obvious at birth but the risk of not identifying the condition is so great that every newborn baby in the United States and Canada and many other developed countries is tested at birth. A newborn baby's TSH is normally higher than that of an older child or adult but still should be under $25\mu\text{U}/\text{ml}$. The TSH level drops gradually so that a normal baby will have a TSH near or below $5\mu\text{U}/\text{ml}$ within several weeks.

Thus, one of the advantages of an instant TSH test is the fact that newborn babies in developing countries could be tested at birth to detect any TSH above 25. These babies could then be referred to a nearby medical facility for confirmatory tests and

(continued on page 12)

Thyroid Cancer: A Modern Protocol

By Martin Schlumberger,
Institute Gustave Roussy,
94805, Villejuif, France.

Over the last three years, a consensus has been reached concerning the treatment and follow-up of patients with papillary and follicular thyroid carcinoma. The prognosis has improved, and persistent and recurrent disease occurs less frequently.

Follow-up of thyroid cancer patients is aimed at controlling the adequacy of thyroid hormone treatment and the early diagnosis of persistent and recurrent disease.

Long-term thyroxine treatment is given in suppressive doses only to those few patients with persistent or recurrent disease. When a cure has been assessed, serum TSH should be maintained in the normal range (around $1\mu\text{U}/\text{mL}$).

The absence of disease is first controlled by a total body scan (TBS) performed three to five days after the post-operative administration of a large activity of radioiodine. When the TBS is informative and does not show any focus of uptake outside the thyroid bed, a subsequent routine diagnostic TBS is usually not necessary.

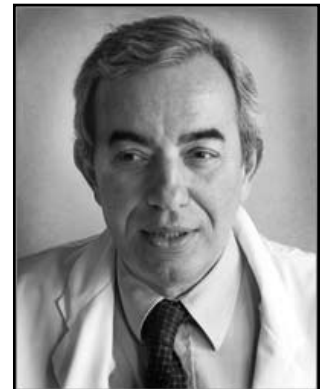
Cure is assessed at nine to twelve months with a neck ultrasonography (US) and a serum μg determination obtained three days after rhTSH stimulation (0.9 mg im, on two consecutive days). The quality of life of thyroid cancer patients is improved with the use of recombinant human TSH (rhTSH) that avoids hypothyroidism, provides an effective stimulation of any thyroid tissue and does not increase the global cost of follow-up.

Low-risk patients with a normal neck US and an undetectable rhTSH stimulated serum μg are considered cured. This reliable assessment of cure helps reassure patients, as do the subsequent use of replacement doses of thyroxine (with a TSH level within the normal range) and the simplicity of the subsequent yearly follow-up with serum TSH and μg determinations. There is a close relationship between basal and TSH-stimulated serum μg levels, and the benefits of TSH stimulation may decrease with μg methods with an improved functional sensitivity. At the present time, TSH-stimulated μg determination

should not be ignored since it provides a reliable assessment of cure and gives reassurance to patients.

When serum μg is detectable at a low level following TSH stimulation, another TSH stimulation should be performed one or two years later. The trend will indicate either irradiated thyroid cells (with decreasing μg level) or neoplastic cells (with an increasing μg level). In patients with an increasing trend, a large course of radioiodine may be administered, and a FDG PET scan may be indicated.

In conclusion, this modern protocol of follow-up uses radioiodine less frequently, is less expensive than previous protocols, is equally reliable and maintains a normal quality of life for the patient. ❁



Dr. Martin Schlumberger

Welcome Dr. Schlumberger

We are pleased to welcome Dr. Martin Schlumberger as Medical Adviser to TFI, joining Dr. Elina Gasparyan and his colleague Dr. Wilmar Wiersinga who came on board last year.

Dr. Schlumberger is a Professor of Oncology at the University of Paris XI, France, and responsible for the department of Nuclear Medicine of the Institute Gustave Roussy in Paris, one of the leading European anticancer centers. He is involved in the treatment of endocrine tumors, with thyroid cancer being his main field of interest. He has provided evidence for tailored treatment and follow-up of these patients, and has written various books and articles about thyroid tumors and the treatment of thyroid cancer. ❁

Ohne Schilddrüse Leben

“Life without a thyroid gland”

Bulletin board for thyroid patients: Germany

Ohne Schilddrüse leben? “Life without a thyroid gland?” Is this possible, what are the consequences? These are questions asked by all those who have to live without a thyroid gland as a result of thyroid cancer or another thyroid disease.

