Working for the benefit of those affected by thyroid disorders throughout the world
**ThyroWorld** is the official newsletter of the Thyroid Federation International, published in Kingston, Ontario, Canada.

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DENMARK: Thyroidia Landsforeningen
GERMANY: Schilddrüsen Liga Deutschland e.V. (SLD)
ITALY: Associazione Italiana Basiodottimi e Iodoti (AIBAI)
THE NETHERLANDS: Schilddierstichting Nederland (SSN)
SWEDEN: Västsvenska Patientforeningen för Sköldkortelsjuka (VPFS)
UNITED KINGDOM: Thyroid Eye Disease Association (TED)
USA: National Graves' Disease Foundation (NGDF)
USA: Thyroid Foundation of America (TFA)

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**From the Editor's Notebook**

ThyroWorld - the first issue of our newsletter is at last in print. To see it through its production and publication has been no easy task. It's amazing, even in these days of sophisticated electronic communication, how many problems crop up and glitches creep in. Fax machines don't work properly, WP disks are not always compatible, photocopies become illegible and then there's always the factor of human error. But, of course, there's also the great bonus of human effort.

With material coming in from all over the world, many people were involved in getting this first issue off the ground. Kudos to Sally Mitchell of the UK for conceiving the idea and for assembling much of the original material which Ann Rigby-Jones processed and sent off on diskette to Canada. Sally also shepherded a first draft through discussion at the Munich meeting. And here we must thank all our contributors, especially our German colleagues for their fine contributions to this first issue. Rhoda Boyce, acting as Canadian courier and contact, arrived back from Munich with tons of material - minutes, articles, stories, press releases and pictures - all of which had to be read, sorted and decisions made. What goes in, what stays out?

The national office of the Thyroid Foundation of Canada in Kingston, Ontario became the central clearing house for this material. Katherine Keen, Administrative Co-ordinator for TFI, did sterling service in tracking it all and in doing much of the word processing, ably assisted by Shelley Cohen-Shnider in Ottawa.

Much as we would like to have a multilingual newsletter, the decision was made to publish ThyroWorld in English, an international language. Indeed, we had enough problems whipping one language into shape as well as coping with the occasional problem of translation from German.

See Editor's Notebook, Page 3
President’s Message: TFI – A Family Affair

Although the Thyroid Federation International (TFI) is young and fragmented by distance, we all share a desire to educate and support thyroid patients throughout the world. The common goal that unites us is helping those with unrecognized problems realize that they are ill and receive a medical evaluation that will lead to appropriate treatment.

In the past year, each of our member organisations has grown and developed, as witnessed by the new ideas, experiences and thoughts shared at our 1997 meeting in Munich. Certainly, our first newsletter, our new homepage on the World Wide Web and our excitement in planning for that meeting all speak well for a healthy organisation. Another sure sign of health is growth and we are pleased to welcome Denmark and Sweden, our newest members.

I want to express my appreciation and admiration to Sally Mitchell in the UK for her leadership in developing this fine newsletter for Thyroid Federation International. Thanks also to Emma Bernini in Italy for her distinctive artwork, as well as to Katherine Keen and June Rose-Beatty in Canada for their work in editing and producing the newsletter. With contributions coming in from all over the world; it has truly been an international effort.

We gratefully acknowledge the financial support of Knoll Pharma of Markham, Ontario, Canada, in sponsoring this newsletter. We are also very grateful to Merck KGaA, of Darmstadt, Germany, for their generous contribution and continuing support.

The Executive Committee joins me in sending our best wishes to all in this landmark TFI newsletter. We look forward to seeing you all again at our spring conference in Greece.

And in all, I think our friends from Denmark and Sweden summed things up best of all when they described feeling immediately at home and among friends from the moment they joined us in Munich. This clearly is the sort of organisation we all want. The spirit of cooperation and friendliness will help us grow to become a truly significant Federation helping thyroid patients throughout the world.

Lawrence C. Wood, MD, FACP
President and Medical Director
Thyroid Federation International

Start of Something Big

In recent years, thyroid disease has been poorly funded by grant-giving bodies because it is perceived as a group of conditions of low mortality, relatively easily diagnosed and treated. And yet there are so many unanswered problems, such as why these conditions develop in the first place and should it not be possible to modify their progress or prevent them altogether.

It was clear to me when I spoke at a meeting of the Thyroid Foundation of Canada in Toronto in 1995 that there is an almost insatiable appetite among patients for more information about their particular disease. This will challenge the less able and poorly communicative doctors. The marked change in doctor-patient relationships is not confined by national boundaries but is a truly international phenomenon.

There needs to be an international umbrella organisation to ensure common policies and guidelines about the diagnosis and management of thyroid disease and to influence governments about preventing diseases such as iodine-deficient goitre.

Our coming together can only benefit the quality of care for patients in the long term and provide a focus for patients with genuine concerns about their thyroid disease.

Following the Toronto meeting, such a group was born - Thyroid Federation International - of which TED is a member, thanks to the foresight of your founding President, Sally Mitchell. This Federation is truly the start of something big.

Dr Toft is President of the British Thyroid Association, Royal Infirmary, Edinburgh, Scotland. Present at the Toronto meeting, Dr. Toft well understands the need for thyroid organisations to join and work together. He is a staunch supporter of the goals of TFI.

Editor’s Notebook

cont’d from Page 2

We will start slowly with perhaps just one or two issues a year.

Our goal is to publish the second issue after the fourth annual meeting in Greece.

Finally, someone has to take the responsibility for errors of commission and omission. That person is the editor. We have done our best with this first issue. We hope you will receive it kindly.

JRB, Editor

Winter 1998
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Page 3
Thyroid Federation International

Thyroid Disease in a Global Perspective

[Participating Organizations] [Board of Directors] [Next Meeting] [Your Questions & Comments] [Other International Links]

Welcome to the Thyroid Federation International Home Page. We plan to keep you informed of the activities of our growing organisation and the development of existing and future thyroid member organisations in the world.

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For thyroid patient information and support: Contact a thyroid organisation in your region.
See Participating Organisations
Thanks to the energy and enthusiasm of Ellen Garfield (Canada), TFI is on the World Wide Web. You can find us at: http://www.thyroid-fed.org

A Backward Glance: A Forward Look

It was a warm September Sunday morning in Toronto, Canada, 1995. The 11th International Thyroid Congress was winding down as was the annual general meeting of the Thyroid Foundation of Canada. Meeting - weary as we were, there was still one more to go - an informal invitation to meet over coffee and discuss the "possibility" of some kind of international thyroid group.

