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Message from the Editors

Once again, it’s conference time – and once again, we are very happy to offer ThyroWorld, the annual newsletter of Thyroid Federation International, umbrella organization of more than 20 patient and patient-oriented organizations from all over the world, to the attendees! This 13th edition presents articles from many countries: Australia, Brazil, Denmark, Finland, France, Italy, Netherlands, Sweden, USA … many thanks to all contributors! And we are very grateful to the former editor June Rose Beaty, who made ThyroWorld “what it is”, and from whom we learnt a lot. I was very happy to meet her on the occasion of the 30th anniversary of the Canadian Thyroid Foundation in Ottawa, 3 months ago, and to talk about good old times, but also about future projects and ideas!

Beate Bartès, co-editor

It is a pleasure to present our ThyroWorld newsletter again. On behalf of TFI we want to express our thankfulness to Mrs. June Rose Beaty, who for more than a decade edited the ThyroWorld alone, spending many hours of work! Now we are two co-editors and as newcomers, we have a lot to learn. I met June the first time at the ITC conference in Kyoto 10 years ago, and I was struck by her beautiful expression of language.

Once again, it is the year of the worldwide thyroid conference. As representatives of patient organizations, we are very pleased to see how the contacts between patients organizations and medical expertise are progressing. Today’s patients have more access to knowledge than ever, but serious misunderstandings can appear without personal contact between patient and doctor. And patients of any educational level generally appreciate information. The professor of tropical medicine, Sven Britton from Stockholm, said to me as we came to work in Africa, “And don’t forget, they cannot read nor write, but they are not any more stupid than you and me.” In our modern times, the decision about the treatment of (continued on page 7)
President’s Message

Dear readers,

TFI has come far since the start in 1995. 15 years of cooperation between patient organizations, on nearly all continents, has brought high quality information to millions of patients. Of course, the use of the internet has been part of this success.

In cooperation with medical professionals many milestones were noted. Some of them were:

- In 1996, TFI decided to have the Annual Meeting in accordance with the Annual Meeting of the ETA and the ITC.
- In 1998, TFI had the first booth at the ETA Conference in Athens, Greece, where our members displayed their information to the attendees. TFI also provided information on how to start a patient organization to doctors from many different countries.
- In 2000, the members of TFI were allowed in the Conference area of the ITC in Japan.
- In 2002, for the first time I was invited by the Organizing Committee of the ETA conference in Gothenburg to address the attendees.
- In 2003, Dr. Anthony Toft, president of the Organizing Committee, made me his guest of honour as I was invited to sit his table at the gala-dinner in Edinburgh.
- In 2005, the first patient meeting was organized in Buenos Aires with the support of Dr. Hugo Niepomniszcze.

The cooperation with the ETA made the World Thyroid Day on the 25th of May, initiated in 2007, possible. It has attracted the attention of medical professionals, politicians and the World Health Organization.

The first International Thyroid Awareness Week in 2009 was a huge success. It made many patients aware of their thyroid and the consequences of thyroid disorders. In 2010 the topic for the International Thyroid Awareness Week was thyroid and pregnancy. The influence, even slightly, of thyroid disorders on men and for pregnant women was news for many journalists and newspaper readers. Many people contacted their patient organization to request further information.

Becoming a grandmother again, it also made me realize how much thyroid disorders influence family life for thyroid patients and their children.

Building up mutual trust and respect takes a lot of time and energy but it is so worthwhile for all parties. I am very proud of the achievements TFI has made and the recognition we have received from the organizations of medical professionals, but things can even become better. I am really looking forward to a future of continuous cooperation for the health of all thyroid patients.

Hope to see you all in Paris. ♡

Yvonne Andersson
President of Thyroid Federation International

News from Professor Ernst Nyström

Professor Ernst Nyström from Sahlgrenska University Hospital in Gothenburg, Sweden is one of my best friends and was the one who got me interested in working for thyroid patient organizations. We have worked together to spread information and support patients.

On December 7th, 2009 Prof. Nyström was struck by severe brain bleeding. It was a great shock to his family as well as his colleagues and friends. Ernst went through two periods of intensive care. His right side was totally paralysed and he was not able to speak.

After half a year, he has made significant progress through rehabilitation. He can walk with support for a couple of minutes and his speaking is improving. When we visited (continued on page 4)
Dear colleagues, patients and friends,

It is a great pleasure to welcome you to the 14th International Thyroid Congress in Paris! This conference has a long history.

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

Despite the variation in their names and locations, the most important component of these meetings has remained unchanged. They are truly international, not only by their name, but by their spirit. When the first “Goiter conference” was held in Bern in 1927, most of the current organizing societies for the 14th ITC did not exist: the Asia and Oceania Thyroid Association (AOTA), the European Thyroid Association (ETA) and the Latin American Thyroid Society (LATS), whereas the American Thyroid Association (ATA), founded in 1923, was known by a different name, “American Association for the Study of Goiter”. However, the international spirit was present at all those meetings.

We are very pleased to welcome you to the 14th ITC at the Palais des Congrès, organized under the auspices of the National Federation of Comprehensive Cancer Centers and the co-organization of the ETA, AOTA, ATA and LATS, which will be truly international in scope and participation. We hope you will enjoy interacting with and learning from colleagues from all over the world. Visit the Thyroid Federation International booth where you can discuss with the representatives of patient organizations ways to increase and improve cooperation and interaction between patient groups and the medical profession, for the benefit of both patients and doctors.

Enjoy the conference and your stay in the “City of Lights”!

Martin Schlumberger
President of the Local Organising Committee
Medical Advisor of TFI

TFI 17th Annual Meeting
September 8-9, 2011
Krakow, Poland
Thyroid Foundation of Canada held its 30th anniversary in its capital city of Ottawa. The festivities were spread over 3 days from June 4th to 6th, 2010. TFC members and executives were represented from Atlantic Canada to Victoria, BC on the pacific coast of Canada. France and Australia were also represented at this landmark occasion in the history of TFC. This was a proud moment for TFC and its members; an organization that was first formed in Canada and spread its message and vision around the globe.

