



# Thyroid Patients Worldwide

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THYRO WORLD

## Thyroid Federation International

*Established in September 1995 in Toronto, Canada*

### Founder

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

### Mentor & First President

Lawrence C Wood, MD FACP (USA)



## Officers of the Association

### Executive Committee

Ashok Bhaseen (Canada), President

Peter Lakwijk (Sweden), Treasurer

Beate Bartès (France), Secretary

### Members-at-large

Linda Henderson (Italy)

Nancy Patterson (USA)

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Yvonne Andersson-Lakwijk (Sweden)

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Peter Lakwijk (Sweden)

Nancy Patterson (USA)

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Dr Elina Gasparyan (Russia)

Pr George J Kahaly (Germany)

Dr Petros Perros (United Kingdom)

Dr Gregory Randolph (USA)

Dr Helton Ramos (Brazil)

Dr Teo San Luis (Philippines)

Pr Martin Schlumberger (France)

Pr Eduardo Tomimori (Brazil)

Dr Michael Zimmermann (Switzerland)

### Conference Coordinators

Beate Bartès (France)

Peter Lakwijk (Sweden)

### Administrative Coordinator

Katherine Keen (Canada)

### Website Coordination

iSquare Logix

## Member Organizations

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

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## Message from the Editors

Welcome to the 2021 spring edition of ThyroWorld. It's more than 1 year since the COVID-19 pandemic has changed not only our plans, but also our lives. Instead of celebrating TFI's 25th anniversary together during the International Thyroid Congress in Xi-an, China, meetings are now "virtual". Our AGM in October 2020 was held online, as will be our AGM next September. But this challenge is also an opportunity – online meetings allow members from around the world to attend.

We are proud to be present at the e-ECE 2021, the fully digital European Congress of Endocrinology. Please visit our "virtual booth", and contact us for more information! We also co-organize a session "The Patient's Voice" with the British Thyroid Foundation on Sunday 23, about the role of iodine for a healthy thyroid and during pregnancy.

TFI celebrated its 25th anniversary in 2020 – from 6 founding members in 1995, to more than 30 member organizations in all parts of the world! We encourage everyone who provides evidence-based information to thyroid patients to apply for membership. We welcome patient-led and patient-oriented organizations.

This edition is an updated version of our 2020 newsletter, with articles about research and new medication for thyroid eye disease, the significance of abnormal TSH tests, T4/T3 combination treatment, an awareness campaign to decrease worldwide iodine deficiency, the development of a hypothyroidism patient experience questionnaire, the difference between "bioequivalent" and "switchable", the problems to access certain drugs ... and testimonies from many of our member organizations about their activities in different parts of the world.

Wishing all delegates an interesting congress – and hoping that we will soon be able to meet again!

BEATE BARTÈS, PETER LAKWIJK  
AND NANCY HORD PATTERSON, EDITORS



Beate Bartès



Peter Lakwijk



Nancy Hord Patterson

### ThyroWorld

Deadline for the next issue: June 30, 2021

Send all submissions to:

The Editors, ThyroWorld

**Thyroid Federation International**

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Internet: [www.thyroid-fed.org](http://www.thyroid-fed.org)

## President's Message

ASHOK BHASEEN, M. PHARM, MMS,  
PRESIDENT, THYROID FEDERATION  
INTERNATIONAL

Dear ThyroWorld Readers,

It has been just over a year of pandemic lockdown around the globe; the scientists, academics, naturalists, and innovators have done their best to understand the virus and come up with solutions. However, skeptics, rumor mongers, failed scientists, and WhatsApp experts too, did not spare a moment to put up their side of fake news and twisted logic which perhaps led to some unnecessary loss of life. At TFI we reaffirmed that it's better to be on the right side of the evidence-based factual medicine and, despite the unprecedented year of 2020, we celebrated our 25th Golden Jubilee year of continuous global growth and have remained focused on our goals. As a result we were able to get our global group together for the 25th AGM in Sept. 2020.

We lost one of our own to COVID-19, Mr. Rajkumar, Treasurer, Thyroid Foundation of Nepal, who was just 41 years old and leaves behind two young kids, 12 and 6, and wife. We at TFI sent his family our heartfelt condolence on this loss. However, we do not know the extent of damage that it has caused; I personally lost some of my friends and some relatives. Many that I personally know and grew up with have recovered now. Some of our members and their families around the globe were impacted by COVID-19 but recovered. Good or bad, nothing is permanent, we will pass through this pandemic with vaccination, and hopefully by the summer of 2022 we will start seeing more normalcy, we do fervently hope to meet in person for the 2022 AGM.

TFI focused on SAFETY first and foremost; hence we did most of our executions online since March of 2020. We will continue to leverage with online means till it is safe to meet in person again. For our 13th International Thyroid Awareness Week 2021 (ITAW) the focus is on Iodine, Mother and Baby, iodine playing a vital role in maintaining a healthy thyroid functioning. We are thankful to Dr. Zimmerman, Switzerland and Prof Dr. Leonidas Duntas, Greece for accepting to speak at each of these webinars planned for May 26th and May 31st, 2021. We are also grateful to our sponsors and volunteers who made this happen.



Ashok Bhaseen

We have maintained communications with our member organizations, Medical Advisory, ETA, ATA, ITC, EEC, EURORIDS, WIC and some other organizations, during this global lockdown period. TFI has invested in virtual booths during some of these online conferences.

We believe opportunities can be focused upon despite the difficulties the pandemic posed; fortunately, technology paved the way to help us to continue to deliver.

We therefore:

- Continue to leverage the online platforms for meetings (i.e. ITAW 2010),
- Continue with the virtual AGM for 2021,
- Make financially responsible decisions, stay nimble yet remain visible during the international forums and meetings,
- Continue SAFETY first! Keep all our members safe,
- Keep moving ahead with our goals, plans and agenda for 2021-22 and beyond.

There is no doubt that the past year has impacted many people financially, many lost their jobs, lost money in business, but we remain positive and focused on a better tomorrow. Some areas in the USA do not need to wear a mask if fully vaccinated. Some countries never had a lockdown but still managed to keep the number of people impacted at a low level. As a patient organization we do know that when there is an issue, we have to know the facts, we have to find solutions and above all we have to keep moving ahead. Among the cautions, some confusion, uncertainty, and tentativeness, there are some positives. The environment and animal kingdom is thriving, families know each other better as, with the pause in travel and going to work, we had an opportunity to spend more time with our dear ones.

On this note of optimism, hope, and a brighter tomorrow, let us do our best to keep moving ahead and prepare and save for normal times. We remain upbeat, financially viable, growing and continuing to remain dedicated to doing work for TFI that is very dear to us.

Thanks to all our TFI members, Medical advisors, ITAW 2020 speakers, Board members, sponsors and supporters and those who follow us in helping us move ahead in 2021.

Also, looking forward to seeing you all at the ITAW 2021 (May 26th and 31st, 2021) and our Virtual AGM planned for Sep 9th and 10th 2021.

[ashok.bhaseen@thyroid-fed.org](mailto:ashok.bhaseen@thyroid-fed.org)

# The President of the European Society of Endocrinology shares his vision

The European Society of Endocrinology (ESE) is at the centre of Europe’s endocrine community. It is **our vision** to shape the future of endocrinology to improve science, knowledge and health. It is **our mission** to advance endocrinology. We unite, support and represent our specialty, promoting collaboration and best practice, and enable our community to develop and share the best knowledge in endocrine science and medicine. You can read more about our strategy [here](#).



ESE’s President, Professor Andrea Giustina, is in the second year of his presidency (2019-2021). The key themes for his tenure are ‘Inclusivity’ and ‘Diversity’ as he firmly believes that diversity gives opportunity and inclusion is ESE’s strength.

Professor Giustina says, “Part of the inclusivity drive is a strong focus by ESE in the policy and advocacy environment within the European Union and Parliament. The aim is to put endocrinology firmly on the map as a key factor in major global public health areas such as obesity, diabetes and cancer as well as in the environmental area with Endocrine Disrupting Chemicals (EDCs).”

He adds, “A second key mission for ESE is to continue to advocate strongly for improving the quality of life, access to drugs and care, and better personalised treatment for endocrine and thyroid patients.

Additionally, consistency of care and access is crucial, and we continue to work with ESE’s 56 affiliated European Societies, who are part of ESE’s Council of Affiliated Societies (ECAS) to help them advocate for this with local Health and Environment Ministers and MEPs.”

The patient voice and patient organisations are also vital to both of these. Professor Giustina is clear that ESE wants, and can, give a voice to patients in Brussels. He says, “We are currently developing an exciting novel initiative to amplify the patient voice and patient support organisation’s outreach activities

in Brussels, further demonstrating ESE’s commitment to inclusion being the Society’s strength.”

ESE’s annual congress has moved online for 2020 and 2021 due to the COVID-19 pandemic. e-ECE 2021 will run from 22 to 26 May 2021, and this is a great opportunity for the world-wide endocrine community to join peers to hear the latest in the field and to keep up-to-date and informed. Professor Giustina concludes, “the digital world gives us an opportunity to be fully inclusive and we hope to see many of you online!”

To keep up to date with ESE’s news you can join the mailing list at [ese-hormones.org](http://ese-hormones.org) or become a member from as little as €10 per year!



# TFI increases its Social Media Presence

## Facebook & Twitter:

The whole world is twittering – so the Thyroid Federation International decided to (re)activate its Facebook page and Twitter account. Our new volunteer, Anna Bokor, regularly adds messages with useful and reliable information for thyroid patients.

You can find us at:

[www.facebook.com/Thyroid.Federation.International/](http://www.facebook.com/Thyroid.Federation.International/)

<https://twitter.com/thyroidfed>

not to forget our website: [www.thyroid-fed.org](http://www.thyroid-fed.org)



## TFI now has its own YouTube channel!

For the International Thyroid Awareness Week 2020, TFI organized three online webinars with thyroid specialists. We now have our own YouTube channel, where you can find these webinars, and also playlists and links with various other thyroid-related videos. Don't hesitate to subscribe, for information about new publications!

**Link:** <https://www.youtube.com/channel/UCRvrPIZiKdJUxNALr1367BA>

For the ITAW 2021, we will again organize 2 webinars, on May 26 and 31, with Dr Michael Zimmermann, Switzerland, and Pr Leonidas Duntas, Greece, about the importance of iodine during pregnancy and in early childhood. They will be available on our YouTube channel – stay tuned!



### Webinar 14 May 2020:

*"The Thyroid and Pregnancy in the era of Covid-19"* Dr Helena Filipsson Nyström, Asst Prof, Senior University Consultant, The Thyroid Dept, Dept. of Endocrinology, Sahlgrenska University Hospital, Goteborg, Sweden.

<https://youtu.be/bE2MkvoeDXc>



### Webinar 25 May 2020:

*"Two Lumps: One Above, the Other Below"*. The impact of a goitrous thyroid and its effect on pregnancy. Speaker: Dr Teofilo San Luis Jr, National Coordinator for the Philippines at the Iodine Global Network and Vice President of the Asia & Oceania Thyroid Association.

<https://youtu.be/3fz5swV2pWM>



### Webinar 31 May 2020:

*"Thyroid Surgery and Voice"*. Speaker: Dr Gregory W. Randolph, Claire and John Bertucci Endowed Chair in Thyroid Surgical Oncology, Harvard Medical School, Boston, Massachusetts, USA.

<https://youtu.be/a5qv17PBBeE>

# Hypo-Hyper Vignettes

TFI created some original vignettes on the most common symptoms of hypo- and hyperthyroidism. You can download them, add text in your own language (and don't forget to mention Thyroid Federation International as owner of the pictures).

A special thank you goes to Elisa Pacitti, a designer from Rome, who with her original drawings manages to represent reality in her own truly innovative way. Her original vignettes have the ability to communicate a message, in a totally different way than usual.

To obtain the vignettes go to: <https://thyroidweek.org/tfi-cms/vignettes/>



Weight loss



Diarrhea



Weight gain



Constipation

**HYPER**

**HYPO**



Difficult sleeping



Sensitive to heat



Sensitive to cold



Tiredness



Mood swings



Irregular or fast heart rate



Slow movements and thoughts



Depression

ELISA PACITTI

# History of ThyroWorld

The history of Thyroid Federation International is written about on other pages. Our “ThyroWorld” newsletter has always been, and still is, aimed at the members of our member organizations. At the same time, the focus has extended to the attendees of thyroid conferences around the world: European Thyroid Association, American Thyroid Association, Latin-American Thyroid Association and Asian-Oceanian Thyroid Association.

Many of these attendees are now well aware of Thyroid Federation International – so the focus is further extended to the colleagues of the attendees. Over the years, we found that many attendees spread their knowledge to their colleagues who do not attend these conferences.

All articles are evidence-based and checked by members of our Medical Advisory Board. The level is meant to be easily readable for patients and for less specialized medical professionals.

June Rose Beaty was the editor from 1998 to 2008. In the first issue of ThyroWorld, June started with:



June Rose Beaty sadly passed away in 2019.

*“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 there’s always the factor of human error. But, of course, there’s always the great bonus of human effort.”*

## 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 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 think 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 mineral. 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.

TFI history (TW 1998)  
- From the Editor's Notebook

## How the (Thyro)World has changed!

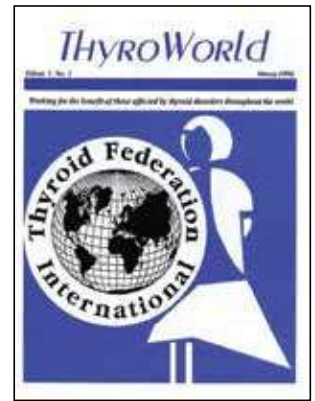
No more problems with fax machines, WP (WordPerfect for the younger readers) and photocopies.

We are all digital now. This issue is the first that will not be printed on paper but will be available in digital form; it is even distributed in digital conference bags.

It still is not an easy task to come to publication, as we found new struggles with emails and conference programs like Zoom and Teams.

Other challenges are the people: “authors to write articles, timelines and, last but not least, the members of TFI”.

The content of ThyroWorld has not changed so much. Contributions from our members, articles about different thyroid issues and about the conferences we took part in. The major change is the amount of information. In 1995 we started with 6 member organizations and now it's nearly 35 from all continents (except Antarctica). The first ThyroWorld was 20 pages, the last was 40 pages. The first was in great part filled by the editorial board, for the last we had to select which articles to use to keep it within our limits.



Cover of first issue of ThyroWorld in 1998.

Most of the earlier ThyroWorlds can still be read through the internet on our website:

<https://www.thyroid-fed.org/tfi-wp/news/thyroworld/>

And we still follow the slogan published in our first edition in 1998: “Action is the difference between “Why” and “Why not”!

## 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 worldwide 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!!**

Page 4 ThyroWorld Volume 1, No. 1 WINTER 1998

TFI history (ThyroWorld 1998).

# Where's Larry?

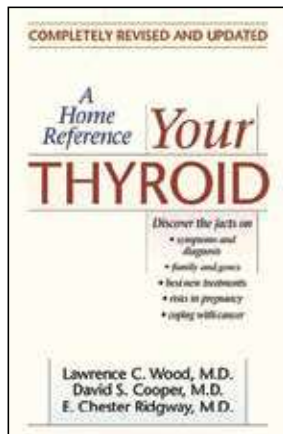
NANCY PATTERSON, TFI BOARD  
GRAVES' DISEASE AND THYROID FOUNDATION, USA

Dr Lawrence C. Wood and his wife, Shann, recently permanently moved from Cape Cod, Massachusetts to Salt Lake City, Utah. A pleasant life of relative leisure is now the standard for living near family and friends. Every day they go for a brief stroll, and in the afternoons, they take the car and go sightseeing in the nearby canyons. When his wife Shann retired in 2015, they sold their house in Weston MA, and began to spend winters in Utah, but continue to live at their house on Cape Cod in the summers. This year, because of Covid-19, they are spending the summer in Salt Lake as well, but hope to return to the Cape next summer. In Salt Lake, they have spent a lot of time with her mother who lived to be 101, and they attend the symphony concerts, the ballet, the Metropolitan Opera broadcasts, spend time with family and friends. Because they are in Utah for more than half the year, that is where they are considered permanent residents, but the Cape will always be a part of their lives.



Larry and Shann Wood.

Dr Wood went to Princeton University, then to Penn Medical School, did his internship at the University of Virginia in Charlottesville, and his residency at Penn. He then served at the US Army hospital in Landstuhl, Germany. Subsequently, he returned to Boston where he did thyroid research under Sidney Ingbar, MD. He then joined Mass General Hospital as a physician and as an associate professor at Harvard Medical School. During this time, he wrote a book for thyroid patients, *Your Thyroid, a Home Reference*, collaborating with co-authors E Chester Ridgway MD and David Cooper MD. Then he founded the Thyroid Foundation of America, TFA, and later TFI.



After Larry retired from Mass General Hospital and TFA, he took five years in which he wrote and published his father's biography, *The Life and Legacy of Francis C. Wood*. His father was Chief of Medicine at the University of Pennsylvania Hospital. Larry did not stop working when he retired. He was on the Board of Advisors of the Graves' Disease and Thyroid Foundation, GDATF, for six years. In addition to the 8 years of his presidency of

the TFI, Dr. Wood and the TFA provided services to thyroid patients for 21 years.

Dr. Wood (was the primary energy surrounding the formation of the Thyroid Federation International in 1995. The founding organizations of TFI were Thyroid Foundation of America (TFA), Thyroid Eye Disease Association UK (TED), Schilddrüsen Liga Deutschland (SLD), Associazione Italiana Basedowiani e Tiroidei (AIBAT), National Graves' Disease Foundation (NGDF) and Thyroid Foundation of Canada (TFC).



TFI Meeting 1995



TFI Presidents from 1995 to 2020.

He was President of TFI for 8 years (1995-2003). He has attended the TFI meetings, ATA, and ETA conferences for over 20 years (with exception of 2004 due to terrorism threats in Turkey). His Presidency was followed by Yvonne Andersson Lakwijk (Sweden), and currently Ashok Bhaseen (Canada/India).

Larry's total dedication to thyroid patients around the world extends even to his automobile tag TSH-1.



Larry still talks to (and entertains) everyone. For example, when he meets people walking their pets, he talks to them, causes them to laugh, and always makes them feel good. The same Larry we have known all these years, all over the world.



# TFI AGM 2020

## Patients around the world, online together!

BEATE BARTÈS, SECRETARY,  
THYROID FEDERATION INTERNATIONAL

Since the start of our organization 25 years ago, TFI always held its Annual General Meeting in the days before or after an international thyroid congress – either the meeting of the European Thyroid Association or the International Thyroid Congress. After our AGM in Budapest, Hungary, in 2019, we had great plans for our 2020 AGM – and intended to celebrate our 25<sup>th</sup> anniversary all together at the ITC in Xuan, China!

Unluckily, the Covid19 pandemic stopped our plans and changed our lives. All congresses went “virtual”, travelling became impossible, and so we decided to organize our annual general meeting online, in October 2020. Of course, a virtual meeting is not comparable to meeting each other “in real life”, and cannot replace all the discussions, get-togethers, exchanges between fellow

patients from all around the world during several days! However, meeting online, without need to travel, to book tickets, to reserve hotels etc, was also a chance to involve many more participants than usual. The 2-days meeting allowed participants from approximately 30 organizations from all around the world, and from all continents, to discuss, to exchange experience and to learn from each other. The members were from Australia, Belgium, Canada, Germany, Finland, France, India, Italy, Kenya, Nepal, Netherlands, Nigeria, Romania, Spain, Sweden, UK, USA.

In 2021, our AGM will again be virtual: on September 11 and 12, 2021.

TFI participated in several international congresses, all held online: e-ECE, with a virtual booth, World Congress on Thyroid Cancer (webinars), International Congress of Endocrinology, Eurordis.