My name is Harald Rimmele. These are the questions I asked when I was diagnosed with thyroid cancer in 1997. It is a relatively rare cancer with a good chance of complete recovery. But after surgery, two radioiodine treatments and great difficulty in finding the correct hormone replacement, I felt the need to talk to others, to exchange our experiences.

To do this I created, on May 3rd, 1999, a bulletin board on the Parsimony web site, named “Ohne Schilddrüse Leben?!“ or “Life without a thyroid gland?!“. It was addressed to all those who have to live without a thyroid gland following thyroid cancer, surgery for benign nodules, autoimmune disease etc. It was the first bulletin board in the German language for thyroid patients. Since 1999, it has grown, and now has members from many parts of the world.

In 2000, I registered the short domain name www.sd-krebs.de, so that the bulletin board is now easier to find on the Internet. Also that year, I invited one of the most active members, Beate Bartès, to be co-administrator, because she was so good at gathering ideas and information. Some months later, with my technical help, she created a bulletin board in French similar to mine in German. Beate and her bulletin board became members of the Thyroid Federation International and she is now its secretary. Since then, many bulletin boards, dedicated to other thyroid problems have sprung up taking “Ohne Schilddrüse Leben?!“ as their model.

The first “real-life“ meeting was organised by some forum members in the autumn 2000 near Darmstadt, with just four patients. Since then, we organize a “big“ annual meeting each autumn. We call it “big“ because some members travel considerable distances to attend the meeting, held each year in a different part of Germany. As well, there are some regional support groups and meetings.

In June 2003, the bulletin board was totally reshaped, and now offers many more features and functions, as well as more security. Since January 2005, the bulletin board is administered by the registered association Ohne Schilddrüse Leben e.V., with a member advisory council and a board of medical advisors. The association is financed by donations, sponsoring and public allowances.

The main objectives of “Ohne Schilddrüse Leben e.V.“ are to provide information and to represent the interests of thyroid patients, mainly those concerned with thyroid cancer. The association is active all over the Federal Republic of Germany, lobbying for the reimbursement of treatments and examinations like rHTSH and PET.

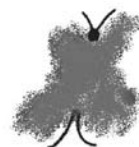
Thyroid cancer, with 3,000 to 4,000 newly diagnosed patients per year, which is less than 1% of all cancers in Germany, belongs to the rare cancers. Therefore, it is difficult for patients to find others with whom they can exchange experiences and there are very few local support groups. The bulletin board enables contacts to be made between German-speaking patients everywhere in Germany, but also in Austria, Switzerland or in other parts of the world. Some local/regional support groups have been created. There are now regular meetings of forum members in Berlin, Bremen, Hamburg, Hannover, Karlsruhe, München, Nürnberg, Wien and in the regions Rhein-Main-Gebiet and Lippstadt/Soest/Paderborn. Groups in Düsseldorf and in the region Saarland/Pfalz will soon be created.

In March 2007, the bulletin board had more than 2,000 registered members and approximately 2,000 hits and 50 messages a day. The association has 75 members and is a very active enterprise – a victim of its own success.

Our bulletin board has also joined TFI as a member. 🐼



Harald Rimmele



www.sd-krebs.de

Brazil's BIG Project

Following the success of its earlier projects in 2001, the Ministry of Health of Brazil will undertake in 2007 a large study concerning nutritional iodine intake. A total of 40,000 school children (6-14 years old) will be the cohort to be studied. All States (26 plus the District of Brasília) of the Federal Republic of Brazil will be evaluated. The number of children to be examined will be in proportion to the population of each State, according to the 2004 Census.

The variables to be considered are: (1) the urinary excretion of iodine (mcg I/Liter of urine) and (2) the iodine content of salt collected at the children's homes – salt that is actually being used for domestic purposes.

Brazil has universal iodized salt for human consumption. No salt should be for sale without the mandatory addition of potassium iodate (the proportion is 20-40mg Iodine/kg salt). Since 1995, Brazil is practically free of iodine deficiency thanks to a National Program of Salt Iodination as well as close surveillance by the National Agency of Sanitary Vigilance (ANVISA).

Thus, the critical need for iodine during pregnancy and breast feeding is being met by the universal iodination of salt.

This survey, will also analyze the possibility of too much salt intake because of elevated



Children (6-14 years old) line up for thyroid examination and urine collection. Domestic salt (actually being used) was brought to the medical team for testing the iodine content.

temperatures in the tropical areas of the North and Northeastern regions of Brazil. Excessive salt consumption may lead to an increase of iodine intake with established risks for autoimmune thyroiditis and hyperthyroidism in the elderly.

