Message from the TCA Board of Directors

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

What a year it’s been. Last year, some of our members took part in ‘Voices on the Path’, walking the final part of the Camino de Santiago to raise awareness for thyroid cancer. See the report and pictures on pages 6-7.

We also organised and hosted a workshop on tyrosine kinase inhibitors and what this means for patients with advanced differentiated thyroid cancer and advanced medullary thyroid cancer, and will be presenting the results during the International Thyroid Congress in Orlando, Florida, this October. See page 2 for a report of the Paris meeting.

Our member organisations have been raising awareness for thyroid cancer around the world. A common theme is that thyroid cancer is NOT the ‘good cancer’ we are sometimes told that it is. We are still learning about the long term consequences of thyroid cancer. While it is highly treatable, and most people can live out a full and active life, the journey through diagnosis, surgery and treatment is still significant and real. Some patients are left with permanent consequences, from voice issues to parathyroid or salivary gland damage, and some will experience progressive and aggressive disease. For a small number it will be fatal.

That is why we welcome the efforts by our members to shine a light on issues faced by thyroid cancer patients, and welcome the shift in the clinical management of the disease from ‘one size fits all’ to a more personalised risk-based approach.

We hope you will find something to interest you in this issue, and if you are visiting the International Thyroid Congress in Orlando in October, please come and visit our stand!

Warm regards

September is thyroid cancer awareness month!

Soledad Rodriguez Perea (Argentina) President
Judith Taylor (UK) Secretary
Carmen Villar (Spain)

www.thyroidcanceralliance.org
First patient-led workshop on kinase inhibitors for advanced thyroid cancer

In October 2014 the TCA organised a unique patient-led workshop. Ten patient ‘leaders’ and ten clinicians met in Paris to discuss tyrosine kinase inhibitors and what this means for thyroid cancer patients. We were honoured that so many distinguished international clinical experts joined us to participate in these discussions.

The workshop was ably moderated by Clive Harmer and Fausto Palazzo.

Opening the meeting, Helen Hobrough explained that the workshop was due to the unique vision of our former President, Kate Farnell, who was however unable to be there due to health issues.

Clive Harmer introduced the first session on access to TKIs in different countries. The material has since been collated and updated and will be presented as a poster during the International Thyroid Congress in Orlando, October 2015.

We were privileged to have two patients who attended part of the workshop and who shared their pilgrimage through their different treatments: Christine, and Isabelle. Their willpower in undertaking new treatments and their courage in facing a room full of clinicians and patient advocates left a lasting impression on participants.

Marcia Brose presented an overview of recent progress in the treatment of both radioiodine-refractory differentiated and advanced medullary thyroid cancer with kinase inhibitors. Jo Grey gave an overview of TKIs in the setting of complex conditions (MEN2 and MEN3). In the afternoon participants divided into two groups to discuss what education and support do patients need and how can we provide this. We hope to use the conclusions of these sessions to develop materials to help patients and to translate these into different languages.

The workshop was made possible thanks to a generous donation from Bayer.

We were saddened to learn that Isabelle passed away in February from her metastatic thyroid cancer. Beate Bartès (pictured here with Isabelle) writes: We are very sad about the passing of Isabelle Monroig, a long-term member of our French association and good friend. She shared her story with us at the TKI workshop despite her extreme weakness, and was very happy at the idea that her experience could be helpful to others.

Summing up, Fausto Palazzo said he was struck by the diversity of access to care around the world and the ‘postcode lottery’. He hoped the break-out sessions would provide a basis for moving forward, and thanked the patients for sharing their moving personal journeys and said he was especially struck by a remark from Isabelle that ‘if you have cancer the whole family has cancer’.

The TCA hopes to present an overview of the workshop findings during the International Thyroid Congress in Florida in October 2015.

ECC congress

The TCA has been awarded a booth in the ‘Patient Advocacy Square’ at the European Cancer Congress in Vienna, 25-29 September. Marika Porrey will represent us there.
ETA meeting in Santiago de Compostela

The TCA had a stand at the European Thyroid Association annual meeting in Santiago de Compostela and was represented by Judith Taylor (UK), Carmen Villar (Spain), and Ans De Kort (Netherlands). We displayed literature from all of the member organisations along with the TCA Newsletter.

The interviews were conducted by Cristina Chamorro of AECAT and filmed by Luis Romero. Videos of the interviews with Professor Furio Pacini, Professor Martin Schlumberger, Dr Colin Dayan, Dr Rosella Elisei, Dra. Alvarez Escola, Dr Fabio Pitoia, Dr J.C. Galofré, Dr Jaime Capdevila and many others are on the AECAT website and on the AECAT Voice of the Experts channel on YouTube Channel.

Carmen, Ans and Judith at the 38th ETA annual meeting

Genzyme LATAM thyroid cancer group leaders’ summit

Genzyme Argentina and Brazil invited TCA leaders of patient organisations and some others groups of patients to attend the first LATAM thyroid cancer group leaders’ summit in Buenos Aires city in April 2015.

