



# Thyroid Federation International

## Thyroid Patients Worldwide

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## 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

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Beate Bartès (France), Secretary

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Nancy Patterson (USA)

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Peter Lakwijk (Sweden)

### Administrative Coordinator

Katherine Keen (Canada)

### Website Coordination

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## 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 autumn issue of our ThyroWorld newsletter.

It's now more than 18 months that the Covid pandemic hit – and changed our plans, our lives and our entire world. Face-to-face meetings are still rare, travelling is complicated... after our first online AGM in October 2020, we now prepare our second online AGM for September 11-12, 2021. But this is also an opportunity – allowing members from all around the world to participate.

TFI attended various online events in the last months, like the e-ECE and the virtual ETA meeting. We co-organized a session “The Patient’s Voice” with the BTF at the e-ECE, gave a presentation on the E-MPATHY project (an online questionnaire for hypothyroid patients) at the ETA, and proposed two online webinars during the International Thyroid Awareness week in May.

Our organization continues growing, with now more than 35 member organizations from all continents – both patient-led and patient-oriented organizations. We encourage everyone who provides evidence-based information to apply for membership.

This issue is a bit thinner than the previous issues – due to these difficult times, with many of us facing difficulties and health issues.

We strongly hope that the situation will improve quickly – and to be able to meet again “IRL”, “in real life”, very soon!

BEATE BARTÈS, PETER LAKWIJK  
AND NANCY HORD PATTERSON, EDITORS



Beate Bartès



Peter Lakwijk



Nancy Hord  
Patterson

### ThyroWorld

Deadline for the next issue: June 20, 2022

Send all submissions to:

The Editors, ThyroWorld

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## President's Message

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

### Dear ThyroWorld Reader,

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, at least virtually.

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 the pandemic 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 was 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 speaking at each of these webinars on 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, EURORDIS, 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
- 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 2021 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 our Virtual AGM planned for Sep 11th and 12th, 2021.

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

# Follow TFI in Social Media

You can find us at:



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



<https://twitter.com/thyroidfed>



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



TFI also has its own YouTube channel, where you can find playlists, links to thyroid-related videos and the webinars we organize during the International Thyroid Awareness Week.

All videos can be found at our channel

<https://youtube.com/channel/UCRvrPIZiKdJjUxNALr1367BA>

**Subscribe for information about new videos!**

In 2021, we organized 2 ITAW webinars:

**The Scourge of Iodine Deficiency on Woman & Child with Dr Zimmermann**

Webinar hosted by Thyroid Federation International  
May 26, 2021

Facilitated by  
**Ashok Bhaseen**  
Ashok Bhaseen, M. Pharm, MMS, President Thyroid Federation International

Guest lecturer  
**Dr Michael Zimmermann**  
Leading thyroid researcher and Chair of Iodine Global Network

THYROIDWEEK  
Thyroid Federation International

**Iodine, COVID-19 and Thyroid Diseases with Professor Leonidas Duntas**

Hosted by Thyroid Federation International  
May 31, 2021

Facilitated by  
**Ashok Bhaseen**  
M. Pharm, MMS, President Thyroid Federation International

Guest lecturer  
**Prof. Leonidas Duntas**  
Professor of Endocrinology and Internal Medicine, Evgenidou Hospital, University of Athens, Secretary of the European Thyroid Association.

THYROIDWEEK  
Thyroid Federation International

During the e-ECE Congress, we coorganized a session *The Patient's Voice* together with the British Thyroid Foundation, with Dr. Pete Taylor speaking about the importance of iodine for a healthy thyroid and in pregnancy.



Channel 1 | 10:45 - 11:15 | The Patient's Voice 3 - The role of iodine for a healthy thyroid and in pregnancy. Organised by Thyroid Federation International and BTF Thyroid

**The role of iodine for a healthy thyroid and in pregnancy**

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**Peter Taylor**  
Clinical presentation

**eECE 2021**  
23rd European Congress of Endocrinology

# 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



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

## TFI Welcomes 4 New Members

### Bangladesh

The Bangladesh Thyroid Society (BTS) is an organization of Thyroid specialists, Medicine specialists, Endocrinologists, General surgeons, Neck surgeons, Obstetricians, General physicians, and scientists.



### South-Korea

The Korean Thyroid Association (KTA) is also an association of thyroid specialists and other professionals with interest in the thyroid. In Korea there are already many small groups of patients working together and with the doctors to inform patients. Regretfully there is no national organisation yet. KTA has taken it upon themselves to get the groups working together in a natio wide organization.



### Serbia

Motived not by her own struggling with Hashimoto, but by her sons diagnosis with Hashimoto at the age of 13, Bojana Jedoksić from Serbia founded the Association of Patients with Thyroid Diseases, called “Inner Wings”, with the main idea to provide support and enable access to professional medical information, so that patients more easily recognized the conditions we are going through, as a consequence of thyroid disease.



### Sweden

Increased knowledge – Individualized care – Healthy life for everyone with thyroid disease. This is the association’s motto. The Thyroid Association is a non-profit organization for people with thyroid disease, relatives, other relatives, and those who want to support the association’s goals and purpose. The association has almost 6,000 members (2020).



# Graves Patient Symposium at EUGOGO Conference



JANIS HICKEY, BRITISH THYROID FOUNDATION

## Presentation Summary, PISA, Italy, November 2019

Dr. Patterson, spoke of the quality of life impacts and the need for the individual, and their family, to be prepared and counselled through the event.

Her talk brought the reality of the disease to life for me. All the way from America, Nancy took the event from tones of medicine that, for me, complicated the facts with terminology and stats that are hard to relate to an individual's experience.

In plain English, she explained that Graves' disease is an autoimmune disease that makes antibodies that target the thyroid, causing it to become overactive. Whilst in TED antibodies target the tissues around and behind the eyes, as well as the eye muscles.

She explained that Graves' usually happens first, but TED may come before or after the onset of Graves'.

My own experience felt validated in some way, and I'm sure others in the room felt the same way, as Nancy called out that essentially every system in the body is affected by the symptoms of Graves'.

That's the muscles, the mind, the heart, brain, reproductive and respiratory.

She talked about some of the very real impacts on life that the disease has, reflecting my own experience of...

- Fatigue
- Difficulty concentrating
- Employment concerns
- Relationship problems
- Worry about the unknown
- Emotional problems (anxiety/ depression)

### Symptoms of TED

- Excessive tearing
- Grittiness
- Redness
- Itchiness
- Dryness
- Appearance
- Light sensitivity
- Pain
- Swelling around eyes



Dr. Nancy Patterson

Despite the picture she was painting of the painful nature of the disease on all levels, she made sure everyone knew that even if things aren't caught in the active phase, there are advanced treatments/surgery that can still help.

Nancy helped us to understand the needs of all of the people involved in the patient journey. Patients experience all their personal physical and emotional symptoms first hand. Families and loved ones experience the emotional symptoms, that can be negative in nature. Doctors and Caregivers experience the confusion of proper diagnosis, the challenges of treatment and follow up, and the complicating physical and emotional symptoms, as well the fact that each patient is different.

She talked about what each of these groups need in the journey.

### Patients need:

- A doctor who is experienced in treating complicated Graves' and/or TED.
- A doctor who will (and has time to) listen.
- A doctor who will see them as a whole person (i.e. in context).
- A doctor who will actively involve them in the treatment process. That includes a TEAM, accurate and understandable information, referrals to support groups.
- Support – both individual and family involvement. They need to know they are not alone.

To understand that, doctors have to be concerned with things like loss of vision due to pressure on the optic nerve, while we are usually more concerned with things like double vision.

### Physicians need:

- Patients who trust them.
- Patients who can give accurate and detailed information.

### Families need:

- Accurate information.
- Communication from/with the patient or to go with them to the appointments.
- Support for themselves.
- Patience.

She urged patients to remember that while dealing with an existence that is complicated by Graves' and T.E.D., we are not governed by them.

(continued on page 7)

## EUGOGO Conference *(continued from page 6)*

“We need to look at our lives from a different perspective. We are quite able to blame everything on our illness. Instead, we need to take credit for what we can do, and what others have helped us do. We need to redevelop our ability to dream and hope”.

### What the Patients said, and What the Doctors said back

One patient called for empathy from doctors and for doctors to be better trained in psychological and emotional support. In response, an Italian patient spoke with passion saying that to have empathy is one thing, but it's nothing without truly listening to what patients are saying. Applause filled the room.

Someone then asked how we can educate doctors and ensure all professionals that are likely to come across patients are fully aware of the symptoms (e.g. ophthalmologists and, of course, endocrinologists, although the latter are well educated in identifying symptoms as it's a connected disease).

Patients wanted to know what doctors were going to do to increase awareness of the disease and increase funding for a cure. The doctors passed that back, and said they needed patient groups to raise the awareness of the importance of increased focus on the disease, as well as patients supporting other patients through the disease, as there is nothing like a lived experience to truly understand what someone is going through.