The goal of this landmark celebration was to ensure that TFC is a revitalized and up to date organization that brings current developments and updates to the their members who can leverage the latest developments in thyroid research and bring their life back to normal. A landmark celebration of this kind takes a year of work – dedication from its core team and members to ensure a smooth execution. When an organization commits itself to such a celebration, it rallies its members that lead to many of the objectives and plans being implemented by its team across Canada.

Day one started with a reception that was attended by many past executives and members who have played an important role in TFC for up to 30 years. The years have not dampened the spirits but only reinforced a strong commitment to the continued growth of the organization. Many of the committed Endocrinologists who care for thyroid disease and who were also chosen as speakers for the 30th anniversary, graced the occasion. Two TFC members who are very talented in their field — Tracy K. from Thunder Bay, Ontario, Canada and Donna Lynn Larson from Vancouver, BC, Canada — kept the audience glued to their chairs during an entertaining and educational evening with their blues and one act play respectively.

To mark this historic occasion one full day was dedicated to continuing education on the thyroid issues with a mosaic of patients facing different issues. The following topics were presented to the patients and physicians who attended the program:

1. Unresolved Issues in the Management of Hypothyroidism: Dr. Gerald JM Tevaarwerk, Victoria, BC Canada
2. Hyperthyroidism: Dr. Hortensia Mircescu, University of Montreal, QC Canada
3. Thyroid Eye Disease, Speaker: Dr. Jack Wall, Sydney, Australia
4. Thyroid Cancer: Dr. Hortensia Mircescu, University of Montreal, QC Canada
5. Thyroid Surgery: Dr. Richard Payne, McGill University, Montreal, QC Canada
6. Pediatric Aspects of Thyroid Disease: Dr. Guy Van Vliet, University of Montreal, QC Canada
7. Thyroid Disease and Pregnancy: Dr. Wendy Rosenthal, Toronto, ON Canada
8. Thyroid and Heredity: Dr. Hortensia Mircescu, University of Montreal, QC Canada

Dr. Hortensia Mircescu was awarded a plaque for her efforts in revitalizing, twelve Thyroid Guides in english and french and Dr. Rosenthal, Dr. Payne, Dr. Guy Van Vliet and Dr. Gerald JM Tevaarwerk were recognized for their commitment and dedication to TFC and its patients needs.

The education day was supported by a number of displays by Chapters, Industry and TFC volunteers. The occasion was marked by TFC 30th Anniversary memorabilia, such as key chains, fridge magnets and T-Shirts. It was great to see some young volunteers with thyroid issues giving sincere helping hands to the efforts of TFC.

The education day was followed by a tribute evening to salute the volunteer efforts of different chapters and individuals who made a significant contribution to the TFC. Some of the chapters recognized in its tribute were Kingston, London, Kitchener-Waterloo, Gander, Toronto and Ottawa. Dr. Jack Wall who came from all the way from Sydney, Australia, was recognized with the ‘Star of TFC’ a special award to recognize his efforts to TFC spanning three decades. Mabel Miller, for her dedicated service to Gander Chapter and TFC National for 15 years; Dagmar VanBeselaere, for her dedicated service to Ottawa Chapter and her contribution to 30th Anniversary celebration; Cathy Fey, voluntary services for the 30th Anniversary; Phillip Morrissey, for excellent legal guidance and support to TFC; Barbara Cobbe, for her dedicated services to the London Chapter and TFC National; Marjorie Miniely, for her decades of dedicated service to TFC; Ashok Bhaseen, for his leadership to TFC during tough times and

(continued on page 6)
**TFC 30th Anniversary (continued from page 5)**

Keith Barklem, the TFC Treasurer, who played an important role in getting all the financial history of TFC together since 2004.

Beate Bartès from France represented the TFI and read a message from the TFI president Yvonne Andersson. She also commenced the session on Thyroid Cancer that was dedicated to her efforts on the subject. She shared her efforts being undertaken in France and also updated the audience on TFI efforts.

The third and final day was dedicated to a keynote speech by Dr. Jack Wall who inspired the members to continue to keep up their efforts. An organization like this plays an important role in generating awareness, helps patients and invests in key research that can benefit patients. This was followed up by a presentation by Ashok Bhaseen, President of TFC, where he shared the vision, mission and objectives of TFC and a strategic plan. The key objectives do not change but remain focused on generating funds for research in Thyroid Disease, Thyroid Awareness and providing all necessary tools to patients suffering from Thyroid issues. There was a renewed pledge from the members to make things happen, as TFC has come a long way and needs to continue to revitalize it to be a viable organization that can make a difference to the patients. Both Joan DeVille (Kitchener-Waterloo) and Mary Salsbury (Kingston) provided an insight into their efforts and shared it with the members during the AGM. Cassandra (Kitchener-Waterloo) also played an old CD of a past TFC meeting that brought back memories to some TFC members.

During the AGM a new team was elected to replace the ones retiring and now the board has following members: Ashok Bhaseen, President; Mabel Miller, Vice President; Donna Miniely, Secretary; Dagmar VanBeselaere, Director; Sandy Hudgin, Director; John Hannigan, Director and Catherine Fey, Treasurer.

The 30th Anniversary truly helped in renewal of faith and dedication in the organization both from the patients and the physicians side. There is a firm commitment to generate funds to some very needed projects in thyroid disease.

Ashok Bhaseen, President TFC

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**Story of Alex, a refugee**

The number of forcibly displaced refugees in 2009 was 43.3 million according to the report of UNHCR, the United Nations Refugee Agency, the highest level since the mid-1990s. Some of them have goiter. The iodine situation can change. Living as a refugee causes physical and psychological stress. The availability of thyroid and other medication is often decreased among these people.

My friend, Alex, who belongs to a small ethnic population, has had bad luck. He was seriously ill and lost his medication when the police took him to prison from the hospital. He was deported back to his original country.

After I was called to visit him in jail, the Red Cross provided him with the necessary medication. I followed his trace back to his home country where he was taken to prison because of “medicine.

Why is he in prison? He has not done anything evil. (an African asked)

(continued on page 8)
Our association strives to provide support to patients, to listen to their problems, to promote meetings for them to share their experiences and to learn more about thyroid pathologies from specialists, to give up-to-date information and raise awareness.