The participants were from Argentina, Brazil, Peru, Mexico and patients from Colombia and Honduras who are in the first steps of organising an association. A Spanish leader also joined the summit.

The organisation invited TCA president Soledad Rodriguez Perea to make a presentation of TCA history and update.

The highlights of the journey were:
Quality of life: aspects in the management of thyroid cancer; increase thyroid cancer awareness; and identify opportunities and challenges when collaborating with industry.

The workshop was moderated by Ariel Carmona and Sindé Cheketed from Genzyme LATAM.

During the meeting we shared our association’s experiences in different countries and our thoughts about continuing to work together and help the first steps of new groups of patients to become an association or foundation.

The TCA has undertaken to help the new groups of patients in Colombia and Honduras and any country who have this intention.

iNATT update

In 2013 the National Anaplastic Thyroid Cancer Tissue Bank (NATT) was launched in the UK to try and address the lack of research opportunities and to enhance our understanding of the disease, its aetiology, behaviour and potential therapeutic targets.

In 2014 it was decided to expand the project and invite international collaborators to participate. The project was renamed the ‘interNational Anaplastic Thyroid Cancer Tissue Bank project’ (iNATT).

All patients with anaplastic thyroid cancer or foci of anaplastic cancer within a more differentiated thyroid tumour are potentially eligible. Patients are asked to donate surplus thyroid cancer tissue following their diagnostic biopsy or surgery along with an optional blood sample and their clinical data.

The project is expected to run for at least five years and we are keen to hear from patients, relatives and colleagues both nationally and internationally.

Funding has been secured from Thyroid Cancer Support Group-Wales. The collection is hosted by the Wales Cancer Bank and the project is sponsored by Velindre NHS Trust.

If you want to find out more, please contact Dr Laura Moss, Consultant Clinical Oncologist, Velindre Cancer Centre, Cardiff on laura.moss@wales.nhs.uk
Light of Life receives PALS Award 2014

Congratulations to the Light of Life Foundation (USA) which was one of the recipients of the 2014 Genzyme Patient Advocacy Leadership (PAL) Awards.

The Light of Life Foundation is planning to create a testimonial video featuring patients’ and survivors’ stories to affirm that ‘no cancer is a good cancer’. The video will be featured on website and shared on social media with patients and medical community.

The other thyroid cancer award winners were APOZ and Friends Cancer Patients Organization (Bulgaria) and Polish Amazons, the Social Movement (Poland).

New Dutch guidelines

The new Dutch guidelines for the treatment of differentiated (non-medullary) thyroid cancer have now been published.

The guidelines include a completely new section on the psychosocial aspects of diagnosis and treatment. It recommends that patients and doctors should discuss these issues together to reduce the burden of the disease and improve the quality of life, and review this regularly.

The guidelines committee was chaired by Professor Thera Links. The Dutch patients’ association, the SON, was represented by Marianne Dagelet.

The full text of the Richtlijn voor de diagnostiek, behandeling en follow-up van patiënten met gedifferentieerd (niet-medullair) schildklierkarcinoom (in Dutch) is online at: www.oncoline.nl/schildklierkarcinoom

Patient representatives meet in Amsterdam

Representatives of several European patient organisations – Vivre sans Thyroïde, AECAT, Thyroid Cancer Support Group Wales, Schildklier Organisatie Nederland, and the British Thyroid Foundation – met in Amsterdam in May at a ‘patient advisory board’ meeting organised and hosted by Genzyme. The participants included Beate Bartes, Helen Hobrough, Marika Porrey, Cristina Chamorro, and Judith Taylor.

A special guest was Teodora Kolarova of the Bulgarian cancer patient organization APOZ and Friends and a member of the Board of Directors of the International Neuroendocrine Cancer Alliance. APOZ and Friends is one of the recipients of the 2014 Genzyme Patient Advocacy Leadership (PAL) Awards.

Teodora gave an impressive presentation about the way the organisation plans to use the award. She explained that in Bulgaria, physicians don’t appear to acknowledge the problems of withdrawal from levothyroxine, patients are unaware, and there is no consistent way of disease management. The aim is to drive change through publicity campaigns and empowering patients. ‘Our key mission is to revise the patient pathway and patient access to treatment,’ she said.

The participants also gave feedback on patient educational information and discussed a recent study which has been published about the effect of levothyroxine withdrawal on driving.

Beate runs for research

Beate Bartès will be joining the AACR Runners for Research at the American Association for Cancer Research Rock ‘n’ Roll Philadelphia Half Marathon in September. The TCA is helping to sponsor her. Beate says ‘There are more than 200 types of cancer, thyroid cancer is one of them, and there is no such thing as a ‘good’ cancer!’
In April 2015 Beate Bartès, Founder/President of the French patient association Vivre sans Thyroide, attended the ‘Scientist-Survivor program’ which was held during the Annual Meeting of the American Association of Cancer Research in New Orleans.

