Welcome to the first issue of the Thyroid Cancer Alliance newsletter! We are distributing it during the World Congress on Thyroid Cancer in Toronto, Canada from 9-14 July, 2013 and hope to bring out a new edition once a year.

The aim of this newsletter is to provide an overview about the TCA and to bring you news about the activities of our member organisations.

The TCA is an international network of national thyroid cancer support organisations and/or thyroid support groups, dedicated to working together towards providing support, information and encouragement to those affected by the disease throughout the world. We now have nine member organisations and three associate member organisations.

The TCA was founded in 2011 and held its first Annual General Meeting in Newark, New Jersey in September 2011.

The aims of the TCA are to bring together leaders of national thyroid and/or thyroid cancer support groups so that they can share information and learn from each others’ experiences; to develop programs and projects that promote education and awareness of thyroid cancer to the general public and medical professionals; to work in partnership with, and share good practice with, expert thyroid cancer medical professionals; and to support the development of national thyroid cancer support groups in countries or regions not currently so represented.

In 2012 eight representatives of our member organisations attended the European Thyroid Association conference in Pisa, Italy in September, where for the first time we had an exhibition stand and displayed patient literature from the member organisations, and hosted a dinner for members of our Medical Advisory Panel.

This year nine representatives are attending the World Congress of Thyroid Cancer in Toronto, Canada in July, where we will have an exhibition stand and hope to meet old and new friends.

We are very happy to report that we have introduced a new associate membership category for emerging patient support groups and for organisations with a broader remit than thyroid cancer who want to keep in touch with developments without having to feel under an obligation to contribute actively. Welcome to Thyroid Cancer Support Group Ireland, to the Association for Multiple Endocrine Neoplasia Disorders (AMEND), and to our newest member from Peru!

We hope you enjoy this issue and look forward to meeting you in Toronto!

Warm regards,
Meet our member organisations

Thyroid Cancer Support Group Wales
www.thyroidsupportwales.uk

Thyroid Cancer Support Group - Wales was founded in 2004 at the suggestion of our Consultant Oncologist Dr Laura Moss. Our aims are:

• to provide help and support to new and existing thyroid cancer patients and their families after diagnosis and during treatment;

• to raise funds to enable the group to function and provide much needed help to patients;

• to provide better conditions in the isolation rooms for patients receiving radioactive treatment; and

• to provide financial help to support the setting up of a tissue bank for research into anaplastic thyroid cancer.

One of the most exciting and appreciated projects that TCSGW has been instrumental in achieving is the development of a beautiful garden area outside the isotopic isolation rooms. The garden has been awarded several prizes in the annual Cardiff In Bloom competition.

Vivre sans Thyroïde
www.forum-thyroide.net

The discussion forum Vivre sans Thyroïde (‘life without a thyroid gland’) was created in 2000 by a thyroid cancer patient, to share her experience and provide information and emotional support to other patients. It is open to patients suffering from all sort of thyroid disease. In 2007, we created a non-profit association. Both are run by volunteer patients and financed by the membership fees of approx. 400 regular members.

The online discussion forum www.forum-thyroide.net, with more than 12,300 registered users, has 5,000 to 6,000 visitors and approx. 100 messages per day. The website provides information on thyroid disease and allows patients to find understandable information, to ask questions, to exchange experiences and to get emotional support from fellow patients. We also organise 3-4 patient information meetings a year, in different towns; attend national and international medical conferences; represent the ‘e-patients’ in events about Health 2.0; and try to raise the awareness for thyroid disease.

The association has a few small local support groups. The Paris group organises a monthly informal thyroid coffee meeting in a bistrot, open to all interested patients. Vivre sans Thyroïde is also a member of Thyroid Federation International.

Thyroid Cancer Support Ireland
www.thyroidcancersupport.ie

Thyroid Cancer Support Ireland group has been growing steadily and the majority of work has been supporting newly diagnosed patients who are currently between surgery and RAI.