The doctors also called for patients' groups to do as much as they can to support doctors in raising this issue, including influencing at a political level. This is what makes organizations like The Thyroid Trust, British Thyroid Foundation, Thyroid Eye Disease Charitable Trust, Thyroid Federation International, and the Graves' Disease & Thyroid Foundation so important.



Left to right: Dr. Terry J. Smith, MD, Chief Medical Officer of GDATF; Dr. Kahaley, TFI Board of Advisors; Dr. Nancy Patterson; Dr. Raymond Douglas, PhD, MD, Board of Advisors, GDATF.

## 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.



# The EMPATHY Project

## E-Mode Patient self-Assessment of THYroid therapy

LINDA HENDERSON AND PETER LAKWIJK

In 2018 Thyroid Federation International (TFI) was approached by Dr. Petros Perros (Consultant Endocrinologist at the Royal Victoria Infirmary in Newcastle upon Tyne (UK) where he specializes in thyroid diseases). A team of medical experts consisting of Dr. Perros, Dr. Hegedus (Denmark), Dr. Nagy (Hungary) and Dr. Papini (Italy) were starting a project with the financial support of IBSA. The objectives:

- Experiences of adults being treated for hypothyroidism.
- Associations between satisfaction and patient characteristics.

The project was aimed at patients all over the world with English as the main language.

The Board of TFI decided that they could be part of this as a full member of the team as experience experts.

TFI expected to get answers to some questions like:

- Why are there remaining symptoms with patients treated for hypothyroidism with levothyroxine?
- Are there similarities between the groups with remaining symptoms?
- Are there differences between the groups that use other treatments?
- Which needs of hypothyroid patients are not covered?
- Is there a connection between remaining symptoms and satisfaction with the medical staff?

Together with Picker Institute, a health and social care research organization, a questionnaire was set up and tested with 300 hypothyroid patients in the beginning of 2020.

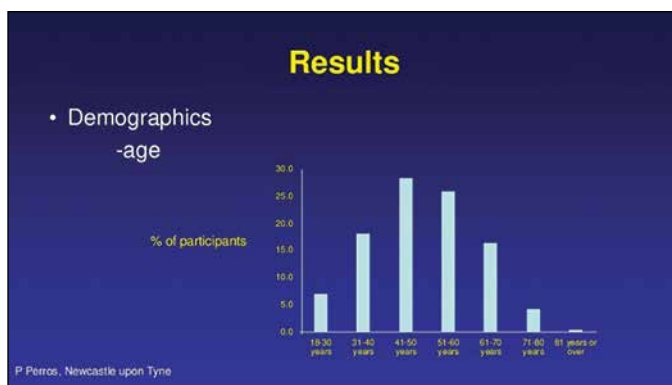
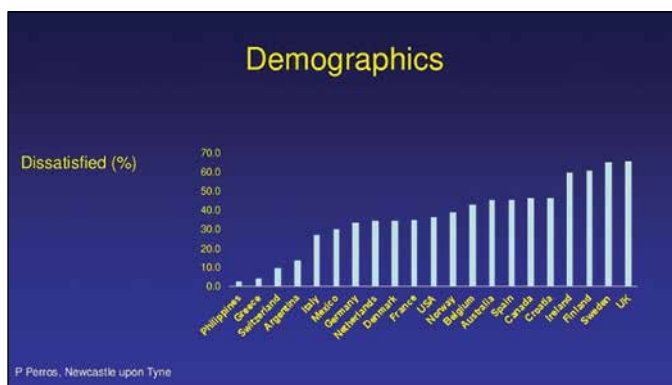
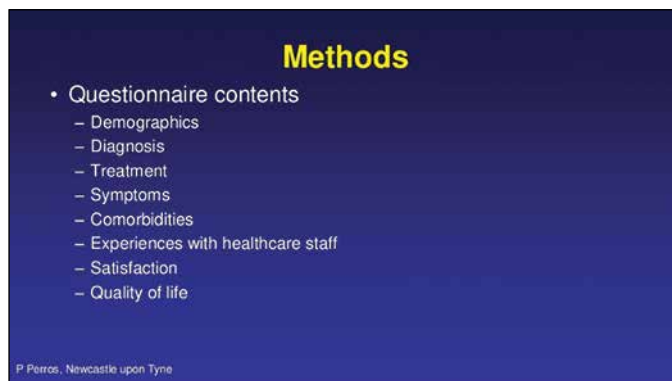
Like so many other things the roll out of the questionnaire was delayed by the pandemic but again started in November 2020. In the beginning of March 2021, the questionnaire was closed.

4,000 questionnaires were fully or partly answered.

### Was this satisfying?

Yes, it gave the possibility to look at the many answers that were given from 69 different countries with a variety of ages, different causes of hypothyroidism and all the different treatments for hypothyroidism. So that was good, and the first results showed the value of these answers.

(continued on page 9)



### Control of hypothyroidism

	Satisfied	Dissatisfied	p
Most recent TSH >4mu/L	13.7% (138/1006)	16.4% (220/1341)	<0.000
Last TFT >1 year	8.1% (106/1313)	12.1% (209/1723)	<0.000
Dose adjusted >once a year	13.8% (172/1243)	19.8% (327/1654)	<0.000

P. Perros, Newcastle upon Tyne



## The EMPATHY Project (continued from page 8)

But there was also some dissatisfaction. The Team expected many more questionnaires to be answered. The questionnaire was made available in 5 different languages (English, French, German, Italian and Spanish). It was sent to 56 thyroid patient educating organizations all over the world, not just to the TFI members. Unfortunately, several organizations (even TFI members) didn't spread it to their members for various reasons, e.g. that there was another questionnaire for their members, that the language was an issue or that the questionnaire needed approval of their medical advisory board and that takes time.

Additionally, the questionnaire was sent to the contact persons of over 360 Facebook groups in the 5 languages with a total of over 2 million members or followers. We couldn't see where the questionnaire was published, but the response was low except for a group where a discussion was started about the project with many reactions in favor and against.

### What are the first results?

Satisfaction with the treatment of hypothyroidism is depending on:

- Age
- Male or female
- Employed or not
- Ethnicity
- Where you live
- Income
- Other diseases
- Autoimmunity
- Psychosocial factors
- Regular check of the thyroid values
- Too few or too many tablets
- Management of hypothyroidism by the patient

### So, what can we do with these preliminary results?

Many factors we cannot influence but some we can.

Regular checks of the thyroid values should be initiated by the doctor. A test every 6-12 months can improve the right dosage and improves the relationship between the healthcare providers and the patient. This is not mandatory in all the guidelines for the management of hypothyroidism.

Forgetting tablets and/or taking an extra tablet, taking tablets on an empty stomach, separating from other medication/food/supplements is management of hypothyroidism by the patient.

If we look at diabetes care, we can see remarkable differences.

### Formulation of thyroid medication

	Satisfied	Dissatisfied	p
<b>Burdensome</b>			
-Taking tablets on an empty stomach	43.4% (464/1070)	56.1% (829/1476)	<0.000
-Defer breakfast	56.1% (582/1037)	72.3% (1049/1451)	<0.000
-Separate from other medications	52.4% (525/1002)	68.8% (1007/1463)	<0.000
-Alternate day dose	54.0% (141/261)	74.4% (256/344)	<0.000
-Splitting tablets	51.6% (234/453)	68.3% (439/643)	<0.000

P Perros, Newcastle upon Tyne

### Symptom interpretation

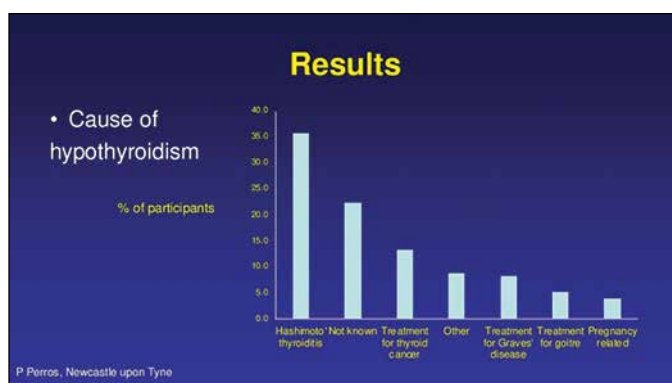
	Satisfied	Dissatisfied	p
<b>Symptoms blamed on hypothyroidism or treatment</b>			
-Stomach pain	19.9% (101/507)	32.4% (313/965)	<0.000
-Back pain	19.2% (121/629)	28.4% (304/1072)	<0.000
-Headache	20.8% (135/647)	36.8% (402/1091)	<0.000
-Chest pain	35.1% (87/248)	42.5% (207/487)	<0.000
-Dizziness	43.3% (181/418)	55.7% (479/860)	<0.000
-Nausea	31.0% (189/609)	48.5% (548/1129)	<0.000
-Painful intercourse	32.9% (79/240)	43.8% (180/411)	<0.000

P Perros, Newcastle upon Tyne

### Experiences with healthcare staff

	Satisfied	Dissatisfied	p
No confidence / trust	3.5% (38/1078)	55.0% (632/1148)	<0.000
Doctors lack knowledge	6.7% (72/1076)	55.0% (632/1148)	<0.000
Not given enough time	13.3% (143/1078)	63.1% (724/1148)	<0.000
Poor communication	4.5% (49/1078)	33.3% (383/1148)	<0.000
Little/no info on how to take medication	5.6% (70/1247)	36.8% (609/1654)	<0.000
No involvement in management decisions	11.6% (153/1320)	54.1% (939/1734)	<0.000

P Perros, Newcastle upon Tyne



There are special diabetes nurses in nearly every hospital to keep track of patients. There are special training courses for doctors and nurses about diabetes. In some countries there are trainings for patients to deal with their diabetes. Unfortunately, for thyroid patients this does not exist.

