Welcome to the second issue of TCA News - the Thyroid Cancer Alliance newsletter!

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.

Our aims 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 programmes 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.

We now have thirteen member organisations. In this issue you can meet our new members and read about the exciting activities our members have been up to.

This year, we will be represented at the European Thyroid Association conference in Santiago de Compostela, Spain, in September and the British Association of Endocrine and Thyroid Surgeons meeting in Liverpool, UK in October – as well as at several Latin American meetings. We will also be represented in the “Voices on the path”, a 100km Camino de Santiago hosted by our Spanish member organisation AECAT and co-sponsored by the TCA (see page 2).

In October, the TCA will be hosting a patient-led workshop on tyrosine kinase inhibitors in Paris with 12 patient advocates and a stellar faculty of health care providers and physicians from around the world (see page 3).

In this issue you can meet our new members and read about the exciting activities our members have been up to.

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

Warm regards

Kate Farnell
MBE (UK)
President

Judith Taylor
(UK)
Secretary

Helen Hobrough (UK)

Soledad Rodriguez Parea
(Argentina)

Carmen Villar
(Spain)

We are thrilled that our President, Kate Farnell, has been awarded an MBE. More details and pictures inside.

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

Warm regards

Kate receives award at Buckingham Palace!

TCA to host patient-led workshop on tyrosine kinase inhibitors (TKIs)

“Sell-out” conference at the Royal Marsden

European Thyroid Association Conference, Leiden, 2013

World Congress on Thyroid Cancer, Toronto, 2013

Genzyme EU thyroid cancer patient group summit - Amsterdam, 27 March 2014

Bayer patient advocacy summit - Chicago, 3 June 2014

Member Highlights

Meet the new representatives

September is Thyroid Cancer Awareness Month!

www.thyroidcanceralliance.org
Many of us have thought of travelling the Camino de Santiago (the “way of St James”) at least once in our lifetime. The city of Santiago de Compostela shelters thousands of pilgrims from all over the world each year, travelling the road to Santiago in a pilgrimage to the known limits that presents a parallel with the journey we cancer patients have to endure.

In September, the 2014 Annual Scientific Meeting of the European Thyroid Association will be held in Santiago de Compostela. AECAT, The Spanish Association of Thyroid Cancer, is taking advantage of this opportunity to host “Voices on the Path”, a Camino de Santiago made up of thyroid cancer patients and supporters from all over the world that will carry our voice all the way to the Congress. The TCA is one of the sponsors of this event and some of our members will be taking part.

The event covers the last 112 km of the Camino, distributed over five stages:

1st Stage (Sarria-Portomarin): Why are we Pilgrims? The impact of the word “Cancer”.

2nd Stage (Portomarin- Palais de Rei): A New Way, the Camino. Understanding treatment and the health system.

3rd Stage (Palais de Rei- Arzúa): Tiredness on the Camino. Hardness of the treatment itself.


5th Stage (Monte do Gozo – Santiago de Compostela): One Step Forward, let your dreams fly. You are not alone, make your efforts be of use for others.

Cristina Chamorro, AECAT President, says: “Our goal is to join all the voices and make them sound when we reach Santiago, in an event the Congress will set up, to raise awareness in society about the importance of early detection, showing the thyroid cancer patients’ day-to-day challenges when facing cancer physically and emotionally while dealing with a thyroid dysfunction.”
Kate receives award at Buckingham Palace!

We are thrilled that our TCA President, Kate Farnell, CEO of the Butterfly Thyroid Cancer Trust, was honoured by Her Majesty the Queen in the New Year’s Honours List as a Member of the Order of the British Empire (MBE). Kate received her MBE from His Royal Highness Prince Charles at Buckingham Palace on 3 April 2014.

TCA to host patient-led workshop on tyrosine kinase inhibitors (TKIs)

One of the challenges of treating patients with tyrosine kinase inhibitors is how to manage the side effects and help patients stay on treatment.

In October, the TCA will host a patient-led workshop on TKIs which will be held at the Hotel Le Meridien Etoile in Paris.

Patient leaders and representatives from around the world will be there to discuss the issues with leading physicians from North and South America and Europe.

The primary objective of this workshop is to provide an overview and discussion about the experience of patients with either radioactive iodine (RAI)-refractory differentiated thyroid cancer (DTC) or advanced medullary thyroid cancer (MTC), and the impact of treatment and side-effects. We also aim to include two patient testimonials, in person, and a short film of other patient testimonials.

The workshop will cover:

- How we can help prepare the patient for treatment with TKIs,

- How best to treat these patients and manage the side-effects,

- The impact of TKI treatment on real people living real lives, and

- How best to support these patients throughout treatment, for example, by introducing them to a ‘buddy’ who has been through treatment.