So a couple of dozen people crowded into a small conference room of a downtown hotel - and that's where the Thyroid Federation International was born.

Of course, it had existed long before as a dream in the minds of Diana Abramsky, Larry Wood and others. But Toronto witnessed its actual birth.

As individuals and representatives of our respective thyroid organisations, we all had enough on our plates to keep us busy but there was something so appealing about the idea of an international thyroid group, of sharing information with other organisations, of tackling world-wide thyroid problems, of helping thyroid sufferers that we couldn't refuse. And when babies and children were mentioned - well, we were hooked!

Six thyroid organisations from five countries were represented at that 1995 inaugural meeting. Canada, USA, Italy, Germany and the UK were soon joined in 1996 by The Netherlands and Australia and in 1997 by Denmark and Sweden.

The second meeting in Amsterdam in August 1996 was well structured and successful. Mission statements and goals were drafted, committees set up and officers elected.

Now, the third annual meeting in Munich is under our belt; we are growing in confidence, in projects and in numbers, ten member organisations. And we have launched ThyroWorld, the first issue of our newsletter.

With our newsletter name and logo, it is only fitting that we are on the World Wide Web, already a source of international information and communication.

All in all, not a bad track record for a very young organisation! We intend to keep on growing in our efforts to spread information about thyroid disease and to help those who suffer from it.

JRB

Action is the difference between why and why not!!
Before the summer of 1980 information about thyroid disorders, at least as far as the Canadian lay person was concerned, was non-existent. For this newly diagnosed individual with a malfunctioning thyroid gland, it felt like a descent into a medical wasteland where fear, anger and isolation were constant companions.

Nevertheless, despite these negative emotions, the frustrating bewilderment, the failure to understand the silence and mystery that seemed to prevail about thyroid disorders, I decided to go public. People needed to know about medical problems that took six years to be diagnosed - about the “all in your head,” and “you need psychiatric evaluation” attitude that were the usual experience of patients one met at thyroid clinics.

With encouragement from Dr. Jack Wall and W W Viner QC, a public meeting was organized to discuss the merits of forming a thyroid organization whose purpose would be to learn and inform the public about the prevalence and nature of thyroid disorders. Informed patients would hopefully encourage their physicians to focus on the need to order thyroid function tests, sooner rather than later, to persuade their physicians to place thyroid gland investigation closer to the top rather than at or near the bottom of the medical investigation totem pole.

Thus, in the summer of 1980, thyroid history was made in Kingston, Ontario, Canada. For the first time anywhere in the world, a public meeting was held, a committee was formed and on July 5, 1980 - a red-letter day - the official founding of the Thyroid Foundation of Canada took place at Kingston City Hall where a plaque recording the event was unveiled in June 1996.

In chapters across Canada, dedicated members of Thyroid Foundation of Canada accepted the challenge to end the strange silence and the casual attitude that had existed for centuries vis-a-vis thyroid disorders.

News of our existence spread across Canada by letters, word of mouth and numerous cross-country media reports. We were inundated with letters from despairing patients - parents, children and, yes, even from teachers, nurses and physicians including a Health Sciences physician in Paraguay who requested our thyroid information for his medical students' educational programs. It was a veritable avalanche of requests.

From these letters it was quite obvious that my vision - my dream of a world-wide thyroid organization - was not far-fetched. The information gap was not unique to Canada. It was a universal problem. Somehow hope and help had to be brought to people everywhere who were suffering from a malfunctioning thyroid gland.

A sense of purpose and involvement is shared by members of thyroid organizations being established around the world as well as the Thyroid Foundation of Canada's educational material.

In the following pages, you will find short descriptions of ten thyroid organizations, outlining their history, aims, activities - and how they survive.

It is amazing - or perhaps not so how similar their stories are. A common thread linking them is that each association came into being from feelings of frustration and anger, loneliness and depression. No patient information or support was available for thyroid sufferers. Determined to do something about this dismal situation, each group started from the grassroots with a handful of dedicated people.

Sharing such similar personal experiences and goals, it is small wonder that, despite distance and language, they have now come together in a larger world-wide family: Thyroid Federation International.

Share our umbrella, our information and support.

Join our Family: Join TFI
AIBAT: Associazione Italiana Basedowiani E Tiroidei

The Italian Association for Basedow-Graves and Thyroid Disease, AIBAT, was founded by two Basedow-Graves patients, Emma Bernini and Donatella Aimi. We had met in the waiting room of a specialist and during a conversation discovered that we had experienced the same depression, anxiety, frustration, anger and loneliness; had felt the need of knowing more about the disease and the cure, about the medical centres and the specialists in the field. We also had in common a strong desire to help other patients and from this came the idea of founding a volunteer thyroid patient association.

AIBAT was created by a group of supporters with the help of members of the medical profession. It is dedicated to promoting public awareness and understanding of the disease; creating occasions for patients to exchange their experiences; improving communication between patients and physicians; providing the best information available on diagnosis, treatment and medical centres; raising funds for conferences, research and educational material.

AIBAT's "birth" was officially celebrated on 27 January 1996 during a conference on Basedow-Graves and thyroid disease. Distinguished specialists were asked to give their support to the newborn association by participating as speakers. At the same time came contact with Dr. Larry Wood of TFA and Ms Sally Mitchell of TED, and it was from them AIBAT learned about the creation of TFI.

AIBAT has established two helplines for patients answered by members and has asked specialists from hospitals to set up a medical helpline. AIBAT intends to extend these activities from Parma gradually to other towns in Italy.

The Association is addressing the need for more information/education and the question of better communication between patients and doctors by organising a series of informal lectures. Guest speakers will be specialists but will speak in terms that anyone can understand. Talks will be followed by a question-and-answer period. The first two conversations given in Parma and Reggio Emilia in the spring of '96 were well attended.

Butterfly, AIBAT's newsletter, is also helping increase membership and support for our cause. Future plans include creating educational material and reaching patients and the general public through the media.

We greatly appreciate meeting our sister organisations and are very happy to participate in the activities of Thyroid Federation International.

Emma Bernini
President of AIBAT

Australian Thyroid Foundation

The Australian Thyroid Foundation was started in 1995 after I found the lack of information available for me as a newly diagnosed thyroid cancer patient truly frustrating.

I contacted an acquaintance who had also been treated for thyroid cancer and suggested we try to form a support group for thyroid patients. With the help of five other caring people with thyroid disorders and Professor Steven Boyages of Westmead Hospital, we managed to create the Australian Thyroid Foundation.