The complete presentation of the first results by Dr. Perros can be seen on the website:

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

# #MOTHERBABYIODINE

## A Global Awareness Campaign

L. LINDA HENDERSON  
BOARD MEMBER, THYROID FEDERATION  
INTERNATIONAL

Thyroid Federation International, a global patient organization came together with six important leaders – Iodine Global Network (IGN), Nutrition International (NI), World Iodine Association (WIA), Global Alliance for Improved Nutrition (GAIN), European Medical Association (EMA) and European Association for Predictive, Preventive and Personalized Medicine (EPMA) to bring attention to the extent and consequences of Iodine Deficiency Disorders (IDD) on women of reproductive age (WRA). IDD continues to affect women in both developed economies and countries in development.

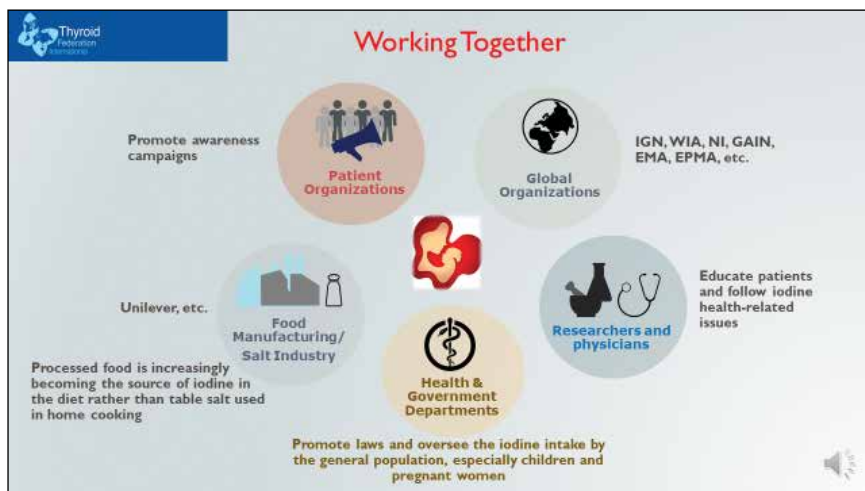
Not enough awareness has been brought to the public and to WRA, especially pregnant & lactating women (PLW) on the importance of adding iodine (in various forms) to their diets to eradicate IDD. This is why an awareness campaign is a vital channel to bring attention to this public health problem.

The project leaders visualize building a coalition of cross-sectored, like-minded stakeholders who are sympathetic to the Mission of raising awareness around IDD, its causes and solutions. It is envisioned to involve International Organizations, Industry (salt, food and feed), Medical Professionals (especially Endocrinologists, Obstetricians-Gynecologists, Pediatricians, General Practitioners, Midwives), Patients’ Organizations, and Ministries of Health, among others, into this project.



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 slash IQ by 10-15 pts.

This year, the **MotherBabyIodine** ([www.motherbabyiodine.org](http://www.motherbabyiodine.org)) project jumpstarted in Indonesia, a country that is severely affected by iodine deficiency. With Unilever support, space was given to the local NutriMenu campaign 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.



During the International Thyroid Awareness Week (ITAW 2021) in the Philippines, a 6-day series of webinars was organized by Dr. Teofilo San Luis Jr (IGN National Coordinator) on the theme: **Mother-Baby-Iodine: The Importance of Iodine on the Woman and her Baby**. International and national speakers took part with Michael Zimmermann (IGN Chair) giving a comprehensive lecture entitled *The Scourge of Iodine Deficiency on the Woman & her Child*.

(continued on page 11)

## #MotherBabyIodine (continued from page 10)

In the meantime, the project has received strong interest from several other countries in Asia: Bangladesh, Thailand, Taiwan, Sri Lanka, Vietnam, Papua New Guinea, Cambodia, South Korea, as well as in several African countries and European countries. TFI is looking forward to working with their representatives.

It is of note that Iodine Deficiency in pregnant and lactating women has not been eradicated in most European countries. The level of awareness of why iodine is necessary for human consumption is declining not only among the general public, but also with policy makers leading to the resurgence of iodine deficiency. For this reason, the goal is to complement ongoing advocacy efforts undertaken by various organizations directed to policymakers in order to generate a wider momentum for the promotion of iodine and iodized salt during and after pregnancy. (see Krakow Declaration on Iodine <https://www.iodinedeclaration.eu/>)

TFI's goal is an increased awareness of IDD and the importance of iodine fortification especially on food through iodized salt. Women of reproductive age, particularly pregnant & lactating women should be made aware where iodine can be sourced from in terms of food. TFI anticipates that healthcare workers, policy makers, as well as family share/spread this knowledge with their target population.

For more information:

[info@motherbabyiodine.org](mailto:info@motherbabyiodine.org)

Contacts:

[linda.henderson@thyroid-fed.org](mailto:linda.henderson@thyroid-fed.org)

[peter.lakwijk@thyroid-fed.org](mailto:peter.lakwijk@thyroid-fed.org)



## September is Thyroid Cancer Awareness Month



# Australian Thyroid Foundation (ATF)

The Australian Thyroid Foundation celebrated our 25th Anniversary in 2020 which is a fantastic milestone. The ATF is the only thyroid patient support and educational organisation in Australia. We are very proud to have the support of our Medical Advisory Team, who are all world leaders in different aspects of thyroid disease. The Endocrine Society of Australia and the Australia and New Zealand Endocrine Surgeons are also great supporters.

**Keep your ATF Membership Current – Thyroid Disorders are for Life!** encourages members to renew their membership and be kept up to date with the latest information and support, with regular email communications and one on one support when required.

New memberships are constant and increasing, which is wonderful to know our member services continue to attract patients and our services are meeting their needs.

The ATF **Thyroid Patient Management** holds all the important day to day references and information to ensure members have the best information about managing their thyroid medications, knowing the correct procedure for thyroid pathology tests and much, much more.



As Australian made Levothyroxine brands Oroxine (original brand) and Eutroxig (generic brand) must be kept refrigerated at all times and are produced and stored in blister strips for easy access. The ATF have available an approval **Medication Travel Pack (MTP)** for members and the public to purchase and use while travelling or away from home to transport their medication. The

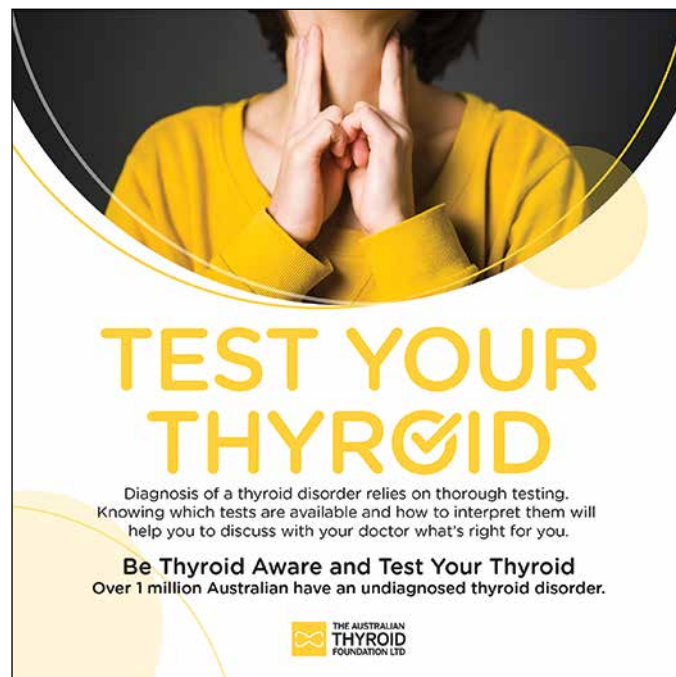


MTP keeps the medication at refrigerated temperature for hours, which prevents spoilage from temperature increases and light.

## ATF Awareness Campaigns

The ATF continues to raise awareness throughout the Australian community during our two main awareness campaigns.

May is the ATF's **Thyroid Awareness Month** and 2021 focused on Test Your Thyroid! Australian statistics show over 2.5 million Australians are living with some form of thyroid disorder. The majority of which is due to an undiagnosed thyroid auto-immune disease – Hashimoto's or Graves' Diseases with many pregnant women affected without prior awareness. These statistics are alarming and more needs to be done to ensure patients are diagnosed and treated when necessary.