At the conclusion of the workshop the goal will be to produce guidelines to help patients to prepare for treatment.
“Sell-out” conference at the Royal Marsden

Kate Farnell and Helen Hobrough attended a one-day conference about thyroid cancer at the Royal Marsden Hospital in London in June.

The event was a “sell out”.

The Royal Marsden is a world-leading cancer centre specialising in diagnosis, treatment, care, education and research.

It was a most interesting and enlightening day with a vast range of speakers from across the UK, Germany and the USA.

The organiser of the event was Dr Kate Newbold, Clinical Oncologist at the Royal Marsden, who introduced the day, welcoming both guests and faculty.

The moderators throughout the day were Fausto Palazzo, Chris Nutting, Laura Moss and Kevin Harrington.

The faculty members were: Jackie Gilbert, Steve Colley, Sarah Johnson, Tom Lennard, Barney Harrison, Kate Newbold, Kate Farnell, Ujjal Mallick, Graham Williams, Iain Nixon, Nicola Glover, Markus Luster, Marcia Brose, and Jonathan Wadsley.

Kate’s presentation on “Support Networks for Patients” was very well received and she gave details of the work of the Butterfly Thyroid Cancer Trust and also the work of and international links with the TCA.

She emphasised the importance of patient support groups and also shared the findings of the surveys that had been carried out.

Awareness campaigns and plans were shared and following this presentation there was a great deal of activity at the stand where information from Butterfly, TCSGW and the TCA were distributed to the delegates.

This was probably one of the most successful conferences to date in terms of follow-up enquiries and demand for the DVD has been overwhelming.

The conference will be repeated in 2015. The provisional date has been set for June 15th. Book early to avoid disappointment would be the best advice - an outstanding event!

Out and about

European Thyroid Association Conference, Leiden, 2013

In September Judith Taylor (UK) and Carmen Villar (Spain) represented the TCA at the ETA conference in the charming Dutch city of Leiden.

They also took part in the first ever thyroid cancer awareness “run”, sponsored by Genzyme, along with Beate Bartes (France) and around 60 physicians, researchers and other conference participants.

As well as attending some of the conference sessions, Judith and Carmen manned an exhibition stand where we displayed TCA materials and leaflets from our members.

The opening addresses and welcome reception took place not in a sterile auditorium but in the Hooglandse Kerk and concluded with an organ recital by ETA President Theo Visser.
Out and about

World Congress on Thyroid Cancer, Toronto, 2013

Last July nine representatives of TCA member associations from the UK, France, Spain, Ireland, Argentina, and the USA attended the World Congress of Thyroid Cancer in Toronto, Canada.

The TCA also had an exhibition stand at the Congress where we displayed the first issue of our TCA newsletter and sample leaflets and materials from the TCA member organisations.

We attended many of the scientific sessions and despite the 6 am start we turned out to support our President Kate Farnell who participated in a breakfast symposium on “Optimising Patient Care” chaired by thyroid cancer guru Dr Mike Tuttle (see page 10).

We also hosted a dinner for our Medical Advisory Panel and other friends and advisors in the stunning restaurant at the top of the CN Tower.

Pictured here from left to right, back: Soledad Rodriguez Perea (Argentina), Jo Grey (UK), Helen Hobrough (Wales), Carmen Villar (Spain). Front: Mary McGarry (Ireland), Beate Bartes (France), Kate Farnell (UK), Judith Taylor (UK) and our scribe, Christine Mcgreal (UK). Joan Shey (USA) is missing from this picture.
Out and about

Genzyme EU thyroid cancer patient group summit - Amsterdam, 27 March 2014

Judith Taylor writes:

In March, Genzyme invited representatives of European thyroid cancer patient organisations to a one-day meeting in Amsterdam to:

• exchange patient - industry perspectives on various topics of interest for the thyroid cancer community;
• facilitate networking opportunities, and
• share best practices between patient groups.

There were seven patient representatives, including myself, and we each gave a short presentation. It was a great opportunity to meet other patient leaders and to share ideas with each other and with the Genzyme patient advocacy.

Beate Bartes writes:

On the occasion of the ASCO congress in Chicago, Bayer invited the TCA, together with various other patient organisations, to attend the second annual Bayer Patient Advocacy Summit – “Partners in Cancer Care” - which I attended on behalf of the TCA.

The focus of this summit was “value”: how is it defined; how it can be described so that all stakeholders have a common understanding of value; and what criteria should be considered when value is assessed.

The participants were from many different countries (Australia, Belgium, Brazil, France, Germany, Italy, Lithuania, UK, USA), and represented many different diseases, together with people from many different Bayer departments. The workshop was moderated by Jean Mossman and Clifford Goodman.