The Thyroid Foundation of Canada was very supportive. The information their office sent was invaluable and we greatly appreciated their generous offer to provide us with their educational brochures.

Since gaining some media attention, we have been inundated with inquiries and the need for our Foundation is very evident. We have grown to 500 members and have just recently formed a support chapter in the state of Victoria.

We have organised two very successful seminars where endocrinologists, pharmacists and surgeons present information and answer questions. These seminars are held on our State Thyroid Day and we hope to organise seminars in other states.

The aims of our Foundation are:
- to offer support and information to patients and families
- to raise the awareness of thyroid disorders in the community
- to lobby the government for research funding

We have a wonderful committee of volunteers who all contribute to the success of the Foundation. The calls we receive from members have been extremely positive. It is very rewarding to hear that we are meeting our aim of providing support and information.

Our funding depends solely on our membership fee of $20. Members receive four newsletters, notification of seminars and access to the telephone contacts. We are in the process of becoming an incorporated body which will benefit the Foundation with tax exemption and enable us to lobby for funding from our Health Department.

We have been very appreciative of the newsletters we receive from other foundations as it gives us an opportunity to learn from each other.

We hope to be able to contribute to Thyroid Federation International but as we are still in the formative years, we have many tasks to complete here in Australia before we can make a worthwhile contribution. We look forward to a long and co-operative relationship with all foundations, in particular the Thyroid Federation International. On behalf of all thyroid patients, thank you for all you have done.

Gail Balkantyne
President

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ThyroWorld Volume 1, No. 1

Winter 1998
Thyroid Foundation of Canada
La Fondation canadienne de la Thyroïde
Support, Information and Care

In seventeen years, our organisation has grown from a handful of dedicated volunteers in Kingston, Ontario, to 4,000 members and 22 affiliate chapters across Canada. We have a series of twelve thyroid Health Guides in both English and French, written by specialists.

These Health Guides and other educational materials from the Foundation are available on our web site. Literature is distributed free to members, hospitals, drug stores, clinics and the public. Encouraging letters and e-mails reflect the value of our educational material and of our web site information.

The Foundation produces and mails to members an informative quarterly publication thyrobulletin. Our chapters regularly hold Public Education Program meetings. Guest speakers present various aspects of a malfunctioning thyroid and other health related topics. Some chapters have special support groups.

In addition to the publicised telephone, fax and e-mail numbers of the National Office in Kingston, chapters across Canada operate telephone Help Lines. Chapter volunteers and National office staff answer thousands of inquiries each year.

As a lay organisation, we avoid giving medical advice or commenting on medical treatment. The main goal is to present pertinent medically authoritative general information to the caller and to listen. We sometimes remind patients that they are entitled to a second opinion.

We have contributed close to $500,000 to Canadian thyroid research. Chapter sponsored fund-raising events, donations from members, corporations, and private individuals have allowed us to grant the Diana Melitzer Abramsky Fellowship Award annually as well as one or two summer student grants, while still retaining our research fund at just over $300,000!

I wish for a World Thyroid Foundation with chapters in every corner of the globe, where the universal problems of thyroid patients may be addressed.

Diana Abramsky, June 1988

Our main concern is that our Education and Services Fund is currently operating at a deficit. Health Canada’s Sustaining Grant of $50,000 annually has gradually been eliminated. The Foundation’s efforts must now concentrate on cost-cutting measures, finding new revenues and fund-raising to maintain administration and general operations. We remain optimistic and confident about the future of the Thyroid Foundation of Canada.

Nathalie C Gifford, CA
Charter Member and
ITFC Past President

Schildrüschen Liga Deutschland e.V.
German Thyroid League

Thyroid disorders are among the most common diseases in Germany. Nearly every second person is considered to have an enlarged thyroid gland as a result of iodine deficiency.

Many people are unaware of their disease because the symptoms are rather non-specific, if not absent, in the early stage. Others feel left alone or insufficiently informed to cope with their illness. To meet these needs, the Schildrüschen-Liga Deutschland e.V. (SLD) an independent charitable organisation for patients with thyroid disease, was founded in 1995.

The aim of the SLD is to support thyroid patients and motivate them to organise in groups with other patients for mutual exchange and help. In the long term, a network for thyroid patients and their families will be built across Germany.

The SLD promotes dialogue and exchange between patients and physicians. Both groups are represented in the scientific committee (advisory council) of the SLD. The organisation works closely together with thyroid specialists and medical societies focused on thyroid disorders. Thus current knowledge is communicated directly to the public.

The quarterly magazine ‘Blickpunkt Schildrüschen’ gives members the opportunity to report on their own experiences, ask questions and get in touch with other patients.

The SLD offers free information and brochures concerning the prevention, diagnosis and treatment of thyroid disease, passes on addresses of specialised physicians and thyroid support groups. It also produces and distributes a manual (Leitfaden zur Gründung einer Selbsthilfegruppe) on how to found and organise a support group with other patients.

Prof Dr med Peter Pfannenstiel
President
It was a very warm welcome extended by Dr. Larry Wood, President and by Dr. Peter Pfannenstiel, Vice-President to delegates at the Third Annual Conference of Thyroid Federation International. Following the first and second meetings in Toronto and Amsterdam, 1997’s was held in the beautiful Bavarian city of München.

As President of the German Thyroid League (SLD), Dr. Pfannenstiel expressed the appreciation of its members in having München as the meeting place, as well as its fortuitous conjunction with the annual meeting of the European Thyroid Association.

It was appropriate that the German Thyroid League, a self-help patient-oriented group, should organize the Saturday forum for patients and physicians which focused on presentations by thyroid patients to a large and interested audience. Patient stories of their moving personal experiences with thyroid disease are told elsewhere in this issue.

Dr. Pfannenstiel also commented on the frequency of thyroid disorders in Germany; nearly every second person suffers because of iodine deficiency.

He outlined the work of the German Thyroid League in building a network of support services for patients and their families.

Dr. Pfannenstiel expressed appreciation to the many, many people who helped organise this most successful conference. Highlights follow.

University of München

Thyroid Federation International
Third Annual Conference
München, August 28-30, 1997

Conference Highlights

The Third Annual Conference of Thyroid Federation International, an alliance of patient-oriented thyroid organisations, was a tremendous success. Held in München, Germany, representatives from ten countries attended: Australia, Bulgaria, Canada, Denmark, Germany, Italy, Japan, Sweden, UK, and the USA. Regrets were received from SSN, The Netherlands. The spirit of friendship, enthusiasm and cooperation for a common cause was extremely high.