Screenshot of some of the participants of our 2020 online AGM:



CONFERENCES AND CONGRESSES

# International Symposium on Graves' Orbitopathy

## EUGOGO 20th Anniversary Meeting, Pisa

NANCY PATTERSON, TFI BOARD  
GRAVES' DISEASE AND THYROID FOUNDATION, USA

Members of TEAMeD were invited to give presentations at the EUGOGO (European Group on Graves' Orbitopathy) meeting in Pisa in November, which marked the twentieth anniversary of the establishment of EUGOGO [www.eugogo.eu] and 10 years since the signing of the Amsterdam Declaration – a project to improve treatment and care of people with TED [https://www.btf-thyroid.org/teamed-page].

Janis Hickey, British Thyroid Foundation, spoke on 'My life with Graves' Orbitopathy' in which she shared the problems she had experienced with diagnosis and understanding of the patient perspective of TED – not just unique to her – and advocated a joined-up approach to treatment and care, with the focus on patients' needs.

Colin Dayan, TEAMeD chair, spoke about the TEAMeD-5 project, and how, step by step, this was being driven forward. Both Colin and Janis would like to thank TED patients for providing information about their TED experiences over the years which have helped to inform this project.

During the scientific meeting, a parallel session was held for patients, which was attended by 65 patients mainly from Italy, but also but also from France, Great Britain, Croatia, Norway, Sweden, Poland and USA, including Thyroid Federation International (TFI) representation. Patients and physicians gave presentations, and an expert panel answered patients' questions. Nancy Patterson of TFI spoke about the Quality of Life aspects of TED, sharing her own particular story, and several Italian patients spoke about their life with TED. There was also time for a question and answer session with the specialists.

<https://www.eugogo.eu/news/29-international-symposium-on-graves-orbitopathy>



## Upcoming Events

To view the most up-to-date information, visit our website:

<https://www.thyroid-fed.org/tfi-wp/events/>

## Annual Awareness Events

**May 25**

World Thyroid Day



**May 25 to 31**

International Thyroid Awareness Week  
[www.thyroidweek.com](http://www.thyroidweek.com)



**June 1**

International Hypoparathyroidism Awareness Day



**September**

Thyroid Cancer Awareness Month



## Thank You!

Thank you to everybody who made this issue possible, most particularly Katherine Keen, who corrected the language of all non-native speakers among our authors, and Lynda Wegner who diligently took care of the layout.



# Out of Range, in for a Surprise: The Significance of an Abnormal TSH Test in Hypothyroidism

N.J. ADDERLEY (LECTURER IN HEALTH INFORMATICS AND EPIDEMIOLOGY, UNIVERSITY OF BIRMINGHAM, UK);

M. LILLEVANG-JOHANSEN (DEPARTMENT OF ENDOCRINOLOGY AND METABOLISM, ODENSE UNIVERSITY HOSPITAL, ODENSE, DENMARK);

K. NIRANTHARAKUMAR (HONORARY CONSULTANT IN PUBLIC HEALTH MEDICINE, UNIVERSITY OF BIRMINGHAM, UK);

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The concept of a “normal range” for thyroid blood results has preoccupied scientists, doctors and thyroid patients for some time. It is the test which ultimately decides whether you are on one side of the fence or the other with considerable consequences either way (Jonklaas and Razvi, 2019). The usual way of deciding what is normal is based on picking a population of individuals that have no evidence of a condition (e.g. no history of thyroid disease), taking blood samples and measuring the parameter of interest. “Normal” is defined as values that are within 95% of the range (Figure 1).

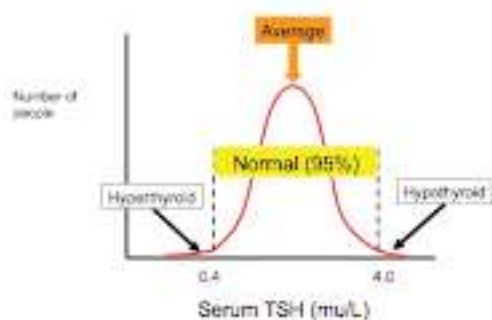


Figure 1: Thyroid Stimulating Hormone (TSH) levels in a normal population.

This is a standard, established, and statistically reliable way of identifying what is abnormal. It has served science and medicine well. This is exactly how doctors can work out if a child is growing normally, whether patients with certain cancers are responding to treatment, or whether we are running seriously short of a vitamin. But there are exceptions and still 5% of normal people will have a value outside the range. Doctors are used to this, and with some knowledge and experience they can interpret abnormal results by putting facts in the right context. If we focus on detail too much, we

can miss the obvious. Imagine that you are looking out into a busy street through a shop window. A frail looking person is hobbling along with a stick. Another passer-by pushes her to the ground. You assume that the passer-by is a thieving criminal. But you have missed the fact that around the corner a motorcyclist having lost control was heading towards a deadly collision with the frail person and in fact the passer-by saved a life. Being alert and aware of the bigger picture helps reach more valid conclusions. How do doctors apply these principles in their daily practice? It's nothing fancy: just by using the incredible power of listening to patients (the history taking) supplemented by an examination and additional investigations if appropriate. Alas, in real life shortcuts are too frequent and it is disheartening to hear of patients' experiences with doctors falling short of this basic expectation, especially not being listened to. It is one of the major reasons why mistrust between some hypothyroid patients and doctors dominates discussions in patient forums and blogs.

The TSH (thyroid stimulating hormone) blood test is used widely in order to diagnose thyroid diseases such as hypothyroidism. Besides it being a diagnostic test, it is also used as a means of assessing whether a hypothyroid patient is on the right dose of thyroid hormones. The American Thyroid Association (ATA) guidelines on hypothyroidism (Jonklaas et al, 2014) state: **“Levothyroxine replacement therapy has three main goals. These are (i) to provide resolution of the patients' symptoms and hypothyroid signs, including biological and physiologic markers of hypothyroidism, (ii) to achieve normalization of serum TSH with improvement in thyroid hormone concentrations, and (iii) to avoid overtreatment (iatrogenic thyrotoxicosis), especially in the elderly”**. The strength of recommendation for this conclusion was classified as “Strong recommendation. Moderate quality evidence”. You will have noticed that normalisation of the TSH test is a major objective in patients on thyroid hormone replacement according to the American Thyroid Association. There are some scientifically valid reasons that challenge the assertion that a normal TSH should be applied as a criterion not just for diagnosing hypothyroidism, but also for judging that a person is optimally treated with thyroid hormones. In fact, some experts have gone as far as to doubt the value of serum TSH in patients treated for hypothyroidism (Hoermann

(continued on page 12)

## Out of Range... (continued from page 11)

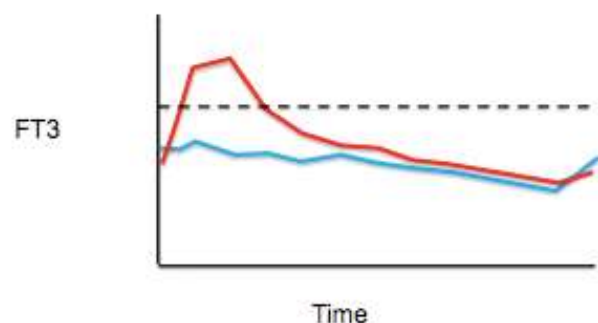
et al, 2019) and place more emphasis on how the patient feels. This has been eagerly adopted by some patient groups to the extent that a low TSH is regarded as trivial and of no consequence (HealthUnlocked, 2019).

Science and Medicine usually progress in small steady steps. So the first question is: if we compare untreated patients with mild hypothyroidism (otherwise known as “subclinical hypothyroidism” when the TSH can be as high as 10 or even 20, but with normal free T<sub>4</sub> levels), and we follow these patients for years, does anything bad happen to their health? Such studies have been performed and the evidence was summarised in a publication by Rodondi et al, (2010). They looked at patients who had mild hypothyroidism and compared them with normal people with no thyroid disease and normal TSH. Mortality from all causes and from cardiovascular disease were greater in patients with raised serum TSH who were untreated with thyroid hormones. This is the evidence that led the American Thyroid Association to conclude that normalising the serum TSH in hypothyroid patients treated with thyroid hormones is to be recommended. The sceptics may still be unconvinced and insist that this is not a fair comparison and that the situation may be very different in patients who are on thyroid hormone treatment, a scenario where the conventional definition of normal range may not apply. Well, we now have some additional powerful evidence on this very topic. In the last two years two very large observational studies from two different countries (Denmark and the United Kingdom) looked at what happens to hypothyroid patients who are on treatment with levothyroxine in terms of their long-term health and correlated that with the level of TSH that they achieved (Lillevang-Johansen et al, 2018, Thayakaran et al, 2019).

The Danish study (Lillevang-Johansen et al, 2018) was a register-based cohort study of 235,168 individuals who had at least one measurement of TSH in the period 1995-2011. The study investigated the risk of mortality in individuals with biochemically verified hypothyroidism, both treated and untreated, compared to euthyroid individuals. Due to access to repeat measurements of TSH, it was also possible to investigate the effect of duration of hypothyroidism (undertreatment) and hyperthyroidism (overtreatment) on mortality. The study found a 5% increased risk of mortality in both treated and untreated individuals for every six months of hypothyroidism. When considering duration of hyperthyroidism in treated individuals as a measure of overtreatment, there was an increased mortality risk of 18% per six months of hyperthyroidism. These results stress the need for monitoring of hypothyroidism and the treatment thereof.

In the UK study (Thayakaran et al, 2019) researchers explored whether certain levels of TSH in patients with an underactive thyroid would increase their risk of death or illness, such as cardiovascular disease and broken bones. They used anonymous records for 162,000 patients diagnosed with hypothyroidism from general practices (GPs) across the UK. Patients’ records were followed over a 22-year study period, and their TSH concentrations were used to analyse mortality and health outcomes. The research team found that in hypothyroid patients whose TSH levels were in the range recommended in current guidelines, there was no evidence of negative long-term health outcomes. However, the study suggested that if levels were below or above the current ‘normal’ range then the risk of death or illness was increased. Patients whose serum TSH was in the middle of the normal range had a lower risk of death than those with a TSH of more than 4 mU/l or less than 0.4 mu/l. In addition, risk of ischaemic heart disease, heart failure, and fragility fractures were increased at TSH concentrations above the recommended upper limit (greater than 4 mu/L), compared to the middle of the normal range.

Here we have two different large, independent studies coming to similar conclusions. Hypothyroid patients on levothyroxine who have a TSH value outside the normal range are more at risk of death and cardiovascular disease. Has this issue been completely settled? The answer is “no”. In order to nail it and prove a cause and effect relationship, we need a prospective randomised double-blind controlled study. Patients will be randomly allocated to receive different doses of levothyroxine and the dose adjusted to achieve and maintain the serum TSH levels within, above or below



**Figure 2:** Free T<sub>3</sub> levels (upper limit shown as the interrupted horizontal line) in patients taking combination treatment of levothyroxine and T<sub>3</sub> (red line) compared to patients taking levothyroxine only (blue line) over a 24 hour period (from Saravanan et al, 2007).

(continued on page 13)

## Out of Range... (continued from page 12)

the normal range. Such a study has been performed, except that it was not sufficiently long to determine outcomes such as mortality or cardiovascular events, but it is worth noting its findings. It was a prospective randomised controlled trial (Samuels et al, 2018) in patients with hypothyroidism who had their dose of levothyroxine altered so that the serum TSH changed over a range from 0.78 up to 9.5. These fairly large changes in blood tests had no impact on quality of life, mood, or cognition. This is a remarkable finding which shows how poorly symptoms correlate with TSH levels and therefore how misled one can be by only taking into account symptoms. A similar study design to that of Samuels et al (2018) but with a follow-up of several years is needed to settle the question of long-term effects on health for good. It will require thousands of participants, a huge amount of resources and will probably never be given the green light by Ethics Committees, because the evidence is already very strong that having a serum TSH outside the normal range in people with hypothyroidism may be detrimental to long-term health.

## Conclusions

So, what does this mean for people with hypothyroidism? For those who have a normal serum TSH, it will be reassuring. For those who are outside the normal range because they forget to take the tablets, one hopes it will provide an incentive to remember to take the pills. For those who are convinced that they feel better when the serum TSH is low, it may come as an unwelcome surprise. But good quality information is always worthy of spreading even if it contradicts our previous experiences and beliefs, because it helps make good decisions. The studies by Lillevang-Johansen et al (2018) and Thayakaran et al (2019) do not apply to patients who are on combined levothyroxine and liothyronine (T3) treatment, T3 alone or animal thyroid extract. While on these alternative treatments the serum TSH may be normal (Saravanan et al, 2007, Celi et al, 2011, Hoang et al 2013), it is accompanied by wide fluctuations in Free T3 (FT3) levels often exceeding the upper limit of normal (*Figure 2*). In these cases we have very little information on long-term safety, but there are reasons to be concerned that the highly unnatural fluctuations in FT3 levels, often exceeding the normal range, may turn out to be detrimental to health.

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# U.S. Food and Drug Administration approves TEPEZZA for TED

On January 21, the U.S. Food and Drug Administration (FDA) approved teprotumumab-trbw (sold as TEPEZZA™) for the treatment of adults with thyroid eye disease (TED). The FDA granted the approval of Tepezza to Horizon Therapeutics Ireland DAC. TEPEZZA™ is the first drug approved specifically for the treatment of TED.

Wiley Chambers, M.D., deputy director of the Division of Transplant and Ophthalmology Products in the FDA's Center for Drug Evaluation and Research noted, "Today's approval marks an important milestone for the treatment of thyroid eye disease. Currently, there are very limited treatment options for this potentially debilitating disease. This treatment has the potential to alter the course of the disease, potentially sparing patients from needing multiple invasive surgeries by providing an alternative, non-surgical treatment option...this approval represents important progress in the approval of effective treatments for rare diseases, such as thyroid eye disease." (1)

## A Discovery Two Decades In The Making

The science behind TEPEZZA™ originated in 2000 in a laboratory at the University of California Los Angeles, led by Dr. Terry Smith, who now serves as Frederick G.L. Huetwell Professor of Ophthalmology and Visual Sciences and Professor, Department of Internal Medicine at the University of Michigan. (Dr. Smith is also Chief Medical and Scientific Officer for the GDATF). Dr. Raymond Douglas, a member of the GDATF's Physician Advisory Board, was also part of the research team.

In Graves' disease, the immune system (which usually protects against infection) begins believing that the receptors for TSH and insulin-like growth factor (IGF-I) are foreign and generates antibodies against "self". Although most research on Graves' disease has focused on the TSH receptor, Dr. Smith and his team at UCLA discovered that the IGF-I and the TSH receptors are physically and functionally connected – and that if you block the IGF-I receptor you can also block the signaling initiated at the TSH receptor.

In May 2017, the New England Journal of Medicine published «Teprotumumab for Thyroid-Associated Ophthalmopathy». The authors included Dr. Smith, Dr. Douglas, and Dr. George Kahaly, another GDATF Physician Advisory Board member. The paper detailed results from a Phase 2 trial of teprotumumab,

which found that patients had a significant reduction in eye symptoms after treatment with Teprotumumab compared to placebo. (2) Based on the findings from this Phase 2 trial, the U.S. Food and Administration (FDA) designated teprotumumab a "breakthrough therapy" for TED. (The designation was originated by the FDA in 2012 to help expedite clinical research studies on new drugs where "preliminary clinical evidence indicates that the drug may demonstrate substantial improvement over existing therapies.") (3)

A Phase 3 trial was initiated, with participating sites located around the United States, as well as Germany and Italy. In February 2019, Horizon Therapeutics announced main results, reporting that the study found more patients treated with teprotumumab compared with placebo had a meaningful improvement in proptosis (eye bulging). (4)

In December 2019, The Dermatologic and Ophthalmic Drugs Advisory Committee of the FDA voted unanimously in favor of recommending approval of a biologics license application for teprotumumab. (This vote did not constitute the final approval, but was an important step in the process.) The vote followed a robust discussion in which committee members expressed concern about the small Phase 3 study population (90 patients). Side effects were also discussed, and committee members expressed particular concern about reports of hearing loss and the need for glucose monitoring. However, at the end of the day, the vote was 12-0 in favor of approval. Committee Chair James Chodosh, MD, MPH, D.G. Cogan Professor of Ophthalmology at Harvard Medical School, Associate Director of Cornea Service at Massachusetts Eye and Ear noted, "I don't say this about every disease, but I hate this disease...it is a devastating problem for patients. This is a disease that we need to do something for. This is a bad disease, and it has a tremendous impact on people's lives. Though the numbers were small, the data presented were quite remarkable for a clinical trial." (5)

Full trial results were published in January 2020 in the New England Journal of Medicine. The authors (which included Dr. Smith, Dr. Douglas, and Dr. Kahaly) noted, "Among patients with active thyroid eye disease, teprotumumab resulted in better outcomes with respect to proptosis, Clinical Activity Score, diplopia, and quality of life than placebo." (6)

(continued on page 15)

## TEPEZZA (continued from page 14)

Of the patients who were administered TEPEZZA™, 83% in the Phase 3 trial demonstrated a greater than 2 millimeter reduction in eye bulging as compared to 10% of subjects who received a placebo. (6) In an April 2019 presentation at the American Association of Clinical Endocrinologists 28th Annual Scientific and Clinical Congress in Los Angeles, CA, Dr. Douglas noted that a 2 millimeter reduction is visible to the naked eye, with a typical orbital decompression surgery providing 3-4 mm of reduction. (7) However, decompression surgeries are typically performed after fibrosis may have developed, while TEPEZZA™ is usually administered earlier in the disease course.

### Safety Profile

Adverse events were mild or moderate in severity during the Phase 3 trial; two serious events occurred in the teprotumumab group, of which one (an infusion reaction) led to treatment discontinuation. (6)

The most common side effects of TEPEZZA™ include muscle cramps or spasms, nausea, hair loss, diarrhea, feeling tired, high blood sugar, hearing problems, taste changes, headache, and dry skin. Women who are able to become pregnant should use an effective form of birth control (contraception) prior to starting treatment, during treatment and for at least 6 months after the final dose of TEPEZZA. (8)

### What's Next for Patients?

With the FDA approval, doctors in the USA can now prescribe TEPEZZA™. The medication is administered via infusion, meaning that it is delivered via a needle inserted into the arm. Infusions are typically given by registered nurses (RNs), nurse practitioners, (NPs), or another medical professional and can be administered in a number of settings, including a hospital, doctor's office, stand-alone clinic, and home setting. Your provider – and your insurance company – can help you decide which setting is right for you.

The amount of TEPEZZA™ that is administered is based on weight. The medicine is delivered via eight infusions, with three weeks in between infusions. The first two infusions are expected to take 90 minutes, with the remaining infusions expected to take 60 minutes, although this can vary by patient. (8)

Out-of-pocket costs will depend on the patient's insurance company and plan. Financial assistance programs are available for those with need; please consult with your own provider about available programs.

For safety information, full prescribing information, and patient resources visit TEPEZZA.com. The site also lists a phone number for TED Nurse Advocates (not affiliated with the GDATF): 1-833-483-7399.

The GDATF has received unrestricted educational grants from Horizon Therapeutics, but maintains editorial independence over all published content.

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# Animal Models in Thyroid Eye Disease Research

ALON KAHANA, MD, PHD

In order to cure thyroid eye disease, we need to understand it. Medical scientists typically utilize laboratory animals to study disease and test therapies. The most commonly utilized research animals are the mouse, rat, rabbit and zebrafish.

Unfortunately, while animals can have thyroid disease, they do not naturally develop thyroid eye disease. Hence, scientists have needed to generate thyroid eye disease in the lab. Recently, a research team in the United Kingdom developed a mouse model of thyroid eye disease by injecting thyroid proteins.