We worked intensely in two groups (“USA” and “others/Europe”), and elaborated various proposals and recommendations, which will now be incorporated in a working document.
Helping new LATAM organisations get started

ACTIRA is a non-profit civil organisation, registered in 2008, and has its origins in an internet forum run by Dr Fabian Pitoia. It offers information to patients and the general public about the different aspects of the disease and gives support to people who are affected. It constitutes a patients’ virtual and real network throughout our country and Latin America. It advocates towards different institutional organisations to defend the right to the health of all the persons with thyroid cancer.

ACTIRA organises “Cyber conferences”, informative online chats for patients and relatives, thanks to Dr Fabian Pitoia and Dra Sandra Licht, about updates in the treatment and follow-up of thyroid cancer.

In several cities, patients meet informally over coffee, inspired by “Vivre sans Thyroïde”. ACTIRA also exhibits ACTIRA and TCA information at professional scientific congresses about thyroid cancer.

ACTIRA plays a key role in inspiring others in Latin America who are interested in forming an association or foundation and helps them take the first steps of starting an organisation. We also enable other organisations to join the TCA. The managerial committee takes part in management training courses.

FADEPOF prize

In 2013, ACTIRA received the FADEPOF (Federation of Rare Diseases) prize and received a bonus from the Lawyers’ College for free societal legal counselling from the prestigious Marval, O’Farrell and Mairal.

Shiatsu massage day

ACTIRA organised a special day of individual shiatsu massage sessions for free in April 2013 and July 2014. Four professionals donated a special day of shiatsu for people diagnosed with thyroid cancer. 40 people participated.

The aim was to raise awareness about what we can do to extend health and reduce stress and tension in a broad concept of health.

SAEM Congress

In November 2013, ACTIRA took part in the XVIII Congress of the SAEM, the Argentinian Society of Endocrinology and Metabolism, at the Panamericano Hotel in Buenos Aires with a stand of ACTIRA and TCA materials. A group of ten volunteers took care of the stand. Mary Pinto Vieyra and Claudia Canchaya of ACTIPERU travelled especially to attend the congress, with a small grant from the TCA. ACTIRA, TCA and ACTIPERU materials were given out to 1,200 endocrinologists, surgeons and specialists and links with professionals were strengthened.

Benign nodular goitre book

Renowned experts from Argentina, Brazil, Chile, Peru, Paraguay, Colombia, the United States and Spain collaborated on a book Benign Nodular Goitre which was conceived and compiled by Dra Laura Sterian Ward, from the Brazilian Society of Endocrinology and Metabolism Regional Sao Paulo (SBEM-SP); and Dr José Luis Novelli, surgeon and President of the Argentinian Association of Head and Neck Surgery (AACC&C). The book brings together research papers from various perspectives about nodular goitre. ACTIRA President Soledad Rodriguez Perea was honoured to be asked to write a prologue from the patient perspective, along with Jorge Kassis from APPAT (Brasil). An innovative idea of giving patient associations a voice, in a book entirely written by professionals for experts on the field.

Looking forward

In October ACTIRA will take part in the FASEN Congress in Cordoba City, Argentina. FASEN is a federation of professional organisations of endocrinology societies in Argentina.
Member Highlights

ACTIPERU
actiperu.org.pe

**Working to improve conditions for patients in Peru**

ACTIPERU started in November 2011 and was formally founded in March 2012.

We have approximately 50 members and work with some doctors of nuclear medicine, endocrinology and especially with a head and neck surgery doctor.

We also work in alliance with national hospitals and other associations such as the National Cancer Patients of Peru and the Peruvian Psico Oncology Society.

Our main activities are to provide personal advice and emotional support to patients; activities for the thyroid awareness week; workshops, conferences, and recreational activities such as meeting up with patients and family members in coffee shops.

Right now, we are organising a medical campaign for early detection and a mass media campaign for the thyroid cancer awareness week in September. We also want to develop research about treatments and quality of life of patients, and to help to improve the conditions for the patients in hospitals here in Peru.

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**AECAT**

www.aecat.net

“Five Voices to Understand Medullary Thyroid Cancer”

The main goal of the Spanish Association of Thyroid Cancer (AECAT) is to provide the patients with all the information and orientation they may need in order to have an active role in their treatment and afterwards. We have therefore put the first patient-to-patient materials about thyroid cancer in Spain, backed by the medical societies, which are now on our website. We also publish a weekly research article on our blog which now gets almost 20,000 visits per month.

In 2014 we set ourselves a new goal. There was barely any information available about medullary thyroid cancer. To fill this gap, and, through a groundbreaking initiative, we therefore launched the campaign “Five Voices About Medullary Thyroid Cancer”.

This campaign, available on our website at: www.aecat.net/5-voces-cancer-medular-de-tiroides/

consists of six professional five to ten-minute-long videos, two by patients and four by specialists in different aspects of medullary thyroid cancer (MTC). We try to answer the most frequently asked questions and to emphasise the importance of a multidisciplinary approach in such diseases.