The president of the Brazilian Thyroid Institute is a member of the Committee that is organizing this survey. When it is concluded, we expect to have a complete map of iodine nutrition in Brazil, a country of huge dimensions with great diversities among its States.

Geraldo Medeiros-Neto, MD
Brazilian Thyroid Institute



Dr. Adriana Rossi with the local mayor, the school teachers and staff (Northern Brazil).



Dr. Adriana Rossi (University Sao Paulo, Instituto de Tiróide) performing thyroid echography.



The ThyroMobil is ready for echographic studies in a small village of Northern Brazil.

A Request from Iraq

In early February of this year, the Thyroid Federation of America received an e-mail from a physician assistant serving in the vicinity of the Khadamiya shrine in Baghdad, Iraq. The writer stated that he and his colleagues had noted a “significant number of children of school age suffering from goiter here in our area.” Goiter, a swollen thyroid visible as a lump in the neck, often results from iodine deficiency.

He asked to be put in contact with a non-governmental organization that is interested in eliminating iodine deficiency and that does work within Iraq. He also asked for any other information about iodine deficiency, goiter and its treatment that could be helpful.

We were very touched to be asked to support this important initiative. Iraq is, indeed, an area that suffers from iodine deficiency. The degree of that deficiency is not well known and may be much more serious than we realize.

We responded immediately, suggesting that he contact the International Council for the Control of Iodine Deficiency Disorders (ICCIDD), which works in this particular area. ICCIDD has many programs devoted to educating health professionals and public health institutions about the need for additional iodine in many countries throughout the

world. The council offers advice and helps establish programs to address iodine deficiency and to reduce its effects.

Iodine deficiency is the leading cause of preventable mental deficiency in the world today. It is remarkable that 38% of the world’s population (2.2 billion people) live in areas of iodine deficiency and risk its complications. As pointed out on the ICCIDD website at www.indorgs.virginia.edu/iccidd/, iodine deficiency “decreases child survival, causes goiters, and impairs growth and development. Iodine deficiency in pregnant women causes miscarriages, stillbirths, and other complications. Children with IDD can grow up stunted, apathetic, mentally retarded, and incapable of normal movements, speech, or hearing.”

In the next few days and weeks, TFA will be working with thyroid specialists in this area and with ICCIDD itself to reach out to these children in Iraq and help prevent the complications of their iodine deficiency. We should be able to reduce goiter and improve mental functioning throughout the country with iodine supplementation, which can be given in salt or by adding iodine to drinking water, depending on conditions in the country. 🍀

Lawrence C. Wood, M.D – TFA.

Iodine Deficiency: A Global Concern

Iodine deficiency is a major global concern and is by far the leading cause of preventable mental deficiency in the world today. Fortunately, there are many organizations that are now working in different ways to improve iodine intake and prevent the mental deficiency that results in all its forms, including cretinism. The Kiwanis International is a wonderful example of the way individuals who care about iodine deficiency can act effectively. Kiwanis members have raised millions of dollars for programs that are proving effective in many countries.

TFA is also a member of the Thyroid Federation International, and when this group of thyroid patient organizations met in Naples in August, iodine deficiency was one of our major agenda items. We hope that by each of us working in

our own countries with thyroid specialists and nutritionists, we can encourage new action by our governments and new efforts at fundraising for this international concern.

This year, TFA will ask the Gates Foundation for their support in eliminating iodine deficiency in the world. Although it is a big challenge, I personally do not think it is an impossible one and hope to join with physician groups and other organizations throughout the United States to do our part. Please let us know if you have a contact at the Gates Foundation or know of any other individuals or organizations that could help us accomplish our goal. 🍀

Lawrence C. Wood, M.D – TFA.



Iodine Deficiency: A Continuing Worldwide Health Problem

By Carolyn Becker, M.D.

Carolyn Becker, M.D., works at the Toni Stabile Osteoporosis Center within the Metabolic Bone Unit, Division of Endocrinology at Columbia University Medical Center in New York City. She is Vice President for Physicians in Practice of The Endocrine Society and also serves as Council liaison to the Clinical Affairs Committee. This was her first trip to Africa.

It was December 28, 2004, and the flight from the capital city of Addis Ababa to Lalibela in northern Ethiopia was spectacular: Overhead, bright blue skies and below, the magnificent hills and valleys of the Abyssinian Massif (the Ethiopian central plateau).