‘But,’ asked Emma Bernini, AIBAT’s President ‘why don’t we also create new events for socialization and enjoyment? The quality of life of patients can be improved by correct information, the right therapies, but also good feelings and pleasure like art and beauty can give’.

This idea inspired Emma and is behind AIBAT’s project Art and Thyroid. It was thus decided that our annual meetings in Parma and Reggio Emilia should include, in addition to the conference with talks by thyroid specialists, a guided visit to a Museum or to an Art exhibition, and possibly even some short musical intermissions between the talks at the conference.

This project was first realized in Parma in 2007 at a meeting dedicated to patients who told the audience the story of their disease from their perspective (we gave it the same title as a section in our newsletter Butterfly, ‘Il paziente racconta’, the patient tells his story). Explanations and comments by their endocrinologists followed it. After the conference, Emma guided a visit to the exhibition of a well known painter, Amedeo Bocchi, and to see the ‘Sala del Consiglio’, the Council room of a local bank the painter had decorated in 1915 with frescoes and furniture designed by him. The day after, Emma guided a visit to the Gallery of Modern Art in Milan to see the works of artists who were Bocchi’s contemporaries. It was a success with patients and doctors alike.

In June 2008, the meeting in Reggio Emilia was organized as a sort of festival: the day after the conference, while the parents were waiting for their turn to a free thyroid ultrasound, performed by Dr. R. Valcavi, coordinator of our scientific committee, and assistants, their children were busy playing and learning at the Ateliers ‘Raggio di Luce’ (learning about and playing with light and images), ‘MaMiMo’ (staging short fairy tales), ‘Icarus Ensemble’ (experimenting with musical instruments). This was made possible by the inestimable support and collaboration of the town administration, the Hospital S. Maria Nuova and local cultural organizations well known also outside Italy.

In September 2008, the meeting in Parma was entitled ‘Environment, Thyroid and the Skies of Correggio’. This time, we invited a group of young musicians, by the suggestive name of ‘Silentia Lunae’, who specialize in Renaissance music, to play between the talks given by endocrinologists and a doctor who does research on toxic substances at a well known research Institute in Milan. To the first 50 people attending the conference free tickets were offered to visit the great Correggio exhibition at Parma’s National Gallery, the cathedral cupola and the S. Paolo convent decorated by this famous Renaissance painter. Emma and Paola Lavagetto, both art historians, guided the visit. A thyroid ultrasound (continued on page 8)
performed by Dr. G. Robuschi, of our scientific committee, and assistants was free for all.

In September 2009, AIBAT with the S. Maria Nuova Hospital organized the meeting Woman

and Thyroid – Prevention and Art in Reggio Emilia. Free thyroid ultrasound and, for the first time, free TSH tests were offered to the public. Again, Emma and Paola guided the visit to the exhibition in Ferrara of the works of G. Boldini, a painter famous for his elegant portraits of women.

Many volunteers, members of our associations, doctors and medical personnel, town administrations and others have made possible the realization of this project. But most of all we must be grateful to our President, Emma Bernini, for her vision of what AIBAT could do for patients, for her creativity and her commitment of time and effort to the success of AIBAT’s projects.

Giovanna Liborio
AIBAT

Story of Alex, a refugee
(continued from page 6)

smuggling’. After some telephone calls with authorities, he was finally released, but without his thyroxine, pain killers and other necessary medicines, including medicine for tuberculosis.

Without his thyroxine he went into a deep depression, his personality as a poet and singer also contributed to the severity of his mental suffering. Finally, through international connections, he avoided being taken to a mental hospital for chronic patients. He has now received the medicines needed and has recovered to his earlier positive mind. Without follow-up Alex would probably not be alive today. He gets his daily thyroxine and is capable to perform a little work, though the problems because of wrong ethnicity continue.

Ulla Slama

Message from the Editors
(continued from page 2)

a patient’s disease can be taken after discussion between doctor and patient. An example of an agreement, focussed on the improvement of patient care, is the recent Amsterdam Declaration for early diagnosis and treatment of Thyroid Eye Disease, initiated by professor Wilmar Wiersinga and professor Petros Perros. Representatives from both doctor and patient organizations were invited to sign the declaration during the 10th International Symposium on Graves Orbitopathy in Amsterdam, in October 2009.

We hope that the ThyroWorld newsletter can also be a medium for patients and doctors.

Ulla Slama, Co-editor
GERALDO MEDEIROS (INSTITUTO DA TIROIDE)

During Thyroid Week the president of the “Instituto da Tiróide”, Dr. Geraldo Medeiros – a non-profit patients and doctors association – was invited to participate in a very well-known talk-show of the Brazilian TV (Globo Channel). Prof. Geraldo Medeiros was interviewed by Mr. Jo Soares, a well known journalist and writer, on two main subjects: Thyroid Diseases during Pregnancy and the Neonatal Screening Program for Congenital Hypothyroidism.

Dr. Medeiros started mentioning the need for all women in child-bearing age to know a few important facts about iodine nutrition and the thyroid gland. Indeed he stressed the fact that pregnant women should be advised to ingest at least 250 µg of iodine per day. As all salt for human nutrition in Brazil is iodinated, the use of iodinated salt would be enough to provide the iodine for both the mother and child. However, if salt restriction is advisable for medical reasons, a multi-mineral pill should be given on a daily basis to provide, at least, 150 µg of iodine per day.

Pregnant women that have a strong history of familial thyroid disease, have had a diagnostic of Autoimmune thyroid disease, goiter or any other thyroid condition should be tested for thyroid function (TSH, Free T4). If found to be hypothyroid, L-Thyroxine should be instituted because mothers do transfer L-T4 (via placenta) to the fetus. It was documented that mothers with non-treated hypothyroidism may cause some impairment of the fetal brain, due to the lack of maternal L-T4 transfer to the child in gestation.

Dr. Medeiros also pointed out the importance of the Neonatal Screening Program for detection of Congenital Hypothyroidism that is performed in most (81%) of all neonates in Brazil (3 million neonates born alive per year). He insisted that it is imperative that this figure of 81% should be, at least, close to 95%. The main reason for Neonatal Screening is to prevent mental retardation due to non-treated neonatal thyroid dysfunction. If the newborn is not treated for the thyroid dysfunction in the first few weeks of life, the brain will not develop normally and some degree of mental retardation may occur.