Meet the Press

This spirit was certainly evident at a press conference in German given by Prof. Dr. med. Peter Pfannenstiel, Mainz-Kastel, President SLD and Vice-President TFI; Dr. Lawrence C. Wood, Boston, USA, President TFI and TFA; Prof. Dr. med. Roland Gärtner, München, President, 24th European Thyroid Association (ETA) Congress; and Prof. Dr. P. Scriba, Honorary President, 24th ETA Congress. A central theme was the body’s essential need for iodine, the devastating effects of its lack and the high incidence of thyroid disease in Germany.

Fourteen representatives of the German media were present and the interest in the problem of iodine deficiency was so high that the conference scheduled for thirty minutes lasted almost two hours. It was a good opportunity to describe the activities of TFI and promote the patient and physician forum held Saturday, August 30.

ThyroMobil

Dr. Ulrike Hostalek, Merck KGaA reported on Merck’s European ThyroMobil Campaign. Full coverage of the Van’s progress can be found on pages 10 - 11.

Newborn Screening

Professor Annette Güters-Kieslich, Pediatric Thyroidologist, Berlin University, presented “Newborn Screening for Congenital Hypothyroidism”. Even when newborns are screened, some children are missed due to human error in the testing process. TFI will promote, as an international project, the need for newborn thyroid screening and lifelong follow-up treatment for congenital hypothyroidism. Dr. Güters-Kieslich will advise us on this project.
A big audience for TFI's Patient-Physician Forum

Thyroid Training

Another initiative TFI will undertake is to write all deans of medical schools worldwide to ensure that students are receiving sufficient training in all aspects of thyroid disorder. Dr. Jim Stockigt, Endocrinologist, Downie Metabolic Unit, Alfred Hospital, Melbourne, Australia will chair this project.

Patient and Physician Forum

Presentation by Patients: My Experience with Thyroid Disease. These moving presentations, given in German, were followed by an audience question and answer session. Attended by approximately 175 people, the discussion was lively and many stayed after the meeting to continue talking with the doctors.

A lively question and answer session

Able Advisers

Dr. Robert Volpe, Canada, has accepted the position of TFI Medical Adviser. He will review thyroid research projects and report to TFI membership at annual meetings.

Cedric Allaby, also of Canada, has accepted the position of Legal Adviser.

TFI is delighted with both appointments.

Prof. Dr. med. Petra-Marie Schumann-Draeger, Frankfurt, Chair, Scientific Division SLD e.V., and Prof. Dr. med. Klaus Mann, Essen, Speaker, Thyroid Section of the German Endocrine Society acted as moderators.

All Work and Some Play

We had a busy agenda and were very pleased with the acceptance of our By-Laws, Mission Statement and Objectives. Donald McKelvie will now prepare a Policy and Procedures Manual and apply for Letters Patent in Canada. But not all was work; there was time for sightseeing in beautiful München, for a visit to the famous Hofbrauhaus to sample Bavarian beer and sausages, listen to Bavarian music and maybe even try a little polka dancing!
Thyromobil: On

That surely seems to be the motto of the Merck KGaA ThyroMobil as it trundles its way across Europe. On its 1994-1995 safari, it covered 30,000 km, visited twelve countries and tested over 7,000 schoolchildren. Its goal in aid of thyroid research was to obtain reliable data on the iodine supply in these countries - deficient or adequate.

Merck KGaA has developed a rapid urine test for iodine deficiency that gives results in ten minutes in the field without a lab being involved. The test results indicate a “yes” or “no” iodine deficiency but do not differentiate between mild or severe cases. It is a tremendous breakthrough in testing.

The investigation was approved by the ethical committee of the University of Brussels, the national Ministries of Health and Education and by representatives of the parents of the schoolchildren in the twelve countries.

To increase awareness of the public to iodine nutrition, the national investigators, the principal investigator of the ThyroMobil project (FD) as well as representatives of the academic bodies and of UNICEF national committees took part in a press conference in each country during the visit of the ThyroMobil van.

The study of the children and of earlier ones on adults generated tremendous press interest “and popular local support from physicians, pharmacists and health insurance groups.”

In the 1992 adult campaign: “Press conferences were held in every large city where the examination van stopped.

During the campaign, numerous articles were published in scientific journals and lay magazines.

Approximately fifty press reports were published in different journals and magazines reaching a total of 21,229,000 readers.

Magazines were selected according to certain criteria in order to reach the target groups of iodine prophylaxis, i.e., parents of young children, pregnant women and nursing mothers.

A major part of these magazines were therefore women’s magazines, magazines giving advice on how to raise children and booklets for pregnant mothers.

And what of the results? Great news. Since 1992, there has been a marked improvement in the status of iodine nutrition in many European countries. In schoolchildren in the Netherlands, Slovakia and France, results were entirely normal.
Thyromobil, seen here on an earlier tour, stops with friends in one of the 12 countries visited

Improvement is probably due to implementation of salt iodization and improved diet. But in spite of improvement, there is room for much more.

Perhaps we should view the results with cautious optimism and with the proverbial "grain of salt".

In February 1998, the ThyroMobil will take to the road again with a visit planned to countries in southeast Asia (the area of the former Indochina). We look forward to that report.

Gute Reise!

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This article has been adapted from an excellent presentation given at the München conference by Dr. Ulrike Hostalek and from the accompanying research study, published in the European Journal of Endocrinology, 136:180-187

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Iodine Study Abstract

Up to 1992, most European countries used to be moderately to severely iodine deficient. The present study aimed at evaluating possible changes in the status of iodine nutrition in twelve European countries during the past few years. Thyroid volume was measured by ultrasonography in 7,599 schoolchildren aged 7-15 years in one to fifteen sites in The Netherlands, Belgium, Luxemburg, France, Germany, Austria, Italy, Poland, the Czech and Slovak Republics, Hungary, and Romania. The concentrations of urinary iodine were measured in 5,709 of them. A mobile unit, the ThyroMobil van, equipped with a sonographic device and facilities for the collection of urine samples visited all sites in the twelve countries. All ultrasonograms and all urinary iodine assays were performed by the same investigators. The status of iodine nutrition in schoolchildren has markedly improved in many European countries and is presently normal in The Netherlands, France and Slovakie. It remains unchanged in other countries such as Belgium. There is an inverse relationship between urinary iodine and thyroid volume in schoolchildren in Europe. Goitre occurs as soon as the urinary iodine is below a critical threshold of 10 µg/dl. Its prevalence is up to 10 to 40% in some remote European areas. This work produced updated recommendations for the normal volume of the thyroid measured by ultrasonography as a function of age, sex and body surface area in iodine-replete schoolchildren in Europe. This study proposes a method for a standardized evaluation of iodine nutrition on a continental basis, which could be used in other continents.