Ethiopia is a largely mountainous and landlocked country with a population of about 75 million people. It is one of the poorest countries on earth. More than 88% of the population lives in rural areas and almost 65% of its citizens live farther than a half-day's walk from a road that is passable during the rainy season. One-half of Ethiopian children under the age of 5 suffer from hunger, and malnutrition is the leading cause of death in this age group.

Outside the capital city of Addis Ababa, goiters (also called "sickness of the thick neck") are endemic in Ethiopia, illustrating the persistence of severe iodine deficiency even in 2005. The country's civil war with Eritrea in the late 1990s permanently disrupted its supply of Eritrean iodized salt and now 80% of Ethiopian households use noniodized salt from the neighboring country of Djibouti. Not surprisingly, surveys have shown a resurgence of iodine deficiency disorders (IDD) throughout Ethiopia.

Endemic goiters and cretinism are the most blatant manifestations of IDD. Much more insidious are stunted growth, mental and psychomotor retardation, significantly lower IQ, apathy, lethargy, and decreased survival among children with IDD, as well as higher rates of infertility, miscarriage, birth defects, and stillbirths in adult women with IDD. Iodine deficiency represents a major threat to the socio-economic health of developing nations and a moral challenge to us all.

Here are some sobering facts illustrating the scope of iodine deficiency as a global public health problem:

1. 2.2 billion people (38% of the world's population) live in iodine-deficient areas, mainly in Africa and East Asia.
2. 113,000 children with severe iodine deficiency (cretins) are born each day.
3. Iodine deficiency is the number one cause of preventable mental retardation and brain damage in the world today.
4. Studies have shown that iodine deficiency causes an average loss of 13.5 IQ points within a population.
5. Elimination of IDD via universal salt iodization can be accomplished at a cost of 4 U.S. cents per person per year.

... "sickness of the thick neck" ...

Iodine deficiency occurs in places like Ethiopia, where the soil has low iodine content and seafood is not readily available. The easiest way to eliminate IDD is to fortify foods such as bread, milk, water, and salt with iodine. A recent report by the U.S. Food and Nutrition Board gives recommended daily iodine intake levels (see Table 1). In the

continued on page 9

Table 1: Recommended Daily Intake of Iodine

	Iodine Intake
Ages 0–6 months	110 µg
Ages 7–12 months	130 µg
Ages 1–8 years	90 µg
Ages 9–13 years	120 µg
Ages 14 to adulthood	150 µg
Pregnant women	220 µg
Lactating women	290 µg

Source: Dietary Reference Intakes for Vitamin A, Vitamin K, Arsenic, Boron, Chromium, Copper, Iodine, Iron, Manganese, Molybdenum, Nickel, Silicon, Vanadium, and Zinc. Institute of Medicine, Food and Nutrition Board. January 9, 2001.

Iodine Deficiency (continued from page 8)

United States and Canada, each gram of iodized salt contains about 100 µg iodine, so that ingesting only 2 grams of iodized salt per day provides adequate iodine for virtually all children and non-lactating adults. In most countries, however, only 10–40 µg of iodine are added to each gram of salt, and in countries such as Ethiopia, most salt contains no iodine at all.

Iodine deficiency is not unique to poor or developing countries. Australia is a case in point. In 1992, the median urinary iodine excretion (UIE) in the Australian population was 200 µg/L. This measurement is considered the best indicator of overall iodine status in a population and levels of 150 µg/L or greater are ideal. Over the past 10 years, however, median UIE levels in both children and adults in Australia have declined by 50%. Of greatest concern are surveys showing median UIE levels well below 100 µg/L in pregnant women. Why would iodine deficiency occur in a wealthy country such as Australia?

- First, the iodine content of milk dropped dramatically after the dairy industry switched from iodine-based to chlorine-based milk sanitizers.
- Second, the consumption of table salt has declined with the public heeding calls to “limit salt and avoid high blood pressure.”
- Third, manufacturers of table salt and food additives have increasingly turned to non-iodized salt for unclear reasons. In 2002, 90% of the table salt sold in supermarkets in Australia and New Zealand was noniodized!