During the talk on TV a booklet was shown (prepared by the Instituto da Tiroide) that describes how to get a few drops of blood from the newborn heel. The blood collected is absorbed in filter paper. Laboratory tests are conducted on this small dry spot of blood. If abnormal, mother and child are recalled, and further testing will be necessary to confirm the diagnosis. Once congenital hypothyroidism is confirmed, L-Thyroxine is prescribed as a single tablet every morning.

This talk show was seen by more than 8 million people and many emails and messages were sent to the “Instituto da Tiroide” asking for more details. In summary, it was extremely useful for the Brazilian population to receive this kind of information, in a simple and direct language, increasing the basic knowledge of the important role of the thyroid gland, both during pregnancy and the neonatal period.

ThyroWorld
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For artwork, please send high-resolution electronic files. Send all submissions to:
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Vitamin D: just another vitamin?
On a multifunctional, crucial vitamin and hormone.

ELISABETH VAN ’T RIET MD
UTRECHT, THE NETHERLANDS

‘Do you take vitamin D supplements?’ That is the question I asked most frequently over the past 15 months.

In the beginning of 2009, I was shocked by the amount of research and publications made on the hormonal functions of vitamin D, with effects on (auto)immunity, cancer and the cardiovascular system, effects I didn’t know of. Moreover, I discovered that the generally accepted reference range of vitamin D in serum appeared to be too low to establish both the known ‘classic’ effect on bone and calcium balance, as well as the more recently discovered multi-organ functions on cell immunity and cell differentiation.

Today, professionals estimate that millions of people around the globe are vitamin D deficient, including US and Canada, Australia and all around Europe. At the European Vitamin D Deficiency conference, held in Brussels earlier this year, 50% of the European population through all ages were estimated to be vitamin D deficient.

Although the number of scientific publications related to vitamin D have grown exponentially over the last years, many people, including health professionals, aren’t aware of the ubiquitous role of this vitamin. So far, specific research on vitamin D status and thyroid diseases has been rare. Interestingly, a presentation on vitamin D and the thyroid has been scheduled for the World Thyroid Congress, September 2010 in Paris.

I hope to introduce you to the already established effects of vitamin and (pro) hormone D, raising awareness in order to diminish preventable health deterioration and chronic diseases.

What is vitamin D?

Vitamin D, sometimes called the “sunshine vitamin”, is produced in our skin after irradiation by ultraviolet B (UVB) containing sunlight. Skin-produced pre-vitamin D is transformed in the liver to 25(OH)D or calcidiol and activated in the kidneys to the active vitamin D form, called calcitriol. This calcitriol facilitates calcium absorption from the gut and maintains calcium balance in the body. By ensuring bone mineralisation, it helps to form and maintain strong healthy bones in children and adults. The efficiency of intestinal calcium absorption is related to the serum vitamin D concentration: when levels of vitamin D are raised from low to adequate, intestinal absorption of calcium more than doubles.

The major source of vitamin D (other than supplements) for humans is exposure to sunlight. Up to 90% of our vitamin D demands can be met by solar derived synthesis. Dietary sources of vitamin D are limited (see table). Best known is fatty fish and egg yoke. In some countries foods are fortified with vitamin D, but daily food intake cannot supply you with enough vitamin D. The type of vitamin D made in the skin and found in oily fish is D3 or cholecalciferol. There is also a plant derived vitamin D2 or ergocalciferol, produced in yeast and certain plants after irradiation.

More functions

In addition to its classic role in skeletal health, vitamin D appears to have several hormonal functions all around the body. A growing body of evidence indicates a role of vitamin D in (auto)immunity, cell differentiation and cell growth. The key to these effects are vitamin D receptors (VDR), which have been found in more than 30 organs, including skeletal muscle, heart muscle, brain, breast tissue, colon, prostate, pancreas and the immune system. Many cell types also contain the vitamin-D-activating enzyme, allowing organs to produce active vitamin D locally, as is seen in different types of immune regulating cells. These insights can explain the benefits of adequate 25(OH)D levels on prevalence of various infections as well as diminished risks of auto-immune diseases like type 1 diabetes mellitus, multiple sclerosis and rheumatoid arthritis.

In cancer research, several cell processes related to cell growth and differentiation have been determined in which intracellular synthesized vitamin D is involved. Vitamin D appears to enhance cell processes which stimulate normal growth and differentiation and acts as a brake on cell degeneration.

It is important to realise that these non-skeletal effects depend on circulating levels of 25(OH)D, the inactive form of vitamin D.
Vitamin D deficiency: symptoms and health effects

A low vitamin D status can cause muscle weakness, bone and muscle pain and fatigue. Typically, muscle problems are situated in the upper part of the limbs, but location elsewhere is also possible. Patients complain about difficulties getting up from a chair or climbing stairs. Vitamin D deficiency can lead to bone diseases like osteoporosis, osteomalacia and rickets (in children).

The double effect on both bone (increasing bone density) and skeletal muscle (improving muscle strength and balance), makes vitamin D a strong factor in diminishing falls and fractures in the elderly. Notably, recent studies have established that vitamin D supplementation has to be higher than previously thought to achieve these benefits and that there is a dose dependent effect: less falls and fractures with increasing dose and vitamin D level.

Vitamin D deficiency has also been associated with many other chronic diseases such as type 1 diabetes mellitus, rheumatoid arthritis, multiple sclerosis, various types of cancer (e.g. colon, breast, prostate), infectious diseases, heart disease and hypertension, depression and cognitive impairment in the elderly.

Many of these associations stem from observational and geographical studies, linking higher risks for these diseases to geographical latitude and/or suboptimal levels of vitamin D. Higher vitamin D levels are associated with lower cancer risk and less mortality from cancer, with the strongest evidence for colorectal and breast cancer. Large clinical trials have to establish a possibly causal relationship and to determine which vitamin D levels lead to maximal risk reduction. Many chronic diseases like cancer and autoimmune diseases are generally thought to be caused by an interaction between genetic and environmental factors. Given the cell mechanisms described above, vitamin D could well be a key environmental factor determining the risk of developing such diseases.