Made in a friendly and educational format, the videos aim to give those who are suffering from MTC the information they need at each stage of their illness. In this way, we not only guarantee the quality of the information but also highlight the importance of the patients’ knowledge about their illness to be able to take part in, and have a voice in important decisions about their health.

As Cristina Chamorro, chairman of AECAT, says: “Patients with MTC often feel lonely and vulnerable when they are diagnosed, due to the general lack of knowledge about the disease and especially because of the lack of official centres they can be referred to. Having the advice of these great professionals and the experience of other patients will contribute to their empowerment.”

Some of the greatest Spanish specialists on the subject took part in the videos, including Dr Mercedes Robledo, responsible for the Endocrine Hereditary Cancer Group at the National Centre of Oncologic Researches (CNIO); Dr José Ángel Díaz, Senior Consultant of the Endocrinology and Nutrition Service in the Hospital Clínico San Carlos of Madrid; Dr Pablo Moreno, head of the Endocrine Surgery Unit at the Hospital Universitario Bellvitge of Barcelona; and Dr Enrique Grande, who heads the Oncologic Medical Service at Hospital Ramón y Cajal in Madrid. All of these professionals have contributed selflessly to this project.

“Give Your Voice” wins Albert Jovell Award 2013

AECAT wins award for the most significant cancer public awareness campaign in Spain

Receiving the award
In September 2012 AECAT launched the first ever National Day of Thyroid Cancer in Spain with a campaign called “Dona tu Voz” (“Donate your voice”), the first campaign ever in Spain to raise awareness about thyroid cancer. This initiative was created with the aim of letting people with this cancer speak out, because they had never had a national day to claim for their needs or a campaign focused on this illness before.

The campaign aimed to collect supporting messages from patients, specialists, friends and celebrities, who helped us reach the media with their support and popularity. This campaign, created to last, has launched a microsite, www.donatuvoz.org, gathering several clips that made the round on the internet where a Spanish actress and thyroid cancer patient, Lara Dibildos, donated her voice and other public figures dubbed patients’ voices “to help the patient’s voices reach farther”.

A year later, on the occasion of the second National Thyroid Cancer Day in 2013, we added new spots to “Donate your voice” with two young Spanish celebrities, Leticia Dolera and Unax Ugalde, asking people to “Take a minute against silence”. Our aim was to break the information gap on the subject and so we asked the media, patients and anybody else who might want to help us to observe a minute against the silence, giving their voices to talk about such an unknown type of cancer.

On the one hand, we gave evidence of the silence we had been denouncing to the media. A survey into Social Perception about Thyroid Cancer in Spain showed that 55% of the Spanish people knew little or nothing about thyroid cancer, 54% didn’t know the role of the endocrinologist in its treatment, and 77% didn’t know about the role of radioactive iodine.

Throughout the day, our logo bug was shown on TV, our spots broadcast and a guerrilla war organised - with TV and radio interviews, conference participation, talks at schools, presence on blogs and a classical music concert to raise awareness about thyroid cancer.

“Happily all this effort has been rewarded and “Donate Your Voice” received the 2013 Albert Jovell award in the category of the most significant public awareness campaign regarding cancer in Spain, a great achievement for a small patient association representing an uncommon cancer!” says AECAT President, Cristina Chamorro.

AMEND’s Project Superhero!

Kids’ resources on multiple endocrine neoplasia (MEN)

The Association for Multiple Endocrine Neoplasia Disorders (AMEND) has sponsored the production of two Medikidz™ comics and two animations on multiple endocrine neoplasia types 1 and 2 (MEN1 and 2).

MEN disorders are inherited syndromes comprising more than one type of tumour, including medullary thyroid cancer. Each child of an affected parent has a one in two chance of inheriting the condition.

It is never easy trying to tell a child that they have or are at risk of having a genetic disorder. Children learn different things at different ages. In many instances, however, this needs to be done, whether to ensure compliance with hospital tests or to discuss genetic testing. This is why AMEND worked with Medikidz™ to produce the exciting, vibrant and simply-written comic books.

The comics, together with a leaflet on how to talk to children about MEN, are available free to patients via AMEND. To learn more about the comics which please visit the AMEND (HON Code certified) website: http://amend.org.uk/how-we-help/project-superhero.html

For more information about Medikidz™, visit: http://www.medikidz.com/

The corresponding and charming children’s website animations on MEN1 and MEN2 are available to view on the AMEND website or YouTube channel (AMEND3).

http://amend.org.uk/how-we-help/childrens-area.html

AMEND is “…the premier provider of quality information on Multiple Endocrine Neoplasia Disorders” - Genetic Alliance (USA)

The comics and animations were produced as part of AMEND’s ‘Project Superhero!’ funded by the UK National Lottery.

www.amend.org.uk/how-we-help/project-superhero.html

www.thyroidcanceralliance.org
Member Highlights
British Thyroid Foundation
www.btf-thyroid.org

Supporting people with thyroid disorders

The British Thyroid Foundation is a charity dedicated to supporting people with all thyroid disorders including thyroid cancer and to helping their families and people around them to understand the condition.