The right salt could go a long way

If iodine deficiency can occur in a wealthy, sophisticated country like Australia, one can imagine the challenge of permanently eliminating iodine deficiency in one of the poorest countries on earth. Nevertheless, progress is being made. In 1985, the International Council for the Control of Iodine Deficiency Disorders (ICCIDD) was created with the sole purpose of achieving optimal iodine nutrition worldwide via universal salt iodization. In 1990, the World Summit for Children pledged to eliminate iodine deficiency by the year 2000, and

since then a massive effort has taken place. Key players have included governments and private citizens, the salt industry, UNICEF, WHO, ICCIDD, and the Micronutrient Initiative, with major funding from Kiwanis International, the World Bank, and aid programs from Canada, Australia, the Netherlands, the United States, and many others. Currently, about 70% of households worldwide consume iodized salt and some countries with previously severe iodine deficiency have become success stories. But other parts of the world, particularly Central Asia and Africa, continue to lag behind and suffer the chronic consequences of IDD. As for Ethiopia, 10 new salt iodizing plants have recently been built that can iodize 25% of the country's salt. On my next trip to Ethiopia, I hope to visit them all. ♣

What You Can Do to Help:

1. Join the ICCIDD; contact iccidd@virginia.edu by email or visit the Web site at: <http://www.people.virginia.edu/~jtd/iccidd>.
2. Become informed and educated about your own country's iodine status.
3. Work with ICCIDD and other organizations to educate the public, politicians, and businesses about the importance of USI (universal salt iodization).
4. Help publicize the issue of iodine deficiency by writing scholarly articles about it in well-known journals and newspapers.
5. Include IDD in discussions about world poverty and world health.
6. Bring your ideas to The Endocrine Society's International Relations Committee to help spread the word about IDD and to achieve the goal of total elimination of IDD in the next decade.

For more information, visit <http://www.people.virginia.edu/~jtd/iccidd>, <http://www.unicefusa.org/zsite/apps/s/content.asp?c=duLRI8O0H&b=27736&ct=268897>, and <http://www.kiwanis.org/service/wsp>. You can also contact John W. Funder, M.D., Ph.D., Prince Henry's Institute of Medical Research in Australia and Chair of The Endocrine Society's International Relations Committee at susan.smith@phimr.monash.edu.au. Or contact Carolyn Becker, M.D., at cb2006@columbia.edu.

Reprinted from Endocrine News (October 2005)



TFI: 12th Annual Conference Naples, Italy 2006

Conference and Congress Highlights

Naples Italy was the splendid site of TFI's 12th annual Conference held at the Congress Centre Ateneo Federico II. Thirteen member organizations were present from ten countries taking part in TFI's own conference and in the ETA Congress as well, held at the University of Naples.

Before the Congress got underway, a press conference had been organized to publicize the event. TFI President Yvonne Andersson spoke about the role of TFI in keeping lines of communication open between physicians and patients and in sharing information with countries around the world.

Common Concerns

The TFI meeting opened with members giving short reports on their organization and on their most important activities of the past year. Many had undertaken to revise their existing literature, others reported on the tremendous number of visitors to their web sites and bulletin boards. Telephone Help Lines were busy as well: many members designated specific times when they receive calls. All groups had held various information meetings for the general public.

They all agreed that being a member of TFI was very important to them in recognizing common problems and in receiving support and information from each other. Coming together, even once a year, gave them a sense of connection as well as the incentive to carry on with their work. Another



Hard at work.

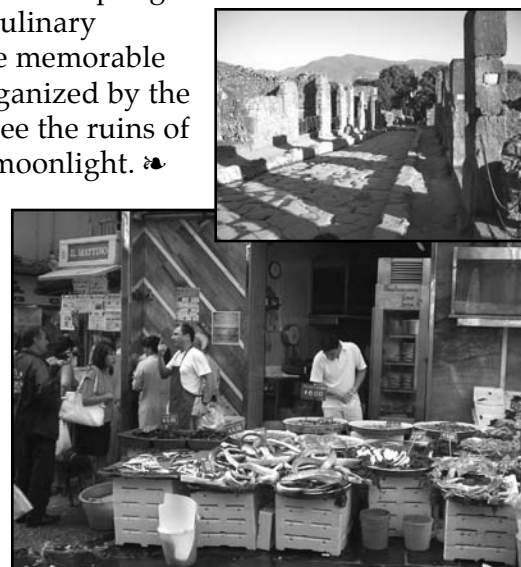
common concern was the continuing need to inform doctors of the value of TFI's work and to find ways of enlisting their support, just as we support theirs. Several members, notably Canada, Norway and UK have research fellowships and grants. These awards help greatly in creating good relations with the medical community.

One concern that all members shared was the prevalence of iodine deficiency in children, still a cause for global concern, as described in the feature article by Dr. Carolyn Becker. In Brazil, the Instituto da Tiróide is taking giant steps to identify this deficiency. A study undertaken by TFI's Dr. Ulla Slama from Finland charts those countries that use newborn blood tests to detect thyroid deficiency.