In Michigan, scientists have utilized zebrafish to study the molecular signals that regulate orbital inflammation and the response to extraocular muscle injury. Importantly, scientists have used these models as well as cells and tissues from patients to study the biology of thyroid eye disease.

Such studies have already led to the development of a novel therapy, teprotumumab, a targeted therapy that was recently approved by the FDA for treating active thyroid



Dr. Kahana holding a tank of zebrafish.

eye disease. Studies that utilize laboratory animals such as mice and zebrafish are critical to the development of even more powerful therapies, with an eye to prevention and cure.

*Dr. Kahana is a Professor of Ophthalmology at Oakland University William Beaumont School of Medicine in Michigan, U.S.A., and Director of the Michigan Center for Thyroid Eye Disease and Orbital Surgery, based in Livonia, Michigan.*

## Celebrating 25 years of TFI – Historical Photos



First TFI booth during the 24th annual meeting of the European Thyroid Association in Munich, 1997.



Ralph Abramsky, Diana Abramsky – TFI Founder, and June Rose Beaty – Editor from 1998-2008 (Toronto 1995).





# T4 plus T3 therapy: a Fad or the Future?

## Summary of a Talk given at the European Thyroid Association Meeting in Budapest, Hungary September 2019

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A small minority of patients (5-10%) with hypothyroidism treated with levothyroxine (LT<sub>4</sub>) monotherapy (i.e., LT<sub>4</sub> only), have diminished psychological “well-being”, depression, difficulty with concentration, and other nonspecific symptoms compared to the general healthy population. The cause of these symptoms is unknown, but attention has recently been directed toward the possibility that LT<sub>4</sub> monotherapy is not a “thyroid transplant”, and may not be the ideal treatment for all hypothyroid patients. T<sub>3</sub>, not T<sub>4</sub> is the biologically active thyroid hormone, and 80% of daily T<sub>3</sub> production arises from removal of one iodine atom from the T<sub>4</sub> molecule to form T<sub>3</sub>. This occurs in peripheral tissues in the body like the liver, kidneys, and muscles.

Some patients taking LT<sub>4</sub> alone have higher circulating levels of free T<sub>4</sub> and lower circulating levels of free T<sub>3</sub> than found in normal healthy controls. This suggests the possibility of inefficient conversion of T<sub>4</sub> to T<sub>3</sub> in various tissues in the body. Some research studies have suggested that hypothyroid patients who have a specific genetic makeup may be at highest risk for this problem.

The control of conversion of T<sub>4</sub> to T<sub>3</sub>, and the entry of T<sub>4</sub> into body cells, is regulated by specific proteins within different body tissues. Proteins are derived from genes, which are made of DNA, in the cell nucleus. Genes are “translated” into proteins in the body’s tissues, and these proteins affect the function of the cells in those tissues. Each protein has a specific gene that “codes” for it. Not all genes are identical from person to person and there are minor variations in certain genes called “polymorphisms”. These polymorphisms may lead to slight variations in the proteins that they code for, leading to slight differences in how the protein “works” in the cells that control various body functions. In the case of T<sub>4</sub>, a polymorphism in the gene that codes for the protein that removes an iodine atom from T<sub>4</sub> to form T<sub>3</sub> (a so-called deiodinase enzyme), may be slightly more inefficient compared to the “normal” deiodinase enzyme. Thus, it is possible that patients taking LT<sub>4</sub> who have persistent symptoms, might feel this way because their tissues are unable to generate an adequate amount of T<sub>3</sub> from the T<sub>4</sub> that they are taking to achieve a blood T<sub>3</sub>

level to be “normal” for that person. This has led to the idea that taking T<sub>3</sub> in addition to T<sub>4</sub> might normalize the T<sub>3</sub> level and improve patients’ symptoms.

Unfortunately, it has been very difficult to prove scientifically that combination therapy with T<sub>4</sub> plus T<sub>3</sub> improves psychological or physical well-being in symptomatic patients taking T<sub>4</sub> alone. Randomized blinded controlled trials comparing T<sub>4</sub> alone versus T<sub>4</sub> plus T<sub>3</sub> have failed to show improvements in how people feel when they take combination therapy. However, few of the studies have included only those patients who actually have symptoms, or who have T<sub>3</sub> levels that are at the low end of the normal range.

At one time, the prescription of combination T<sub>4</sub> plus T<sub>3</sub> therapy to patients was not considered to be based on scientific evidence. However, clinicians are now more willing to try combination therapy in those patients who have continuing nonspecific symptoms on T<sub>4</sub> monotherapy. In my own personal experience, results of switching from T<sub>4</sub> monotherapy to combination T<sub>4</sub> plus T<sub>3</sub> therapy are mixed: some people note improvement in their sense of well-being immediately; some note no improvement or even a worsening in anxiety symptoms; and some feel improved for a few months, but then their symptoms recur despite continued combination therapy.

Professional organizations of thyroid specialists including the European Thyroid Association, the American Thyroid Association, the British Thyroid Association, and the Italian Thyroid Association all recommend levothyroxine monotherapy as the mainstay of treatment of hypothyroidism. However, in contrast to previous position statements and guidelines, they now all say that a trial of T<sub>4</sub> plus T<sub>3</sub> combination therapy is reasonable in patients with persistent nonspecific symptoms on T<sub>4</sub> monotherapy. Future research should provide a stronger scientific basis for using T<sub>4</sub> plus T<sub>3</sub> combination therapy in treating hypothyroidism.

One of the problems in treating patients with T<sub>3</sub> is the lack of a long acting T<sub>3</sub> preparation. With currently available T<sub>3</sub> tablets, levels of T<sub>3</sub> are not consistent in the bloodstream and therefore the medication needs to be taken two or three times a day. It is likely that a longer acting T<sub>3</sub> preparation will become available that will allow us to treat patients with T<sub>4</sub> plus T<sub>3</sub> therapy that will be more aligned with normal body thyroid hormone production.

# #MOTHERBABYIODINE

## An Awareness Campaign to Decrease Worldwide Iodine Deficiency

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In last year's ThyroWorld, I wrote an article about the MotherBabyIodine project in which TFI, together with WIA, IGN, GAIN, EMA and EPMA was initiating. I am happy to report that this is ongoing and moving forward. Another prestigious NGO has joined the project as well – Nutrition International.

TFI, together with its leaders, feel that this initiative is a significant means to bring attention to the extent and consequences of Iodine Deficiency Disorders (IDD) in pregnant women and women of reproductive age which continue to affect both developed economies and countries in development.

Iodine Deficiency during pregnancy results in adverse health effects not only to the mother but more so to the child during its first 1000 days of life beginning from conception. The mother with IDD and consequent hypothyroidism will give birth to a child threatened with cretinism and growth retardation. Severe iodine deficiency can reduce IQ by 10-15 pts but even mild iodine deficiency reduces IQ by much less (5 pts or less).

Not enough attention has been raised to the public and especially to women of reproductive age and pregnant women on the importance of why adding iodine (in various forms) to their diets to eradicate IDD is important. This is why an awareness campaign was thought to be a vital channel to bring attention to the general public.

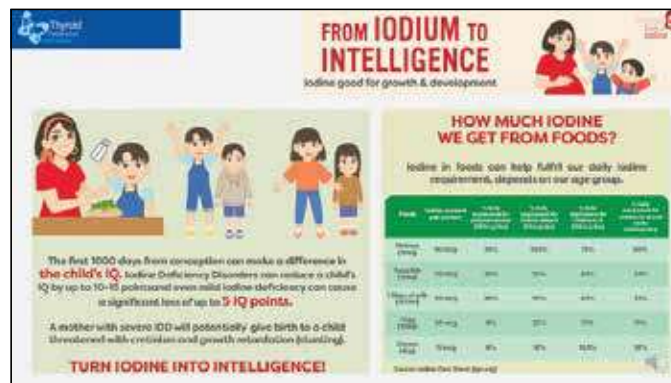
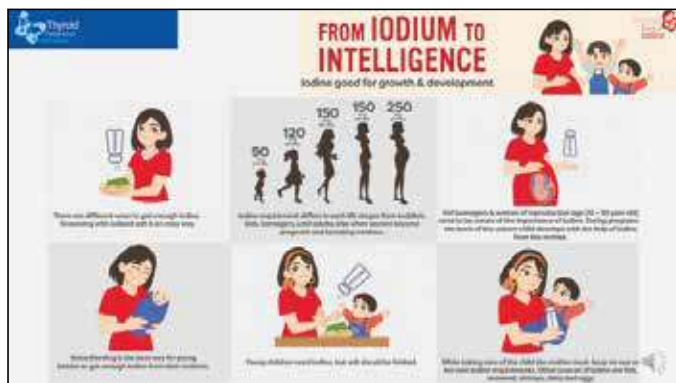
This year, the Project kick started in Indonesia, a country that is severely affected by iodine deficiency. With support from Unilever, we were given space in their local NutriMenu campaign. This campaign is geared to educate the public on the safety and efficacy of the use of iodized salt to prevent Iodine Deficiency. The aim is to reach a target of at least 1,5 million mothers and teenagers.

In the meantime, we have received interest from many other countries in Southeast Asia – just to name a few: Bangladesh, Thailand, Taiwan, Sri Lanka, Vietnam, Papua New Guinea, Cambodia, South Korea, as well as several African countries ... and we look forward to working with their representatives.

The goal that we are all aiming for will be an increased awareness of IDD and the importance of iodine fortification. It is important that pregnant women and women of reproductive age be aware where iodine can be sourced from in terms of food. We anticipate that healthcare workers, policy makers, as well as family share/ spread this knowledge with the target population.

For more information:

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# Levothyrox formula change: “bioequivalent” doesn’t mean “switchable”

CATHERINE HILL, MARTIN SCHLUMBERGER  
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The French medicines agency asked Merck to improve the stability of its levothyroxine formulation (Levothyrox®). The pharmaceutical company complied by introducing a new formulation to the market in the spring of 2017. At this time, Levothyrox® was the only brand of levothyroxine as a solid formulation on the French market. It was prescribed for approximately 3 million patients. Numerous unwanted side-effects of the new formulation were notified shortly after its introduction. The French authorities and the drug company downplayed the expressed concerns, which they attributed to a miscommunication with the patients. In 2019, a publication<sup>1</sup> suggested that the statistical analysis of the bioequivalence (BE) study comparing the two formulations of Levothyrox®, as conducted by Merck,<sup>2</sup> did not suffice to ensure the switchability of the old formulation (OF) with the new formulation (NF); the latter intended to replace the former. For transparency reasons, the raw (individual subject) data from this BE trial were released online by the French Authorities.<sup>3,4</sup> This allowed us to deploy this complicated problem as a tutorial presentation.<sup>5</sup>

Merck had studied the BE of its two formulations of levothyroxine by giving them, successively and in a random order, to 204 healthy volunteers. Nineteen blood samples per subject were taken: three before drug administration (30 minutes, 15 minutes and immediately before) and 16 commencing 30 minutes after drug administration and final samples taken 72 hours later ( $t_{72}$ ). For each subject and each formulation, the three plasma thyroxine concentrations obtained before Levothyrox® administration were averaged to indicate the basal endogenous concentration of levothyroxine.

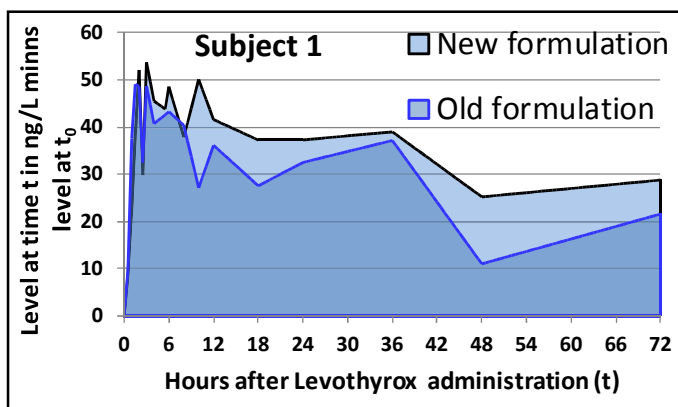


Figure 1: Thyroxine concentration (ng/mL) at time t minus basal concentration for the first subject.

This baseline levothyroxine concentration was subtracted from measured concentrations following administration of the two Levothyrox® formulations. This difference indicated the net contribution of the drug (in OF and NF) to plasma levothyroxine concentrations. **Figure 1** illustrates the plasma thyroxine concentration at the 16 sampling times for the first subject, after subtraction of basal concentrations, as recommended by the European (EU) Authorities. From these derived data, one can compute, for each formulation and each subject, the Area Under the Curve (AUC) of thyroxine concentrations. This area directly measures the relative bioavailability of levothyroxine for each formulation.

## Analysis of the average bioavailability, as conducted by Merck, is neither conclusive nor sufficient

Merck submitted to the French agency an analysis, comparing the average levothyroxine bioavailability of the NF, for the 204 subjects, to the average bioavailability of the OF in the same 204 subjects. They concluded that the two formulations were, in average, bioequivalent. This data analysis did not take into account the fact that an irreversible replacement of the OF by the NF was going to be imposed on almost three million French patients. Merck simply followed the European guideline on BE. However, they ignored the key consideration that this guideline is not intended to demonstrate, for individual subjects, switchability between two formulations, but only the prescribability of a new product (formulation). Prescribability refers to the choice between two possible marketed products: typically between a new generic and the pioneer product when initiating a treatment in a naïve patient. Switchability differs fundamentally: for this French situation, it refers to the irreversible substitution in a patient who is already being treated and well controlled with the OF by the NF. The EU guideline does not address formulation switchability to support a substitution – simply because substitution policy is a national issue, not one regulated by the EU. A more appropriate trial would have involved comparing the individual subject AUC for the NF and OF. To conclude an individual BE of the two formulations (as opposed to the average BE) the differences between the two formulations must be close to zero for each subject. **Figure 1** shows the time course of levothyroxine concentration with each formulation for the first subject in the study, as a specimen example.

(continued on page 20)

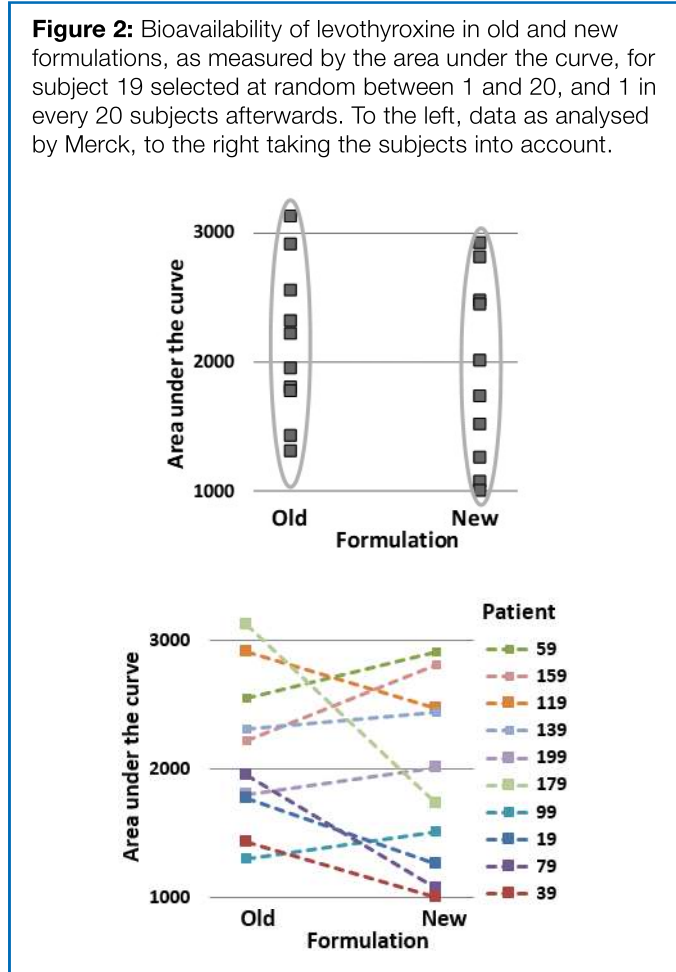
Levothyrox® formula change... (continued from page 19)

Patient's number	Old formulation a	New formulation b	Difference (b- a)/a
19	1772	1265	-29%
39	1429	1003	-30%
59	2556	2914	+14%
79	1952	1073	-45%
99	1306	1515	+16%
119	2913	2472	-15%
139	2316	2446	+6%
159	2218	2807	+27%
179	3122	1729	-45%
199	1800	2008	+12%

**Table:** Values of area under the curve from the basal value, for 10 subjects selected every 20 subjects starting from a number taken at random between 1 and 20.

The **Table** and **Figure 2** present the AUC data for 10 patients. **Figure 2A** shows the data as analysed by the drug company, i.e. comparing the two averages. **Figure 2B** shows the same data, taking the subjects into consideration.

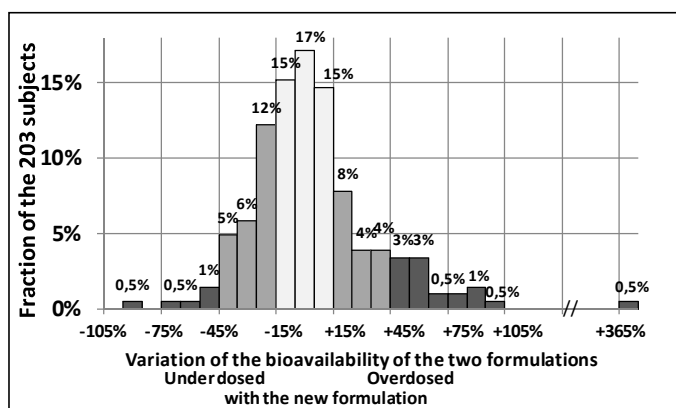
Considering the 204 subjects, the individual differences between the two formulations for the AUC ranged from -89 % to +100 % (plus one extreme value of 369 %), demonstrating an important level of individual variability for the relative bioavailability of the two



formulations from one subject to another. **Figure 3** shows that, with the new formulation, 26 % of the subjects were underdosed by at least 15%, and 27 % were overdosed by at least 15%; 2.9 % of subjects were underdosed by at least 45% and 11% were overdosed by at least 45%. This analysis demonstrates the importance of within-subject variability in considering the relative bioavailability of the two formulations. The daily dose of levothyroxine, generally between 50 and 150 ug, is usually adjusted by steps of 25 or even 12.5 ug/d; in this respect, a sudden overdose of 45% is indeed considerable.

In their second article,<sup>6</sup> Concordet et al explained that by planning an average BE trial with more than 200 subjects, Merck admitted knowing, à priori, that there was a large intra-individual variability for its formulations. Indeed, most BE trials are conducted with a number of subjects ranging between 24 and 36, this number being generally sufficient to demonstrate an average BE. On the other hand, when the intra-subject variability is large, a greater number of subjects is needed to successfully demonstrate an average BE. This is because it is the confidence interval of the difference (or of the AUC ratio) of the two formulations which must meet the regulatory requirements – and the confidence interval, all other things being equal, becomes smaller as the number of subjects used in the trial increases. The EU regulatory authorities set the limits, within which the calculated confidence intervals must be enclosed. For a drug with a narrow therapeutic margin, like Levothyrox®, the limits are set at -10% /+ 11%. This a priori interval is narrower than that used for most drugs, for which they are set at -20 /+ 25%. This narrowing of the limits is said by the EU Authorities to be a precautionary measure for drugs with narrow therapeutic margins. In fact, it is not. By simply increasing the number of subjects, it is always possible to encompass between these limits, when the difference between the means of the formulations does not exceed 10%. From a patient perspective, this is unacceptable. As **Figure 3** illustrates, for many patients the difference can reach 45% even when the means are practically equal. It is specifically to avoid this situation that the FDA now requires – in its guideline on levothyroxine<sup>7</sup> – that, in comparing the bioavailability of two formulations of levothyroxine, not only the means of the two formulations, but also their intra-individual variances must be compared. This requires the adoption of a more complicated experimental design, involving repeating twice the administration of each formulation. It is then possible to evaluate the intra-individual variance for each formulation. It is our firm opinion that such a protocol must now be implemented as an essential requirement at European level. We acknowledge that this BE study in healthy volunteers does not itself provide evidence that the symptoms experienced

(continued on page 21)



**Figure 3:** Distribution of differences in bioavailability between the two formulations of Levothyrox for the 204 subjects. For 17 % of the subjects, the two bioavailabilities differed by less than 5 %.

by many patients, after introduction of the new formulation, were related to an over- or an under-dosing of the drug. However, the comparison of the bioavailabilities of the two formulations within each subject reveals that some individuals may be facing a large change in drug exposure with the new formulation. The data therefore support the hypothesis of a causal relationship between the adverse effects and the formulation switch from the OF to the NF, in at least some patients.