We are working on a series of short awareness films about thyroid disorders - including one on thyroid cancer which we hope will be released in time for Thyroid Cancer Awareness Month in September. We’ve also started work on the new edition of the BTF booklet Thyroid Cancer – For Patients By Patients to bring it into line with the latest treatment guidelines from the British Thyroid Association (see page 16).

Butterfly Thyroid Cancer Trust
www.butterfly.org.uk

A busy and exciting year!

It has been a very busy and exciting year for the Butterfly Thyroid Cancer Trust!

In July 2013 we were delighted when our CEO Kate received an invitation from Dr Mike Tuttle of the Memorial Sloan Kettering Center in New York to open the World Congress on Thyroid Cancer (WCTC) in Toronto alongside him at a breakfast symposium. Kate and Dr Tuttle engaged in a doctor-patient discussion which was enjoyed by over 350 delegates.

The WCTC was also the venue to showcase the BTCT patient information video Thyroid Cancer Uncovered. This is the first film of its kind and was two years in the making. The film was shown on a large TV screen throughout the congress and seen by around 1,000 doctors and healthcare professionals. The feedback was excellent.

The DVD went into production and was released in the UK, free to patients, in September. Demand has been overwhelming with over 3,000 copies going out up to June 2014. Patients have welcomed it as a vital source of information at diagnosis, messages from the clinicians have been equally complimentary, and many hospital trusts across the UK have adopted it as their patient information source standard.

The DVD was runner-up in the Royal Television Awards and Advancing Healthcare Awards.

Kate has been working closely with Cancer Research UK on the trial management committee for the latest thyroid cancer clinical trial: ION (Iodine or Not). The trial will investigate whether the use of radioactive iodine makes any difference in the long-term survival rates of low risk patients.

BTCT has recently undertaken a patient survey “What the patient wants” and has submitted an abstract to the British Association of Endocrine and Thyroid Surgeons (BAETS) conference in October 2014.

An awareness campaign is planned for September which will involve running the TV advert and hosting a roadshow event across the Newcastle upon Tyne Hospitals together with our Thyroid Cancer Nurse Specialist.
Member Highlights

Grupo de Pacientes con Cancer de Tiroides de la Republica Mexicana

Supporting patients in Mexico

The Grupo de Pacientes con Cancer de Tiroides de la Republica Mexicana is a not-for-profit Mexican association that directs its efforts to the prevention and reduction of thyroid cancer in Mexico and to strengthen those affected by the disease, who recover healthily and have a better life, after being diagnosed. We help patients to feel better and explain to them what they need.

The Mexico group has the support of a Surgical Oncologist, Dr Ernesto José Zepeda Castilla, who helps us. As well as being an excellent head and neck surgeon he is an extraordinary person, we appreciate his help and friendship.

We have about 35 members, most of them live in Mexico, throughout the Mexican Republic, and some live in the United States. Some we know personally, others only by mail or Facebook. When a patient joins, we arrange breakfast or lunch to get to know them and try to support them.

We support, and guide patients who are going through surgery or radioactive iodine treatment, and we receive support and help from doctors and oncologists, too.

In the future we want to help patients to find good treatment, doctors and hospitals, and try to help them when they feel sad or bad, or need information about treatments, and doctors. We organise dates to get to know patients. We want to try and meet every month.

Hypopara UK

www.hypopara.org.uk

The Hypopara butterfly flutters on

It has been a momentous year for Hypopara UK. In 2013 the member database was hacked by a member of the notorious Lulzsec hacking group, which necessitated months of hard work, including setting up a new member forum. We are grateful to the professional security community and all the volunteers who worked tirelessly to get up and running again and to the many messages of encouragement we had from other patient organisations. All were as shocked as we were that a small patient support charity could have been targeted in this way.

Following the breach we decided that the time was right for change and announced our new name - Hypopara UK - and our new website address www.hypopara.org.uk. Doctors around the world already use this term and other patient organisations around the world have agreed to switch to it too. Our rebrand is the brainchild of Isabel Wray, hypopara patient and senior creative producer, and her business partner, Pete Hambling. It was launched on 28 February to mark Rare Disease Day. Isabel and Peter also designed the new World Hypopara Awareness Day butterfly which has fluttered all around the globe and is being adopted by other Hypopara organisations worldwide.

Each year we celebrate World Hypopara Awareness Day on 1 June by adding to and promoting our "Living with hypopara" stories on our website. Living with hypopara is challenging, especially as it often affects young women of childbearing age. So this year we decided to focus our 2014 campaign on how hypopara affects pregnancy, birth, and breastfeeding.