1st September is the ATF's **Gold Bow Day** – which promotes awareness of symptoms and changes to the thyroid, which may be due to Thyroid Cancer! Younger Australians are increasing to be diagnosed and statistics show 363 patients were diagnosed in 1982 with 2973 in 2016. This may be due to more frequent ultrasound requests and early diagnosis, however either determining or eliminating the possibility if a patient is experiencing symptoms is the key to continuing good thyroid health.

(continued on page 13)

**Gold Bow Day**  
1st September

**Thyroid Cancer - Be Aware of Symptoms and Changes**  
If you are concerned please ask your doctor to order a Thyroid Ultrasound and Thyroid Function Pathology

Research states Thyroid Cancer has increased and particularly in younger Australians. Therefore identifying and diagnosis through ultrasound and pathology is essential.

Symptoms ranging from an enlarged or painful thyroid gland, persistent cough, voice changes, trouble swallowing or sleeping due to discomfort need to be investigated.

Types of Thyroid Cancers – Follicular, Papillary, Medullary and Anaplastic

Please visit [thyroidfoundation.org.au](http://thyroidfoundation.org.au) for more information

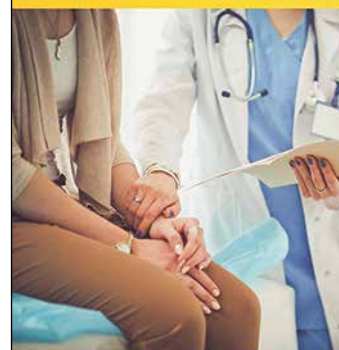
Order your Gold Bow pin today to support Thyroid Cancer Awareness!

**THE AUSTRALIAN THYROID FOUNDATION LTD**  
25<sup>th</sup> Anniversary  
25 Years of Support, Education, Awareness and Advocacy

## ATF Healthcare Professional Honorary Membership!

The ATF continue to encourage GP's, specialists and other healthcare professionals to take advantage of ATF Honorary Membership and have access to our Healthcare Professional Section on the ATF website. The benefits of (free) membership gives HCP's access to our Medical Advisory Team with one on one contact, entrance to the HCP Section which holds audio, video and written information to help HCP's to better understand and treat patients with thyroid disorders, with ongoing membership to ensure they will continue to receive updates and changes to treatments, medications etc. when available.

**As a HCP you are invited to register for Honorary ATF Membership**



The Australian Thyroid Foundation (ATF) supports thyroid patients and their families.

The ATF is recognized as the Australian Consumer Advocacy Organisation for Thyroid Disorders and Iodine Deficiency

The ATF look forward to continuing into the future and improving outcomes for thyroid patients through the many services provided by the ATF!

## ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

## Canada

# TFC President's Report for Thyroworld

LAZ BOUROS  
PRESIDENT, THYROID FOUNDATION OF CANADA

This past year has been a difficult one for everyone. For the Thyroid Foundation of Canada (TFC), this past term was a shorter one due to the delay from holding our last AGM in November rather than in June. We adopted new ways of working by regularly using Zoom videoconferencing for all our board meetings and regularly use Zoom to communicate with a variety of stakeholders. We also produced two issues of our Thyrobulletin newsletter.

On March 7th, we held our first virtual public education Zoom webinar. This pilot, which was planned to allow us to learn more about hosting educational webinars, was a resounding success! It featured our own

medical advisor, Dr. Deric Morrison as guest speaker, and a panel of thyroid patients who each spoke about their experience with thyroid disease. The panelists included Kim McNally, our Vice-President and Director of Patient Support, who spoke about Thyroid Cancer; Lauri Martin, a key volunteer on our Help Line Team who spoke about Hashimoto's Thyroiditis; and Tatyana Medvedyeva, our Director of Public Relations who spoke about Toxic Multinodular Goitre. After each patient's story, Dr. Morrison commented on the highlights of the thyroid condition. Once all the panelists completed their stories, Dr. Morrison answered questions from the audience. Attendees were asked to use the Q & A feature of Zoom to enter their questions.

(continued on page 14)

## TFC President's Report (continued from page 13)



The Panelists

We have completed over half of the initiatives in our Strategic Plan and continue to make incremental progress in the plan. On the research side, the agreement we signed with the Canadian Society of Endocrinology and Metabolism (CSEM) last October to manage our research grants was implemented. In March, the CSEM announced on their website that the Thyroid Foundation of Canada Research Award, “an award of \$50,000 per year for 2 years will be granted to a researcher focused on thyroid disease”. The award will be presented to the selected thyroid researcher at the Annual Professional CSEM Conference in November 2021. We added a “Research” tab on our website to showcase current and past TFC and other thyroid research projects.

In looking to the future, we must first recognize that we are a small registered charity and there are limitations to our capabilities. While we need to maintain the organization’s commitment to federal regulations to support our current status, update our bylaws and policies, and manage our finances, we must also recognize that our mission is to provide services for our members and thyroid patients across Canada. I have often said that there are two types of activities that we perform: those focused internally on supporting the organization and those focused externally on providing services to members and thyroid patients. The challenge for us is to keep the internal and external activities in balance.

Too much focus on internal activities and we are seen as an organization that does little for thyroid patients. Too much focus on external activities and we risk non-compliance as a charity and poor management of our resources.

At our AGM last June, I introduced a theme called “Work Smart” to be considered in future years. This has to do with adopting initiatives that have a multiplier effect for our small organization (and conversely, stay away from those activities that create or generate a lot of work for us).

For example, last year we switched to using Zoom for our board meetings. As an internal initiative, it saved several hundred dollars by going from teleconferencing to videoconferencing for our board meetings and improved our communications as we now see the members in the meeting. Another example is the outsourcing of our Thyroid research grants to CSEM which alleviated us of the burden of managing the grant process. We need to continue finding new ways to innovate our internal and external capabilities to grow the organization and improve our service delivery.

Next year, we are looking to continue to build on the improvements we adopted in the last term and take on some new ones. Externally, we need to provide additional educational webinars for thyroid patients to follow up on the success of our first webinar. We need to continue updating our medical and other information on our website. Internally, we need to find better ways to manage the investment of our research funds, update our support software, and update our bylaws and policies. I hope that we will find new innovative ways to get things done with our small group and continue providing quality services to our members and thyroid patients across Canada!



Thyroid Foundation of Canada

La Fondation canadienne de la Thyroïde

# Stofskifteforeningen in Denmark

For 24 years we have been present in Denmark and we are a growing organization. Our focus is, as always, on information and education of patients with thyroid disease. We cover all thyroid diseases and try to have as much information for all groups as possible.

This past year has been a year where we have made changes. As the rest of the world, we and our members have learned to use online tools to stay in contact. Before Covid-19 we have never held an online meeting and it has never been very high on our list of priorities, but now because of Covid-19 we have held several online information meetings and our members love it. We have had a members' conference with more than 300 participants, meetings where you can ask the doctor with 200 participants, and a meeting about hyperthyroidism with 90 participants.

We have decided to continue these meetings even after we are allowed to hold physical meetings again. With the online meetings we have been able to include participants from all over Denmark, participants that normally are not able to participate because of lack of transport, not well enough to travel and just members that do not have the time to participate in a physical meeting because it takes more time than sitting down in front of your computer and joining an online meeting.

In Denmark we are working with awareness among the general public, doctors and politicians. There has never been a great focus on thyroid disease in Denmark and one of our focus areas it to increase awareness for all about thyroid disease. We have had several meetings with members of the Danish parliament where we have spoken about thyroid disease, and we are often joined by leading Danish endocrinologists that support our work.



Bente Lasserre and Dr. Birte Nygaard at the Danish Parliament.



Members' Conference

Most of the work is still done based on volunteer work, but we now have employed a part time and a student worker, we hope the coming year will make us grow even further. We are a growing organization, and we now have 2600 members in Denmark, we have not reached our goal yet so we keep working and getting more members. We support our members by our magazine that comes out 4 times a year and we have a weekly telephone service where we answer questions from thyroid patients; we are constantly updating our website and planning new activities for members.



THYREOIDEA  
LANDSFORENINGEN

# Finnish Thyroid Association

MIRJA HELLSTEDT  
MANAGING DIRECTOR, EDITOR-IN-CHIEF  
FINNISH THYROID ASSOCIATION

The Finnish Thyroid Association increases the awareness of thyroid and parathyroid diseases, treatment and research, as well as the physical, mental and social wellbeing of patients with thyroid and parathyroid disease.

Our association offers information and support. Priorities for action are multichannel communication (e.g counselling by phone and email, active social media presence, video lectures, magazine, medical articles and brochures), lobbying, organization of rehabilitation courses for thyroid patients and parathyroid patients and promotion of rehabilitation and work volunteering.

We cooperate with other Finnish patient organizations, the *Ministry of Social Affairs and Health*, the Finnish Endocrine Society *and media*.

Our activities are financed with public funding, membership fee income and fundraising. Very important public funding comes from the Funding Centre for Social Welfare and Health Organisations (STEA). STEA is a state-aid authority operating in connection with the Ministry of Social Affairs and Health.