Pregnant women need extra attention, as the developing fetus is totally dependent on maternal vitamin D. Obviously, maternal vitamin D deficiency can lead to reduced maturation of the fetal skeleton. Moreover, observational studies point to higher risks for immune system disorders later in life, after early life deficient levels of vitamin D.

Vitamin D deficiency: who is at risk?

As mentioned above, the skin has an enormous capacity to synthesize vitamin D. Surplus of vitamin D made by the skin in summer, will be stored in fat tissue and muscles. When solar radiation contains too little UVB, however, production of vitamin D will be hampered. This is the situation in countries away from the equator (roughly at latitudes above 37°N and below 37°S), where the sun contains sufficient UVB only half the year. Additionally, several other factors influence vitamin D production or bio-availability in humans: age (capacity diminishes 4 x with age), pigmentation of skin (melanin absorbs UVB, thus preventing vitamin D synthesis), clothing and cultural habits. Sunlotions with sun protection factor 15 prevent 98% of vitamin D production and many moisturisers contain unnoticeable UV-filters. In overweight people circulating levels of vitamin D are lower, due to storage of the vitamin in fat cells. Pregnant women are also at risk for deficiency of vitamin D, as well as their breastfed children (breast milk contains little vitamin D). Infants and young children are considered vulnerable groups as they are exposed to little sunshine.

Table 1: Vitamin D Content in Food (Holick)

<table>
<thead>
<tr>
<th>Source</th>
<th>Vitamin D Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salmon fresh, wild (3.5 oz)</td>
<td>About 600–1000 IU of vitamin D3</td>
</tr>
<tr>
<td>Salmon fresh, farmed (3.5 oz)</td>
<td>About 100–250 IU of vitamin D3</td>
</tr>
<tr>
<td>Salmon, canned (3.5 oz)</td>
<td>About 300–600 IU of vitamin D3</td>
</tr>
<tr>
<td>Sardines, canned (3.5 oz)</td>
<td>About 300 IU of vitamin D3</td>
</tr>
<tr>
<td>Mackerel, canned (3.5 oz)</td>
<td>About 250 IU of vitamin D3</td>
</tr>
<tr>
<td>Tuna, canned (3.6 oz)</td>
<td>About 230 IU of vitamin D3</td>
</tr>
<tr>
<td>Cod liver oil (1 tsp)</td>
<td>About 400–1000 IU of vitamin D3</td>
</tr>
<tr>
<td>Shiitake mushrooms</td>
<td></td>
</tr>
<tr>
<td>Fresh (3.5 oz)</td>
<td>About 100 IU of vitamin D2</td>
</tr>
<tr>
<td>Sun-dried (3.5 oz)</td>
<td>About 1600 IU of vitamin D2</td>
</tr>
<tr>
<td>Egg yolk</td>
<td>About 20 IU of vitamin D3 or D2</td>
</tr>
</tbody>
</table>

IU denotes international unit, which equals 25 ng.
To convert values from ounces to grams, multiply by 28.3
To convert values from ounces to milliliters, multiply by 29.6

(continued on page 12)
combination of risk factors may increase the risk of a vitamin deficient state: immigrant people, with almost totally covered skin, living in northern countries or housebound elderly people are examples of extra vulnerable groups.

Besides the traditionally recognised risk categories, investigations have shown that many more people appear to have inadequate vitamin D levels. Due to a changed lifestyle, we spend less time outdoors, exposing only very little of our skin to the sun. Some people in sunny climates habitually seek the shade and many others use sunscreens to protect themselves from sunburn. This is a sensible way to reduce skin cancer, but can bring about a vitamin D deficiency at the same time. Studies have shown severe deficiencies of otherwise healthy elderly people in sunny Mediterranean countries as well as in pregnant women in southern California.

**Vitamin D deficiency: diagnosis**

Determination of vitamin D status should be done by testing 25(OH)D in serum. 25(OH)D is the major circulating form of vitamin D and reflects both vitamin D intake and vitamin D produced after sun exposure. Reference ranges can differ between laboratories and many laboratories still work with outdated ranges for 25(OH)D. A level of 50 nmol/l must be considered as absolute minimum and is, in fact, inadequate to maintain bone health. Many experts agree that the preferred level of 25(OH)D should be > 75 nmol/l throughout the year, for children and adults. Levels between 75-110 nmol/l have been proved to provide optimal benefits for fall and fracture prevention without increasing health risks and these levels are expected to provide optimal benefits on cardiovascular health and cancer prevention as well. Generally, 250 nmol/l is seen as the upper limit of normal. Above this limit toxicity may occur, with symptoms caused by raised calcium levels. Test results of serum 25(OH)D are given in nmol/l or in ng/ml. Coming from ng/ml multiply by 2.5 to get results in nmol/l. So mostly recognised optimal range of vitamin D is 80-250 nmol/l or 32-100 ng/ml.

**Supplementation: safety, toxicity and daily intake**

As suntanning may enhance risk of skin cancer and dietary sources are limited, many people will have to take vitamin D supplements to achieve optimal levels of vitamin D. Many countries have vitamin D supplementation guidelines, designed to prevent bone diseases in vulnerable groups. Along with the growing knowledge of vitamin D’s hormonal functions and the increased number of people at risk, supplementation doses are being adjusted upwards. The maximum safe daily dose is still considered to be 2000 international units per day (IU/day), but this may be changed in coming years.

Vitamin D, which is fat-soluble, can be toxic in large amounts, but intoxication is rare. Special caution is needed for people suffering from granulomatous diseases like sarcoidosis (also called Besnier-Boeck’s disease), specific type of tuberculosis and some cancers (e.g. lymphoma) or people suffering from hyperparathyroidism (hyperfunction of glands next to the thyroid). In these cases, vitamin D supplements can cause dangerous levels of calcium. Therefore, these people should only take vitamin D under the care of a knowledgeable physician. This also applies to pregnant women at levels higher than the nowadays recommended 400 IU/day.

The following recommendations are indications and will be likely to differ between countries. It is expected that scientific research will lead to higher recommended daily intakes in future.