The group are in the process of organising Ireland’s very first thyroid cancer patient and survivor get-together in September / October 2013. June 2013 was Ireland’s very first Thyroid Cancer Awareness Month. A radio interview was held for the beginning of June to raise awareness of the group and how we can help raise awareness of thyroid cancer in Ireland.

At the beginning in May all the GP’s in Co. Westmeath, Co. Offaly and Co. Longford were contacted and supplied with leaflets. All relevant disciplines relating to thyroid cancer in Ireland have already been contacted.

AMEND
www.amend.org.uk

AMEND (the Association for Multiple Endocrine Neoplasia Disorders) was founded in the UK in 2002 and became a registered charity in 2003.

AMEND is run by patients for patients with the help of an expert medical advisory team.

We provide information and support services to patients and their families around the world who are affected by multiple endocrine neoplasia (MEN) disorders and related endocrine conditions.

MEN disorders are rare genetic syndromes characterised by the development of tumours in two or more endocrine glands. In MEN type 2, almost 100% of patients develop medullary thyroid cancer (MTC), which is still the main cause of death in this syndrome. Treatment for MTC differs from that of other forms of thyroid cancer.

AMEND provides patient-aimed information resources on MEN and MTC through information booklets, our website and social media. Support is provided through a telephone helpline, an annual patient information day, and three Roadshow patient meetings per year throughout the UK.

AMEND recently embarked on a two-year project to produce information resources on MEN for children and young adults to encourage communication about the disorders within affected families and better engagement by young people in their healthcare as they grow older. The Marvel
Hypoparathyroidism (HPTH or Hypopara for short) is a deficiency or lack of parathyroid hormone (PTH) produced by the parathyroid glands in the neck. It is a rare endocrine condition which occurs if the glands are affected by a congenital, genetic or autoimmune disorder or is the inadvertent result of surgery to the neck. Because a number of our members come to us following a thyroidectomy for thyroid cancer, HPTH UK is very pleased to be a member of the TCA to raise awareness about this potential risk. While most cases of hypoparathyroidism are temporary, there is still a small percentage that will be permanent. To go into hospital with one condition and come out with another is not something anyone wants to experience.

Hypoparathyroidism causes low calcium (hypocalcaemia) and, as calcium is vital to life, this is a serious and lifelong condition. It can be difficult to manage and is one of the few hormonal deficiency syndromes for which replacement therapy is not yet available. Treatment is further complicated by the lack of national or international consensus management guidelines.
Hypoparathyroidism UK (or HPTH UK) is the only organisation in the UK dedicated to supporting people with all types of rare parathyroid conditions though our online forums, website, helpline and local group network. We work closely with a team of endocrinologists across the UK who specialise in calcium and bone metabolism to write and disseminate advice on managing HPTH to patients and doctors alike and to improve treatment. Following our participation in a global clinical trial we hope that treatment with recombinant PTH will soon be available!

AECAT

www.aecat.net

The Spanish Association of Thyroid Cancer (AECAT) is a non-profit organisation that was born out of the lack of information or support that both thyroid cancer patients and their families suffered in our country. Founded in 2004, our association rose first around a forum, completed, later on, with a helpline and a solidarity chain of buddies with the same aim of helping, guiding and supporting people affected by this illness. Being the only association of patients with thyroid cancer in Spain, we try to raise awareness in society and be the thyroid cancer voice to represent the patients’ interests in front of medical professionals, society and sanitary authorities. A task that started with the website www.aecat.net, a blog with the latest news that may interest patients with thyroid cancer and an active profile in social networks (Facebook, Twitter and Youtube) that aim to send patients all the information they need.

With this same aim and with all the medical societies backing, we generated the first materials of thyroid cancer from patients, specialists and the public. Last May AECAT received the award of the most relevant cancer awareness campaign in the First Awards Edition of the Spanish Cancer Patients Group (GEPAC).