## KILPI Magazine

The Finnish Thyroid Association has "KILPI" - a magazine that appears four times a year. This magazine is very popular with readers who are mainly thyroid and parathyroid patients. Peer stories are usually the most interesting articles. Readers also appreciate very much Q&A pages where doctors answer readers' questions.



KILPI magazine is very popular among readers.



## Cooperation with healthcare professionals

Our association is constantly cooperating with doctors as well as researchers, nurses and students. Cooperation is a necessary condition for the development, access to scientific knowledge and hearing the patient's voice. International cooperation is also important.

One of our long-term partners is Doctor Ulla Slama. In June 2021 she was awarded gold medal of social and health care. The award is recognition of her long-term and meritorious work for thyroid and parathyroid patients, regionally, nationally and internationally.



Doctor Ulla Slama

## Facts about the Finnish Thyroid Association

- founded in 1999
- nationwide organization working closely with 15 regional Thyroid associations
- the office is located in Helsinki
- 4.2 employees
- more than 10,000 members



# Thyroid Ghana Foundation (TGF)



The Thyroid Ghana Foundation (TGF), launched on 13th July 2018, has been implementing its mandate of creating awareness on thyroid disorders, supporting thyroid patients, and encouraging thyroid research. TGF is mainly supported by the College of Health Sciences (University of Ghana, Legon) with strong backings from various departments including Medicine and Therapeutic (Endocrine Unit), Medical Laboratory Science and Pathology. TGF also seeks to engage government agencies such as the Ministry of Health and the Food and Drugs Authority to introduce policies toward promoting thyroid health.

## Past and Present Activities

The Foundation has in place a patient support program which pays regular visits to the Endocrine Clinic and Surgical Clinics to educate patients on lifestyle changes needed for managing the condition. TGF has reached an agreement with two medical laboratory companies and currently offers discounts on all thyroid related blood tests and thyroid scans. Currently, TGF in collaboration with University of Ghana Medical Centre (UGMC), is performing subsidized surgeries for thyroid patients.

## COVID 19 and Thyroid Disorders

As a result of the COVID-19 pandemic, the Foundation has now moved most of its activities online. Education on COVID-19 and thyroid disorders was carried out through online platforms for thyroid patients and the public. Additionally, the Foundation assisted patients in adjusting to new online systems at the Clinic by helping book appointments and sending laboratory results to doctors electronically for review.

## Media Campaigns

Thyroid Ghana Foundation has been very active within the media space to increase the awareness on thyroid and its related issues through frequent appearances on TV and radio, including coverage by United Television (UTV) during the launch of the International Thyroid Awareness Week. There is continued support from the various media outlets, who invite us for subsequent appearances to create more awareness on thyroid disorders.



## Thyroid Research

The Foundation is making preparations towards supporting its first thyroid research. Contacts have been made with scientists in various fields to initiate this collaborative research. Towards this, steps have been taken to expand and re-organize our patient's data using a research friendly format.

## Upcoming Projects

TGF intends to step up its media campaigns to increase awareness of thyroid disorders. Having obtained the consent of thyroid patients visiting UGMC, Thyroid Foundation Ghana is collaborating with the Medical and Scientific Research Centre, which is the research hub of UGMC to conduct studies into thyroid conditions and treatment outcomes. This is aimed at contributing knowledge to the management of thyroid disorders.

## Report on International Thyroid Awareness Week Celebration (May 25 to 31, 2021)

**Thyroid Ghana Foundation (TGF) collaborates with the University of Ghana Medical Centre (UGMC) to perform subsidized and sponsored thyroid surgeries for the underprivileged.**

The Thyroid Ghana Foundation (TGF) celebrated International Thyroid Awareness Week (ITAW) with a launch and a seminar titled "Allaying the fears around thyroid surgery". This topic was based on the theme the foundation chose for the ITAW celebration which was "Promoting Affordable Thyroid Surgeries for Thyroid Patients in Ghana". The week was a collaboration between Thyroid Ghana Foundation and University of Ghana Medical Centre (UGMC). This webinar attracted people from diverse backgrounds such as the CEO of UGMC, Director of Medical Affairs, medical practitioners, staff, volunteers of TGF, and some persons with thyroid disorders.

The speaker of the webinar Dr. Solomon Brookman, a consultant general surgeon at UGMC, shared his knowledge on the types of thyroid disorders, causes, symptoms, treatment, and medical research. To mark the celebration, the Thyroid Ghana Foundation in collaboration with UGMC initiated a project to provide subsidized thyroid surgeries for people with thyroid related health problems. This project was initiated as part of the activities in celebrating the International Thyroid Week, 2021, and also marked the start of a relationship between the Thyroid Ghana Foundation and UGMC.

(continued on page 18)

## Thyroid Ghana Foundation (continued from page 17)

The CEO of UGMC Dr. Darius Osei, in his interview with United Television (UTV), said that “thyroid patients are either treated medically or surgically depending on which of the treatments is best for the patients. But as the doctor explained at the seminar, a lot of people fear the surgery, so the whole idea behind this awareness is to try and allay the fears of these patients. Medicine has developed over the years with the use of state-of-the-art medical equipment and medical research to carry out surgeries without any complication”.



A cross section of in-person dignitaries present at the Launch/Seminar.



Mrs. Nana Adwoa Konadu Dsane, Founder/President of TGF.

Consultant general surgeon at UGMC, Dr. Solomon Brookman also told UTV that “the surgery is not scary these days; research into human healthcare and medical treatments has improved so much such that carrying out these procedures comes without any complications”. The founder and president of the Thyroid Ghana Foundation, Mrs. Nana Adwoa Konadu Dsane, told UTV that many people with this condition have limited knowledge about the disease and tend to attribute it to spiritual and other factors rather than seeking appropriate medical treatment. Therefore, it is important that we continue creating awareness of the disease. Currently, nine successful surgeries have been carried out under this project with more upcoming.

<https://www.facebook.com/utvghana/videos/313348766925892>

<https://www.peacefmonline.com/pages/videos/202105/43666.php>

<https://www.facebook.com/1684771281777916/posts/29075631894989813/?sfnsn=mo>

<https://www.facebook.com/officiarealshow/videos/2768541800111333>



# May 25th World Thyroid Day



# Italian Association of Basedowians and Thyroid



BY EMMA MARIA BALDUCCI GAZZOTTI  
REGGIO EMILIA, ITALY

AIBAT (*Italian Association of Basedowians and Thyroid*), despite these difficult times caused by Covid-19 which prevented access to hospitals, has nevertheless carried out an intense activity to assist patients suffering from the pathology of Basedow-Graves. The contacts with the patients were numerous and even higher than in previous years. Contacts that were not limited to a single conversation but consisted of a personal connection that created a caring relationship with people who also required psychological support.

We are confident that direct contact with patients will be possible in the coming months. During these past months our Association also created new relations with doctors and specialists. In the hospital where AIBAT operates – Arcispedale Santa Maria Nuova in Reggio Emilia, a new and concrete sensitivity towards Graves patients was formed. This was amply illustrated in a popular television program by Dr. Andrea Frasoldati (endocrinologist) and by Dr. Alberto Neri (ophthalmologist), two important specialists of the hospital.



Prior to the television program a series of meetings took place to discuss creating a close link in Reggio Emilia between Endocrinology, Surgery and Ophthalmology for the treatment of Graves. A dedicated 'center' to this still hasn't been created, yet we can say that the hospital in Reggio is moving towards a comprehensive and organized treatment of the disease. Work has already begun to organize a conference in 2022 dedicated to Basedow-Graves disease together with La Lumaca Association of Perugia.

The date has yet to be determined but among the most noteworthy presences we count on that of Dr. Mario Salvi, Director of the Center of the Maggiore Hospital in Milan, an important presence of the EUGOGO Group who will update us on the research and treatments dedicated to this pathology.

Therefore, attention and measures relating to such a complex disease are rising. Another important sign came from the CAPE (Endocrine Patient Association Committee) which, thanks to its President, Anna Maria Biancifiori, wanted Basedow-Graves disease as a fundamental theme of the World Thyroid Week 2021 in Italy.



## May 25 to 31, 2022

### 13th International Thyroid Awareness Week

[www.thyroidweek.org](http://www.thyroidweek.org)

# Thyroid Disease Awareness Kenya (TDAK)

The Thyroid Disease Awareness Kenya (TDAK) is a nonprofit organization legally registered in Kenya under the society’s act ‘Cap 108’ of the constitution of Kenya. Founded in 2017, the Thyroid Disease Awareness Kenya Foundation (TDAK) is dedicated to improving thyroid care in Kenya. TDAK focuses its efforts on creating awareness, promoting research, and advocacy in order to improve the quality of life for people with thyroid disorders. A core group of thyroid educators at TDAK supports people with thyroid disorders to manage their health situation to the best of their abilities, to allow them to make informed choices and take actions based on informed judgment.



and hence bridging the gap between healthcare seekers and healthcare givers.