As well as serious work and discussion, there was time for a little sight-seeing, strolling along the seaside and sampling Neapolitan culinary delights. One memorable excursion organized by the ETA was to see the ruins of Pompeii by moonlight. ☾



Busy at the booth.



A Naples market.

Bienvenidos Mexico

The Mexican Thyroid Association (Asociación Mexicana de Tiroides) has recently become a member of the Thyroid Federation International. We welcome them to the thyroid family

The Mexican Thyroid Association (AMET) is a multidisciplinary medical association of interest to physicians (both clinical and those involved in research), other professionals, patients and the general public.

AMET (www.tiroides.org) provides leadership in thyroidology by innovation in clinical diagnosis, treatment, follow-up and research of thyroid diseases as well as in physician, patient and public education.

Founded in 2000, AMET is a professional society of about sixty Mexican and international physicians



and scientists with special interest in the study of thyroid disease.

Every three months AMET holds a scientific meeting where distinguished state-of-the-art lectures are given and special topics are discussed. Once in a while special meetings are organized for in-depth discussion of the literature and personal or group experiences in the diagnosis, treatment and/or follow-up of thyroid diseases in the Mexican population, such as the meeting recently held in the city of Cuernavaca, Morelos. The basics were put on the table for the actualization of the Mexican Guidelines for the Diagnosis and General Management of the Thyroid Nodule (*see picture*).



Dr. C.M. Duncker,

All of the above while trying to maintain and strengthen relationships with other Mexican and International Medical Associations in search of mutual academic benefit. ☺

*Carlos M Duncker, MD, PhD
President, Mexican Thyroid Association
carlosduncker@yahoo.com*



Norway Celebrates Thyroid Day

Oslo, May 2007

The Norwegian Thyroid Association has declared the 25th of May as National Thyroid Day. Now in its third year, the annual event has become a great success.

Thyroid Day is celebrated all over Norway with open meetings, usually with a lecture by a well known endocrinologist. There are stands with information pamphlets to be distributed to doctors, chemists, clinics, libraries, schools etc. The main theme of the day and of our work this year is "Mastering thyroid disease". Local newspapers give good coverage of the activities, and we register an increased rush of new members in areas where Thyroid Day has been celebrated and commented on in the local press.

The Norwegian Thyroid Association was founded in 1990 and as of 31st December 2006, we had 5,576 paying members out of a total population of 5,5 millions. We have a regional assembly in each of the five Norwegian health regions and fifty local clubs. We hope that the Thyroid Day will help us enlist even more members. Our goal is 6,250 members by the end of 2007. An ambitious goal but hopefully not an impossible one. ☺



*Bente Bakke
President
Norwegian Thyroid Association*

Finland: Notes on Newborn Screening

Dr. Ulla Slama of Finland undertook an ambitious task to prepare a chart of countries that do – or do not – use some form of blood screening (TSH or Core blood) in newborn babies. She was looking for the following information: In what year did each country begin to use newborn blood screening; when did each country begin to use iodized salt and what is the medium iodine level. To chart these responses, she relied largely on information from WHO, ICCIDD and UNICEF, leaders in this field. The countries surveyed were mainly in Europe, North America and Japan in Asia. The incidence of congenital hypothyroidism reported through TSH newborn screening was: Europe 1 in 3500; USA 1 in 4500 and Japan 1 in 7500.

The purpose of the screening is to detect possible thyroid deficiency in the infant and, with proper treatment, avoid the horrendous physical and mental conditions that might otherwise occur. TSH blood levels in newborns are sensitive to iodine deficiency and are thus a valuable indicator. The increase in the number of newborns with moderately

elevated TSH levels is in proportion to the degree of iodine deficiency. It may be higher than 40% in areas that are severely deficient in iodine. Sensitive tests with



ThyroWorld

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For logos, photos and other artwork, please send *originals or high-resolution electronic files*. Other copy may be sent electronically. Send all submissions to:

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WHO: Recommended Levels

90 ug	for children	(0 to 59 months)
120 ug	for children	6 to 12 years
150 ug	for adults	(above 12 years)
200 ug	for pregnant and lactating women	

TSH can indicate hypothyroidism caused by iodine deficiency. The level of TSH can be extremely high in newborn hypothyroidism due to a disorder in the development of the thyroid gland.

When iodine intake falls below recommended levels, the thyroid gland may no longer be able to produce sufficient amounts of thyroid hormone. The resulting condition of hypothyroidism causes damage to the developing brain including psychomotor defects, decrease of cognitive capacity, mental and growth retardation. The extreme form is cretinism. It also increases susceptibility to nuclear radiation.