Instead of being warned of the possible difference in the bioavailability of the two formulations and advised to consult their doctor in case of any concerns, patients who complained of adverse effects were told that the problem was “only a communication problem” – or even a “nocebo effect”.

### Final comment on our request for information from Merck

We wrote to the first author of the Merck<sup>2</sup> paper describing the analysis conducted by the company,<sup>2</sup> querying that analysis. The reply was that the analysis had been conducted “as required by the Authorities”, and this is confirmed by Concordet et al.<sup>1</sup> It therefore seems that the Authorities encouraged Merck to correctly answer an irrelevant question – the relevant questions being: “is it acceptable to switch 3 million stable / euthyroid patients from the old to the new formulation and what test should be done to support this switch?”

There have been other occasions when a drug company has placed responsibility on the requirements of the regulatory authorities: for instance, Sanofi explained its lack of information on the teratogenicity of sodium valproate – despite numerous signals demonstrating an 11% risk of malformation and a 30% to 40% risk of neurodevelopmental problems - by stating that it followed the recommendations from the regulatory agency.<sup>8</sup>

And Merck persists, even now, in this strategy by stating that “the equivalence of the two formulations has been studied according to the approach required by the European authorities” – but omitting to acknowledge that a guideline is not set in tablets of stone. It is a non-binding document, which aims at facilitating European harmonization in BE studies. Any company can perfectly well adopt an alternative protocol, provided it is scientifically justified and when, manifestly, it is in the best interests of future patients.

### Conclusion

We conclude that Merck has not demonstrated that the substitution of its OF by its NF, in a monopoly situation, has been done with adequate safety conditions for a majority of patients in mind. We propose that the European Authorities now seriously consider the American guideline for adoption in the EU. Had it been implemented in this case, it would very probably have confirmed that the two formulations were bioequivalent “on average”, but would also have demonstrated that they were not “switchable”.

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- 3 Agence nationale du médicament et des produits de santé. *Levothyrox.* <http://bit.ly/2WpwyCZ>
- 4 Agence nationale du médicament et des produits de santé. *Levothyrox. Bioequivalence trial of new Levothyrox formulation versus old formulation.* <http://bit.ly/2IkM8R> (page 442)
- 5 Hill C, Schlumberger M. *Les deux formules du Levothyrox sont-elles bioéquivalentes ?* La Revue du Practicien, oct. 2019, 2°10 ;69(8) :831-37
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# Access to Medication for MCT8 Deficiency Affected Children

## How “drug repositioning” may restrict access to essential medication

VERONICA POPA

PRESIDENT OF THE MCT8-AHDS FOUNDATION, ROMANIA

What happens when a medication that severely affected children rely on for their treatment is taken out of the market? The answer is simple, panic. This is what is happening within the MCT8-AHDS community at this point.

But let's start at the beginning. MCT8 Deficiency, also known as Allan-Herndon-Dudley Syndrome, is an X-link genetic disorder associated with lack of head control, central hypotonia, cognitive and motor disability, low bone density, dystonia and the list can go on. MCT8, the thyroid hormone transporter to the brain, is mutated and due to this the blood brain barrier does not allow it to pass into the brain and deliver the hormones. As a result, the body fights severe thyrotoxicosis, while the brain is left to develop without thyroid hormones.

No cure exists for MCT8 deficiency - but what does exist is a forty years old substance called *tiratricol* (*triac*) that can reduce thyrotoxicosis and improve the symptoms associated with it. This active ingredient exists in only one commercial product within the European Union. The medication is called Teatrois and, until recently, it was produced in France. I'm using the past tense because this medication is being taken out of the market this year by the new company in charge.

The new owner, a Swedish company, Rare Thyroid Therapeutics, created a medication with the same active ingredient (Triac), same dosage, but a different name, *Emcitate*. The price per pill is very different as well; more than 35 times more expensive than it was three years ago when it was bought.

*Emcitate* is also not commercially available anywhere in the world yet, because it is not registered either with the EMA or with the FDA or any other authority. The producer intends to offer this medication ONLY through the Named Patient Basis procedure that does not exist in a lot of countries. Theoretically, through this procedure, the doctor in charge of MCT8 patients may write to the producer and ask them directly to deliver medication for the particular patients in his or her care. The health system pays, the patient gets the medication and everyone is happy.



Ondine Sherman, mother of three children, has released a memoir called *The Miracle of Love* – her journey about her twin sons' rare genetic disorder.

In the real world however, that doesn't happen as easily – or not at all. Early access schemes are in their very early stages in lots of countries, if they even exist – and limiting access to life impacting medication for severely affected children based on the questionable existence of one procedure alone is not only unreasonable, it is also economically unfeasible.

But this is only our community's story. There are lots of others; stories of anguish and desperation thinking of what tomorrow will bring for their children or for their loved ones. *Triac* is not only used to treat MCT8 deficiency. There are other patients that are impacted by this change. Among them are the patients with resistance to thyroid hormone, or needing to keep their TSH suppressed after thyroid cancer, the previous indication Teatrois had.

It's very easy to pick a fight when you feel wronged, because in some way you feel entitled to – but conflict has rarely reached desired resolutions for anyone. I understand that patient and pharma are organically connected; one cannot live or strive without the other. I'm a strong believer in collaboration, not conflict. This article is about viewing both sides of the coin and trying to find solutions that take into account the whole picture, not just pieces of it.

We don't have a solution regarding access to Triac for our community or for any other community at this moment, but we are doing our best to find one.

(continued on page 23)

## Access to Medication for MCT8 Deficiency...(continued from page 22)

If anyone reading this article has experience with these kinds of situations and how they can be solved, please do let me know. I'd like to hear your thoughts. Thank you!

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**MCT8 - AHDS  
Foundation**

*Ultra-rare syndrome*  
Striving for a cure. Empowering families

### NEWS FROM THE THYROID FIELD

## Patient Quality of Life and Satisfaction during Treatment for Hypothyroidism

DR. JACQUELINE JONKLAAS  
GEORGETOWN UNIVERSITY, WASHINGTON, DC

When patients are being treated with thyroid hormone for hypothyroidism, the goal of treatment is not only to make thyroid test results normal, but, more importantly, it is also to ensure that a patient feels well and is restored to their normal state of health. The standard treatment for hypothyroidism is levothyroxine. Levothyroxine provides the thyroid hormone T<sub>4</sub> to the patient and relies on the body's ability to convert T<sub>4</sub> into T<sub>3</sub>. The presence of T<sub>3</sub> is important as this is the active hormone responsible for thyroid hormone's action in cells.

Although population studies show that most patients feel well while taking levothyroxine, up to 15% of patients do not feel fully restored to health. The possibility that T<sub>3</sub> levels may be less than optimal in individuals who are dependent on taking levothyroxine, and that lower T<sub>3</sub> levels may be responsible for less effective treatment results, has led to physician and patient interest in "combination therapy". Combination therapy is given most usually by providing both levothyroxine and manufactured liothyronine (T<sub>3</sub>), or sometimes by providing an animal product, desiccated thyroid extract (also known as DTE), that contains T<sub>4</sub> and T<sub>3</sub>, but with a relatively large amount of T<sub>3</sub>. Fourteen studies of levothyroxine combined with liothyronine have not shown a consistent benefit of this compared levothyroxine therapy alone. One trial of desiccated thyroid extract compared with levothyroxine therapy alone has also shown no benefit for patients. However, each of these studies potentially had some weaknesses in the way that they were designed.

Survey type studies that seek information from patients about their quality of life while taking thyroid

hormone have allowed patients who do not feel well to share their experiences. One such study (Peterson et al. *Thyroid* 28 (6): 707-721, 2018) showed that those responding to the survey had significant concerns with their weight and their energy levels and reported impaired memory and concentration. When responses were broken down according to which type of thyroid hormones the patient was receiving, patients being treated with desiccated thyroid extract had significantly lower levels of concerns about these issues than patients being treated with synthetic T<sub>4</sub>/T<sub>3</sub> combinations or levothyroxine alone. Analysis of data from online patient forums shows similar trends with patients having greater preference for being treated with desiccated thyroid extract compared with other therapies. One concern with a full understanding of these data is that it is difficult to understand the impact that other medical conditions and willingness to share experiences may have had on the results.

Patient and physician interest in combination therapy remain high and although physicians wish to prescribe the thyroid hormone therapy that makes their patients feel most well, they are also worried about side effects of the potentially high T<sub>3</sub> levels in these therapies. There is an increased awareness of the importance of the outcomes reported by patients and patient preferences. The encouraging news is that better designed "combination therapy" studies are about to be launched in several countries. These studies are concentrating on examining "patient-reported outcomes" and are trying hard to avoid the design flaws of previous studies. They are also including desiccated thyroid extract among the therapies being studied. There is hope that the results of these studies will give us information to help us individually tailor thyroid hormone therapy so that it is safe and of maximum benefit to all patients.

# The Ecological Function of Thyroid Hormones

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Thyroid hormones are well known for their critical functions in human health as major regulators of metabolism, body temperature and heartbeat. Their role is so important that when the thyroid gland, which produces these hormones, is surgically removed for medical reason, it is then essential to get a substitute treatment that precisely deliver the necessary daily dose of thyroid hormones. This importance for human health tends to mask another major function of thyroid hormone in most vertebrates: the regulation of metamorphosis.

The use of this term immediately recalls the transformation of the aquatic and herbivorous tadpole into the terrestrial and carnivorous frog. It is known since the early XXth century that this spectacular and rapid transition is controlled by thyroid hormones. For example, one can induce this transformation by treating the tadpole with thyroid hormones. It is also possible to suspend this transformation by removing the thyroid or by blocking the action of thyroid hormones with specific chemical molecules, which can give rise to giant tadpoles that can survive for years.

More specifically, the metamorphosis of the tadpole into a frog is first marked by an increase of thyroid hormones levels in the thyroid gland. These hormones then navigate the whole body and bind to receptors that will turn on a specific metamorphosis program in each organ. Thyroid hormones are therefore the keys that control and coordinate the tadpole to frog

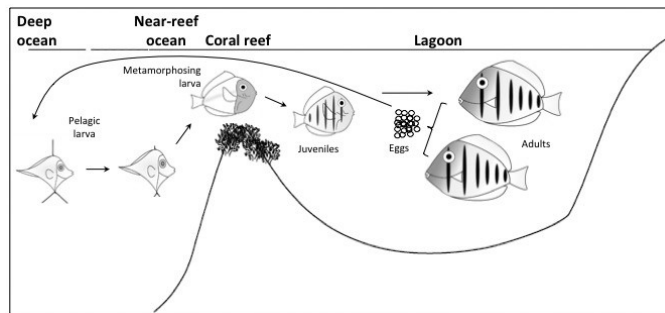


Figure 2: Typical life cycle of a coral reef fish, the surgeonfish *Acanthurus triostegus*.

metamorphosis, for instance by regulating the formation and growth of the legs, the disappearance of the tail and the transformation of the intestine.

The importance of thyroid hormones in animal metamorphosis is not restricted to amphibians. Indeed, most fish also undergo a metamorphosis controlled by thyroid hormones in their life cycle. This is the case for coral reef fish, whose larvae disperse and develop in the ocean before returning to the coral reefs to metamorphose in juveniles that will later grow into adult fish. The return of larvae to reef areas, or larval recruitment, is accompanied by important and rapid morphological, physiological and behavioral transformations: this is coral reef fish metamorphosis. In a few days or even a few hours, transparent larval fish transform into brilliantly colored juvenile fish (Figure). Metamorphic transformations are not limited to pigmentation as most often everything change: the shape of the fins and the orientation and organization of the jaw are changed, internal organs such as the intestine are remodeled, and external sensory organ rapidly develop. The behavior and the diet of the young fish is also transformed. Given the harsh competition and predation pressure existing in coral reefs, there is no room for

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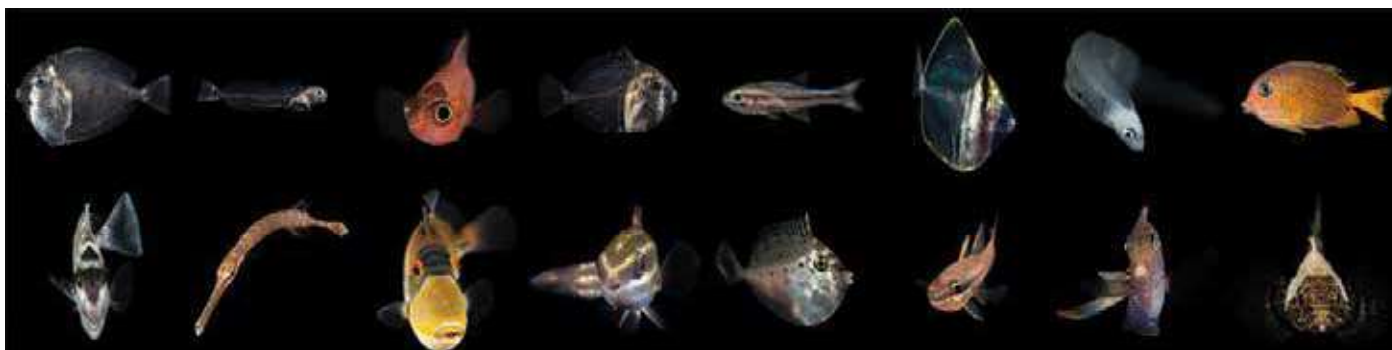


Figure 1: The diversity of larval stages of coral reef fish is fascinating.



## The Ecological Function of Thyroid Hormones *(continued from page 24)*

runts, and the metamorphosis stage is therefore critical for the survival of young fishes and ultimately for the replenishment of fish populations and stocks.

In our laboratory we are very interested in this ecological function of thyroid hormone and we use coral reef fishes to better understand how thyroid hormones mediate these morphological, physiological and ecological transformations. In collaboration with David Lecchini from the Center for Insular Research and Environmental Observatory (CRIOBE, EPHE, USR 3278) in French Polynesia, we showed that coral reef fish larval recruitment, a critical step in coral reef fish life cycle, corresponds to a metamorphosis controlled by thyroid hormones. We also observed that unlike the amphibian metamorphosis during which an herbivorous tadpole transforms into a carnivorous frog, the metamorphosis of herbivorous coral reef fishes involves thyroid hormones for the transformation of carnivorous larvae into herbivorous juveniles and adults. It is therefore particularly interesting to notice that the same thyroid hormones can regulate these totally inverted transformations. But most of all, given that over-abundant algae are detrimental to coral reefs as they compete with corals for space and photosynthesis, herbivorous fish play a very important

role in maintaining healthy reefs with a great coral cover, and this can be influenced by thyroid hormones during fish metamorphosis! More recently, we also observed that anthropogenic stressors such as increased temperature and a pesticide can alter thyroid hormone levels in larval fish, ultimately impairing their sensory systems and ability to avoid predators. Studying the role and importance of thyroid hormones in coral reef fishes can therefore provide critical information for the conservation of coral reefs.

Thyroid hormones are therefore important for human health, but they are also present in all vertebrates. In most of them, thyroid hormones play critically important roles for the completion of their life cycle. It is therefore important to understand their mode of action and their role not only in humans but also in these myriad other species. Coral reef fishes are fascinating models from a purely fundamental point of view, but they are most of all-important economic resources for many countries, and ecological models of broad importance in a world where coral reefs are among the most threatened ecosystems on the planet. Given that these species rely on thyroid hormones for the completion of numerous ecological processes, our research will allow to better understand the ecological role of thyroid hormones.

## Celebrating 25 years of TFI – Historical Photos



Group picture at the annual meeting of the TFC in Toronto, Canada, 1995, where TFI was founded.



**TFI 2009 Annual Meeting – Lisbon, Portugal, 2009:**

Taking a break from an intense and hardworking TFI meeting. (L to R) Standing: Peter Lakwijk, Netherland-Sweden; Harald Rimmel, Germany; Yvonne Andersson, Sweden, President TFI; Dr. Ulla Slama, Finland; Dr. Geraldo Medeiros-Neto, Brazil; Jytte Flamsholt, Denmark; Beate Bartès, France; Nancy Patterson, USA and sitting Ashok Bhaseen, Canada.



# Hypothyroidism Patient Experience Questionnaire

PETER LAKWIJK (TFI)

Two years ago Thyroid Federation International (TFI) and four leading international endocrinologists (Petros Perros- UK, Laszlo Hegedus - Denmark, Enrico Papini - Italy, and Endre Nagy - Hungary) came together to develop and implement an online questionnaire to understand the needs and experiences of those living with hypothyroidism and, in particular, patients’ satisfaction with treatment of hypothyroidism and the identification of any unmet patient needs.

The research is being carried out by Picker, a healthcare research charity in the UK, and the work is funded by Institut Biochimique SA (IBSA).

The questionnaire was tested in the beginning of this year with 30 patients by telephone interviews. Due to the pandemic, the 2nd “pilot” phase of the questionnaire was delayed and sent out at the end of June. The aim was to reach about 300 English speaking hypothyroid patients in the UK, Australia and Ireland to ensure that the questions were accurate and easily understood. TFI provided assistance with the recruitment and distribution of the survey.

By the beginning of August nearly 400 patients had answered the questionnaire and their answers are presently under evaluation.

In the autumn of 2020 the “full rollout” of the final questionnaire in at least 4 languages (French, German and Italian, Spanish) will be sent worldwide.

The survey is for all hypothyroid patients:

- Hashimoto or autoimmune disease
- Following radioactive iodine for Graves’ disease or a benign goitre
- Surgery for thyroid cancer
- Surgery for non-cancerous thyroid disease
- Medication used to treat another condition
- Pituitary disease
- Congenital hypothyroidism
- Iodine deficiency



The research project will seek to explore the following key research questions:

- What factors contribute toward satisfaction/ dissatisfaction with levothyroxine treatment for adults (aged 18 and over) with hypothyroidism?
- What are the perceived treatment barriers and enablers for successful levothyroxine treatment?
- What are the unmet treatment needs of those with hypothyroidism treated with levothyroxine?
- What associations can be drawn between demographics, comorbidities, personality, and tablet administration behaviours with satisfaction with levothyroxine treatment?

TFI hopes that all medical professionals will help spread the survey to their patients. If you are willing to help us, you can send an email to [linda.henderson@thyroid-fed.org](mailto:linda.henderson@thyroid-fed.org) or [peter.lakwijk@thyroid-fed.org](mailto:peter.lakwijk@thyroid-fed.org). As soon as the final “full rollout” of the survey begins, we will provide you with a link to the questionnaire that the patients can use and ad hoc “advertisements” with the link to the questionnaire.



**May 25th**  
**World Thyroid Day**



# Update in Thyroidology in Iran

Herewith, we briefly present some activities related to different topics of thyroidology in I.R. Iran, including updates regarding iodine nutrition, congenital hypothyroidism, and thyroid disorders especially hyperthyroidism.