## Where we are in 2021

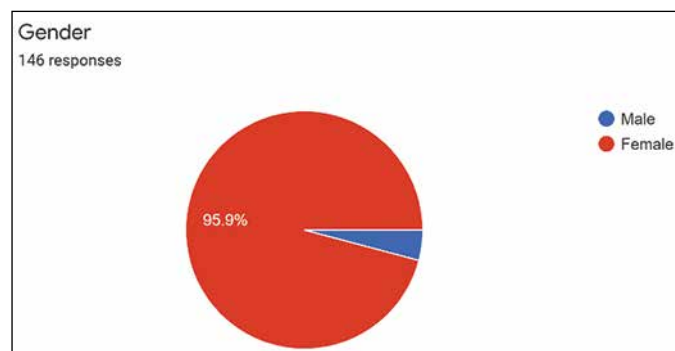
We have seen a steady growth in numbers as more and more people learn about us and are joining our movement. We have a following of 600 people on our Facebook page, up from

330 last year, 473 members in our Facebook Private group up from 245 last year, a WhatsApp group with 211 members up from 97 last year, and 550 followers on Instagram most of whom are non-Kenyan. This increase in numbers has been triggered by our steadfastness in using social and mainstream media like television and print as a means of conveying and disseminating information about thyroid disease. Because of covid-19, we have been restricted in holding social gatherings or even moving around the counties within Kenya. But we worked around that and strengthened our ability to use technology as a means of reaching people. And so far it seems to be working as we realize that we are reaching more people from other countries within the East African Community (EAC).

Thyroid disease is globally listed among the most common type of auto immune non – communicable diseases. In the East African region, thyroid disorders are commonly neglected, overlooked, and their impact underrated, presenting a severe public health problem (prevalence of 60.2%) that is amplified by the scarcity and insufficiency of medical treatment and equipment laboratories specializing in endocrinology. National health policies and strategies by governments in the region continue to underrate the impacts and the intensity of thyroid disorders in their respective jurisdictions.

From our survey, we have also noticed that word of mouth has really helped to make people learn more about us, and when they find us they feel so relieved and at home. This lets us know that there is more to be done.

Disease incidences have largely been under-reported due to low testing rates (under diagnosis) and mis-diagnosis by medical practitioners most of whom are not thyroid specialists. National data on the prevalence of thyroid disorders is also non-existence in the region, as health-care systems are traditionally geared towards the management of acute illnesses and infectious diseases, such as tuberculosis, malaria and cancer and these further utilize the resources needed to focus the attention to other non-communicable diseases like thyroid disease.



A substantial percentage of our populations continue to suffer in silence due to the high threshold for testing, scarcity of specialized facilities, and outdated disease management practices by health practitioners. Specialists in thyroid health are few and they are only in densely populated, major cities like Nairobi, not forgetting they charge hefty fees for consultation.

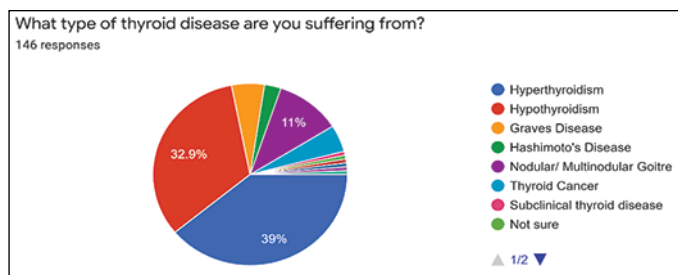
According to the data that we are collecting, in this region, women are more affected with thyroid disease than men. But we are also reaching out to the men to come forward. The number of men with thyroid disease is under represented because most of them are scared to say that they have a disease that mostly affects women; still a taboo here in Africa.

The TDAK Foundation’s role as a leading authority on thyroid health, is to support, promote and work with other stake holders to advocate and to advance knowledge, and to translate discoveries about thyroid disorders and its complications as well as treatment options into practical solutions that make everyday life better for people living with or at risk of thyroid disease

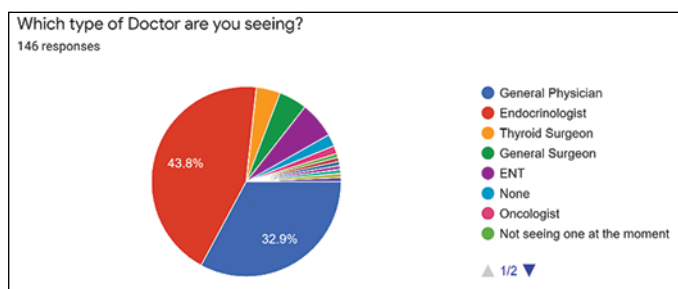
Every type of thyroid disease is represented in this region with thyroid cancer cases being on the rise.

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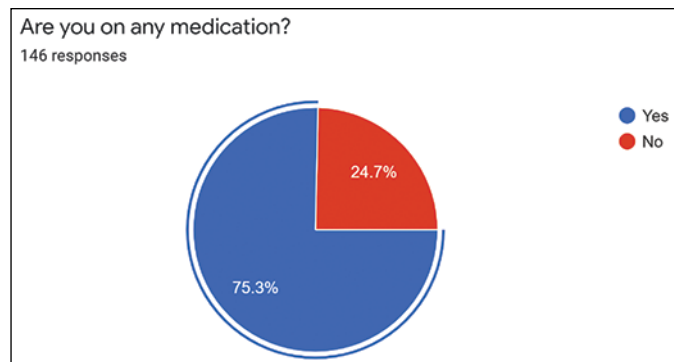
## Thyroid Disease Awareness Kenya (continued from page 20)



Most patients are working with general surgeons who are fairly priced compared to a specialist, making it clear that treating thyroid disease in this region is very expensive, as we can see in the chart below.



Many patients are unable to afford to buy medication as is required in the treatment of thyroid disease as most of them are on the minimum wage of less than \$200 Dollars per month.



We are seeing steady growth in what we are doing and we are looking forward to reaching and helping even more people in future.

## ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

## Nepal

# Common Diseases in Nepal : An Overview

GANDHI PRASAD SHARMA  
GENERAL SECRETARY, THYROID FOUNDATION OF NEPAL

While we talk about the common diseases in Nepal, one must first examine some of the facts and statistics that make the country prone to disease. Nepal, a Himalayan country with a population of 30.0 million, is located in South Asia. It is home to some of the highest mountains in the world, such as the third tallest mountain, Kanchenjunga, situated on the border of Nepal and India, and the world's highest mountain, Mount Everest, located on its border with China. The birthplace of Gautama Buddha, Nepal is a favorite tourist destination for mountaineers and trekkers, while also attracting visitors for its rich cultural heritage, ancient temples and palaces.

Nepal was a monarchy for centuries until it was abolished in 2008 and the country was declared a republic. It is one of the poorest countries in Asia, and between 2010 and 2011 nearly 25 % of its population was living on less than \$1.25 a day. The mountainous and tectonically active terrain makes Nepal highly prone to natural disasters, which are some of the most common causes of death in the country, and obstruct its development. A devastating earthquake in 2015, that killed nearly nine

thousand people and injured thousands more, remains one of the worst disasters in the country's history.

Plagued with geological vulnerability, poverty and the associated issues of poor sanitation, air pollution and a lack of proper healthcare, Nepal is replete with both communicable and non-communicable diseases. According to data from the Institute for Health Metrics and Evaluation (IHME) and the World Health Organization (WHO), below is a list of common diseases in Nepal with some of the highest death rates.



(continued on page 22)

**Common Diseases in Nepal : An Overview** (continued from page 21)

**Most Common Diseases in Nepal:**

**Chronic obstructive pulmonary disease (COPD):**

The term COPD encompasses a set of chronic lung diseases such as emphysema and chronic bronchitis. It is the leading cause of death in Nepal. COPD killed 17,200 people in the country in 2012, and there was a 22.1 % increase in its death rate from 2005 to 2015. Long-term exposure to lung irritants causes this disease, and cigarette smoking, use of biomass fuels and air pollution are some of the risk factors.

**Ischemic Heart Disease (IHD):** Also called coronary artery disease, IHD killed 17,100 people in 2012 alone and is the second leading cause of death in the country. The major predisposing factors for this disease are high blood pressure, smoking, poor diet and diabetes. The country saw a surge in some of the conventional risk factors such as obesity and hypertension.

**Cerebrovascular Disease (CVA):** Cerebrovascular disease encompasses a set of disorders that affect blood vessels and alter blood supply to the brain, which can lead to a cerebrovascular accident (CVA), also known as a stroke. A leading cause of mortality in the world, strokes killed 15,300 people in Nepal in 2012. The country has seen a 25.7 percent increase in its death rate since 2005. Hypertension, cigarette smoking, alcohol consumption and diabetes are the main risk factors for strokes.

**Tuberculosis (TB):** An airborne bacterial infectious disease, TB is a major public health threat in Nepal. With several innovative programs run by the government in close partnership with collaborators, Nepal has achieved tremendous progress in controlling TB, and there has been a 19.1 percent decrease in TB related death rate from 2005 to 2015. Still, TB remains one of the major causes of death in the country.