European Journal of Endocrinology 136:180-187
Thyroid Eye Disease Association
United Kingdom

When I was finally diagnosed in 1989 as having thyroid eye disease, there was no written information available for patients in the UK in layman’s terms on treatment and care. Unheard of as far as the general public was concerned, within the medical profession it seemed to have an extremely low profile. “Nothing we can do but monitor you, you will have to learn to live with it.” In other words, what cannot be cured must be endured. This presented a big challenge to me!

My dream was to change the way of looking at thyroid eye disease and to help others affected by this distressing condition. So the TED Association was born and it now:

- provides information, care, and support to those affected by thyroid eye disease (over 500 members, information given over the past seven years to a further 1,000);
- has a network of 15 support groups and 50 telephone help lines throughout the UK;
- has promoted better awareness of the condition amongst the medical profession and general public (current mailing list of 2,000 includes hospitals, general practitioners, opticians, dentists, health information services, government agencies - eg Prime Minister, Secretary of State for Health, Social Services, Disability Living Allowance Board);

“Illness is the greatest leveller in life, you either become its slave or its master.”
Sally Mitchell, June 1997

- has set up a Medical Help Line of consultants both in the UK and overseas with awareness of the disease (42 endocrinologists, 43 ophthalmologists, 1 radiologist, 1 counsellor);
- circulates quarterly newsletters;
- raises money for research. We have been able to give financial support to important research studies at Moorfields Eye Hospital in London and are at present closely involved with research into the psychological effects of thyroid eye disease on patients.

TED is in contact with members of the medical profession and patients overseas (49 countries) offering the TED patient’s information leaflet, which is regularly updated, for translation (with a disclaimer) to all those affected by this rare and sight-threatening condition. To date consultants in four countries (Denmark, Pakistan, Turkey and Yugoslavia) have translated our leaflet for their patients.

Thyroid eye disease/thyroid disorders are world-wide problems so we all need to help each other and work closely together for the benefit of all people and nations.

We of the TED Association feel very honoured to be involved in the creation of Thyroid Federation International.

Sally Mitchell, Founder President
Ann Rigby-Jones, Vice President

Schildklierstichting Nederland SN
Thyroid Foundation of The Netherlands

The aim of the Thyroid Foundation of The Netherlands is to provide thyroid patients with support and information. The SN contacts patients by letter and telephone, publishes brochures and a quarterly periodical for members.

The many, many letters and questions we receive yearly demonstrate an urgent need for information. Patients feel that their doctors do not have time to properly explain thyroid conditions and that the information they get is too complex and fragmented.

In co-operation with a pharmaceutical company, the SN tries to alert, through mailouts, doctors who treat thyroid patients. Our leaflet is available in every hospital in The Netherlands.

When the SN does not know the answer to a question, we consult our medical advisers. The SN aims to be better known by both patients and doctors.

Why do I work for SN?

When I was diagnosed with a thyroid condition, in 1988, I went looking for information. It was then that I came into contact with SN, which had been established just a year before. Some information was available but not as much as I wanted. Motivated by my own experience, I decided to join the Committee of the SN when I was asked in 1989. A year later I was elected president.

The Committee has worked hard to profile SN, to spread information, to obtain the support of medical advisers and to arrange a training program for the volunteers who are working for SN. We all have a good feeling about SN which is, we think, quite professional. SN gives support and information to patients in many ways. We are happy to have such enthusiastic volunteers. In September we celebrated our tenth anniversary. We look forward to the next ten.

Eva de Goedere-Kroon
President
National Graves’ Disease Foundation

Started in the United States, the National Graves’ Disease Foundation (NGDF) aims to be a multidisciplinary resource to the complex problem of Graves’ disease. It is open to patients, family members, friends and health care professionals. We provide written material on a variety of Graves’ disease subjects (there are currently 43 bulletins), have 25 support groups in 18 states, and participate in research by providing subjects for researchers. We are a lay organisation with extensive medical support.

The focus of our work is social, psychological and educational support. To that end, we have responded to nearly ten thousand requests for information, and have about one thousand members.

Now coming of age in the information era, the need is clearly demonstrated by sheer numbers. Over 120,000 contacts on the Internet in less than one year. These contacts come from every state, as well as many international sources.

Patient education and knowledge are truly the keys to excellent medical care and management of Graves’ disease. We validate without victimisation. We heal ourselves best by helping others to heal.

Dr Nancy Patterson
Founder/President

The Thyroid Foundation of America, Inc.

The Thyroid Foundation of America (TFA) was created in 1985 with a grant from two individuals whose mother died of thyroid cancer.

All services are free of charge to the general public with the exception of the quarterly newsletter, The Bridge, which is provided to members as a special benefit. TFA has established three Chapters: Maryland, Massachusetts, and Tri-State (New York, New Jersey and Connecticut area), as well as a network of support groups and information volunteers throughout the country.

Goals of the Foundation
- educate and support thyroid patients;
- increase public awareness of thyroid problems;
- raise and distribute funds for research.

TFA Programs

Information services
TFA responds to inquiries from patients and families as well as from the general public, answering questions, providing written information, support and reassurance.

We answer an average of 250 letters and 1,500 telephone calls a month. We also have an Internet site from which we generate approximately 30 new members a month and provide information on articles and activities.

Collaboration with Medical Associations
TFA has gained the respect of medical professionals who treat thyroid patients. We work closely with the American Thyroid Association, The Endocrine Society and the American Association of Clinical Endocrinologists.

Patient Referral
We also refer patients seeking thyroid specialists to the physicians of these three organisations.

Media Contacts
The media have been very helpful in informing the general public about the Foundation. We have had popular articles in a number of health and seniors’ magazines.

For a long time I have wanted to be part of an organisation which would work to improve communication between thyroid patients and their physicians. From the beginning, I viewed the Thyroid Foundation of America as a potential bridge of better understanding, a concept so important to us that we chose to call our quarterly newsletter The Bridge.

The numbers of people who contact TFA for information and support appear to be increasing as public awareness of thyroid illness grows.

TFA has 4,300 members including thyroid patients and health care professionals.