Many doctors have never had to manage a hypopara woman, let alone a pregnant one! Four young women with post-surgical hypoparathyroidism describe how they met this demanding challenge with a positive attitude - and the most beautiful results.

Sacramentoooooo!

Thanks to a travel grant from NPS Pharma, committee members Judith Taylor and Claire Butchers set out on the long journey to Sacramento in June to attend the eighth annual Hypoparathyroidism Conference, organised by the US patient organisation HypoPARAthyroidism Association Inc.

The conference consisted of three days packed with talks by internationally renowned experts and afternoon breakout sessions where patients could share experiences with each other. The topics ranged from parathyroid allotransplantation and the genetics of hypopara, to nutrition, women’s health, and how to maximise your quality of life. There were also yoga and meditation sessions!

It was so moving to meet people who have until now just been names and faces on Facebook, and to share stories and experiences. We came away very impressed and can’t wait to see if we can organise a conference in the UK in the next year or so.
TCSGW tenth anniversary year!

As always our awareness-raising campaigns for the Thyroid Cancer Support Group Wales have taken a variety of forms, including working with a local radio station.

Helen was interviewed about thyroid cancer from a patient's perspective and about the work of TCSGW.

Cy, Brenda and Helen attended the Patient and Carer Conference sponsored by the South Wales Cancer Network Patient Forum which was held at the Orangery at Margam Abbey. Over 112 delegates from different cancer services attended and the keynote introductory speech was given by Professor Mark Drakeford AM, Minister for Health and Social Care in the Welsh Government in Cardiff. TCSGW was invited to have a stand at the conference to showcase the group's work at a national and international level. Links with the TCA were highlighted and shared with the many delegates in attendance - it was an extremely successful conference.

2014 is the tenth anniversary of TCSGW and there are a number of events to mark this, along with our regular meetings.

We have several events planned for 2014 - some are our regular fundraising events whilst others are awareness raising events - another very busy year for the group!

We are delighted to announce that we have received a generous grant from the TCA to enable us to have our website redesigned. We have had several planning meetings with our web designer Peter. We look forward to the website being launched in the not too distant future - watch this space!

**Afternoon tea**

Members and guests met recently at a local hotel for a celebratory afternoon tea.

Over 70 people attended and enjoyed reminiscing, looking at the timeline of photographs which showed the work of the group since its initiation. Such a lot has been...
TCSI hosts Ireland’s first gathering of thyroid cancer patients

Thyroid Cancer Support Ireland is dedicated to the support of thyroid cancer patients in Ireland. TCSI encourages the highest standards of support and patient care, and has a mission to improve the quality of life for thyroid cancer patients through support, education and development.

TCSI founder Mary McGarry has promoted awareness of thyroid cancer in Ireland and is encouraging the highest standards of patient care for patients during and after treatment. The organisation is patient led and entirely altruistic. The group has two medical advisors: Dr Marie Louise Healy, (Consultant Endocrinologist, Dublin) and Dr James Paul O’Neill (Otolaryngology, Head and Neck Surgeon, Dublin). There are now over 100 members.

The last year has been very busy for TCSI. In July, Mary attended the second World Thyroid Cancer Congress in Toronto, which was an excellent opportunity to meet other members of the TCA.

In October, Mary hosted Ireland’s first gathering of thyroid cancer patients and survivors, a dinner in the Annebrook House Hotel in Mullingar. People from all over Ireland attended the evening and it was a great success.

With the assistance of a grant from the TCA, TCSI will be providing the Butterfly Thyroid Cancer DVD to newly diagnosed thyroid cancer patients in Ireland. The DVD is a good example of best practice and is a valuable resource for thyroid cancer patients in Ireland. Correspondence has been forwarded to all endocrinologists and surgeons who specialise in the field of thyroid cancer in Ireland informing them that this resource is available to patients.

Mary says: “I envisage an organisation that supports those who have just received a diagnosis of thyroid cancer at every stage of their journey and beyond. TCSI aims to increase awareness of thyroid cancer, and to encourage best quality patient care. The Butterfly Award which has recently come into being, with the assistance of the Butterfly Thyroid Cancer Trust, aims to honour a person who has made an outstanding contribution to thyroid cancer in Ireland.”

The NATT project

TCSGW continues to provide the financial support for the National Anaplastic Thyroid Cancer Tissue Bank (NATT) project - a world first!

NATT is expected to run for at least five years and Dr Laura Moss is keen to hear from colleagues both nationally and internationally who may wish to participate. For further details please contact Dr Laura Moss, Consultant Clinical Oncologist, Velindre Cancer Centre, Cardiff on laura.moss@walesnhs.uk
Mary McGarry

Network for French-speaking patients all over the world

Creating a support network

Member Highlights

Vivre sans Thyroïde
www.forum-thyroide.net

Meet the new representatives

Mary McGarry

Vivre sans Thyroïde is a patient organization based in France, with a discussion forum active since 2000 and open to French-speaking patients all over the world including France, Belgium, Switzerland, Morocco, Tunisia, Algeria, and Quebec.