**Lower Respiratory Tract Infections (LRTI):** Lower respiratory infections are some of the most common infectious diseases and are a leading cause of morbidity

and mortality in children and adults worldwide. They include conditions such as pneumonia, acute or chronic bronchitis and bronchiolitis. These diseases in Nepal were responsible for 13,100 deaths in 2012. As with TB, the last decade saw an impressive decrease (42.3 percent) in its death rate in the country.



According to the annual report of the Department of Health Services, Government of Nepal, for the years 2014 and 2015, combined efforts by the government and various national and international organizations toward the prevention and control of diseases in Nepal have achieved improved health outcomes over the years. These outcomes include higher life expectancy and reduced maternal and infant mortality rates. The report also identifies existing problems and challenges in the health sector and delineates possible actions for addressing these issues for continued progress.

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# Reports on Activities of Goldheart Thyroid Awareness Foundation

FLORENCE OKETONA  
PRESIDENT, GOLDHEART THYROID AWARENESS FOUNDATION

## Brief History of Goldheart Thyroid Awareness Foundation

Goldheart Thyroid Awareness Foundation was created in 2018 with the sole purpose of creating awareness on thyroid disorders and malfunctions. The organization however became saddled with the responsibility of supporting patients living with the malfunction with access to cheap and affordable tests and medication, counselling and support during and after surgeries, follow-up sessions with doctors and counselling to families of those living with the malfunction for support.

Prior to the creation of Goldheart Thyroid Awareness Foundation, there had never existed any organization with the same function in the part of the country where we are located, this makes Goldheart the first Thyroid Awareness organization in Northern Nigeria.



Nigeria Goldheart creating awareness on thyroid health at the 2021 international women's week.

## Activities in 2020/2021

The past two years have been very challenging for our organization due to the Covid-19 pandemic. The pandemic, apart from the fact that it has taken attention away from other health challenges, has made it increasingly difficult for our organization to carry out a physical awareness campaign. This has limited our reach to the people with thyroid malfunction.

However, in the absence of a physical awareness campaign, we have resorted to mostly radio programs to spread our awareness of the disease. This year 2021, our organization partnered with about two radio stations to carry out awareness campaigns on the thyroid disease. Through our radio programs, a good number of people living with the malfunction reached out to us. Our organization was able to raise some money out of donations from friends and well-meaning individuals for some of our patients who are not financially able to carry out their tests.

The challenges posed by radio awareness campaigns is that those who live in rural areas who have no access to electricity or radios have no opportunity to hear us when we carry out our campaigns.



Nigeria Goldheart Speaking at the campus campaign against drugs about thyroid health and drug abuse

## Social Media and Online Awareness

Aside from our radio programs, we take advantage of the social media to create awareness, our Facebook, Instagram and WhatsApp groups give us the opportunities to educate people about thyroid disease. Our social media pages have recorded more successes during the pandemic than any other time.

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## Our Successes

Despite the challenges faced by the pandemic, our radio and TV campaigns have yielded a great result as many people reached out to us and were referred for tests which mostly came back with thyroid malfunctions.

In addition to radio programs, we also organized webinars for our members and liaised with some other organizations to carry out campaigns in our region of the country.

In order to reach out to rural areas in our region, Goldheart Thyroid Awareness Foundation registered formally with another Non-Profit organization, Christian Rural and Urban Development Association of Nigeria (CRUDAN). This is a giant stride for our organization in the right direction as it has opened us up and enabled us reach rural areas with our awareness campaign. Being a member of CRUDAN enables us to have access to communities which cannot be reached.

Our organization also approached Women for Women International headquarters in Nigeria to enable us create awareness among rural women. During the 2021 International Women's week, Goldheart participated fully in collaboration with Women for Women International and so many women living with Thyroid Malfunction were discovered and have commenced treatments.

## Challenges

The pandemic has seen a lot of people out of jobs and finances have become tight. This has made it increasingly difficult for our members to access medication. Some of our members who are on medication have had to stop due to lack of finances. Some of them have begun to experience a return of their symptoms as the organization can no longer fund their medication. The organization relies on donations from friends and moneys raised from members to buy medication for some of our members.

## High Cost of Thyroid Function Test

The thyroid function test remains one of the most costly tests among the autoimmune diseases. A typical laboratory charges about N12,000.00 (Fifteen Thousand Naira) for a thyroid function test, this is about \$24 USD going by the present exchange rate of dollar to Naira and more than 60% of Nigerians earn below \$5 USD per day and are living below the poverty level. This has made it increasingly difficult for ordinary people to access thyroid function tests and medication.

## Incessant Industrial Strikes In The Medical Industry

Because of poor working conditions and lack of proper working tools, the medical personnel of the country are always embarking on industrial strikes; this leaves the patients with no other option than to resort to self-medication and visits to quacks in private clinics.

## Ethno-Religious Crisis and Insurgency

The past year has witnessed the rise of ethno-religious crisis, insurgency, banditry and kidnappings in the Northern region of the country where Goldheart is domiciled; this has made it increasingly difficult for us to assist our patients. Some of our patients have lost their homes and are living in Internally Displaced Peoples camps; some have lost their means of livelihood due to insurgency and are finding it difficult to access proper healthcare. In Goldheart, we try to reach out to the few whom our finances can cater for and believe in God for the rest.

REPORT VERIFIED BY:

EBUNOLUWA B. ADEJOKUN ESQ., SECRETARY, GOLDHEART  
THYROID AWARENESS FOUNDATION

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e-mail: [goldheartthyroid@gmail.com](mailto:goldheartthyroid@gmail.com)

Instagram: [goldheartthyroid](https://www.instagram.com/goldheartthyroid)





# Thyroidism Awareness and Support Initiative (TASI)

AMB. IRUOMA OFORTUBE, EXECUTIVE DIRECTOR  
FOR: THYROIDISM AWARENESS AND SUPPORT INITIATIVE (TASI)

## Brief History and Report of Thyroidism Awareness and Support Initiative

Thyroidism Awareness and Support Initiative (TASI), is the foremost patient led not for profit organisation established in Nigeria in 2017, primarily to create awareness on 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 passing through and what potential victims will face due to ignorance, therefore TASI was established to bridge the gap.

### Major Projects in a Year

#### First Quarter

January Annual Public Lecture  
Media Sensitisation

#### Second Quarter

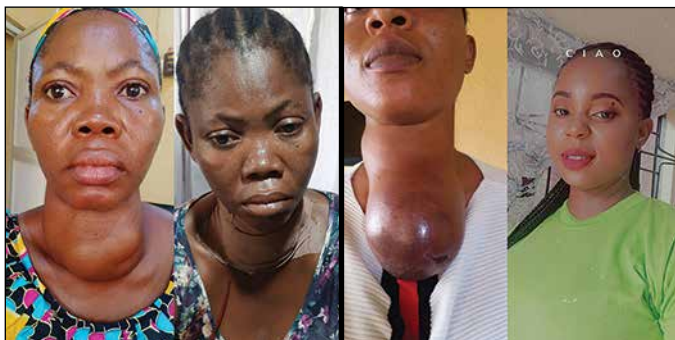
Free Surgical Outreach

#### Third Quarter (ITAW & World Thyroid Day)

Awareness and Sensitisation Walk  
Media Awareness  
Support Group Meeting

#### Fourth Quarter

Community Outreaches and Sensitisations



These projects are usually our annual programs but since 2020 & 2021 most of them that require unavoidable physical meetings were cancelled while the rest are done virtually. During the World Thyroid Day, themed: **Mother-Baby-Iodine**, Endocrinologists and other experts hosted the program via virtual medium.

### Achievements

Our greatest achievements are the massive awareness evidenced by the feedback and countless number of patients supported through our **Free Surgical Outreaches**, numbering about 60 beneficiaries in 2 years. The highest point is more strategic collaborations with media healthcare providers and more medical experts in achieving our organizational roles in spite of the pandemic.

### Constraints

Our constraints remain paucity of funds limiting our organization from making more impact considering the number of existing cases.

We are open for more local and international collaborations in achieving our goals and meeting the needs of thyroid patients in the sub-Saharan Africa.

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

email: [tasinigeria1@gmail.com](mailto:tasinigeria1@gmail.com)

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

Facebook: [Thyroid Awareness And Support Initiative](https://www.facebook.com/Thyroid-Awareness-And-Support-Initiative)



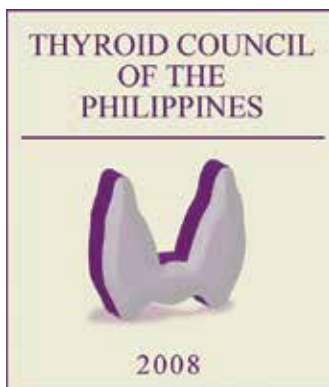
# Philippine Thyroid Cancer Survivors, Inc. (PhilThyCas)

## History

The Department of Health ranked Thyroid Cancer as the 7th overall leading cancer in the Philippines. The incidence of Thyroid Cancer increases every year affecting women in the reproductive age group more than men.