Dr Nancy Patterson
Founder/President

ThyroWorld
Deadline
Copy for the next issue is due June 20, 1998
Send submissions to:
The Editor, ThyroWorld Thyroid Federation International 1040 Gardiners Road Kingston, Ontario, Canada K7P 1R7

Lawrence C Wood, MD, FACP President and Medical Director
My Personal Experience with Thyroid Disease

Ms. Dagmar Euteneuer,
Essen, Germany

In June 1986, during the removal of a cold thyroid nodule, a well-differentiated papillary thyroid carcinoma was diagnosed on the right side of my throat. A few days later, part of my thyroid gland was removed, with no further tumour findings. In July, a further tumour was discovered which, however, disappeared after RAI treatment.

Tumour follow-up examinations were carried out, first every three months, then every six months, and finally just once a year.

In May 1996 (some ten years later), a routine ultrasound examination once again indicated thyroid carcinoma, now on the left side of my throat. Needle aspiration biopsy strengthened the suspicion of malignant cells.

After radioiodine therapy, a further thyroid tumour, a cervical tumour and lymph node metastases were diagnosed in July 1996.

Another operation was performed in September. The thyroid and cervix were irradiated in October and November 1996. Since then, the follow-up examinations at three-monthly intervals have shown no abnormal findings.

I am very pleased with the medical care I received during this time. There were no complications in any of the four operations, with no impairment to my vocal cords.

The surgical wounds have all healed well. However, I am suffering from the after-effects of the irradiation. Even today I still have severe pain in my throat.

My emotional state often fell by the wayside during this time. I got little support in this respect from the doctors treating me.

Their time is scarce and they have to take care of an ever-growing number of patients. I had to learn how to assert myself, to ask questions and to think for myself.

If I got no answers to my questions or I couldn't understand the answers, I had to insist on being informed but always with a guilty conscience for taking up the doctor's precious time.

I noticed, however, that I am only taken seriously if I ask questions; then the doctors take time for me.

It's not surprising that my trust in the doctors was shaken. Then I very quickly realised how "nearly normal" I actually am.

Unfortunately, I have met many patients who didn't have the courage to ask questions and who lay in their hospital beds with many unasked questions and uncertainties after the doctor had finished his round.

My advice to any patient is to keep asking questions until he or she gets the information needed.

It is often difficult to straighten out one's thoughts after being told the diagnosis of "cancer". Personally, it has always helped me to write my questions down.

This has enabled me to come straight to the point in my next talk with the doctor and to clarify my questions one by one.

Worst of all were the visits to the specialists. The patient has to repeatedly give an account of his or her suffering and is confronted with the memories of this.

Sometimes a general physician may be consulted about some everyday illness.

Unfortunately, the doctor then often jumps to the conclusion that it has something to do with the previous cancer which completely unnerves the patient. Generally the ailment soon turns out to have nothing to do with the cancer.

A further examination by another doctor is frequently required, who again has to reassure the patient. I am glad, of course, that the doctor follows up any suspicion of a new disease because it is only for my own good, after all.

But, can't I expect a doctor to delay breaking the news to the patient until his suspicions of the disease have been confirmed?

This has often been my wish - for my own sake and for my family's sake.

I found a clear account of the course of my disease in the documentation I received from Prof. Pfannenstein, the chairman of the German Thyroid League.

There was also a detailed description of the methods used for my treatment. This has helped me a lot personally. I had always thought until then that my disease was so rare that any therapeutic approach was just experimental and not based on established knowledge.

This was simply a feeling I had got through the reactions of the doctors who had treated me and who repeatedly expressed their astonishment about this unusual course of disease.

I found myself confronted with this at nearly every visit. So it's not surprising that my trust in the doctors was shaken.

Then I very quickly realised through this documentation how "nearly normal" I actually am.

That discovery was a very reassuring feeling for me indeed.

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Patrons

TFI welcomes Sir Richard Bayliss, UK, an internationally known physician and author of "Thyroid Disease: The Facts" and Pat Bradley, USA, an outstanding woman golfer and member of the LPGA Hall of Fame as our Honorary Patrons.
Did You Know... Part 1

- that thyroid disease affects approximately 5% of the world's population and that all ages can be affected, even a fetus?
- that 1.5 billion people, in 110 countries around the world, do not have enough iodine in their diet?
- that a third of those at great risk from iodine deficiency are children?
- that to ensure normal mental and physical development, babies born without sufficient thyroid hormone need to be started on thyroxine replacement before they are 30 days old? Thyroid testing at birth is imperative. TSH is the recommended test. (Guidelines for Newborn Screening and Treatment, European Society of Pediatric Endocrinology, American Academy of Pediatrics)
- that thyroid disease may be the most common cause of correctable growth retardation in children?
- that iodine deficiency is now recognized as the most common cause of preventable brain damage and mental disability in the world today?
- that both mental and physical effects of iodine deficiency can be prevented with the simple use of iodized salt or oil?
- that a teaspoon of iodine taken over a lifetime is generally enough to ensure mental and physical health? A small amount but one critical to life.

TFI has pledged a cooperative effort to increase public awareness throughout the world about the need for every baby to have a TSH blood test at birth, the best way to diagnose congenital hypothyroidism and thereby prevent permanent brain damage by early treatment with thyroid hormone. Newborn screening is now universal in the United Kingdom, Canada and the U.S. as well as many developed countries. Unfortunately universal newborn screening is not common in most underdeveloped countries where iodine deficiency often compounds the problem, increasing the ultimate waste of life and intellectual function in these children. (L.C. Wood, The Bridge)

Special Thanks
TFI thanks Dr. Pfannenstiel and his committee for the superb arrangements of this Conference, and Dr. Larry Wood for his numerous hours and tremendous effort in organizing TFI.

Enjoying the Ambience

Luncheon break for new delegates at a local restaurant

Lobbying for Thyroid

During the Munich meeting the public was invited to have free thyroid ultrasound examinations courtesy of the Siemens Company. Some 120 people took advantage of the ultrasound testing taking place in the lobby.

Report: everyone tested had thyroid pathology!

Sincere appreciation to Siemens for providing this service. At our information booth in the lobby, 89 physicians from 23 countries requested information on TFI and patient brochures from our members.

We are steadily climbing the ladder of awareness.
A Personal Crisis

Mr. Franz Jügen Scharnickel, "Die Schildbürger" Self-Help Group, Inden-Pier, Germany

On August 20, 1995, I suffered an acute health crisis. My wife found herself compelled to call the emergency medical service for me at our home. In view of my desperate condition, the emergency doctor diagnosed an extreme psychosis and, after administering medication (a sedative), ordered my compulsory hospitalisation in a psychiatric clinic.