Too much iodine (more than 300 ug a day) if taken regularly can cause hyperthyroidism or autoimmune thyroiditis.

Unfortunately, the cost of using these blood tests is too high for many developing countries. Thus congenital hypothyroidism still remains a worldwide problem.

For further information, contact Dr. Ulla Slama at: ullslama@tawi.fi



A Test Kit for the Future (continued from page 3)

necessary thyroid treatment before irreversible mental and physical damage occurs.

According to the International Council for the Control of Iodine Deficiency Disorders (ICCIDD), iodine deficiency is the most common cause of preventable mental deficiency in the world today. Thus, severe hypothyroidism may also occur in children who simply do not have enough iodine in their diets. These children are at risk for permanent brain and bodily damage. The TSH Test Kit could also detect this deficiency which could be followed up with appropriate treatment. 🍷

A Thyroid Tale of Twins

My name is Audrey from Belgium. I am the happy mother of a four-year old son Thomas, and of identical twin girls Juline and Orienne, now two years old. I first held them in my arms on July 28, 2005. Because of possible complications in a normal birth, the doctor performed a Caesarean section, fifteen days before term. All went well and I was overcome with joy at their safe arrival. Their big brother Thomas welcomed them with love. They made a happy trio.

A week after our return home, I received an alarming telephone call from the clinic advising me that there was a medical problem with Juline and that we should return to the clinic within the hour. Panic set in. Fortunately, their grandmother came with us to look after Orienne. At the clinic, they explained that the newborn blood test indicated a thyroid problem. A further battery of tests, including ultrasound and scintigraphy, confirmed that Juline had been born without a thyroid gland. Between the abrupt telephone call and this unexpected problem, I was quite overwrought. I was assured, however, that Juline could live a normal life but would have to take medication for the rest of her life.

A few days later, the twins' father and I had an appointment with the doctor who explained clearly, completely and carefully the whole situation. This discussion helped reassure us. For Juline, more blood tests followed to help determine the correct dosage of thyroid medication for this tiny baby but there didn't seem to be any improvement in her condition. She was very quiet and listless and, without the proper medication, there could be serious problems in her development. It became urgent to find the solution. The doctor advised us to give her the pill with water – not milk – and to wait an hour before the first morning feeding. And it worked! The blood tests showed change and



enabled us to find the right dosage.

Orienne also had to have blood tests as she and Juline were identical twins. The result was negative: she had a normal thyroid gland. Juline's condition was a random event and not a genetic fault.

Juline is developing normally and leads the active life of a child that age. Looking ahead to when she is older and more independent, she will be in charge of her own medication. If she should forget

to take her pill, there would be no serious consequences as long as she makes up the missed dose as soon as possible and has regular tests.

I would like to reassure other parents who are coping with the same situation as we are that, once the first shock and fear have passed, life returns to its normal rhythm.

In the beginning, I felt guilty and told myself that I had done something wrong during my pregnancy, that I wasn't a good mother. Now I have accepted that I was in no way responsible for this lack of thyroid gland. It was an oversight of nature.

Today I am indeed blessed. Orienne and Juline are two lively little girls. Thomas takes good care of them and all goes well in my little family. 🐾



A happy ending for all.

An Alarming Situation

Thyroid patients treated with radioiodine may find themselves detained if they set off radiation detectors monitored by security officials, according to a Jan. 28 news article distributed by Reuters.

Security officials use radiation detectors to scan individuals for signs of bombs at airports, seaports, border crossings, large public events, and government buildings. In addition to finding bombs, however, the sensors also respond to traces of radioactive materials remaining after certain medical tests and treatments, including radioiodine procedures for thyroid conditions. Thyroid patients can remain “hot” for as long as three months after treatment.

The Reuters article cited a British Medical Journal report of a thyroid patient who was detained for triggering an alarm at the Orlando,

Florida, airport six weeks after he’d had thyroid treatment with radioiodine. The article also noted an incident in which New York City police stopped a bus after it set off a radiation detector in a tunnel; on board was a thyroid patient who had recently had radioiodine treatment.

Thyroid specialists and other physicians who give radioactive iodine to thyroid patients for testing or treatment are increasingly aware of this problem. Many supply their patients with a note or card verifying their condition and radioiodine treatment and providing a number to call if there is a problem. If you are treated with radioisotopes, make sure you receive such a written statement, and keep it with you until your radiation level drops to undetectable levels—particularly if you plan to attend a major public event, enter a government building, or travel. 🍷

Suggested Reading

1. Your Thyroid Gland

A Guide for Thyroid Patients by Associated Endocrinologists. Privately published, 50-page paperback, 4th edition.