**Adults:**

- Age 60 and up: daily intake of 800-1000 IU vitamin D3
- Women between 50 and 60: 400 IU vitamin D3/day
- Pregnant and lactating women: 400 IU vitamin D3/day
- Those avoiding sun and/or dark-skinned: 800-1000 IU vitamin D3/day

**Infants and children:**

- 200-400 IU vitamin D3/day

If possible, a blood 25(OH)D test will help to determine your vitamin D level. When severe vitamin D deficiency is diagnosed the above-mentioned doses will not be high enough to restore vitamin D levels in reasonable time. Physicians can use high weekly or monthly loading doses of cholecalciferol to achieve vitamin D sufficiency. Afterwards, daily intakes of 800-1000 IU are often needed to keep levels up.

Preferably, vitamin D3 (cholecalciferol) supplements are taken. D3 is considered somewhat more active than D2 to raise 25(OH)D levels.

(continued on page 16)
Thyroiditis

Adapted by Dr. Lawrence Wood from Your Thyroid: A Home Reference by Dr.'s Lawrence C. Wood, David S Cooper, and E. Chester Ridgeway

Thyroiditis is the general term used to describe several different disorders in which the thyroid gland becomes inflamed. Most commonly the inflammation takes the form of chronic, progressive disease known as chronic lymphocytic thyroiditis or Hashimoto’s disease in honor of the Japanese physician who first described the microscopic changes in the thyroid tissue of patients with the condition.

Hashimoto’s disease appears to be an inherited condition. As with hyperthyroidism due to Graves’ disease, you probably inherit a gene or a set of genes if you are to develop this disorder. In addition, there appear to be other factors that contribute to this condition and cause it to develop. These other factors include age, the bodies immune system, and being female. In fact, women are affected at least two times more often than men. This form of thyroiditis is more common after the age of 40, although you may develop this form of thyroiditis in childhood or adolescence.

The condition is caused by your body’s immune system, which makes antibodies which damage thyroid cells. When enough tissue has been destroyed, your thyroid hormone production falls below normal, the blood level of thyroid stimulating hormone (TSH) rises, and symptoms of hyperthyroidism appear.

Approximately 20 to 30% of women over the age of 60 have positive antithyroid antibodies, as well as 10 to 15% of men at the same age.

If you develop this condition, the first indication of a problem may be a mild painless swelling of your thyroid gland. Later, symptoms of hypothyroidism usually appear causing you to feel sluggish and tired. At first some people simply attribute these symptoms to aging, but if you visit your doctor for an appointment it is likely that he or she will recognize your problem and correct it by treating you with thyroid hormone until your thyroid levels are normal.

If other members of your family have had an overactive or underactive thyroid or other autoimmune disorders like juvenile diabetes, rheumatoid arthritis, or pernicious anemia, these can also suggest to your doctor that you are at risk for thyroid dysfunction even if you lack symptoms. The elevated TSH level is the most important test result, and your doctor will gradually increase your dose of thyroid hormone until the TSH is normal and your symptoms have subsided.

Postpartum Thyroiditis

A woman’s immune system often becomes more active following delivery of a baby. Thus if you have a genetic tendency toward autoimmune thyroid problems, you may experience a painless inflammation of your thyroid gland in the months following delivery. Treatment with thyroid hormone should relieve symptoms and complete recovery is possible after a few weeks or months, but about 25% of all women with postpartum thyroiditis progress to permanent hypothyroidism within a few years and require lifelong thyroid hormone.

Subacute Thyroiditis

Thyroid inflammation may also follow an upper respiratory viral infection including viruses that cause mumps, measles and the common cold. Usually the symptoms of subacute thyroiditis are unforgettable and begin about two weeks after the first sign of a viral illness. Gradually a painful enlargement of the thyroid, fever, muscle aches, and severe fatigue cause you to see your doctor, who can confirm the diagnosis and treat your symptoms. Often this disorder follows a pattern of hyperthyroidism followed by hypothyroidism once the thyroid inflammation has subsided. If your neck is very painful, your physician may recommend an anti-inflammatory drug such as Ibuprofen. If the pain is even more intense, the inflammation may be treated with a steroid medication such as cortisone or prednisone. Fortunately, in most patients a total and complete recovery occurs within five or six months.

Acute Suppurative Thyroiditis

This is most often a disease of children, but may occur at any age. It is more common in individuals with compromised immune systems. If you develop this rare condition, you will be quite ill. A bacterial infection is the usual cause (continued on page 14)
ThyroWorld

In front of the conference hall participants relaxing during a break. (L to R) Dr. Ulla Slama, Finland; Prof. Klaus Wenzel, Berlin; Dr. Hanna Mäenpää, Finland and Dr. Lies van Riet, the Netherlands.

Thyroiditis (continued from page 13)

of acute suppurative thyroiditis, so you may have chills, high fever, and a hot tender thyroid gland. There may be an abscess within the gland. As with other bacterial infections, antibiotics are required for treatment and local surgical drainage or removal of abscessed thyroid tissue may be needed. Fortunately, in spite of the severity of acute suppurative thyroiditis, complete recovery is the usual outcome in this disease.

Physicians have known for some time that autoimmune thyroiditis and other immune disorders are inherited conditions and tend to affect other family members. Therefore, you should let your relatives known about your illness and suggest that they make an appointment with their physician to have their thyroid levels checked and to be sure that they do not have other immune problems. These might include type I diabetes, pernicious anemia due to a lack of vitamin B12, intestinal disorders such as celiac disease or other inflammatory bowel disorders including ulcerative colitis. The presence of one or more of these conditions suggest that other relatives on that side of the female should be tested for thyroid and other autoimmune disorders before and during pregnancy and at other times under the guidance of their physicians.

TFI 2009 Annual Meeting
Lisbon, Portugal, September 2nd-4th

As every year, the annual meeting of TFI took place in the days preceeding the ETA congress. Instead of a classic hotel, we were hosted in a big apartment and in a small pension nearby, in the heart of the typical Alfama district, and also held our meeting there. We worked hard, elaborating new statutes for the registration of TFI in Europe (Sweden), starting to make a draft for new internal rules and other projects for the future.

During the ETA congress, TFI had a booth in the exhibition area, to promote our work and to inform doctors about the interest of cooperating with patient organizations – and we also attended many interesting lectures.