Here I spent the whole night without any specialist medical care or even an examination. I could not leave the clinic until the doctor who came on duty the next morning discharged me after I had signed a declaration saying that I had entrusted myself to the care of the clinic of my own free will.

In a subsequent examination at our district hospital, I was found to be in a life-threatening thyrotoxic crisis which made it absolutely necessary for me to stay in hospital. During the examinations, Graves' disease was diagnosed and the urgently required treatment was initiated immediately. After getting over the worst, I was discharged from hospital after a few weeks.

In my search for specialist help that now followed, I discovered, much to my regret, that the doctors (mostly general practitioners and internists) usually know which medication has to be given in the case of general hyper- or hypothyroidism, but unfortunately show very little expertise in other conditions. In addition, my endeavours to find any sort of organisation (thyroid specialists or self-help groups) ran aground.

During my almost endless search, I discovered a great many other people in similar situations to mine, alone and helpless, so I decided to establish such a self-help group myself. I got some extremely important and highly valuable assistance for my plan from the German nonsectarian welfare association and, in particular, from NAKOS (National Contact and Information Centre for the Promotion and Support of Self-Help Groups) in Berlin.

After gathering the first information and preparing the premises for the group meetings, I set up the first self-help group for thyroid patients and their families in the whole of the Federal Republic of Germany. It was founded on February 1, 1996 under the name of "Die Schildbürger".

Regrettably we all too often encounter a high-handed manner and ignorance among doctors and self-named experts.

For that reason, our self-help group is trying to do the best we can with the modest knowledge that we possess. We welcome any kind of support whatsoever with deep gratitude.

Salt of the Earth: Salt for Athletes

Iodine deficiency in Germany is particularly prevalent in young athletes. A well-trained athlete loses about 1.5 litres of perspiration per hour and with each litre, approximately 10 µg Jod (10 micrograms) of iodine.

So with each litre of perspiration, 15% of the average daily intake of iodine is lost. In a two-hour training session, an athlete can lose 30 µg Jod (micrograms) of iodine through perspiration. When the daily iodine intake reaches only half of the recommended amount of 200 µg (micrograms), losses of this magnitude can be serious for athletes.

A Simple Remedy

Athletes lose so much iodine through perspiration that the increased need cannot be met solely through balanced diet. Reduction in achievement can be overcome by the supplemental use of iodized salt.

Poor performance in achievement and concentration are often not the result of a flawed training program but the result of an imbalance in iodine intake. Many cases of spring lethargy and fatigue are in reality a hidden iodine deficiency. Increased need of iodine cannot, as is the case with other mineral deficiencies, be met by a balanced diet alone. Other than seafoods and mineral waters containing iodine, there are no natural food sources containing iodine in large amounts.

Dr. J. M. Peil, chief of staff of the Sports Clinic in Bad Nauheim, is physician to many athletes in various Olympic events. He pointed out in meetings of sports experts that more and more often, there is increased use of synthetic preparations within a basic sports diet. Unfortunately, simple but effective means to help performance at a high level, such as the use of iodized salt and foods prepared with iodized salt do not receive the attention they deserve. Simple means are indeed often the most effective. A final caution: athletes who do not replenish iodine losses can expect drastic reduction in achievement.

Translated and adapted from a German sports magazine.

1998 Thyroid Federation International Conference

Our 1998 Conference will be held in Piria, Greece, in late May tentatively May 26-27. TFI has been invited to participate in an International Symposium on "Advances in Thyroid Eye Disease" taking place May 28-29, Piria. On May 30, we will travel to Athens to present a forum for patients similar to the one so successfully held in Münich. We will again have an information booth at the ETA Congress opening May 30 in Athens.
Notes from Newcomers

Denmark

When I was diagnosed with thyroid disease, I was unable to find patient information in Denmark. This was the motivating factor in my decision to start a Danish thyroid group. The Danish Thyroid Association (DTA) was founded in Rigshospitalet, January 23, 1997 with the full support of the Department of Endocrinology, Medicinsk Endocrinologisk, and the highly obliging and helpful physicians at the hospital.

DTA now has 200 members. We have only one small leaflet which we print and mail to hospitals all over the country. Two hours a day, I run a Help Line. Deputy Chair, Lis Larsen, sends out leaflets on thyroid disorders and DTA to new members.

In the autumn we held home meetings and also meetings in other centres in Denmark with specialists lecturing. In conjunction with one of these lectures, we hope to found a subdivision of DTA in Fjenden. Currently we are trying to attract media attention but without much success to date. Hampered by lack of sponsor support, we must work hard to raise funds.

Our first newsletter, published October 1, included a page of medical information. Unfortunately, there is a lack of written information in Danish on thyroid disorders so we have made good use of material from the Canadian and American foundations. We need more information on the structure and work of other thyroid associations as well as funds for material and a small office.

Janette Schonrock, Past Chair
Thyreoida Landsforeningen
Danish Thyroid Association (DTA)

Physician of the Year

Dr. Peter Pfannenstiel, internationally known thyroid expert, has been named “Physician of the Year” 1997. Dr. Pfannenstiel was chosen as the recipient of this award by committees of fellow physicians under the auspices of the PMI Publishing Company, Frankfurt and by Hoffman and Hoffman Ltd., as announced in Frankfurt on April 30.

With some 650 scientific papers to his credit and 700 speeches given in Germany and abroad, Dr. Pfannenstiel has made a significant contribution to the prevention, diagnosis and therapy of thyroid disease. His publications *Thyroid Disease: Diagnosis and Treatment and Nothing Good Within the Shield* have been published in several editions for doctors and patients. Now regarded as standard works, over 500,000 copies have been published.

Dr. Pfannenstiel attended university in Marburg as well as in Heidelberg, Innsbruck and Freiburg where he received his doctorate following a two-year research grant in the United States. The establishment of RAI therapy for thyroid disease is considered his most important contribution to medical progress in Germany. In 1969, as internist and nuclear physician, he was asked to establish the thyroid department of the German Diagnostic Clinic (DKD). In 1989, after twenty years there, he established his private thyroid practice in Mainz-Castel.

A handsome monetary award was presented along with a medal and citation. Dr. Pfannenstiel is generously donating the award to the German Thyroid League, which he was instrumental in founding in 1995. It will be used to continue the work of self-help groups for thyroid patients.