Light of Life Foundation

www.checkyourneck.com

The mission of the Light of Life Foundation is to improve the quality of life of thyroid cancer patients through continual education of the lay public and the medical community, and by promoting research and development. In 1997, while in recovery from her thyroid surgery and radiation treatments, Joan Shey created the Light of Life Foundation to create a support and education network that was not available at the time of her diagnosis. She asked the doctors who saved her life to join her mission. Together, they began distributing gift baskets to patients in isolation, organised support groups, held informational seminars, and sold merchandise to fuel awareness and raise funds for thyroid cancer research. The foundation has grown into a national and international network of patients and physicians who are bringing attention to the importance of this disease.

The foundation supports an annual fellowship at Memorial Sloan Kettering Cancer Center, New York, through which an outstanding physician is funded to train alongside an interdisciplinary team of top endocrinologists, head and neck surgeons and nuclear medicine specialists. The fellow then returns to his or her home institution with an advanced understanding of treating thyroid cancer that they disseminate. Over the last decade, the Light of Life Foundation Honorary Award has become recognised amongst the worldwide thyroid cancer medical community.

Through our research fund, the Foundation also supports development of new diagnostic and treatment approaches for thyroid cancer.

ACTIPERU

We are delighted to welcome ACTIPERU - the Asociacion de Apoyo e Prevencion de Cancer de Tiroides in Peru. Founded by Claudia Toledo, ACTIPERU is a Peruvian non-profit association that directs its efforts to the reduction of thyroid cancer in Peru and the strengthening of those affected by the disease, who recover healthily and have a healthy lifestyle.

We look forward to hearing more about the organisation in Peru as it evolves.

Looking forward

We look forward to meeting you at the following events:

7-11 September 2013
European Thyroid Association, Leiden, The Netherlands

10-11 October 2013
British Association for Endocrine and Thyroid Surgeons, Rome, Italy

6-10 September 2014
European Thyroid Association, Santiago de Compostela, Spain (provisional)
Anaplastic thyroid cancer has historically proven very difficult to research due to the combination of its rarity and the associated short survival period for those affected.

In 2009, 2340 patients in the UK were diagnosed with thyroid cancer with 70-90 expected to be the anaplastic subtype. For these patients average life expectancy is in the range of 2-6 months with only a very small number surviving for more than one year. It is a highly aggressive form of cancer that is refractory to current treatment options.

By collecting tissue and blood samples along with clinical data across the UK we will be able to accumulate numerically significant numbers of samples and data points which will facilitate research opportunities.

Researchers will be encouraged to apply for access to the collected samples in order to try and establish the causal mechanisms for disease development, potential therapeutic targets and to relate clinical course and outcome with specific molecular defects.

Due to the rarity it is not feasible for a single cancer centre or cancer network to accumulate sufficient samples for research in a meaningful timeframe hence the need for national collaboration in order to try and offer patients with this disease hope in the future.

All UK patients with anaplastic thyroid cancer would be potentially eligible. The project is expected to run for at least 5 years and all thyroid cancer clinicians will be encouraged to participate. Patients will be asked to donate surplus thyroid cancer tissue following routine biopsy procedures along with an optional blood sample.

The entire project has been funded by Thyroid Cancer Support Group Wales and the specimen collection will be hosted by the Wales Cancer Bank.

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TCSGW and the NATT project

We are exceptionally proud to be funding the world’s only tissue bank of this type.

Many fundraising and social events were held to raise the necessary funding. As part of our 2012 Awareness Campaign, we distributed our leaflets and flyers to GP surgeries and continued with our patient support services.

As a group we are committed to making a difference in the lives of those people diagnosed with thyroid cancer - also offering support to their families if needed.

TCSGW - we are small enough to care yet big enough to make a difference. One person may be diagnosed but there are many on hand to offer support!
The Thyroid Cancer Alliance met at the annual European Thyroid Association conference, which was held in Pisa, Italy on 8-12 September 2012.

The European Thyroid Association (ETA) is a professional organisation of researchers and clinicians in Europe who meet every year to present their latest results.

The TCA participants were: Kate Farnell (Butterfly Thyroid Cancer Trust, UK), Judith Taylor (British Thyroid Foundation and HPTH UK), Beate Bartès (Vivre sans Thyroide, France), Helen Hobrough (Thyroid Cancer Support Group Wales), Amelia Corcuera (AECAT, Spain), and Soledad Rodriguez Perea (ACTIRA, Argentina). Brenda Beckingham of TCSG Wales attended as our scribe.