Since June 28, 2008, the Philippine Thyroid Cancer Survivors, Inc. (*PhilThyCas*) has aimed to support all thyroid cancer patients. This group is a non-stock, non-profit organization with a mission to provide survivors opportunities to increase their knowledge about their disease through education, and help provide emotional and practical support to its members. *PhilThyCas* organizes activities that brings patients and their family members together and ensures everyone is well-informed of the trends and the proper care for thyroid cancer patients.

Since its early beginnings, the organization has strived, and continues to strive, to carry out its mission by holding quarterly patient support meetings at St. Luke's Medical Center in Quezon City (SLMC-



QC). *PhilThyCas* is a major proponent of the Republic Act 10786 (House Bill No. 5307), an act which declares the 4th week of September as National Thyroid Awareness Week, which was approved by the late former president Benigno “Noynoy” Aquino III. With this act, the aim of *PhilThyCas* to replicate and promote meeting activities nationwide becomes even more attainable, boosting the possibility to reach out to more thyroid cancer patients nationwide.

One of the major events that *PhilThyCas* supported and promoted includes the extensive 5-day webinar titled “Mother-Baby-Iodine: The Importance of Iodine on the Woman and her Baby”, which was organized by Dr. Teofilo San Luis, Jr. from the Philippines. This webinar and the International Thyroid Awareness Week were introduced by Ms. Linda Henderson of the Thyroid Federation International.



For the next event, *PhilThyCas* will be participating in the National Thyroid Cancer Awareness Week which will be held on September 20th – 25th, 2021.

# Giving “Voice” to Thyroid Patients



The Portuguese Thyroid Disease Association (ADTI) was founded in 2012 from the urge to support patients and their families. Backing-up the interests and representing thyroid patients is the main mission of ADTI, which also gives support, clarifies thyroid dysfunctions, cooperates with health professionals, and intervenes to back-up the interests of these patients.

Many activities have been made over the years, which had their highest point at the International Thyroid Week, when, in partnership with other organizations and institutions, we manage to take even further the message about the importance of the thyroid and the need for greater attention to its health.

This year, between the 25th and 31st of May, once again, the thyroid was highlighted in the Portuguese media. The week kicked-off with a one-hour webinar, on May 26, in partnership with a national newspaper based on the theme “Living with hypothyroidism: Take care of your thyroid and fly higher”, with tens of thousands views and over a thousand interactions. A

**VIVER COM HIPOTIROIDISMO  
CUIDE DA SUA TIROIDE  
E VOE MAIS ALTO**

**WEBINAR**  
**26 de Maio 17h30**  
Em direto no Facebook, no Youtube e no site do Jornal Público

**CONVIDADOS**  
João Jácome de Castro, presidente da Sociedade Portuguesa de Endocrinologia Diabetes e Metabolismo (SPEDM)  
Celeste Campinho, presidente da Associação Portuguesa de Doenças da Tireoide (ADTI)  
Testemunho de Noémia Pires, doente com hipotiroidismo

VOE MAIS ALTO E CUIDE DA SUA TIROIDE | P | ADTI | SPEDM | MERCK

doctor, a patient, and ADTI’s President were together for a conversation on what it is like to live with thyroid dysfunction and how it is still possible to fly higher.

The theme was also highlighted on ADTI’s and its partner’s social networks. A filter was created for Instagram, in the shape of a butterfly, shared by a well-known digital influencer, which took the message even further.

ADTI, decided to make a countrywide survey, addressed to all people diagnosed with hypothyroidism, which aimed to better understand the different experiences of those living with the disease. As a result, a report which will be released shortly, confirms the need for more information about this disorder. The inquiry had a huge participation, which was a nice surprise to ADTI, and will allow reaching very important conclusions for closer actions with patients having hypothyroidism.





# The Thyroid Trust

LORRAINE WILLIAMS

The Thyroid Trust is still a very new organisation, registered in 2019 by a group of volunteers who had previously run events for thyroid patients in Central London since 2010 and set up the new charity to continue those events and commence much needed advocacy and awareness raising initiatives. We work closely with leading medics and share reliable evidence based information.

From the outset, we have been very involved in UK issues around the pricing of and access to liothyronine LT3, for those patients with hypothyroidism who require it.

Our energetic advocacy work, with our partners, on this issue resulted in the publication of revised national prescribing guidance and subsequent assurances from NHS England that they will communicate to all local health authorities that they are expected to follow this guidance and allow LT3 to be prescribed when recommended by an endocrinologist where levothyroxine treatment has failed, regardless of the cost. This assurance was reiterated most recently in July 2021.



For reasons which remain unclear LT3 is more expensive in the UK than in other countries, which has caused a great many difficulties for patients, some of whom have resorted to travelling overseas to buy their medication overseas. The Thyroid Trust has been influential in bringing the plight of these patients to the fore, generated media coverage and winning high level support, but our capacity has been very stretched over the last year due to illness in the team, very limited resources as we are still very small and new, our growing stakeholder base, which is increasingly challenging to support and of course the impact of the pandemic.

We published a report in March 2021 which revealed that 52% of local health authorities in England are still not following national guidance for LT3 and patients in these areas are being denied treatment, hence this work is very much ongoing.

In August 2021 the Competitions and Markets Authority fined the original UK licence holder and their backers over £100million for artificially inflating the price of LT3 to the NHS. National media covered the story, featuring The Thyroid Trust and we were able to highlight the impact on patients and the national guidance. It is hoped that the fine and publicity around it will make a positive difference for patients. We continue to be in active discussions with a wide range of stakeholders, seeking to resolve this matter once and for all.

We organised a number of activities for International Thyroid Awareness Week this year, including butterfly themed fundraising, a special Facebook Frame, online events, a talk with Dr Peter Taylor and a Creative Thyroid Cafe with artist Vicky Roden, our first tweetchat and a partnership with Fahmidan Journal, who published a special issue on World Thyroid Day full of poetry about thyroid disease as well as other autoimmune conditions and mental health. We were proud that many of our thyroid friends had poetry included, most excitingly the well known author and broadcaster, Michael Rosen.



Michael Rosen

(continued on page 29)

## The Thyroid Trust (continued from page 28)



Our general awareness raising work has included a new partnership with UK Health Radio and providing clinicians and patient voices for TV, radio and print media. Drs Simon Hodes, a GP and Vincent Simpson, an endocrinology trainee, kindly collaborated to write an article for us for Health Triangle Magazine who are now featuring thyroid health in each issue.

Our YouTube channel is growing and now has several patient interviews, including one with Michael Rosen, as well as new expert talks from several of our Information Events, featuring Dr Atul Kalhan, Dr Bernard Khoo, Professor Simon Pearce and Torquil Watt of Copenhagen University, as well as a new short awareness video kindly created for us by well known Loose Women GP, Dr Catherine Millington-Sanders and a fun video by artist Vicky Roden featuring fondant thyroids!

Thanks to our amazing volunteer speakers and video editors, we have more videos and online events in the pipeline and we can provide patient speakers for external events. Our Director, Lorraine Williams, spoke at a University of Birmingham Institute of Metabolism and Systems Research event on the Power of the Patient Voice in June 2021.

We are celebrating Thyroid Cancer Awareness Month in September with online resources and a thyroid cafe hosted by two times thyroid cancer survivor, Judith Taylor.

We are in active discussions with several research groups aiming to provide a patient perspective and help strengthen research plans and proposals and involve more patients as much as possible. Our patient registry is also available for researchers to learn from.

Our strategic aims are to raise the profile of thyroid disease, empower the patient community, support evidence based understanding of thyroid health issues and become a sustainable, well resourced organisation, so that we can build on our work to date and do more in the future, to make things better for people 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>

# TFI Member Organizations

## AUSTRALIA

*Australian Thyroid Foundation Ltd.*

[www.thyroidfoundation.org.au](http://www.thyroidfoundation.org.au)

## BANGLADESH

*Bangladesh Thyroid Association (BTS)*

[www.buhs.ac.bd](http://www.buhs.ac.bd)

## 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.thyreoidea.dk](http://www.thyreoidea.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.capecitalia.org](http://www.capecitalia.org)

## JAPAN

*Dr Fumito Akasu (Contact)*

[www.akasu.com](http://www.akasu.com)

## KENYA

*Thyroid Disease Awareness Kenya*  
*Foundation*

[www.facebook.com/](http://www.facebook.com/)

[thyroiddiseaseawarenesskenya](http://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

*Stoffskifteforbundet*

[www.stoffskifte.org](http://www.stoffskifte.org)

## THE PHILIPPINES

*Thyroid Council of the Philippines*

[rolsanluis@gmail.com](mailto:rolsanluis@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)

## SERBIA

*Inner Wings, Krila u nama*

[krilaunama.org](http://krilaunama.org)

## SOUTH KOREA

*Korea Thyroid Association (KTA)*

[south\\_korea\(at\)thyroid-fed.org](mailto:south_korea(at)thyroid-fed.org)

## SPAIN

*Asociación Española de Cáncer de*  
*Tiroides*

[www.aecat.net](http://www.aecat.net)

## SWEDEN

*Svenska Sköldkörtelföreningen*

[www.skoldkortel.se](http://www.skoldkortel.se)

*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)