Written by five associated endocrinologists, this book is filled with basic information, common questions in bold type, and clinical before-and-after photographs for each thyroid malady.

2. Your Thyroid

A Home Reference by Lawrence C. Wood, M.D., David S. Cooper, M.D., and E. Chester Ridgway, M.D. Ballantine Books, 294-page paperback, 4th edition, revised in 2005.

A one-stop source for patients and others who wish to know more about the thyroid and its maladies, this book provides the latest in medical information as well as showing how individuals can deal with their difficulties

3. The Thyroid Guide

By Beth Ann Ditkoff, M.D. and Paul LoGerfo M.D. HarperCollins, 172-page paperback, 2000.

Written by two thyroid surgeons, this book gives an overview of the thyroid and its functions, how to choose a thyroid surgeon, deal with medications, and other specific problems. Responding to patients’ frequent questions, they help you to understand diagnosis, treatment, and maintenance of a healthy thyroid.

4. Overcoming Thyroid Problems

By Jeffrey R. Garber, M.D. McGrawHill, 244-page paperback, 2005.

A Harvard Medical School Guide, with expert information on key signs and symptoms of thyroid conditions, medications, and up-to-date research and developments.

5. The First Year -- Hypothyroidism

By Maureen Pratt. Marlowe, 242-page paperback, 2003.

An essential guide for the newly diagnosed, in which a patient-expert walks you through everything you need to learn and do.

6. Thyroid for Dummies

By Alan Rubin, MD

A reference guide with detailed information on new methods for detecting thyroid disease, alternative treatments, pros and cons of new drugs and advice for managing the disease.

7. The Thyroid Solution

By Ridha Arem, MD

The Ballantine Publishing Group, 1999

A mind-body program for beating depression and regaining your emotional and physical health. 🍷



ETA – 32nd Annual Meeting September 1st – 5th, 2007 Leipzig, Germany

Dear Colleagues,

On behalf of the Local Organising Committee of the 32nd Annual Meeting of the European Thyroid Association I have the great pleasure to invite you to the Association's next meeting in Leipzig from September, 1st to 5th, 2007.

The selection of Leipzig is a honour and obligation for all thyroidologists in Leipzig and Halle. For many of you this meeting will be the first opportunity to see directly the enormous changes in society, architecture, infrastructure and science which have happened after the Fall of the Wall.

However, Leipzig is also a city of rich cultural life, especially arts and literature and has a long tradition in music. We will therefore do our best to give you an impression of both, the changes and the culture that originated in Leipzig, primarily known for the work of Johann Sebastian Bach as the Cantor of the St. Thomas Church. The Welcome Reception in the new Museum of Fine Arts will give you the opportunity to see old and new paintings of the Leipzig School. The Gala Dinner in the historical restaurant Auerbach's Keller will be a possibility to get a closer look into Goethe's Faust. The Social Programme will also expose Leipzig's music and European history to you. We will create a fruitful atmosphere for the scientific programme to meet your colleagues and friends and to make new contacts. The vital attendance of young scientists will be facilitated by accommodation for 25 Euro per night.

Please visit the web site www.eta2007.de for further details of this meeting. 🍷

Ralf Paschke
Chairman Local Organising Committee

ETA 33rd Annual Congress

September 19-24, 2008
Thessaloniki, Greece

TFI Member Organizations

(continued from page 16)


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Canada Hosts Panel

On June 1 in Toronto, the Thyroid Foundation of Canada arranged a special panel for patients as part of the general meeting of the Endocrine Society and the Hormone Foundation. 

With six Canadian specialists taking part, it was a highlight of the meeting for patients to gather information and put their questions to the experts.

Each specialist gave a short presentation on their area of interest: Patient Experience, Thyroid Cancer Update, Thyroid Nodules, Thyroid Eye Disease, Hypothyroidism, and Dosing and Prescribing Challenges.

After each set of presentations, there were questions from the floor to which the doctors responded generously with their time and expertise. Well attended, it was a successful event. The doctors proved as popular as hockey stars! And in Canada, that is high praise indeed. 🍷

TFI Conference

The 13th Annual Thyroid Federation International Conference will be held in Leipzig, Germany from August 30 – September 1, 2007

Be sure to visit our booth.

For information: tfi@on.aibn.com

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