This was only the second time that the TCA had met and was the first time the Alliance members had attended a professional medical meeting together, and for several members it was the first medical conference they had attended.

The ETA kindly provided us with space to exhibit information about the TCA and to display literature on behalf of the Alliance member organisations. It was an excellent opportunity to meet thyroid specialists to learn about the patient support organisations in their countries and for them to learn more about our own organisations. While there are several patient organisations in the UK providing information and support to thyroid cancer patients, there are many countries around the world where there is no organised peer support.

Kate Farnell from BTCT had two posters accepted for presentation at ETA: Thyroid Cancer Awareness-Neck Check 2011 and Patient Survey ‘Burden of Disease’, both were well attended by the doctors.

During the conference we held our Annual General Meeting and Kate Farnell (Butterfly Thyroid Cancer Trust UK), Judith Taylor (British Thyroid Foundation and HPTH UK) and Joan Shey (Light of Life Foundation USA) were re-elected to the Board of Directors. We have two new board members Helen Hobrough (Thyroid Cancer Support Group Wales) and Soledad Rodriguez Perea (ACTIRA Argentina) increasing the board to five people.

We also hosted a very successful dinner to which we invited members of the TCA's Medical Advisory Board and other friends from medicine and industry.

It was a steep learning curve for all of us, but it was very rewarding to see it all come together. We hope that the clinicians we met during the conference will be better informed about the help that patient organisations can provide to their patients and that we can work with them to develop support groups in their countries.
First International Future of Thyroid Cancer Care Workshop

Four members of the TCA - Judith Taylor, Soledad Rodriguez Perea, Ana Villejo and Beate Bartes – participated in the First International Future of Thyroid Cancer Care Workshop held in New York in February.

Patient support representatives and health professionals from eight countries in North and South America, Europe, and the Asia-Pacific, provided a brief overview of the state of care management within their region, highlighting areas of excellence and identifying unique needs and gaps to improving patient outcomes.

The group looked at the needs of patients in early stage disease and the current challenges and needs of patients with locally advanced and metastatic disease, as well as the treatment and management of RAI-refractory disease and quality of life from the patient perspective.

During the workshop Kate Farnell (President of TCA) was able to make a video link presentation of a patient case with metastatic disease to all of the delegates present.

This was greatly appreciated and highly acclaimed by those present at the workshop.

This is another example of the challenging and exciting international role that the TCA fulfills. A formal report is being prepared, capturing the discussions and counsels of the group.

The meeting was made possible by Bayer Healthcare AG.
Butterfly Thyroid Cancer Trust premiers its breakthrough patient information DVD

Butterfly Thyroid Cancer Trust has produced the first ever comprehensive patient information DVD on thyroid cancer which will be free to all patients.

BTCT’s patient information film “Thyroid Cancer Uncovered” had its premiere on May 18th at a cinema in Newcastle and was a “sell out”.

You can watch an excerpt from it at: https://vimeo.com/68316792
Light of Life Foundation Annual Awards Dinner

On Wednesday, January 16, 2012, the Light of Life Foundation held its 14th Annual Honorary Awards dinner in NYC. We were very proud to present the “Light of Life Foundation Award” to Professor Henning Dralle. Dr. Dralle is from the Department of General, Visceral and Vascular Surgery at the University of Halle-Wittenberg, Germany.

As part of this award Dr. Dralle’s presented his research at “LOL Award and the Martin Sonenberg Visiting Professor” grand-round lecture at Memorial Sloan Kettering Cancer Center the following morning on “Progress in surgical technique, research and care of medullary thyroid cancer”.

It was an honor to present this award to Dr. Henning Dralle.