## Iodine deficiency disorders (IDD) program in I. R. Iran

The first report of iodine deficiency, as a nutritional problem in Iran, dates back to 1968; however, prevention of IDD had not been implemented then. After the Islamic Revolution in 1978, the first nation-wide survey in 1988 revealed that all provinces of the country were suffering from endemic goiter. It was then recognized as a major health problem by the Ministry of Health in 1984. In 1990, salt factories began production of iodized salt and in 1996, the second national survey indicated that about 50% of school-aged children had goiter, and their median urinary iodine excretion was 205 µg/L. In the third national survey conducted in 2001, total goiter rate and median urinary iodine concentration (UIC) were 9.8% and 165 µg/L, respectively; the fourth national survey conducted in 2007, seventeen years after iodized salt consumption by Iranian households, showed that the total goiter rate had decreased significantly to 5.7% and median urinary iodine was 145µg/L. In our last audit, the fifth national survey, conducted in 2013, all school-aged children showed adequate UIC, with median UIC being 161 µg/L(1).

The first national survey of iodine status and thyroid function of pregnant women in 2014, showed UIC of pregnant women to be 87µg/L, demonstrating that despite iodine sufficiency of school-aged children in Iran, iodine intake of pregnant women was inadequate. This was followed by national implementation of the iodine supplementation program in pregnant women in 2016. Two years later, the second survey was conducted in 12 provinces of the country. Results of this national interventional study clarified that iodine supplementation with at least 150 µg iodine per day has improved iodine intake status of this vulnerable group and overall median UIC of pregnant women was 188 µg/L, which was in optimum range (150-249 µg/L) recommended for pregnant women(2).

## Implementation of congenital hypothyroidism screening program after salt iodization in Iran

Congenital hypothyroidism (CH) is one of the most preventable causes of mental retardation that can be

detected through neonatal screening. Late diagnosis of CH results in reduction of intellectual quotient (IQ) at different levels in patients suffering from the condition.

Screening for CH was first implemented by Azizi et al in Tehran using cord blood TSH measurement in 1987; however, after 2 years, the program was discontinued due to iodine deficiency-induced hyperthyrotropinemia and high recall rate.

Following elimination of iodine deficiency in I. R. Iran, and due to lack of a largescale program indicating CH incidence, a pilot study aimed at determining the CH incidence was re-established in 1998 and the acceptable recall rate in this survey showed the screening program to be operationally feasible. Also, the high prevalence of CH, thyroid dysgenesis and blood-related marriages in Tehran and Damavand, probably reflecting similar patterns in other regions of Iran, warranted a national screening program. The activities by Azizi et al led to the integration of a CH screening program in the National Public Health System and it has been launched nationally since 2005 using the protocol of TSH measurement in heel prick blood spot in neonates within 3-5 days after birth.

Up to now more than 20,000 CH neonates have been early detected and timely managed which has been not only economically beneficial, but also preserved the patients' IQ and prevented mental retardation as well as growth complications and reduced the social burden accompanied by irreversible effects of the diseases. Azizi et al also evaluated the CH screening program in Iran by evaluating the processes of diagnosis, management and follow-up of neonates in a 3-year retrospective cohort study and determined the incidence of transient and permanent forms of hypothyroidism at 3 years of age and the role of iodine dietary status in the incidence and recall rate in the program and developed a risk prediction model to discriminate permanent and transient CH before 1 year of age(3, 4).

Although in Iran, screening and detecting CH subjects are well established, stricter implementation of a structured system for monitoring and surveillance is needed to promote the management of patients and to reduce the rates of loss to follow-up. Determining and addressing the causes of high false positive rates should be prioritized. Frequencies of TSH  $\geq$  5 mU/L may be a more sensitive indicator for iodine status during pregnancy rather than in the general population. As higher recall rates reflect inadequate iodine nutrition, sufficient iodine supplementation is needed to reduce the recall rate.

(continued on page 28)

## Hyperthyroidism and long-term methimazole treatment

Treatment of Graves' hyperthyroidism with antithyroid drugs (ATD) for the conventional duration of 12-18 months is associated with a high recurrence rate. Long-term ATD therapy is an effective and safe therapeutic modality for Graves' disease (5).

Activities related to this topic are as follows:

1. Published articles addressing challenges regarding preferred therapeutic choice for Graves' hyperthyroidism to reduce the recurrence rate.
2. Published articles showing increased remission rate of Graves' hyperthyroidism accompanied by good safety profile with long-term methimazole treatment in adults and children(6, 7).
3. Published articles addressing the comparison of radioactive iodine therapy with long-term methimazole treatment in toxic multinodular goiter(8) and subclinical hyperthyroidism in the elderly.
4. A special issue for the International Journal of Endocrinology and Metabolism entitled "Long-term Antithyroid Drug Treatment" included 8 articles from Iranian and international authors titled as follows:
  - Management of Graves' hyperthyroidism: More than a century of progression
  - The concept of cure in thyroid diseases
  - Prediction of relapse after antithyroid drugs withdrawal: A narrative review
  - Long-term treatment with antithyroid drugs: Efficacy and safety
  - Long-term antithyroid drug treatment: Trends in serum TSH and TSH receptor antibody changes in patients with graves' disease
  - Remission rate of Graves' disease and the trend of changes in serum TSH receptor antibodies in prolonged antithyroid drug treatment

- Long-term antithyroid treatment in pediatric and juvenile Graves' disease
- A new perspective in the management of Graves' hyperthyroidism

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**September is  
Thyroid Cancer Awareness Month**



# Thyroid Patient Care in South Africa

The first hospital in South Africa was started by the Dutch Oost-Indische Compagnie (the Company) at the Cape of Good Hope in 1652. It was a shelter for sick sailors with diseases such as typhoid and scurvy. Over 50 years ago surgeon Christiaan Barnard performed the first successful human-to-human heart transplant in the world in the Groote Schuur Hospital in Cape Town.<sup>1</sup>

But how is patient care for thyroidism in South Africa nowadays?

South Africa has about 55 million inhabitants and South Africa's Constitution guarantees every citizen access to health services and the National Ministry of Health is responsible for policy development and coordination. The majority of the population has access to health services through public clinics and hospitals and, like in most countries, the private sector is accessible for those that can pay. The Provincial Departments of Health have the public health services divided into primary, secondary and tertiary through health facilities that are located in and managed by the provincial departments.<sup>2</sup>

In South Africa hypothyroidism and hyperthyroidism are some of several diseases that qualify for compulsory Prescribed Minimum Benefits (PMBs). In addition, it's classified as a Chronic Disease List (CDL) condition. This means that medical aid schemes are required to cover chronic medication associated with the condition.

PMBs are defined sets of Diagnosis and Treatment Pairs (DTPs) associated with a particular disease. Together with healthcare providers, the South African government has developed best practice guidelines for DTPs, based on the efficacy and affordability of available treatments.

All medical aid schemes in South Africa are obliged to cover the cost of these PMBs in full, regardless of members' benefit levels, provided a designated doctor or specialist has diagnosed the disease according to the corresponding ICD-10 code or codes.<sup>3</sup>

The medical guidelines 2019/2020 for Adult Primary Care<sup>4</sup> are commissioned and published by the South African National Department of Health and only gives rudimentary rules for the treatment of hypothyroid patients and no referrals to medical specialists. There is no reference to the involvement of patients or patient representatives.

Earlier guidelines, like the SEMDSA/ACE-SA Guideline for the Management of Hypothyroidism in Adults<sup>5</sup> 2015, seems to be more focused on the secondary health care in hospitals by endocrinologists.

There is a lot of information available on the internet for thyroid patients, yet there is no thyroid patient group or organization active in South Africa. So every patient has to judge for themselves how trustworthy the information is.

Further in this magazine are three articles about thyroid specialists and their hospitals in South Africa.

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- 3 <https://www.medicalaid-quotes.co.za/articles/medical-aid-schemes-cover-hypothyroidism>
- 4 <https://www.idealhealthfacility.org.za/docs/guidelines/APC%202019-20%20pdf%20for%20website.pdf>
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**May 25 to 31, 2021**  
**13th International  
 Thyroid Awareness Week**  
[www.thyroidweek.org](http://www.thyroidweek.org)

# Role of Otolaryngology in Thyroid Patients in Eastern Cape South Africa

SARITA PANDEY-BHATTARAI, GENERAL OTORHINOLARYNGOLOGIST, FRERE HOSPITAL EASTERN CAPE

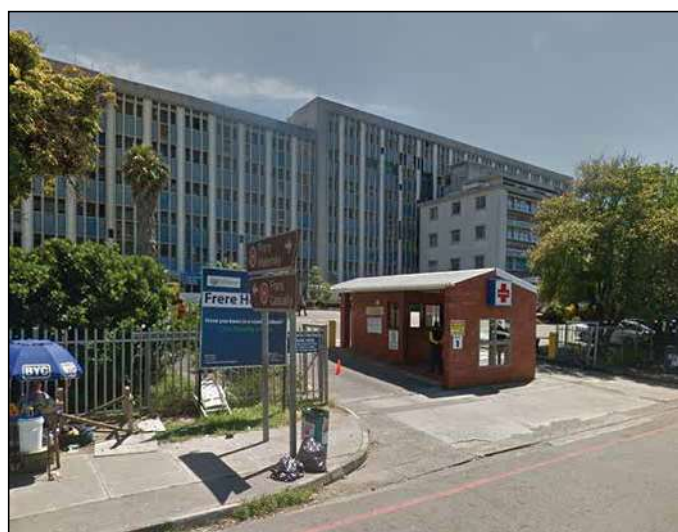


Established in 1881, Frere Hospital is a 910 bed, tertiary, Government funded hospital in East London, South Africa. It was named after Sir Henry Bartle Frere, who was Governor of Cape Colony from 1877 to 1880. Frere Hospital is a teaching hospital affiliated with Walter Sisulu University (in Mthatha). The Hospital has complete medical and surgical departments and both paediatric and adult oncology units. It offers a full scope of Allied health services, pharmacology and a complete diagnostic and interventional radiology services. We also have a NHLS laboratory, blood bank, and mortuary, along with the laundry and kitchen services within the hospital. Frere hospital is one of the three tertiary hospitals in the Eastern Cape.



Broadly speaking, in South Africa, General surgeons come in contact with thyroid pathology first (anecdotal experience from working in ENT departments in three different provinces in South Africa). ENTs generally get involved with thyroid patients first at a preoperative stage when the surgeons request us to evaluate the vocal cords prior to total thyroidectomy or partial thyroidectomies. We often get involved again in the postoperative period when there has been injury to the recurrent laryngeal nerve and we then take over the patient and provide them with various surgical modalities available for decompensating vocal cord paralysis post thyroidectomies. We also get involved in oncology cases when there is a need for salvage surgery and a neck dissection in patients that have had thyroidectomies and have nodal recurrences of their primary cancers.

In my personal experience and opinion, if we were to be involved earlier on from when the patient presents to hospital with a suspected thyroid malignancy and we are asked to give our input and surgical assistance during the surgery, we could perhaps prevent some of these iatrogenic recurrent laryngeal nerve injuries. Similarly, in oncology cases, we could offer these patients a modified radical neck dissection at the same setting as the thyroidectomy, which would have a massive difference in outcomes, long term hospital stays and even potential decreases in nodal recurrences. From psychosocial perspectives, ENT could counsel the patients on expected complications and give the patients options on how we would manage the complications. This would serve to prepare the patient better in terms of the post-operative recovery period and thus result in improved handling of complications and less mitigation.



My name is Sarita Pandey-Bhattarai. I am a general Otorhinolaryngologist working in Frere Hospital Eastern Cape. I have a specific interest in head and neck oncology and I intend to train further in it. I trained in and around Eastern Cape and rotated to Cape Town at Groote Schuur Hospital for further exposure before I sat for my College exams. I have been working as an Otorhinolaryngologist from 2016 at Frere hospital and have worked as a registrar and prior to that, as a Medical Officer in ENT. In total I have 15 years of experience in ENT.

## Dr Alan Cairns

Specialist Surgeon MBBCh (WITS) FCS (SA)



Following undergraduate medical training and specialist general surgical training at WITS University Medical School, I joined the breast and endocrine surgical unit at the Charlotte Maxeke Johannesburg Academic Hospital as a consultant surgeon, before starting private surgical practice at the WITS



Donald Gordon Medical Centre in Johannesburg, South Africa.

This is the only private teaching hospital in South Africa, and is closely allied to WITS University's Faculty of Health Sciences, allowing for training of specialists and sub-specialists under the guidance of experts in their respective fields.

My main clinical focus is on endocrine and head and neck surgery, where we perform a number of thyroid and parathyroid surgical procedures weekly. Patients

are referred from specialist and general practitioner colleagues from Johannesburg and surrounds, as well as from countries throughout Africa.

We have excellent diagnostic facilities at our disposal, in the form of ultrasound, CT and MRI scanning, with highly-skilled thyroid and head and neck radiologists interpreting images and performing guided-biopsies where indicated.

Our hospital also has a number of specialist medical endocrinologists and a nuclear medicine department headed up by an internationally-recognised member of the nuclear medicine fraternity, which allows us to provide a team-based approach to our thyroid patients both before and after surgery.

We are fortunate to have a surgical ICU managed by specialist intensivists, where high-risk surgical patients are managed post-operatively.

These patients are often referred to our pre-operative assessment clinic prior to undergoing surgery, where they are thoroughly assessed to optimise any medical comorbidities before having an anaesthetic and surgery.

## Dr Kershlin Naidu

Clinical endocrinologist, Netcare Waterfall City Hospital

Dr Kershlin Naidu is a clinical endocrinologist in private practice at Netcare Waterfall City Hospital in Johannesburg, South Africa. The hospital has approximately 200 beds with intensive care, high care and general wards, operating theatres, radiology and allied health services.

Dr Naidu has a special interest in thyroid nodules, thyroid malignancy and autoimmune and inflammatory thyroid disorders. He was a participant in the inaugural Endocrine Society Ambassador Exchange programme at the Perelman School of Medicine at the University of Pennsylvania with Professor Susan Mandel. Dr Naidu completed the Asan International



Masters Radiology course in radiofrequency/ethanol ablation of thyroid nodules/cancer at the Asan Medical Centre in South Korea under Professor Jung Hwan Baek.

He is one of the first endocrinologists in South Africa trained in thyroid ultrasonography and thyroid fine needle aspiration (FNA). He has performed in excess of 1000 thyroid FNAs to date and also performs percutaneous ethanol ablation for selected thyroid nodules. Dr Naidu is part of a multi-disciplinary team including surgeons, nuclear physicians, cytopathologists and histopathologists that provides specialist care for patients with thyroid nodules and malignancy.

# ATF is Celebrating 25 Years!

The Australian Thyroid Foundation was founded by Gail Ballantyne in 1995. After being diagnosed with thyroid cancer, Gail was unable to find any information or support to help her through her thyroid cancer journey or for that matter information about any other thyroid disorder. With the support of her Endocrinologist, Prof Steven Boyages, Gail and her first committee established the ATF.

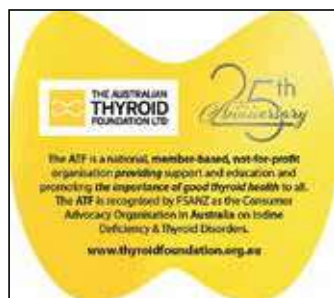


directed our attention to social media videos, featuring our Ambassadors who presented their personal thyroid journeys, highlighting their various thyroid conditions, which was very well received.

25 years on, the ATF has not forgotten the reason why the organisation began and continues to provide education, information, support and advocacy for its members and promotes awareness about the benefits of Good Thyroid Health, throughout Australia.

2020 has been a difficult year for everyone, due to the COVID-19. The ATF had intended to celebrate our 25th Anniversary during 2020 with organised events to promote the organisation throughout Australia, however the current COVID-19 situation has made that impossible.

Due to COVID-19 restrictions, we celebrated our 25th Anniversary with our members, sending a 25th Anniversary Postcard, ATF Brochure and ATF Magnet to place on their refrigerator. The magnet will remind them the ATF is always available for them when they need support.



ATF Magnet



ATF 25th Anniversary Postcard

During this year, we will continue to connect to our members, provide updates and information via our newsletter 'Thyroid News' to ensure they are updated with the latest research and treatments to keep them connected.

May each year in Australia is Thyroid Awareness Month! This year instead of our usual events, the ATF

During May, the ATF Thyroid Awareness Month attracts a lot of attention with radio interviews, which continues to raise awareness throughout the country. It is encouraging to know that thyroid is a hot topic during this time. As a member organisation of TFI, the ATF is able to also connect to TFI messaging with World Thyroid Day and International Thyroid Awareness Week, also during May.

The ATF has decided to move Gold Bow Day away from Thyroid Awareness Month, to its original date of 1st September. The Gold Bow is the symbol of the ATF and Gold Bow Day is the ATF's Thyroid Cancer Awareness Day. As thyroid cancer increases amongst younger Australians, it is important to ensure the younger population is aware and any symptoms are not overlooked which may either determine or eliminate a diagnosis and ensure the best outcome.

Leading up to Gold Bow Day video recordings presenting ATF members who are thyroid cancer patients will be available to view on our social media channels and website. Gold Bow Badges will also be available for purchase to support the ATF and Thyroid Cancer Awareness.

The ATF will be launching a Health Care Professional Section on our website during this year. This section will give GP's and other Health Care Professionals, the ability to connect to the ATF as Honorary Members. The Health Care Professional Section will include videos, audio and written information all presented by our Medical Advisors and the ATF to assist doctors and other specialist services with up to date educational material. It is intended this section will encourage and improve patient outcomes through information which will be continually reviewed and improved.

Two Australian brands of Levothyroxine, must be refrigerated at all times. The ATF continue to provide an approved Medication Travel Pack (MTP) for these brands to use for transporting the medication between one



Medication Travel Pack

(continued on page 33)



**ATF is celebrating 25 years** (continued from page 32)

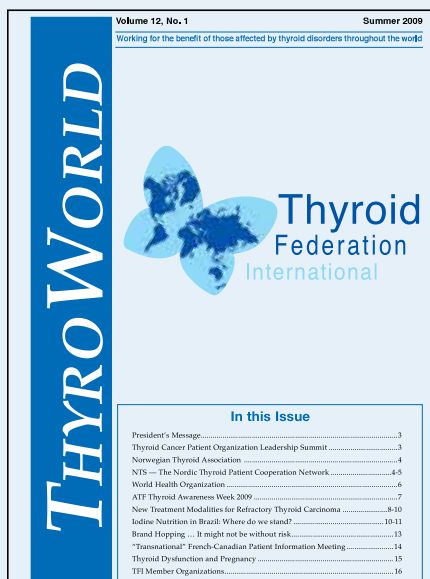
refrigerator and the next. It is particularly important for all patients using these brands to have a pack to use when needed. MTP's are always available on our website for ATF members and the public to purchase.

It is an honour for the ATF to have the support of such a wonderful team of Medical Advisors. All are world leaders in their preferred area of thyroid disease and have continued to provide the ATF with education

and information for much of our 25 years. As well as our Medical Advisors, the ATF has the support of a team of thyroid specialists, Australia wide, who can be called upon when needed and continue to support the work of the ATF.

BEST REGARDS FROM THE ATF,  
BEVERLEY GARSIDE  
CHIEF EXECUTIVE OFFICER

**Celebrating 25 years of TFI — a sample from the 2009 Newsletter**



New cover design in 2009.