Taking a break from an intense and hardworking TFI meeting

(L to R) Standing: Peter Lakwijk, Netherland-Sweden; Harald Rimmene, Germany; Yvonne Andersson, Sweden, President TFI; Dr. Ulla Slama, Finland; Dr. Geraldo Medeiros-Neto, Brazil; Jytte Flamshtol, Denmark; Beate Bartès, France; Nancy Patterson, USA and sitting Ashok Bhaseen, Canada.

In front of the conference hall participants relaxing during a break. (L to R) Dr. Ulla Slama, Finland; Prof. Klaus Wenzel, Berlin; Dr. Hanna Mäenpää, Finland and Dr. Lies van Riet, the Netherlands.
At the thyroid conference in Warshaw, 2001 we met, at the TFI booth, a thyroid biologist, Abebe, born in Ethiopia, but working in Gothenburg, Sweden. At the conference in Edinburgh, 2003 she again appeared at our booth. She could not keep quiet about her thoughts every time she saw our booth, “I met you some years ago, and came at every thyroid conference to your booth. You try to do international work for thyroid patients, but what do you do for Africa? There they need you the most!” I called Abebe in March, 2006 before going to Ethiopia to practice in tropical infectious diseases. She was very happy that I was going to Ethiopia, but she herself left Sweden some weeks afterwards, because she was invited to do research about stem cells in the United States.

Iodine Deficiency and Goiter, Problem in Ethiopia

Ethiopia is among the world’s 13 most iodine-poor countries. The required intake of iodine per day for an individual should be about 150 mikgr/l, deficient is 100 mikgr/l. In Ethiopia, the median score is 52 mikgr/l. (according to the Global Scorecard 2010 at the ICCIDD homepage). In my home country, Finland, the average daily intake is 162 mikgr.

Sixty years ago iodine deficiency was still a serious problem in Finland, especially in the eastern parts farthest from the coast, where people had less fish in their nutrition. I remember from my childhood women with large goiters in their necks. In 1949, Finland applied iodine to the salt and today the occurrence of goiter due to iodine deficiency is extremely rare, slightly enlarged thyroid glands are most often caused by autoimmune thyroid disease. Pregnant women should get at least 200 mikgr iodine per day. In Ethiopia, the low iodine intake is still today seriously affecting the offspring, the problem has even worsened the last years.

In the year 2006, as I was training in medicine in Ethiopia, I had the honour of meeting Dr. Shitaye, who was teaching doctors at the university hospital of Gonder. She was teaching our group from the Karolinian Institute of Stockholm about tropical infectious diseases, mainly tuberculosis and AIDS. I asked her about the thyroid speciality, but she said they have to concentrate most of their resources on the infectious diseases in order to save more lives.

This spring, 2010, I visited Ethiopia again, visiting an young Ethiopian man who received his nurse exam, sponsored by my husband. We once more met with Dr. Shitaye, who is among the population, a queen of Sheeba of our time. Most people in the streets of Gonder know Dr. Shitaye and could tell when they last saw her, “They all want to have Dr. Shitaye as their doctor, her knowledge is great”. Like once the queen of Sheeba answered to King Salomon as he asked her to be his wife: “My country needs me”, Dr. Shitaye had answered the same to the head-hunters of western countries.

She remembered we had talked about thyroid disease in Ethiopia when we last met and she told us she was now changing her speciality from infectious diseases to endocrinology, primary to diabetes, but she is also interested in thyroidology.

We also took part in a ceremony starting a hospital sponsored by the Finnish mission in Hosaina, about 100 km to the south west of Addis

(continued on page 16)
Where is Africa among the thyroid organizations? (continued from page 15)

Abeba. At the dinner after the ceremony I was seated in front of the Lutheran bishop in Ethiopia. Also, his family has occurrences of thyroid disease. The bishop told that he would be interested in starting a project concerning thyroid disease.

One evening I was called to an Ethiopian women working at the Finnish missionary station where we had our lodgement. She had chest pain and rapid heartbeat with extremely high blood pressure. I gave her a beta blocking agent to help calm her acute symptoms, the electrocardiography showed only tachycardia. At her neck was a large goiter, so I ordered thyroid function tests.

Next we wanted to send an email home to Finland, the kind young man at the internet site also had a goiter.

If you travel to the mountainous country of Ethiopia and look at the necks of people there, you will see many goiters. The Ethiopian people are very kind and polite in spite of their suffering, even of famine in certain areas, and the thyroid problems need our support.

Ulla Slama

Vitamin D: just another vitamin? (continued from page 12)

Amounts are given in IU or micrograms. 10 micrograms equals 400 IU. 

Abbreviations: UVB: ultraviolet-B, 25(OH)D: 25-hydroxy-vitamin D, VDR: vitamin D receptor, IU: international units

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Literature and Sources


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http://www.vitamindcouncil.org
The Nijmegen Outpatient’s Thyroid clinic is accessible, fast and effective.

The Netherlands Thyroid Foundation (Schildklierstichting Nederland) participates in the Dutch research project ‘Gold in Hands’ (Goud in handen) in order to gain a better understanding of the patient’s point of view with regards to the best treatment. One of the recent initiatives that was taken by a Dutch hospital to improve care is the outpatient’s thyroid clinic in Nijmegen. Patients with thyroid disorders can now go to St. Radboud University Medical Centre (UMC St Radboud) to the outpatient’s thyroid clinic in the department for endocrine disorders. Why does there have to be an outpatient’s clinic especially for this target group? Ad Hermus, the head of the department of endocrine disorders explains, ‘We want to offer the best possible care to patients, even if it concerns relatively simple pathology. In the past few months we have collaborated closely with GPs when setting up the outpatient’s clinic, in order to deal with their needs immediately.’

Ingeborg Hakstege, in “Radboud Actueel – a newsletter for GP's"

One of the greatest advantages for patients is that from now on they can be seen at the outpatient’s clinic in the evenings. According to Hermus ‘Our patients include a relatively large number of young people, between twenty and forty years of age. Often they are trying to combine a busy job with caring for children. It is important for this target group that the outpatient’s clinic is also open in the evening.’