Past recipients of the Light of Life Honorary Award: Dr. Ernest Mazzaferri (1999), Dr. Orlo Clark (2000), Dr. Martin Schumberger (2001), Dr. Bruce Weintraub (2002), Dr. Furio Pacini (2003), Dr. Samuel Wells (2004), Dr. Jacob Robbins (2005), Dr. Massimo Santoro (2006), Dr. Aldo Pinchera (2007), Dr. Norman Thompson (2008), Dr. Christoph Reiners (2009), Dr. Nancy Carrasco (2010) and Dr. Rosella Elisei (2011).
The findings from an international survey of thyroid cancer patients and survivors conducted by founding members of the TCA has been accepted for publication and is due to be published shortly in the journal Hormones.

The questionnaire, which was available in English, German, French, and Spanish, was conducted predominantly online and was completed by 2,398 respondents from the US (37.9%), Germany (21.3%), the UK (11.5%), Canada (11.4%), France (9.0%), and 35 other countries.

The results showed that at diagnosis, few respondents were offered psychological or other professional support or referred to a patient organisation and no clear written disease and/or treatment information was given to 63.0% of respondents.

This large, multinational, cross-sectional survey identified that thyroid cancer patients and survivors have substantial unmet informational and psychosocial support needs, and suffer frequent treatment morbidity. The disease management and some patient/survivor experience differ appreciably among countries.

The investigators propose five leading care improvement suggestions including improvement in written explanatory materials, referrals to and closer relationships with patient groups, and a greater focus on identifying and preventing unwanted treatment effects.

The results of this survey were presented by Prof Markus Luster and Kate Farnell to 800 clinicians at the International Thyroid Congress, Paris, September 2010.

Reference: Psychosocial/Informational Support Needs, Treatment Side Effects, and International Differences in Care: Results of the Thyroid Cancer Alliance International Patient/Survivor Survey, by Rita Banach, Beate Bartès, Kate Farnell, Harald Rimmele, Joan Shey, Susanne Singer, PhD, Frederik A. Verburg, MD, PhD, and Markus Luster, MD (corresponding author), for the Thyroid Cancer Alliance. Hormones (in press). Accepted for publication 23 January 2013.

Judith Taylor represented the TCA at a patient advocacy roundtable session with Bayer senior representatives during the American Society for Clinical Oncology conference in Chicago.

The session was called ‘Partners in Cancer Care – Looking into the future’ and brought together US and global advocacy group representatives and Bayer senior representatives and aimed to take a strategic perspective on addressing the challenges in patient access to innovative care; best practices for Bayer and advocacy groups to work collaboratively around patient needs; and how best to ensure the patient voice is heard throughout the drug development process.

This was also a rare opportunity to meet with representatives of coalitions and alliances of patient organisations in different cancer fields, to compare ways of working and consider how non-profits which are often run by volunteers can address issues of training and sustainability.

The British Thyroid Association, the professional association of thyroid specialist doctors and researchers in the UK, is revising its guidelines for the treatment of thyroid cancer.

Judith Taylor (British Thyroid Foundation) is a member of the BTA guidelines development committee which is chaired by Dr Petros Perros (Newcastle, UK) who is a member of TCA’s Medical Advisory Panel. Representatives of all five UK member organisations are working together to revise and update the BTA’s patient information leaflets to bring it into line with current practice. The leaflets are being expanded to cover anaplastic thyroid cancer and medullary thyroid cancer. It is hoped that the new guidelines and patient leaflets will be published by the end of 2013.
TCSGW recipe book cooks up a storm!

In January 2012 TCSGW decided to raise funds to enable the NATT project to be based at Velindre Cancer centre Cardiff. (For more information on the NATT please see TCSGW article on this in this newsletter)

It was agreed that the group would fund this project and a target of £10,500 was set.

It was decided that the group would produce a recipe book which included favourite recipes from famous - and not so famous people.

The work of researching and compiling the book began in January - it was given in to the printer in November 2012.

The very first response to the hundreds of emails and letters that were sent out was from Sir Tom Jones - whose recipe for Bavarian pork with bacon and lentils has been a favourite with people buying the book!

The book was actually available for sale from November 26th 2012 and within 5 days 500 copies had been sold with many more on order - it was an amazing response to an idea that was very straightforward - though very time consuming!