**Thyroid Cancer Patient Organization Leadership Summit**

Toronto, August 2009

Participants: Joan Shey, Light of Life (USA), Beate Bartès, Vivre sans Thyroïde (France), Sandra Licht, Light of Life (Argentina), Gary Bloom, ThyCa (USA), Yvonne Andersson, Nordic Thyroid Cooperation/TFI, Harald Rimmel, Ohne Schilddrüse Leben (Germany) and Kate Farnell, Butterfly Thyroid Cancer Trust (UK)  
(not pictured : Rita Banach, Thyvovs, Canada)



**Enjoying a Well Deserved Dinner**

Annual TFI meeting in Thessaloniki, Greece: at the end of a long meeting, a well deserved dinner at the port of Chalkidiki.

From left to right: Jytte Flamsholt, Beate Bartès, Ulla Slama, Yvonne Andersson, Peter Lakwijk, Julie Bente Lasserre, Shannon Wood, Harald Rimmel, Annemaarit Lavikainen and Larry Wood.



**2008 TFI Annual Meeting in Greece**

From left to right: Jytte Flamsholt (Denmark), Beate Bartès (France), Harald Rimmel (Germany), Yvonne Andersson (Sweden), Nancy Patterson (USA), Larry Wood (USA) and Annemaarit Lavikainen (Finland).

# Thyroid Foundation of Canada Report for ThyroWorld

LAZ BOUROS  
PRESIDENT, THYROID FOUNDATION OF CANADA

As the Thyroid Foundation of Canada (TFC) celebrates its 40th anniversary, I would like to congratulate Thyroid Federation International on its own 25th Anniversary and for successfully establishing a global network of thyroid patient organizations in over 30 countries around the world! TFI came into existence right here in Toronto, Canada, as a result of a vision by our own founder, Diana Meltzer Abramsky, who wanted to build a thyroid organization to deal with the problems of thyroid disease in a global perspective. Over the past 25 years, TFI has grown from a base of six organizations to become voice of thyroid patients around the world!

This summer, I attended a Zoom online public education session on the Impact of COVID-19 on People Living with Adrenal Insufficiency sponsored by the Canadian Society of Endocrinology and Metabolism (CSEM) and The Canadian Addison Society (CAS). The session showcased two speakers: an endocrinologist and a psychologist. The presentations were very interesting and judging from the attendee response, were very well received! TFC is also interested in establishing a Zoom-based online educational session over the next year on some aspect of thyroid disease. The session would provide national coverage, reach thyroid patients in remote areas of Canada and supplement our existing website information, Help Line support and local public education sessions for thyroid patients.

Over the past year, TFC has continued to implement its five-year Strategic Plan (2018-2023). The big push this year has been in the area of thyroid research. While we have funds for thyroid research, we did not have a Peer Review Committee to review thyroid research proposals and the completed research projects. Establishing a new Peer Review Committee proved difficult until a solution presented itself. Over the past two years, we established a good relationship with CSEM. CSEM is a professional organization for the 600 endocrinologists in Canada. As it turned out, they already had an Awards and Grants Committee in place. After some discussion, they agreed to let TFC use their Grants Committee to manage TFC grants for thyroid research. TFC is looking into entering into a formal agreement with CSEM to help us manage our Thyroid research. The TFC research grants will be awarded in the areas of thyroid disease that impact



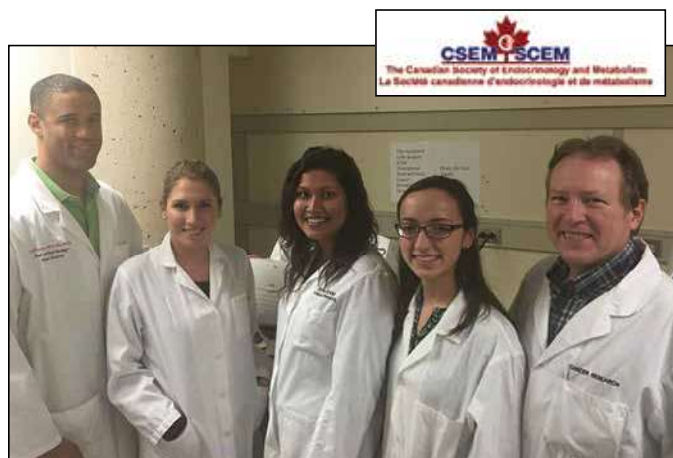
Thyroid Foundation of Canada  
La Fondation canadienne de la Thyroïde

patient care. The award will be presented to the selected recipient at the annual CSEM Professional Conference.

The advantages of partnering with CSEM are as follows:

- CSEM has an existing Awards and Grants Committee, procedures, and endocrinologists that are knowledgeable in the research area;
- CSEM regularly send out requests for proposals to university medical schools and hospitals for other grants that they manage;
- TFC will have member representation on CSEM's Awards and Grants Committee;
- Thyroid research results will be vetted by CSEM (research process, etc.) and provide greater legitimacy for the thyroid research;
- By participating in the CSEM Awards Committee, TFC can gain valuable insight into managing its own research.

The CSEM agreement necessitated the development of a written document to provide details of the arrangement. The first draft was created in December 2019 and had gone through several iterations with legal advisors from both organizations. While this process has been slow, we are hoping to have the formal agreement finalized and approved this fall.



Anthony Nichols, MD. (left), Head and Neck Cancer Surgeon Chair, Head and Neck Cancer Disease Site Team from the London Ontario Regional Cancer Program Research Project – “The Detection of Circulating Tumour DNA in Thyroid Disease”

# Report 2020, Croatia

ROKO GRANIĆ, MD, ON BEHALF OF THE CROATIAN ASS. FOR THYROID DISEASE

In Croatia, as I believe also in your countries, we are still coping with the corona virus aftermath. Speaking from my personal medical point of view we have barely endured the pressure put on us by this new disease. Our patients were not able to come to their medical appointments because many of our clinics were closed because medical personnel had to be in home isolation for weeks, myself included. It made us think of alternative means to communicate with our patients so we organized online as well as telephone checkups. Our patients were very consoled and even touched when we called them and asked how they were doing.

As you may have heard, during the peak of the COVID-19 epidemic in late March, our capital Zagreb was struck by a devastating 5.2 earthquake, and on the same day, when we all ran out of our homes to the streets, the only snowfall of the season occurred. It felt really like we were actors in some low cost disaster movie that was unfortunately not a fantasy but reality: pandemic, destructive earthquake and snowfall all at once! A lot of our landmarks took heavy damage as well



stubborn unrelenting president Verica, during all that commotion, we managed to celebrate World Thyroid Day in May by an online humanitarian sale of T-shirts depicting butterflies and carrying the emblem of our Association. People were very happy and enthusiastic to be able to support us even through the tough times of isolation and earthquake aftermath. With this online sale that is still very active, we are raising funds to help the renovation of the radioiodine therapy ward of the Nuclear medicine department of the Sisters of Mercy University Hospital centre here in Zagreb, that also sustained some damage during the quake. In early July, with the support of the Zagreb athletic club, we are organising a mini marathon in a park near the centre of Zagreb (Peter and Yvonne visited it during their stay in Zagreb), raising awareness of thyroid disease. For this autumn we are preparing the first edition of our association's newsletter, celebrating our first 13 years helping people, our thyroid patients, their families and friends.



as our cathedral that lost one of its 100 meter towers. It is a miracle that only one person lost his life (actually there were two earthquakes that happened one after another but early Sunday morning and during the corona lockdown so no one was in the streets). I am happy to say that our headquarters were not severely damaged although it is situated downtown in the heavy hit center. We are still unable to fully occupy and use our headquarters as public transportation to the centre is still not fully functional after the quake so our older members cannot walk that far.

Nevertheless, thanks to our members' indestructible enthusiasm, as well as our



So, to conclude, as the ground under my feet is still shaking (yesterday we had a 3.2 quake as every now and then in the last 3 months), we will not be defeated or discouraged neither by this pandemic nor the quake nor any other problem standing in our way! We will stay strong and united in international friendship that stretches over the continents and national boundaries! This pandemic must make us more aware of each other and make us think of the needs of others, especially those suffering from thyroid diseases that are close to our hearts. Forgive my length but we are missing you all and hoping to see our TFI friends in person soon, to shake hands (not elbows) and to give a hug.

And to paraphrase a saying of our Chinese friends: May you live in boring times! :-)

Best regards to all our friends and take care!

## Guided online peer-to-peer support in thyroid disorders

JOHANNA ERKKILÄ  
PROJECT COORDINATOR  
FINNISH THYROID ASSOCIATION

Since autumn 2019, the Finnish Thyroid Association has been offering guided online peer support chats to people with thyroid disorders and cancer. There has been an increasing need for online support as traditional in-person meetings are not convenient for all. The reasons vary from hectic life situation to long distances. Thanks to technology, in-person meetings are no longer the only option, as individuals can find online support in various formats.

However, there is a difference between online support and guided online support. Digital support groups can be found from Facebook, blogs, chat rooms and websites.

However, just discussing with peers, whilst important, is not always fruitful. The conversations can start to repeat the same themes and become stagnant. In these situations, the peer group leader can support and guide the discussion and help the group to seek solutions together on how to cope with thyroid disorders.



Johanna Erkkilä, Project Coordinator

To fulfil the need of guided online peer support, Finnish Thyroid Association has organised one-day courses for volunteers who are interested in guiding peer support chats. During this one-day course individuals have studied what it means to be a volunteer especially in online contexts. Since autumn 2019, guided online support has been offered to people with hypothyroidism, hyperthyroidism and thyroid cancer.

Online peer support is delivered through chat interfaces. Participation is confidential and safe, and the identity or background of participants is not disclosed to others. Feedback from the chats has been mainly positive. Participants have got support from each other as well as tips on how to cope with thyroid disorders. There have been

some problems with the technical platform, which have negatively impacted the user experience. However, the platform provider has taken the feedback seriously and hopefully these will no longer be an issue when the chats start again in the autumn 2020.

In the future, we will continue to increase the awareness of this online peer support format, expand support to other target groups and investigate other online support formats, such as video meetings. Hopefully by the end of 2020, anyone in need of online peer support regarding thyroid or parathyroid disorders, can participate in a low threshold from anywhere in Finland.



# Bundesverband Schilddrüsenkrebs – Ohne Schilddrüse leben e.V., Germany, celebrated its 20th anniversary

HARALD RIMMELE  
HARALD.RIMMELE@SD-KREBS.DE

The German organization «Bundesverband Schilddrüsenkrebs - Ohne Schilddrüse leben » for thyroid cancer patients celebrated its 20th anniversary in October 2019.

It started in spring 1999 as a small online discussion forum, created by a thyroid cancer patient, aimed at exchanging information and experience with fellow patients. Over the last 20 years, it has grown: the online forum is very active, with thousands of registered users and 36 local support groups. A non-profit association was created in 2005. The organization cooperates with doctors and specialized centers, participates in work

groups, conferences and congresses. It has various work groups and project groups: hypopara network, workgroups for guidelines elaboration, rehabilitation, support of local groups, website development...

The organization receives support from the German Cancer Aid Foundation and is totally independent from pharmaceutical sponsoring. It is a member of various German and international umbrella organizations, and cooperates with many networks, groups and organizations both in Germany and abroad.

In October 2019, we celebrated our 20th anniversary with a symposium on the topic “Quality of Life of thyroid cancer patients” (with more than 180 participants) and a festive evening event in Berlin.



# Ghana Anniversary Celebrations



The Thyroid Ghana Foundation celebrated its 1st Anniversary on 13th July, 2019 with a Health Walk along some principal streets of Accra. The walk was attended by members of our patients support programme, volunteers, and friends of the Foundation. The aim of the walk was to raise awareness of thyroid issues and to promote the need for regular physical activities among our members. We distributed pamphlets with information on thyroid disorders to members of the communities along the route. The walk ended with a brief forum to discuss the benefits of a healthy diet for the treatment and management of thyroid diseases. The walk has so far proved to be successful since we have had many calls from persons who took our contacts from the pamphlets to ask for more information on thyroid disorders.



Section of participants for the Thyroid Health Walk.



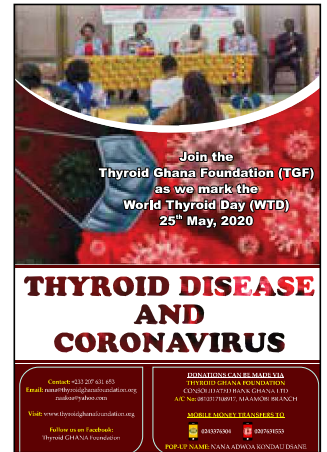
Donation to the 5th floor Surgical Ward in support of thyroid patients.

TGF visits the International Central Gospel Church (Joy Temple) for a Talk on Thyroid Health.



## COVID-19 and Thyroid Disorders

Due to the corona virus pandemic the Foundation has been forced to host most of this year's activities online. We began by circulating information on coronavirus and thyroid disorders, which was reviewed by the Endocrine Clinic of the Korle-Bu Teaching Hospital. The circular focused on ways by which thyroid patients could stay safe from a corona infection and also included an update on measures put in place by the Clinic to cater for thyroid patients during the pandemic. We also took the time to assist our patients in adjusting to the new online systems at the Clinic by helping them book appointments and sending laboratory results to the doctors electronically for review.



## World Thyroid Awareness Day

The TGF celebrated World Thyroid Awareness Day with a live discussion on Facebook with our Registered Dietician to talk about the importance of diet on maintaining good thyroid health. Based on the positive response from our Facebook live we have held subsequent online meetings for thyroid patients which also mainly focused on healthy diet. TGF has an upcoming Zoom meeting again on diet and thyroid health which we plan to convert into a monthly forum instead of a one-off event.

## Media Campaign

The Foundation has throughout our existence and during this pandemic been visiting television and radio stations to spread the word on thyroid disorders. The local restrictions on social gatherings have shifted our operations from physical meetings and fora to making frequent appearances on tv and radio. Most notable among them was our two-hour long session at a popular radio station to celebrate the world thyroid awareness day. Our media campaigns have so far been extremely effective. We have had many calls from viewers and listeners who are either suffering from thyroid conditions or are related to someone who is. We have also received massive support from the media outlets. Most of our interviews have been hosted during prime time and on

(continued on page 39)

## Ghana Anniversary Celebrations *(continued from page 38)*

several occasions the Foundation has been re-invited for a second appearance. Due to popular demand our focus for the year would be on diet education and thyroid health.



TGF appearances on "Facts of Health" TV Show.

### Thyroid Research

The Foundation is making preparations towards supporting our first thyroid research. We have made contacts with scientists in various fields to initiate a collaborative research. In the meantime, we have taken steps to expand and re-organize our patients' data using a research friendly format.

### Upcoming Projects

The Foundation intends to intensify our media campaign to increase awareness of thyroid disorders. We had plans to organize a major fundraising event at

Graphic Design and Photography by: Prince Badasu, A2T Media.

the four largest churches in the Country to support the refurbishment of the Surgical Floor at the Korle-Bu Teaching Hospital dedicated to thyroid patients. When the Foundation exceeds our target the extra funds would be committed to an account for supporting thyroid surgeries for needy patients. To wrap up the year the Foundation would be producing a book which would serve as a manual to all persons in Ghana living with a thyroid disorder on how to access the right hospital treatment and implement the appropriate lifestyle choices for better management of their condition.

## ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

## India

# COVID-19 Thyroiditis Thyroid Disorders during COVID-19 Era

## Our firsthand treatment experience in India

DR. M.S. SENTHIL KUMAR, MBBS, MS, MCH, FAES, FAIS, FCLS, FIMSA, FMMC, FICS

PRESIDENT, THYROID FEDERATION OF INDIA, ENDOCRINE TUMOUR SURGEON & SENIOR ENDOCRINE FACULTY, MADRAS MEDICAL COLLEGE

DR. E. PRABHU, MD, DNM  
PHYSICIAN & NUCLEAR MEDICINE SPECIALIST, OMANDOORAR MULTI SUPERSPECIALITY HOSPITAL



Dr. Senthil Kumar

The entire globe is contained indoors during the COVID-19 crisis except the front line warriors which include doctors and nurses. As President of Thyroid Federation of India it would be of immense benefit to share my first-hand information regarding the prevalence of thyroid disorders while treating COVID-19 infected patients. I am directly involved in the treatment of

COVID-19 patients as primary specialist in a premier tertiary care teaching hospital which is the oldest in India, and the first to use methyl prednisolone and Ivormectin to control morbidity and mortality of COVID-19.

COVID-19 treatment should be broadly classified into community therapy and patient therapy.

### Community Guidelines for Thyroid Dysfunction

1. The community at large which is at risk of exposure for COVID-19 infection neglects their routine activity.
2. This affects normal metabolic activity especially in the elderly and hypothyroid patients.

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## COVID-19 Thyroiditis... (continued from page 39)

3. While all precautions of COVID-19 need to be adapted for the global pandemic in India, it is advised to incorporate breathing exercises like pranayama and indoor activity like yoga in order to regulate energy and metabolism.
4. The thyroid hormone function needs to be checked along with calcium and thyroid antibodies for regulating thyroxine titration therapy.
5. Dose alterations are needed due to low or no physical activity.
6. Walking, skipping, swivel chairs and rocking chairs are advised along with stretches and postural changes.

### Guidelines from Experience after treatment of COVID-19 Patients

Once a person is positive for COVID-19 then the following patterns of progress are observed in India.

1. COVID-19 positive patients may be asymptomatic.
2. COVID-19 positive patients may exhibit symptoms the after 8th to 14th day where oxygen desaturation becomes evident.
3. COVID-19 patients may be symptomatic with upper respiratory tract symptoms like prodromal symptoms or fever, ageusia, anosmia, pharyngitis or sore throat and dry cough.
4. The COVID-19 patient may exhibit symptoms of lower respiratory tract like laryngitis, difficulty in breathing, fever and even gastrointestinal symptoms.
5. COVID-19 patients may develop COVID-19 pneumonia with lung infection leading to difficulty in breathing, hypoxia and oxygen desaturation. They may need prompt ICU care and may even warrant ventilation assisted breathing.

Our experience after my personal treatment of 52 doctors and 32 nurses affected with COVID-19 compared to 64 patients who are from general walks of life, I would like to summarise the effects of COVID-19 on thyroid function.

The front line warriors like doctors and nurses exhibit severe viral load and progress fast from upper respiratory to lung pneumonia especially above the age of 50.

Since the COVID-19 pneumonia leads to severe difficulty of breathing and the dreaded COVID-19 myocarditis, it is imperative to check the thyroid function in all patients admitted after COVID-19 infection.

I had treated a doctor who was COVID-19 positive and recovered from ventilator after Remdesivir and methylprednisolone therapy and became COVID-19 negative after 21 days. His IL 6 returned from high levels yet he was desaturating and was in ICU.



Dr Senthil and colleagues working during the COVID-19 Pandemic.

Another doctor was an inpatient for 42 days with similar picture.

A serial ECG and multi para monitor exhibited rhythm disturbances with desaturation attributed to COVID-19. The Cardiologist, after echo cardiogram and holter monitor observation for 48 hours with enzyme check, cleared cardiac pathology.

A prompt check of thyroid function and antibodies revealed thyroiditis in both patients which was treated with cardio selective agents and Naproxen therapy and then desaturation improved and patients were discharged.

With these experiences, we advocated screening for thyroid function and thyroid antibodies as a routine in all cases treated under my care. We found that the thyroiditis quotient was surprisingly high among thyroid infected front line doctors and nurses.

Among the general public or non-doctors and nurses, new hypothyroid cases were detected.

Both these findings were significant because both lead to difficulty in breathing and cardiac symptoms. This mimics COVID-19 Myocarditis and COVID-19 pneumonia and hence needs to be primarily ruled out to initiate appropriate treatment.

Peninsular India is an Iodine sufficient zone supplemented with iodised salt and hence the incidence of thyroiditis is more than other parts of India especially the sub Himalayan belt which is Iodine deficient.