Prof Dr med Peter Pfannenstiel

From everyone at TFI, our warm congratulations to our distinguished Vice-President, Dr. Peter Pfannenstiel.

Translated and adapted from
QualiMed 5 (1997)
Sweden

There are three thyroid groups in Sweden with about a hundred members in each (Gothenberg, Stockholm, Northern Sweden). The Gothenberg group (Western Sweden) was founded in 1994-1995. All three are working towards the common goal of providing patient information. For example, the Swedish Thyroid Association has published a book for family physicians on thyroid disease. The three associations may combine their efforts and organise in the near future.

In my own case, I was diagnosed only after I had asked my doctor to test for thyroid disease. I noticed that I was experiencing the same symptoms as my dog who had thyroid disease!

In Sweden, about 10% of women have thyroid disorders and 12% of these have a goitre. Iodized salt has been used in Sweden since 1936 so there is no lack of iodine. Surgery is the treatment of choice for patients under 35 with Graves' disease. For those over 35, RAI is used.

Thank you all for making me and Kerstin feel welcome and like part of a family. We are very enthusiastic about joining TFI.

Yvonne Andersson, Chair (President),
Kerstin Crafoord, Treasurer
Västavenska Patientforeningen för Skoltorkortjska (VPFS)
Thyroid Patient Association of Western Sweden

Japan

There is no thyroid foundation in Japan as yet for patients but Dr. Akasu has personally started providing thyroid patients with information in two ways.

First, he has written a thyroid book for lay persons in the style of Your Thyroid by Drs. Wood, Cooper and Ridgway.

The Japanese title is Kojosei no Byo (Diseases of the Thyroid). It was recently published by the Japanese publisher, Kodansha Co.

Second, Dr. Akasu was fortunate in connecting with Dr. Naonari Hata, a thyroid specialist in Osaka, who has set up a home page on the internet where Japanese patients are now able to get thyroid information:

http://www.osh.three.webnet.or.jp/~whata..

There is a bulletin board on the home page where both Drs. Hata and Akasu answer patients’ questions.

Dr. Hata has already answered more than 300 questions from patients and Dr. Akasu became involved soon after his book was published.

He noted that communicating with patients on the internet saves both time and money.

Japan has no iodine deficiency problem. Although salt is not iodized, Japanese people eat a lot of kelp and also use seasoning made from kelp.

More than 90% of iodine in the world is produced in Japan as a by-product of natural gas.

Kelp is much more expensive than iodine tablets which, unfortunately, are available only in 50 mcg units making it difficult for the physician to fine tune the correct dosage.

Dr. Fumito Akasu, Endocrinologist
Japanese Red Cross Medical Centre,
Tokyo, Japan

Bulgaria

Half the regions of Bulgaria are iodine deficient. As a result, many children suffer from related thyroid problems. In Sofia, 9% of the school children have a goitre.

After the Chernobyl nuclear accident, the number of children with nodular goitre and autoimmune thyroid disease (Hashimoto's and Graves') greatly increased.

The only pediatric clinic of endocrinology to serve a population of 1.5 million children in Bulgaria is in the University Pediatric Hospital. The hospital has 420 beds and a staff of 660.

On average, 400 children visit the outpatient department daily and of these, one out of every five or six have

See Bulgaria, Page 19
Success! We’ve met our goal!

Fundraising Chair Report

Our 1997 fundraising committee, John Borthwick (T.D.), Hans-Joachim Cramer (S.L.D), Don McKeVie (TFC), Dr. Larry C. Wood and myself, has raised enough money to survive another year and hold our 3rd Annual Conference Sept. 28-30 in beautiful Munich, Germany. My appreciation to the committee for a job well done!

I am pleased to inform you of the continued generosity of Merck KGaA, Darmstadt, Germany.

Our major donor in the past, they have pledged 10,000 DM this year to Thyroid Federation International. Our sincere thanks to Merck KGaA for their continued support in helping us build a strong Federation.

This spring, Don McKeVie, Past President of TFC and I met with Douglas Ross, Knoll Pharma Inc., Markham, Ontario, Canada. Realizing the importance of our work to thyroid patients, Mr. Ross arranged for the presentation of a cheque for $15,000 to TFI at the June AGM of TFC.

Part of this generous donation will be used to finance the publication of our newsletter, ThyroWorld. We are very proud to have Knoll Pharma Inc. as its sponsor.

On behalf of all member organizations of TFI, I would like to express sincere appreciation to both Merck KGaA, and Knoll Pharma Inc. for helping us carry out our objective of increasing awareness of thyroid disease throughout the world.

Remember, money is not given unless it is asked for!

If we are to achieve this objective, Thyroid Federation International must now move on and create a permanent funding strategy with specific goals. In Canada, and in other countries, government support to charities has been drastically reduced and competition for funding is tremendous. For example, in Canada alone, there are over 75,000 registered charitable organizations all vying for part of the eight billion dollars donated annually by corporations and individuals. Serious thought should be given to ‘planned’ giving which is becoming more and more popular, advantageous for the donor and for TFI.

An interesting note is that women are becoming an increasingly important donor group.

Working together as a team, we can all make a tremendous difference for thyroid patients worldwide.

Joe Boyce
Director of Fundraising
Thyroid Federation International

Newcomers
Bulgaria, cont’d from Page 17
thyr0 pathology. The doctors are all extremely busy; having enough time for all the patients is always a problem.

The children are treated according to current knowledge of the problem but many parents cannot afford to continue treatment as medication can cost half a month’s salary.

There is no thyroid group for patients at present but we are very interested in receiving information which can be translated for patients.

We are grateful to TFI for permission to copy and translate its material.

Dr. Alexander Kutev, Endocrinologist
University Pediatric Hospital, Sofia

Thanks to TFI

Sincere appreciation also to the Thyroid Foundation of Canada for their generous assistance by providing rent-free office space, to Katherine Keen, Administrative Co-ordinator for her able assistance, and to all who have volunteered to help Thyroid Federation International get established.

Joumana Soussou, a Thyroid Foundation of America volunteer, is returning to Lebanon soon and plans to establish a thyroid foundation for patients with the help of local physicians and government. Joumana hopes to join us in Athens next year.

TFI Objectives

- To encourage and assist the formation of patient-oriented thyroid organizations.
- To work closely with the medical profession to promote awareness and understanding of thyroid disorders and their complications.
- To provide, through member organizations, information and moral support to those affected by thyroid disorders.
- To educate and research related to thyroid disorders.

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