The book contains over 80 recipes - both sweet and savoury and people's responses have been phenomenal, with photographs even being sent to TCSGW of finished recipes!

So great was the demand that more books were ordered with many request for a second volume to be completed as a future project for the group.

Local Barry businesses were very generous in their support for the book, paying for advertising which enabled greater profits to be made from book sales.

Books are available from TCSGW - contact us via the website to arrange purchase!

e mail thyroidgroup@tiscali.co.uk

BTF booklet for thyroid cancer patients

Designed to help patients facing a diagnosis of thyroid cancer, the second edition of the British Thyroid Foundation booklet: Thyroid Cancer - For Patients, By Patients is a practical guide for patients who are going through diagnosis and treatment, and for their families and people who support them. The booklet has been written or reviewed by people who have themselves experienced thyroid cancer. Included are their experiences, and medical information as well as details of the low-iodine diet and a seven-day meal plan and recipes; possible side effects of surgery and radioactive iodine treatment; advanced thyroid cancer; research into new treatments for iodine-resistant cancers; thyroid cancer and pregnancy and issues such as insurance and getting back to work. A glossary of terms, a checklist of questions to ask your doctor and useful contacts are also incorporated. It is available via the BTF website www.btf-thyroid.org.

The booklet has been endorsed by the British Thyroid Association (BTA), the British Association of Endocrine and Thyroid Surgeons (BAETS), AMEND, Butterfly Thyroid Cancer Trust, Thyroid Cancer Support Group - Wales, and HPTH UK. The British TV presenter and sports journalist Clare Balding and BTF Patron who is herself a thyroid cancer survivor wrote: 'If you’ve ever been diagnosed with thyroid cancer or suspect that you may have it, this booklet is a must-read. There is valuable information on every page...Within the last ten months, I have had two lots of surgery and radioactive iodine treatment and I have barely missed a beat as far as work and life in general are concerned. I decided to attack the disease full on, never to use it as an excuse, and never to get negative about the outcome. It not only helped me to be positive but I do think it helps those around you, who can often worry more than you would. I can ... recommend reading it more than once, and perhaps getting those you love to read it too.' Clare went on to cover the London Olympic and Paralympic Games in 2012, to great acclaim.
Medical Advisory Panel

Shereen Ezzat, MD, FRCPC, FACCP
Professor of Medicine & Oncology
University Health Network
Toronto, CA

Clive Harmer, MB, BS, FRCP, FRCR
Consultant Clinical Oncologist (Retired) - Royal Marsden Hospital
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Sandra Daniela Licht, MD
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Markus Luster, MD, PhD
Department of Nuclear Medicine
University of Ulm - Ulm, GER

Fausto Palazzo, MS, FRCS
Imperial College Healthcare NHS Trust. London, UK

Petros Perros, BSc, MBBS, MD, FRCP
Consultant Endocrinologist - Royal Victoria Infirmary - Newcastle upon Tyne, UK

Anna Sawka, MD, PhD, FRCP
Endocrinologist, University of Toronto - Toronto, CA

Martin Schlumberger, MD, PhD
Professor of Oncology
University of Paris-Sud
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R Michael Tuttle, MD
Professor of Medicine - Weill Medical College of Cornell University Memorial Sloan Kettering Cancer Center - New York, USA

World Congress on Thyroid Cancer

an international meeting on thyroid cancer and nodules

July 10-14, 2013
Sheraton Centre Toronto
123 Queen Street, West Toronto, Canada

Making a difference together

TCA at WCTC, Toronto

The TCA will be exhibiting on stand #509 at the World Congress on Thyroid Cancer, Toronto, 11-13 July, 2013.

If you are attending the Congress we look forward to seeing you there!

TCA President Kate Farnell is presenting a joint poster with Dr U.K. Mallick on ‘The doctor- patient relationship’. Kate will also be co-presenting with Dr Mike Tuttle on “Optimising Patient Care”.

BTCT is showcasing its patient information film 'Thyroid Cancer Uncovered'.