The website provides “understandable” information, emotional support and the possibility to exchange experiences with other patients – not only on thyroid cancer, but also on other thyroid diseases, surgery, hormone substitution etc. At present, the forum has just over 14,000 registered users, 5,000 to 6,000 visitors and approx. 120 messages per day.

The association is entirely run by patient volunteers. We also have a Facebook page, a Facebook group (more than 1,600 members), a Twitter account and a YouTube channel where we publish videos of our patient conferences and other thyroid-related subjects.

Each year, the association, in cooperation with Professor Martin Schlumberger and the French TUTHYREF network for refractory cancers, organizes an information event for patients, with information about the newest evolutions in the field of thyroid cancer. In 2014, it took place in Paris and had more than 100 attendees. We made an online survey about “what patients expect from their endocrinologist”, and will present a poster with the results at the French endocrine congress (SFT) in Lyon in November 2014.

Our association takes part in various events: patient conferences and information days in hospitals, medical conferences and congresses, congresses on “patient expertise” and medicine 2.0 ... We also cooperate in making patient information (French national cancer institute INCa etc.), and make various surveys on patient needs, quality of life etc.

To raise awareness, we take part in sporting events, such as runs against cancer.

The association has a few local antennae - in particular in Paris -organising a monthly “café thyroïde”, open to all, to meet other patients “in real life” and exchange experiences, addresses and advice.

One of our present projects is the development of a smartphone application called “e-thyroid”, allowing patients to register and follow their various health parameters, medication, symptoms etc., and to create PDF files easy to share with their doctor.

We are also working on a book, 100 questions & answers about the thyroid gland, together with two doctors, and on a web portal to make the access to the information on our website easier.

I was diagnosed with papillary thyroid cancer in May 2005 weeks after the birth of my son John. My husband Frank noticed a lump in my neck and my Mother, who is a retired nurse, mentioned I should get it looked it immediately.

I had a lumpectomy in Mullingar General Hospital and received a diagnosis of papillary thyroid carcinoma.

I was the first patient of the Medical Assessment Unit (MAU) in the hospital in Mullingar, Co. Westmeath. My photo appeared in the paper and is on the wall as you enter the unit. I am very pleased that the MAU is doing very well.

It was difficult. I had a full thyroidectomy and neck dissection. I was put on Tertroxin (levothyroxine) until February 2006 when I had radioactive iodine. Coming off my meds was a very difficult experience. I enjoyed my time in isolation but after I returned home I struggled physically and mentally.

In September 2008 I returned to college and completed a BA degree in Counselling & Psychotherapy followed by postgraduate training in Cognitive Behavioural Therapy (CBT) in Trinity College/St. Patrick’s Hospital. I have recently completed two online courses, one with the University of Glasgow titled ‘Cancer in the 21st Century: The genomic revolution’ and the second with the University of Bath titled ‘Inside Cancer: how genes influence cancer development’ both of which I found very beneficial.

Almost from the moment of my diagnosis in 2005 I asked to speak to another survivor of thyroid cancer in Ireland. I knew from my own experience that speaking to another person, who had been on a similar journey, could make all the difference. So I established Thyroid Cancer Support Ireland, a patient-led organisation, dedicated to the support of patients with thyroid cancer and encouraging the highest standards of patient care. The organisation officially came into being in 2010.
**Claudia Canchaya**  
started up the patient organisation ACTIPERU in Peru. She writes: 
I was diagnosed in 2011. My experience was a great opportunity to review my life, to strengthen myself, learn and grow as a person and in a spiritual way, to enjoy little things and all the blessings in life, to be thankful, change my style of life and start to live happier enjoying every day. Right now I’m very well, always with good results at my check-ups, without any evidence of regression of the disease. To summarise, I live happily now.  
I started up this support organisation because from my own experience, I realised that patients usually have limited and sometimes wrong information. My tumour could have been discovered earlier and it is common for patients that when they hear the word ‘cancer’ they associate it with death and that is not the usual case, especially with thyroid cancer. Finally, that there are many good cancers!  
My personal aim is to let people know that it is not a “good” cancer. There are no good cancers! There is a great need for experiential knowledge in my experience.  
I work as a secretary in neurosurgery at the hospital in Tilburg from 1998, until I became ill in 2006.  
Since 2010 I work as a tax consultant for Trade and Tax for 24 hours a week. I’m also Secretary of the Hilvarenbeek tennis association.  
I have had four neck operations and six radioactive iodine treatments since 2006 so I am an “expert patient”. Given my broad experiences as a patient, I found it important to communicate these to the outside world. I am active as a volunteer with the SON. In 2009 I opened a “SON thyroid cancer” telephone helpline to offer an open ear to thyroid cancer patients. There is a great need for experiential knowledge in my experience.  
I organise an annual day for cancer patients and I have also raised funds for the purchase of a PET-probe for the Vrij Universiteit (Free University) Medical Centre in Amsterdam. See: http://www.vumc.nl/afdelingen/CCA/nieuws/PET-probe. The fundraising activities included the NY marathon and the tennis marathon in my hometown.  
I also give presentations in hospitals about quality of life with thyroid cancer.  
Ans featured on the cover of the SON magazine Schild recently!  