Accessibility

Romana Netea-Maier, Specialist in internal medicine-endocrinologist, recounts that fast, efficient and client-friendly care is what is important to this busy and mature target group. ‘We therefore try to keep the care as accessible as possible and geared to these patients’ specific wishes. We try to combine, if possible, examinations with a consultation so that the patients don’t have to keep coming back for an appointment. That is one. But we also collaborate emphatically with the patient during treatment. For example, by allowing patients to view their own blood test results. And allowing them to have a say in the form of treatment. Should we or should we not perform surgery? Which medication should we apply? These are important personal choices, especially for those who would like to have children. To an increasing extent, we try to pass on information digitally. For example, via our department’s web site. And we offer patients the possibility to ask short questions via email. In fact, this is the beginning of a digital outpatient’s clinic.’

Expertise

The digital developments are also playing an increasing role in the collaboration with GPs. During the past few months Nike Stikkelbroeck, specialist in internal medicine-endocrinologist in training, has mapped the needs of GPs. ‘This revealed, for example, that they appreciate it if the special needs referrals have been completed as accurately as possible on “ZorgDomein”, an Internet based referral system between primary and secondary health care providers. And that they benefit from a clear and unambiguous referral for which a telephone call is enough.’ As Stikkelbroeck stated, it was also noticeable that a large number of GPs were not aware of the fact that they could contact the department for Endocrine disorders directly. ‘This, however, is possible. We feel that this also fits in with this day and age. Every patient is entitled to high-quality care in this specialised field. And GPs are entitled to utilise our tertiary-line medical expertise.’

Feedback

Another point: amongst GPs there is a need for a kind of digital expertise centre. An accessible handbook. Stikkelbroeck: ‘We have therefore created an email address – schildklier@endo.umcn.nl – through which a GP can ask short questions or is able to double check the correctness of his decision. The latter mainly applies to GPs who treat thyroid patients themselves.’ Other useful options for the GP are video consultations – the Health Bridge pilot programme was very successful – and hopefully it will soon be possible to send letters via Lifeline. Hermus: ‘Fast feedback is a clear and logical wish amongst GPs. Being able to send letters digitally is certainly a step forward. Feedback is also important because we usually see the patients for a limited period of time for check ups; sometimes one visit to the outpatient’s clinic is enough. In such cases the GP obviously needs to know exactly how to continue.’
Gold Bow Day Initiative

The Australian Thyroid Foundation’s (ATF) Gold Bow Day is an annual event. This day is held on September 1 each year.

The Gold Bow is a symbol of the thyroid gland on either side of the neck. The gold colour is a symbol that your thyroid gland is more important to you than gold.

In 2008, Australian research revealed thyroid cancer had increased by 84% in women and 40% in men. The indicators for this increase; better detection and early detection, iodine deficiency and soy products all have a bearing.

The ATF decided to focus Gold Bow Day on Thyroid Cancer Awareness with the money raised for sales of Gold Bows going toward improving and upgrading Radio-Active Iodine (RAI) Treatment Rooms in public hospitals around Australia.

We all know after thyroid cancer patients have had their diseased thyroid gland surgically removed, they are then isolated in a RAI Treatment Room for 3 – 4 days after swallowing a RAI capsule to kill off any remaining cancer cells.

In June 2010, the ATF opened our first two upgraded rooms at Royal North Shore Hospital in Sydney, NSW. These rooms previously had paint peeling off the walls, old worn and torn sparse furniture and were very intimidating for patients undergoing treatment.

With the help of Oz Design Furniture and Royal North Shore Hospital, the ATF made this initiative a reality. The two rooms each now include a leather recliner chair, tallboys, side tables, CD/DVD, radio, entertainment units with screens to watch DVD’s and internet access, paintings, new bar refrigerators, books, DVD’s, ATF newsletter and information, new bed linen, lamps, and outdoor furniture for the balcony.

One endocrinologist commented, the rooms now look more like hotel rooms.

The main objective was to make the patient’s stay comfortable and ensure their well-being. The ATF have received positive feedback from patients and staff alike. We know the ATF has made a difference.

The next hospital targeted for an upgrade is in Brisbane, Queensland, where we will help and improve the stay for thyroid cancer patients in Queensland.
New formulation of GlaxoSmithKline’s Eltroxin have created problems for Danish thyroid patients

End of 2008 GlaxoSmithKline (GSK) decided to change their T-4-product Eltroxin in Denmark. NO notice were given neither to the doctors or the patients. Just a small red text on the Eltroxin-box saying “new formulation same effect”. The box that only the patient sees no the doctor.

For your information we had no choice of T4-product in Denmark. GSK was the only supplier on the Danish Market.

The Danish patients organization, Thyreoidea Landsforeningen, (TL) immediately contacted (GSK) and were very surprised to find out that NO Danish doctor were informed about the new formulation – not GP’s, not endocrinologist – no one at all. One thing is not wanting to inform the patients organization but not informing the doctors is not a good decision. The doctors need to know what they prescribe to their patients and when there is a change in it.

Through our good relations with friends from Thyroid Federation International we found out that GSK had done the same in New Zealand in 2007 and more than 700 patients had had problems with the new formulation. GSK in Denmark still claims not to have been aware of the problems in New Zealand.

Some of the approximately 100,000 patients in Denmark using T4 began to have problems with the new Eltroxin. Some experienced a change in their TSH – still within the normal range but enough for some patients not to feel well. Other symptoms are the classical symptoms for low thyroid function.

More than 1100 patients have reported problems with the new formulation to the Danish Health Authorities and they now recommend that every patient have a bloodtest taking after some weeks use of the new formulation. A new dosage may be necessary.

Luckily Merck decided to launch their Euthyrox on the Danish Market at the end of December 2009 so now we at least have another product on the market and a choice for the patient.

However there is still patients not feeling well even if they change to another product.

GSK have changed the formulation of Eltroxin worldwide but only experienced the massive problems in Denmark and New Zealand but in other countries there have been other T4 products on the market and therefore a free choice for the doctor and the patient.

I really hope that we’ll never experience a drug being changed without notice to patients and doctors again!

Bente Julie Lasserre
Past vicepresident of Thyreoidea Landsforeningen
and Thyroid Federation International

TFI – 17th Annual Meeting
September 8-9, 2011

The 17th annual meeting of Thyroid Federation International is planned on September 8 and 9, 2011, in conjunction with the 35th ETA congress (September 10 to 14), in Krakow, Poland.
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