Hence these significant titres of increased thyroid antibodies are now taken into account to segregate or integrate treatment with COVID-19 Myocarditis and newly found hypothyroid patients among COVID-19 infected patients.

A detailed study will soon be published according to our institutional ethical committee guidelines.



# Activities of Thyroid Foundation of Nepal

GANDHI PRASAD SHARMA  
GENERAL SECRETARY, THYROID FOUNDATION OF NEPAL

The Thyroid Foundation of Nepal is a newly established thyroid organization in Nepal and was inaugurated by the President of Thyroid Federation International, Mr. Ashok Bhaseen, in August 2018. We feel very proud that our international President was here to help launch our program.

From the beginning the Thyroid Foundation of Nepal has been carrying out various activities in Nepal, such as our thyroid awareness programs and health camps. We currently have 11 members altogether.

We implemented the following tasks after the establishment of the Thyroid Foundation of Nepal:

- We registered our organization, Thyroid Foundation of Nepal, with the Government of Nepal.
- We carried out four thyroid awareness programs and free thyroid health camps where members of the public benefited from free checkups and free thyroid tests.
- We are managing the expenses of the Thyroid Foundation of Nepal via memberships and donations among the members; we have not had any financial support from the government or any other organizations or donors.

### Future Planning:

- We will expand our organizational structure in all districts of Provinces No. 5, 6, and 7.
- We will hold three health camps in the western part of Nepal, one of the most affected areas of thyroid disorders in Nepal.
- We will search for donor organizations to support the thyroid projects in the western part of the country.
- We will collaborate with the Provincial Government of Provinces No. 5, 6, and 7 to detect thyroid disorders in these areas.
- We will develop a Health sub-committee to conduct health camps in different districts of western parts of the country.
- We will develop a website and post all the information and activities on it.
- We will coordinate with the Central Government of Nepal to carry out thyroid awareness programs and free thyroid health camps for the needy people of Nepal.



Thyroid Federation International's President, Ashok Bhaseen, hands over a certificate of affiliation to Thyroid Foundation Nepal, on Saturday, August 4, 2018.

We have been conducting our meetings via Zoom during this COVID-19 situation. To date, we all are safe from Coronavirus and we, the Thyroid Foundation of Nepal, would like to pray to God for your safety from COVID-19.

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## Celebrating 25 years of TFI – Historical Photos



**TFI AGM and ETA in Leiden, 2013:**  
SON/TFI patient-doctor workshop at the ETA: Patient representatives from TFI and SON – Ashok Bhaeen, Joke van Galen, Rietje Meijer and Niko de Jong.



# Prevalence of Thyroid Disorders in Western Nepal: An Overview

GANDHI PRASAD SHARMA  
GENERAL SECRETARY, THYROID FOUNDATION OF NEPAL

Thyroid dysfunction is a major public health problem among the Nepalese population. It has been estimated that 0.2% of the deaths in Nepal result from endocrine disorders, among which Iodine deficiency has been a major cause. According to the WHO, greater than 190 million suffer from iodine deficiency disorders. The thyroid disorders may be due to congenital factors, a genetic predisposition, inadequate levels of dietary iodine intake, pregnancy, radiotherapy, viral infections, surgery, and underlying diseases such as infiltrative disorders, or even autoimmunity.

Nepal is a mountainous landlocked area which is situated far away from the sea. The geographical placement of the country, along with a high annual rainfall, leads to a low soil iodine content. These factors lead to a very high incidence of iodine deficiency disorders. Iodine deficiency is prevalent in the Himalayan, sub-Himalayan and the Terai regions of Nepal. The prevalence statuses of hyperthyroidism (13.68%) and hypothyroidism (17.19%) were studied in the eastern part of Nepal. Though the prevalence of thyroid dysfunction had been studied in other parts of Nepal, to the best of our knowledge, this is the first study which is being reported from the western part of Nepal. This type of study has not been reported from our region so far. The objective of this study was to assess the prevalence of thyroid dysfunction in the western region of Nepal.

A retrospective study had been carried out in 2011/12 A.D. to find out the situation of thyroid disorders in the western part of Nepal. In this retrospective study, a total of 1504 subjects were

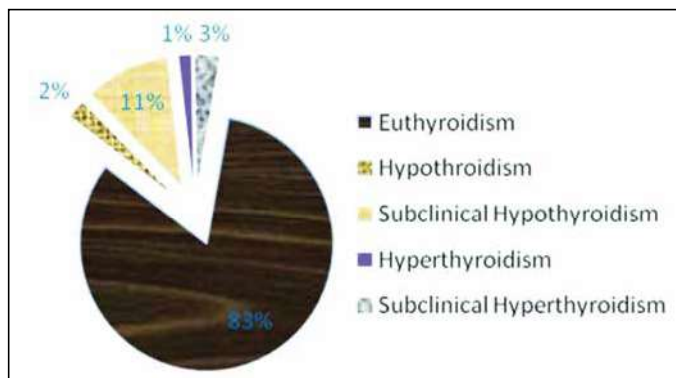


Figure 1: Prevalence of Thyroid dysfunction

enrolled from January 2011 to January 2012. Among these subjects, 1155 were females and 349 were males. The subjects were classified according to their thyroid status as hypothyroidism, hyperthyroidism, subclinical hypothyroidism, subclinical hyperthyroidism and euthyroidism, by taking the reference of the normal thyroid function test. Total hypothyroidism included hypothyroidism plus subclinical hypothyroidism and total hyperthyroidism represented hyperthyroidism and subclinical hyperthyroidism.

Figure 1 represents the prevalence of thyroid dysfunction in the population of the western part of Nepal. Among the 1504 subjects, 17.42% (n = 262) had thyroid dysfunction. Among the deformity subjects, 192 were total hypothyroid and 70 were total hyperthyroid. A high proportion of the subjects were suffering from hypothyroidism and sub-clinical hypothyroidism.

In the present study, the female to male ratio was 3.4:1. Among the euthyroidism subjects, 962 were females and 280 were males. The prevalence of thyroid dysfunction was 16.70% (n= 193) in 1155 female subjects and it was 19.77% (n= 69) in 349 male subjects, as has been shown in Figure 2. The numbers of the female subjects with thyroid dysfunction were greater than those among the males.

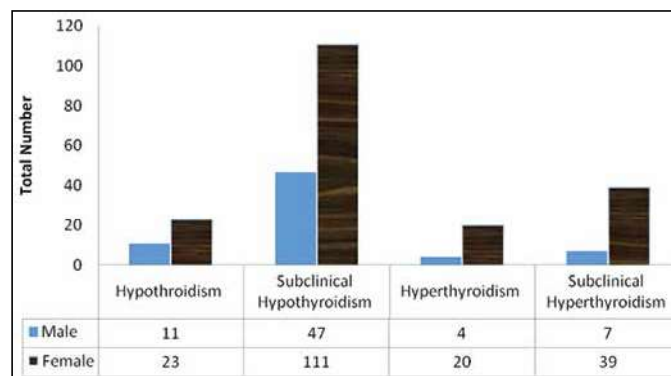


Figure 2: Gender wise prevalence of thyroid dysfunction

Figure 3 represents the distribution of thyroid dysfunction with the various age groups. Among the different age groups, the highest number of subjects lay between the age group of 41-50 years. A high degree of total hypothyroidism was observed in the 41-50 years age group.

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Prevalence of Thyroid Disorders... (continued from page 42)

Thyroid Status	Age Group (in years)							Total
	Below 10	11-20	21-30	31-40	41-50	51-60	Above 60	
Euthroidism	5	80	223	253	253	189	239	1242
Hypothyroidism	1	2	4	4	12	7	4	34
Subclinical Hypothyroidism	1	4	20	40	41	27	25	158
Hyperthyroidism	1	2	6	7	3	3	2	24
Subclinical Hyperthyroidism	1	1	3	6	13	5	17	46
<b>Total</b>	<b>9</b>	<b>89</b>	<b>256</b>	<b>310</b>	<b>322</b>	<b>231</b>	<b>187</b>	<b>1504</b>

Figure 3 – Age wise distribution of thyroid dysfunction

Figure 4 represents the comparison of the thyroid hormone levels in males and females. The mean TSH level in males was higher than that in females, but it was not statistically significant. The fT3 and the fT4 levels were not significantly different in males and females when the Mann Whitney Test was applied.

Thyroid Hormone	Male (Mean ± SE)	Female (Mean ± SE)	P value
T3 (pg/ml)	2.40 ± 0.04	2.51 ± 0.03	0.074
T4 (ng/dl)	1.25 ± 0.01	1.28 ± 0.01	0.220
TSH (IU/ml)	3.71 ± 0.2	3.34 ± 0.12	0.178

Figure 4 – Comparison of Thyroid hormone levels in males and females

Thyroid Hormones	Euthyroidism (Mean ± SE)	Hypo- thyroidism (Mean ± SE)	Subclinical Hypothyroidism (Mean ± SE)	Hyper- thyroidism (Mean ± SE)	Subclinical Hyperthyroidism (Mean ± SE)	P value
T3 (pg/ml)	2.48±0.18	0.88±0.46	2.07±0.04	6.83±0.68	2.88±0.10	<0.001
T4 (ng/dl)	1.28±0.01	0.45±0.03	1.10±0.02	2.94±0.21	1.49±0.05	<0.001
TSH (IU/ml)	2.25±0.03	21.46±1.68	10.25±0.41	0.19±0.02	0.22±0.01	<0.001

Figure 5 – Represents comparison of thyroid hormone levels among various thyroid dysfunction level

Figure 5 represents the comparison of the thyroid hormone levels among various thyroid dysfunction levels. When ANOVA test was applied, the TSH, fT3 and fT4 was found significantly different among various groups of thyroid dysfunction.

The estimates of the prevalence of thyroid dysfunction depend upon the methodological factors, the classifications of hypothyroidism, and the composition of the community, which are examined by age, ethnicity, and gender, making comparisons between the studies of limited value. The prevalence and the pattern of hypothyroidism depend on ethnic, geographic, and environmental factors, which include the iodine intake status.

The prevalences of hyperthyroidism and hypothyroidism were 4.65% and 12.07% respectively in this study. A similar study observed that nearly 30% of the population were suffering from thyroid dysfunction in the eastern part of Nepal. The prevalence of hypothyroidism in various studies from around the

world shows a considerable variation and its current prevalence ranges from as low as 1% to as high as 20% for subclinical hypothyroidism and from 1 to 2% for overt hypothyroidism.

In this study, females showed a higher prevalence of thyroid dysfunction than males. However, a contrasting result was observed by Baral N et al, where they reported equal prevalences of thyroid dysfunction in males and females. It had been reported earlier that there was a 20% overall prevalence of thyroid dysfunction in eastern Nepal in subjects who were above 20 years of age. Few studies were concordant with the present study, which reported that subclinical hypothyroidism and overt hypothyroidism were more prevalent in females as compared to males. In another similar study, the prevalence of thyroid dysfunction was found to be more common among women (13%) than among men (5%).

The prevalence of hypothyroidism was higher than that of hyperthyroidism in this study. Hypothyroidism is

(continued on page 44)

## Prevalence of Thyroid Disorders... (continued from page 43)

generally associated with iodine deficiency and Nepal is an endemic area of iodine deficiency with a prevalence of approximately 26.5% iodine deficiency disorders. Iodine deficiency and hypothyroidism may be exacerbated due to the geographical structure and the food habits. Soil erosion with the washing away of iodine from the soil in hilly areas, the use of non-iodized salts and the intake of various goitrogens may also aggravate the problem. In a study conducted by Niafar M et al., hypothyroidism was found to be common in the Iranian population, as 12.8% of the women and 4.7% of the men had hypothyroidism; however, most of them were mildly hypothyroid. These data are consistent with the reports of the high prevalence of hypothyroidism in other iodine-sufficient populations. As has been seen in other studies from the developed countries, hypothyroidism tends to increase with age and it is more common in women, and in people with goiter.

Furthermore, hypothyroidism is the most common thyroid disorder in the adult population and it is more common in older women. However, the thyroid dysfunction in elderly individuals often goes unnoticed, and the methods for an accurate detection may be controversial. Hypothyroidism is usually autoimmune in origin, presenting as either primary atrophic hypothyroidism or Hashimoto's thyroiditis and rarely, can pituitary or hypothalamic disorders result in secondary hypothyroidism. By contrast hyperthyroidism is much less common as compared to hypothyroidism. Graves' disease is the most common cause and it primarily affects young adults. Toxic, multi-nodular goitres tend to affect the older age groups. In this study, the prevalence of total hyperthyroidism was 4.65%, which included both subclinical hyperthyroidism and hyperthyroidism.

In this study, a large number of subjects with thyroid dysfunction were observed in age group of 41-50 years. One similar study reported that the mean age of thyroid dysfunction was approximately 39 years, which showed the accumulation and the manifestation of the disorder symptom in this age group. Few studies have revealed that the incidence of thyroidism increases with advancing

age. Children with hypothyroidism below 15 years of age may be associated with an iodine deficiency disorder or Down's syndrome, which ultimately retards the physical and mental growth and development. Few studies have shown that obesity, diabetes and metabolic syndrome have strong associations with thyroid dysfunction. Some studies have also shown the association of hypothyroidism with depression.

There were few limitations in this study. The TSH test is an excellent tool for screening new patients for thyroid disease, but the complete thyroid panel is needed for an accurate diagnosis and assessment of the thyroid function. Firstly, the present study was based on the routine thyroid function test, i.e. a serum free T3, free T4 and TSH measurement. The present study could have been strengthened if the Total T4, Total T3, thyroglobulin, anti-thyroperoxidase (anti-TPO), anti-thyroglobulin (anti Tg), TSH receptor antibodies and Thyroid Stimulating Immunoglobulin (TSI) tests were included in stratifying the thyroid dysfunction. Secondly, there was a possibility that the TSH cut-offs which were used in the present study may have understated the health risk. The cutoffs which were used were recommended by the manufacturer of the kit and by other studies, because Nepal does not have its own reference interval for the thyroid function test panel.

As the present study was a hospital based study, it may not represent the whole population. But it has identified the burden of thyroid dysfunction in the western development region and its results can be used as a baseline data for future studies. The present study has revealed the prevalence of thyroid dysfunction; typically, hypothyroidism and subclinical hypothyroidism were higher in the western development region, but the etiology of the disease remained unidentified. Moreover, the diseases were preponderant in women and in the elderly.

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## We thank our Sponsors



# Report of Activities of Goldheart Thyroid Awareness Foundation, Nigeria, 2019/20

The year 2019/20 has been a challenging year for our foundation. After a successful debut during the International Thyroid Awareness Week in May 2019 and a great result in awareness in the region where GOLDHEART is situated which is Northern and North Central Nigeria, the foundation looked forward with enthusiasm to attend the Annual General Meeting of the Thyroid Federation International in Budapest, Hungary in September 2019.



While we were preparing for the meeting, we had a patient who, through our campaign, got to know about her thyroid issues, Mrs Oiza Anthony. Mrs Anthony had given up hope of ever getting healed from insomnia, depression, constant headache, and dizziness which had hitherto been attributed to Malaria and Typhoid fever, which she had treated severally with little respite after which the symptoms returned. She heard for the first time in her life about Thyroid malfunction through one of our radio call-in programs. She contacted us and she was referred to one of our doctors who placed her on medication.

She has since had surgery with total removal of her thyroid and has been placed on hormone replacement medication.

Another success story was that of Mrs Joy Ezinne Ernest. Mrs Ernest had lived with a thyroid disorder for 15 years and was told by her mother-in-law that she would die if she attempted to have surgery to remove the very swollen mass on her neck. She encountered our foundation on one of our street awareness campaigns and we were able to convince her to seek medical help. We referred her to our doctors and she was scheduled to have her surgery in September 2019. Due to lack of funds, she could not have the surgery and we began raising funds by ourselves. While raising funds, a team of medical doctors from India

came to Jos University Teaching Hospital and performed free surgeries for lucky patients and Mrs Ernest was among the beneficiaries. Mrs Ernest now has her life back. Her surgery was successful and she lost weight and is in good shape.

We also had a number of success stories; chief among them was that of Lisa Eglah Manomi who got pregnant even while on medication for Hypothyroidism which the doctors said was a rare occurrence. Lisa was among those who were rescued from prayer houses due to thyroid disorders and were encouraged to have a thyroid function test and go for treatment in the early days of our foundation. She successfully gave birth to a baby girl and has since had a partial removal of the thyroid gland.

## Army Officers' Wives

As part of the activities to mark International Women's Day in March, Goldheart Thyroid Awareness Foundation wrote to the General Officer commanding the 3rd Armoured Division of the Maxwell Khobe Cantonment in Plateau State Nigeria to have a week long sensitization and awareness campaign for the army officers' wives in the barracks. There was a large turnout of women and we had several women submit their samples for testing after the public lecture delivered by our team of doctors. We also had testimonies from women who had suffered from thyroid disease.



A cross section of soldiers' wives during the Thyroid awareness event on international women's day 2020.

Something remarkable happened at the barracks. We discovered that most of the women who tested positive to thyroid malfunction were the women who were notorious for quarrelling among the junior army men's wives who lived together in large blocks of several rooms. We suggested that the disease may have been responsible for their aggressive nature. This prompted a large turnout of more women in the following days of the week long awareness campaign. The wife of the General Officer

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Mrs Lisa Eglah Manomi after her successful operation for partial removal of her thyroid gland.

## Goldheart Thyroid Awareness Foundation (continued from page 44)

commanding the division, who is a medical doctor herself, Dr. Angbazo, was so happy that she asked us if we could go with her round the barracks in the whole country to create awareness. We were about to begin the process of signing papers which would co-opt our organization into trips round the country when COVID-19 struck. Everything thereafter was put on hold.

### International Thyroid Awareness Week

The 2020 Thyroid awareness week came with a lot of challenges due to the COVID-19 pandemic; we were unable to organize public lectures and our usual street awareness programs. We adhered to the social distancing rules by having radio programs to mark the week. We organized webinars and had our campaigns mostly online and on social media.



Lecture in progress with Florence Oketona, founder of Goldheart Thyroid Awareness Foundation.

The highlight of this year's campaign and the major success recorded was our ability to get the National Agency Food Drug Administration Control (NAFDAC) in our region to allow us to sensitize pregnant women on the use of iodized salt and to enforce the sale of only iodized salt in the market. We spoke to one of the key staff of the organization who promised to help us get an appointment with the zonal Director who can grant us permission to carry out the campaign and possibly share iodized salts to pregnant women.

We had begun the process for the meeting which will resume once things return to near normal. This would go a long way to improve the health of women and prevent iodine deficiency in infants born to such women.

As a result of our social media campaign and our radio programs, we were able to get ambassadors and members in other states of the Northern Nigeria where we are situated who are also carrying out campaigns in their states.

### Challenges

The North Central of Nigeria, especially Benue, Plateau and Nassarawa states have the highest number of thyroid disorders. We are not sure whether it is due to diet, water or weather; we hope our organization can get funding to carry out research to determine the causes of

the high rates of Thyroid disease in this region.

We are constrained by the following in carrying out our activities::

#### High Cost of Thyroid Function Test

The cost of carrying out the tests is way beyond the reach of most. We hardly receive any assistance from other sources apart from ourselves and partners. Unlike foundations that have to do with malaria, cancer, mental health, HIV etc., thyroid foundations receive very little or no assistance to help sufferers. So many sufferers get discouraged and continue to live with the disease due to the high cost of testing and medication.

#### Few Specialists in the Area

The doctors who specialize in thyroid disease are so few that it is difficult to get an appointment at the government hospitals to treat thyroid disease. Most patients have reached the advanced stage of disease before they are diagnosed which has caused untimely deaths among many sufferers.