**Claudia Figueroa**  
recently founded the Mexican organisation Asociacion de Pacientes con Cancer de Tiroides de Mexico. She writes:  
I was diagnosed in June 2007 and my surgery was in July. The surgery was very successful, it took about seven hours. I had a total thyroidectomy, radical modified bilateral neck dissection and central and bilateral lymph node dissection - in total 44 of about 60 nodes with metastasis from papillary cancer of the thyroid.  
My experience at first was very bad, because I felt so alone, but I now know people with the same disease in Argentina, and two from Mexico, and I began to contact patients, and think I should do something to help people who had this and other types of thyroid cancer.  
I started up this organisation because when I was diagnosed I felt very much alone, and I could see that patients and some doctors and surgeons in my country don’t have access to the latest information about this disease. I try to support people who are newly diagnosed and try to give them more information. Thyroid cancer is a disease with a good prognosis, if you are diagnosed on time, or if not, we can still have a good prognosis and if we are followed for a long time we can live a normal life.  
I started to look for people with the same experience in about February 2008 because I wanted to try to understand this cancer. A lot of people helped me, and I began to help people and support them. I like this experience, and discover new patients every day. We now have around 35 members.  

**Marika Porrey** now represents the Schildklier Stichting Nederland in the TCA, together with Ans de Kort. She writes:  
I live and work in Rotterdam, the Netherlands. I am 47 years, I have a husband and a daughter (11) and a son (8). I have my own business as a webdesigner/builder, graphic designer and social media expert for small businesses.  
I was diagnosed with thyroid cancer at the beginning of 2012. I have Hurthle cell cancer and due to that it is really hard to check if I am really clean, because my blood results cannot be used as an indicator. I have a Pet-scan (with a sort of radioactive sugar) every year now.  
I joined the SON in November 2012 as a volunteer to start and boost the social media. My personal aim is to let people know that thyroid cancer changes your life for ever and that it is not a “good” cancer. There are no good cancers!  

**Ans de Kort**, who represents the Schildklier Stichting Nederland along with Marika, writes:  
I am 46 years old and living in the south of the Netherlands with my husband, two daughters and one son (11-14-15).  
I worked as a secretary in neurosurgery at the hospital in Tilburg from 1998, until I became ill in 2006.  
Since 2010 I work as a tax consultant for Trade and Tax for 24 hours a week. I’m also Secretary of the Hilvarenbeek tennis association.  
I organise an annual day for cancer patients and I have also raised funds for the purchase of a PET-probe for the Vrij Universiteit (Free University) Medical Centre in Amsterdam. See: http://www.vumc.nl/afdelingen/CCA/nieuws/PET-probe. The fundraising activities included the NY marathon and the tennis marathon in my hometown.  
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Claudia Canchaya started up the patient organisation ACTIPERU in Peru. She writes:
TCA News is the annual newsletter of the Thyroid Cancer Alliance, PO Box 359, IP22 9BA, Diss, Norfolk. Editor: Judith Taylor. Design: Juan Gordo. Aims and scope: The purpose of the TCA News is to raise awareness about the Thyroid Cancer Alliance and to disseminate information about member organisations and their activities to the thyroid cancer community. © 2014 Thyroid Cancer Alliance. All rights reserved. No part of this publication may be reproduced, stored in a retrieval system or transmitted in any form or by any means without the prior permission of the copyright owner.

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BTA guidelines published

The much awaited third edition of the British Thyroid Association guidelines for the diagnosis and treatment of thyroid cancer has been published online in Volume 81 Issue S1 (July 2014) in the journal Clinical Endocrinology.

Representatives of the UK thyroid cancer patient organisations - consisting of Kate Farnell, Helen Hobrough, Jo Grey, Liz Glenister, and Judith Taylor (who represented the team in the guidelines committee), were closely involved in the consultation process and in revising the patient information leaflets that accompany the guidelines.

Dr Laura Moss (Wales) kindly contributed her expertise by drafting two new leaflets on anaplastic and advanced thyroid cancer.

Voices on the Path

3-7 September 2014 / Santiago de Compostela, Spain

A Camino de Santiago made of thyroid cancer patients and supporters from around the world and supported by the TCA.


Making a difference together