#### High Cost and Scarcity of Medication

The region where our foundation is located is the not too advanced and backward part of Nigeria which is the Northern Nigeria; to get thyroid medication for sufferers is an uphill task because most of the people in this region live below the poverty level. The high cost of medication and scarcity leaves so many sufferers unable to properly get help. Sometimes we have to send to the capital city of Abuja to get thyroid medication for some of our patients.

#### Aspiration

We at Goldheart hope to be able to get help through other supports and collaborations with other organizations to make the thyroid function tests as cheap as possible. We have already partnered with some laboratories. NANEL MEDICAL LABORATORY Jos, Plateau State and HOPE HAVEN HOSPITAL Kwang Plateau State have graciously agreed to give all patients from our organization a 50% discount in their thyroid function test. This is part of their support towards making the thyroid function test accessible to more people. Last year, we had only one laboratory, but this year, we have been able to have another medical laboratory to assist us.

We also hope to speak to manufacturers of thyroid medications to make donations to us or enable us to buy at them at much reduced prices.

We hope to get more and more people aware of thyroid malfunction through our social media engagements, skits and public awareness campaigns.

We have a number of patients awaiting funds for surgery and we have not been able to gather enough money for that. We hope to be able to do so very soon.

# Thyroidism Awareness and Support Initiative (TASI Nigeria)

## Brief History of Thyroidism Awareness and Support Initiative

LADY IRUOMA OFORTUBE  
EXECUTIVE DIRECTOR  
THYROIDISM AWARENESS AND SUPPORT INITIATIVE (TASI)

Thyroidism Awareness and Support Initiative (TASI), is the foremost patient-led not for profit organisation established in Nigeria in 2017 primarily to create awareness of thyroid disease, and also to support people affected by thyroid diseases in Sub Saharan Africa. TASI is the first in Africa to join Thyroid Federation International (TFI).

TASI emerged from what will always be referred to as a journey from “pain to purpose”. The pain, suffering, hopelessness, frustration and near death experience the founder of the organisation passed through while she battled thyroid disease for four years, before she got cured, exposed her to what victims of this disease must be experiencing and what potential victims will face due to ignorance, therefore TASI was established to bridge the gap.

## Projects (Past and Present)

We have major Projects in a year designed for the four quarters of the year infused with other media outreaches and health missions. These major events took effect from 2018 as we were officially registered and approved to commence activities in 2017.

### January Annual Public Lecture – 1st quarter

This is designed along with other awareness activities to commemorate the January Thyroid Month initiated by the American Thyroid Association. It was a convergence of medical experts and the general public, with brilliant presentations on issues surrounding thyroid health and its related disease, proffering solutions and networking with medical experts.

### Awareness/Charity Walk. May 25-31 – 2nd quarter

This is a week devoted to carrying out awareness campaign outreaches in both urban and rural communities. These programs are designed to suit the goals and objectives of International Thyroid Awareness Week (ITAW) / World Thyroid Day (WTD) from May 25-31.



## Support group Activities/Cell outreaches – 3rd quarter

We devote this quarter to our support group members, holding meetings with medical experts who came in to address our individual concerns and attend to people’s issues, and also outreaches in collaboration with our partners providing free thyroid screening to the general public and offering medical support including thyroidectomies.

## Media Campaigns/ Interviews – 4th quarter

We deploy diverse conventional media to disseminate information continually, via programs and interviews. We also embark on advocacy visits to government agencies, as well as health talks in conferences on thyroid, meetings, corporate organizations, etc.

## 2020

The year started with the news of the coronavirus pandemic, in some parts of the world posing threats to the execution of our annual goals and projects. This consequently changed our plans and mediums of execution rather than stopping our activities in 2020,

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## Thyroidism Awareness and Support Initiative (TASI Nigeria) *(continued from page 47)*

though some could be executed as planned. Sadly, our January annual Public Lecture was cancelled due to a social distancing law that was necessitated by the pandemic; on the alternative, we channeled the January awareness activities to media and virtual awareness activities - articles on social media, print media, electronic media, interviews and awareness campaigns.

Our 2nd quarter activities took on another new normal via virtual mediums - during International Thyroid Awareness Week (ITAW), we prioritized TFI activities by participating in the three wonderful live webinars held on the 14th, 25th and 31st respectively, to commemorate ITAW and WTD and most especially to celebrate the 25th of TFI.

TASI also embarked on some conferences with experts who made presentations on the Theme of ITAW 2020 – “Thyroid issues: Mother and Baby” - THE IMPACT OF THE THYROID ON THE FEMALE REPRODUCTIVE HEALTH, which was brilliantly given by a team of experts led by Prof Olufemi Fasanmade (A Consultant Endocrinologist & Professor of Medicine) on the 30th of May, with about one hundred participants across Africa and globally. (This sentence doesn't need to be a new paragraph) Also within the ITAW week we had a series of virtual and Media interviews.

In spite of the COVID 19 pandemic, in the first half of 2020 we also worked hard to maintain the momentum in delivering our vision by attending to some medical needs and assisting our thyroid patients in accessing proper and quality healthcare. This was demonstrated by TASI achieving successful thyroid surgeries for six of our people who were in critical conditions. We are relentlessly on course joining efforts to end the year in a most impactful way while we observe and maintain proper safety standards.

### Achievements

In the past and present, through our organization (TASI) we have been able to reach out to more than five million people with valuable information via diverse media: social media platforms, our websites, print and electronic media and conferences both physical and virtual.

We have given more than 200 people treatment support, free thyroid screening, free consultations and free drugs in collaboration with some philanthropists, our corporate sponsors and our local partners.

To date we have carried out about 32 surgeries, all in diverse severities; we were able to achieve this feat with the support of our partner thyroid specialists and surgeons who offer free consultation and subsidise the

surgery fees to the barest minimum. We shall achieve more if supported with enough funds.

In this pandemic we have been able to assist thyroid disease patients who are on thyroid replacement drugs and antithyroid drugs to secure free drugs, especially during the lockdown, for them not to break off from their routine medication. This was made possible by Phamatex Nigeria Limited, and our other sponsors who market and sell thyroid drugs.

### Challenges

Among all challenges, the major one is still dearth of knowledge about thyroid health and its related diseases both in the rural and urban communities. As a leader and the foremost thyroid focused organization in Africa, we have been saddled with diverse responsibilities and overwhelmed with requests and attention from several communities and People Living With Thyroid Disease (PLTD).

Sadly and unfortunately, governments, International Agencies and other stakeholders have not given attention to the awareness and sensitisation to the prevention, management and treatment of thyroid disorders significantly, as with other diseases like cancer, diabetes etc. This has resulted in heaping an avalanche of responsibilities on TASI. Paucity of funds has been the bane of our progress in achieving our goals.

It is our core objective to reach out to the rural communities with proper awareness and support to enlighten them so that the myths and superstitions that give rise to abuse and stigma on people suffering from thyroid disorders will be addressed and demystified. It is undoubtedly witnessed that people living with goiter in most rural communities in Africa are maligned and dehumanized because of their health condition and regarded as evil and witches, and the victims on the other hand see their condition as a spiritual or diabolic attack. These are caused by ignorance and lack of knowledge. With proper funding and support we will be able to reach out to them to enlighten the local community leaders and their subjects to also support the indigent suffering from thyroid disorders.

It is our pleasure and deep passion to serve humanity with all sense of dedication and love. We are proud also to be a member country of TFI. Hoping life returns back to normal.

### In TASI We Care, We Support, We Advocate

visit our website: [www.tasinigeria.org](http://www.tasinigeria.org)

email: [tasinigeria@gmail.com](mailto:tasinigeria@gmail.com)

instagram: [thyroid\\_awarenessnigeria](https://www.instagram.com/thyroid_awarenessnigeria)

twitter: [@fighthyroidism](https://twitter.com/fighthyroidism)



# The Thyroid Trust



LORRAINE WILLIAMS

Since completing registration with the charity commission in May 2019, The Thyroid Trust has gone from strength to strength, including receiving funding from the National Lottery Awards for All - for our popular events programme, which is now taking place online - and National Lottery Reaching Communities - to cover our core costs to continue to operate during the pandemic.

Despite the pandemic we organised a number of activities for International Thyroid Awareness Day this year. See separate article.

The charity's youtube channel now includes films of Professor Fausto Palazzo's talk on the evolution of thyroid surgery, Dr Paul Jenkins' talk on modern management of hypothyroidism, Dr Anthony Toft's talk on hypothyroidism treatment, #ToftTalk, a 2 minute awareness video and interesting talks from our March 2020 event with Sense About Science and The MS Society on using evidence to be influential.

Other speakers at our events this year have included Dr Kristien Boelaert, who talked about the new NICE guideline for thyroid disease assessment and management in London in January and Dr Renee Hoenderkamp, who talked about hypothyroidism from both sides of the stethoscope via Zoom in May.

With support from TFI we were able to send a representative to the EUGOGO conference in Pisa. Kelly's report is published on our blog.

In December we attended the ATA, ETA, BTA T3 Conference in London, along with representatives from several other patient groups, who were all very interested. We will be following up with a report of that event too, which Professor Colin Dayan has very kindly agreed to review. It was a lot to digest.

The Thyroid Trust is listed on the new NICE guideline, as approved information providers, having engaged energetically and positively with the development process. A new NICE guideline on thyroid cancer is now in development and TTT is once again an active stakeholder, proud to have already had some positive influence on the final scope and to have been able to involve thyroid cancer patients who may not otherwise have connected with the process.

In February 2020 we helped produce a new report for the Department of Health, on T3 prescribing, with our partners, including the British Thyroid Foundation, Thyroid UK, TPA, ITT and Thyroid Support Group Norfolk. The UK thyroid patient scene is quite

fragmented with several organisations that had not been very joined up until recently. We are all now working together, sharing information, amplifying patients' voices and learning a lot through this process and we are finding that collectively we can make more of a difference for patients through our collaborations.

A summary of national guidance and the government's position on T3 has been produced and is available on our website to help inform patients and doctors who are experiencing difficulties.

We convened a meeting in Westminster with NHS England and NHS Clinical Commissioners, along with Professor Chatterjee of the British Thyroid Association, Lord Borwick, Lord Hunt, Thyroid UK and Healthwatch England, to push for resolution of the long standing issue with access to T3 in the UK. Although assurances were given that steps would be taken to highlight that T3 should be provided on the NHS to patients who require it, the pandemic has meant that the agreed actions have not yet taken place.

We are continuing to receive reports of patients around the country having their prescriptions denied and many are still resorting to self-sourcing which is very concerning. These reports are being collated and will be presented to the Department of Health and other stakeholders at the earliest opportunity.

As a small and new organisation it is hard for us to support all the patients who need us but we do our best and are committed to ensuring we only share reliable information and signpost to evidence based resources such as NICE, British Thyroid Foundation and the NHS.

We are getting some great feedback: "I feel like The Thyroid Trust takes a real individualised approach to support - which is how patient care should be. I feel you're a very people-centered organisation and that mattered to me."

Our patient registry is available for researchers to learn from.

We have been proud to share the pilot questionnaire for the important international study by Picker on the experiences of patients with hypothyroidism.

Looking at the year ahead, we will continue to provide regular events online and are always keen to hear from prospective speakers, we are working to grow our team and supporter base so that we can increase our impact - and are devising a new strategy for growth. Our commitment remains to raise awareness and improve

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## The Thyroid Trust (continued from page 49)

understanding of thyroid disease while providing access to reliable information and peer support for everyone affected by thyroid disease.

Anyone who would like to support our work is invited to get in touch. We would love to hear from you!

<https://www.thyroidtrust.org/thyroid-awareness-week-2020.html>

<https://www.thyroidtrust.org/media-coverage.html>

<https://www.youtube.com/channel/UCieO-MH5qgL24bRcXLOZ0DA>

[https://www.thyroidtrust.org/uploads/3/1/8/1/31816005/l-t3\\_information\\_v4.pdf](https://www.thyroidtrust.org/uploads/3/1/8/1/31816005/l-t3_information_v4.pdf)

<https://www.thyroidtrust.org/nice-thyroid-cancer.html>

<https://www.thyroidtrust.org/blog>

### ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

### United Kingdom

## The Thyroid Trust and International Thyroid Awareness Week 2020

LORRAINE WILLIAMS

Despite the pandemic, we felt it was important to do as much as we could for International Thyroid Awareness Week.

We were thrilled that we managed to mobilise some very engaging fundraising and awareness raising activity.

International Thyroid Awareness Week 2020 has never really had much of a profile in the UK before. Our Team of 6 fundraisers raised a total of £3250, including Gift Aid. 101 people donated, which is amazing for such a little known cause and a brand new charity.

This year's activity aimed to highlight that the thyroid is a butterfly shaped gland and that thyroid disease is common but seldom talked about – the butterfly theme was devised to get people talking.



TTT Team at The Wellcome Collection



TTT Helga Taylor as a butterfly for International Thyroid Awareness Day.

Some good press coverage included a lovely article in the Daily Express with a photo of one of our runners dressed as a butterfly and BBC Radio Kent, twice.

We were delighted to have had some influence in the Scottish Parliament's motion for International Thyroid Awareness Day:

“That the Parliament acknowledges International Thyroid Awareness Day on 25 May 2020, which starts Thyroid Awareness Week; considers that, despite ongoing parliamentary debates and petitions in the UK, people, the majority of whom are women, are still not being fully listened to; acknowledges that the COVID-19 pandemic is adding to this challenge; appreciates the work being done by charities, such as the Thyroid Trust and Thyroid UK, in supporting people to fully understand and manage the disease, and hopes that Thyroid Awareness

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## TTT International Thyroid Awareness Week *(continued from page 50)*

Day will help encourage ministers and health providers to ensure that all people with thyroid disorders are given full and easy access to all options of treatment, including Liothyronine.”

The motion was brought by Elaine Smith MSP, who kindly attended our event in London in January. It was supported by MSPs: Iain Gray, Anas Sarwar, Alex Neil, Alison Harris, Jackson Carlaw, Richard Lyle, David Torrance, Bill Kidd, Sarah Boyack, Neil Findlay, Monica Lennon, Clare Adamson, Colin Smyth and Ruth Maguire.

We also held a Special Self Care event online, using Zoom, on 28th May, with volunteer speaker thyroid patient and yoga teacher, Michelle Varchione, who talked about the importance of moving and being gentle with ourselves. Over twenty people joined this session and all enjoyed it very much. We practiced self-massage and chair exercises and even had a participant in butterfly fancy dress.



The Thyroid Trust celebrate National Lottery Support in November 2019.



## Celebrating 25 years of TFI – Historical Photos



Warsaw 2001: Dr David Cooper (US) & son, Larry Wood, Shann Wood



### **Bulgaria: Joining the family**

At the 2002 meeting in Gothenburg, Maria received a warm welcome from Ulla and Bente Julie. *(Published in the 2003 ThyroWorld issue.)*



**TFI: 11th Annual Conference, Buenos Aires, Argentina 2005:** Australia, Canada, Denmark, Finland, France, Russia, The Netherlands, United Kingdom, United States



### **TFI: 8th Annual Conference**

*Gothenburg, Sweden*  
Displaying our wares. *(Published in the 2003 ThyroWorld issue.)*

# TFI Member Organizations

## AUSTRALIA

*Australian Thyroid Foundation Ltd.*  
[www.thyroidfoundation.org.au](http://www.thyroidfoundation.org.au)

## BELGIUM

*Leven Zonder Schildklier*  
[www.levenzonderschildklier.be](http://www.levenzonderschildklier.be)

## BRAZIL

*Instituto da Tiróide*  
[www.indatir.org.br](http://www.indatir.org.br)

## BULGARIA

*VIOM*  
[www.thyroidbg.com](http://www.thyroidbg.com)

## CANADA

*Thyroid Foundation of Canada /  
La Fondation canadienne de la Thyroïde*  
[www.thyroid.ca](http://www.thyroid.ca)

## COLOMBIA

*Asociación colombiana de pacientes de  
cáncer de tiroides*  
[www.acolcat.com](http://www.acolcat.com)

## CROATIA

*Croatian Association for Thyroid  
Disease*  
[www.stitnjaca.eu](http://www.stitnjaca.eu)

## DENMARK

*Stofskifteforeningen Blekinge*  
[www.thyreoida.dk](http://www.thyreoida.dk)

## FINLAND

*Suomen Kilpirauhasliitto ry*  
[www.kilpirauhasliitto.fi](http://www.kilpirauhasliitto.fi)

## FRANCE

*Association Vivre sans Thyroïde*  
[www.forum-thyroïde.net](http://www.forum-thyroïde.net)

## GEORGIA (EU)

*Georgian Union of Diabetes and  
Endocrine Associations*  
[diabet@access.sanet.ge](mailto:diabet@access.sanet.ge)

## GERMANY

*Bundesverband Schilddrüsenkrebs –  
Ohne Schilddrüse leben e.V.*  
[www.sd-krebs.de](http://www.sd-krebs.de)

*Schilddrüsen-Liga Deutschland e.V.*  
[www.schilddruesenliga.de](http://www.schilddruesenliga.de)

## GHANA

*Thyroid Ghana Foundation*  
[www.thyroidghanafoundation.org](http://www.thyroidghanafoundation.org)

## GREECE

*Hellenic Thyroid Patients Organization*  
[ledunt@otenet.gr](mailto:ledunt@otenet.gr)

## INDIA

*Thyroid Federation of India*  
[medisen@gmail.com](mailto:medisen@gmail.com)

## ITALY

*CAPE –Comitato delle Associazioni dei  
Pazienti Endocrini*  
[www.capeitalia.org](http://www.capeitalia.org)

## JAPAN

*Dr Fumito Akasu (Contact)*  
[www.akasu.com](http://www.akasu.com)

## KENYA

*Thyroid Disease Awareness Kenya  
Foundation*  
[www.facebook.com/  
thyroiddiseaseawarenesskenya](http://www.facebook.com/thyroiddiseaseawarenesskenya)

## NEPAL

*Thyroid Foundation of Nepal*  
[gandhiprasadsharma@gmail.com](mailto:gandhiprasadsharma@gmail.com)

## THE NETHERLANDS

*Leven Zonder Schildklier*  
[www.levenzonderschildklier.nl](http://www.levenzonderschildklier.nl)

*Schildklier Organisaties Nederland*  
[www.schildklier.nl](http://www.schildklier.nl)

## NIGERIA

*Thyroidism Awareness and Support  
Initiative*  
[www.tasinigeria.org](http://www.tasinigeria.org)

*Goldheart Thyroid Awareness  
Foundation*  
[www.goldheartthyroid.com](http://www.goldheartthyroid.com)

## NORWAY

*Stofskifteforbundet*  
[www.stofskifte.org](http://www.stofskifte.org)

## THE PHILIPPINES

*Thyroid Council of the Philippines*  
[tolsanluis@gmail.com](mailto:tolsanluis@gmail.com)

## PORTUGAL

*Associação das Doenças da Tiróide*  
[www.adti.pt](http://www.adti.pt)

## ROMANIA

*MCT8-AHDS Foundation*  
[www.mct8.info](http://www.mct8.info)

## RUSSIA

*Thyroid Foundation of St. Petersburg*  
[gasparyan@peterlink.ru](mailto:gasparyan@peterlink.ru)

## SPAIN

*Asociación Española de Cáncer de  
Tiroides*  
[www.aecat.net](http://www.aecat.net)

## SWEDEN

*Svenska Sköldkörtelföreningen*  
[www.skoldkortel.se](http://www.skoldkortel.se)

## UNITED KINGDOM

*The Thyroid Trust*  
[www.ThyroidTrust.org](http://www.ThyroidTrust.org)

## UNITED STATES OF AMERICA

*Graves' Disease & Thyroid Foundation*  
[www.gdatf.org](http://www.gdatf.org)



[www.thyroid-fed.org](http://www.thyroid-fed.org)