Beate writes:
Attending this huge congress, specially aimed on cancer research, and working together with patient advocates and mentors from different countries and different diseases, was a fantastic experience. I learned a tremendous amount of things, not only from the various sessions, but also from the exchanges with the participants!

‘Until the AACR congress, most congresses I attended were specially aimed on thyroid disease and thyroid cancer, and I attended mainly lectures about treatments and further treatment options, but not so many about research.

‘I have no medical background myself, so many of the AACR lectures were too scientific for me – but others were perfectly understandable, and really fascinating! I particularly appreciated a plenary session on “Drug Resistance” and its mechanisms, with the question (and the corresponding explanations) “Why can we cure mice, but not humans, who were very interested in translating discoveries into the clinics (Alice T. Shaw).

‘The closing ceremony also included some really fascinating talks, about all the new ways to improve cancer treatment: immunotherapy, better prevention and detection, biomarkers, precision medicine, cell based medicine, epigenetics … and about the importance of “big data”!

‘Before the AACR congress, I had of course already come across all these notions, but they remained rather “abstract” for me… attending these lectures, and seeing thousands of researchers join their forces to find a better cure for our diseases, was really encouraging! And this is also the information that I now bring back to our patients, in all my talks and written messages: research is going on, there is still a lot to do, but there are many progresses, many new pathways … to take up the 2015 message promoted at the AACR. “Hope is : research, progress, working together, finding a cure together!”

‘Attending a workshop specially designed for approx. 30 patient advocates, like the SSP program, was a totally new experience – I was really impressed how well it was organised, with lectures on various subjects, specially designed for us (the “Mini-Med School about Cancer” with Carolyn Compton was absolutely stunning, we all followed her talk, fascinated, for 2 ½ hours, and would have been willing to continue all night!), a meeting between patient advocates and the FDA, another one about the Intersection of Science Policy and Cancer Research…

‘It was also a fantastic opportunity, for us as patient representatives, to present posters about our organisations and activities in the main hall, among all those hundreds or even thousands of scientific posters – and to explain our work to all those who passed by, many of them “lab researchers” more used to treat mice than humans, who were very interested in meeting patients “in real life”, and in seeing what we do and how important research is for us!

‘One of the most important and interesting parts of the SSP program was the work in small groups, with five to six patients and two mentors (one of them a scientist) in each group. Each group had another question to treat, and was asked to give a PowerPoint presentation on the last day. I was surprised by the high level of the presentations, which were really “professional”! The subjects were ambitious, and “up-to-date”, very close to the subjects treated during the scientific sessions: “Big Data” (that was our group’s subject), “Biomarkers”, “the Omics family”, “Cancer complexity” and “Immunotherapy”. Each group produced a really good PPT, in many early-morning and late-evening brainstorming sessions. After the presentations there was a graduation ceremony where each participant received his/her certificate from Anna D Barker, and a wonderful dinner.

‘On the last day, we were all sad to leave – we shared so many things during these days, and we also have so many things in common, even if our diseases are different, that we became really close and feel like we found a lot of new friends! I hope very much to see them again, and in the meantime, we became friends on Facebook, so that each of us can follow the activities of the others, over the year.

‘Participating in the SSP program has been a fantastic and very rich experience for me. Although some of the subjects (like fundraising, lobbying etc) were more aimed at patient advocates in the US (the situation in France, with its public health insurance system, is quite different), I gathered a tremendous amount of information and new ideas!'
‘Voices on the Path’

In September 2014, some 35 thyroid cancer patients and survivors walked the final 114km of the Camino de Santiago – the Way of St James – arriving in Santiago de Compostela in time for an awareness event in the main square before the opening of the scientific meeting of the European Thyroid Association. On the last day the number swelled to around 100 patients and supporters including representatives of other thyroid patient associations.

The five-day event was organised by the Spanish patient association AECAT, which hosted all the patient associations coming to take part in the meeting and also arranged for media coverage. Patients from Argentina, the UK, France, and the Netherlands took part in the walk alongside patients from all corners of Spain. Several TCA members took part and the TCA contributed to the event by providing a grant towards the purchase of t-shirts and the awareness campaign. The planning of the route, accommodation and meals, the bonding exercises each evening, and the celebrations in the city, were all managed by a dedicated and capable body of AECAT volunteers.

Luis Romero, himself a thyroid cancer patient, filmed tirelessly throughout the five days of the Camino and also filmed interviews with specialists during the ETA meeting. The resulting video is on the AECAT website and on YouTube.

Everyone agreed that it was a remarkable event, and the final hours in the main square were stunning. As we arrived, the city was festooned with purple and there were t-shirts hanging from the windows of the main square. Dr Clara Alvarez, the ETA meeting chair, was there along with representatives of the regional health authorities to greet the pilgrims. The pilgrims all received the ‘compostelana’ certification. Many attended the Pilgrims Mass in the Cathedral afterwards, where several AECAT representatives read the admonitions.

AECAT President Cristina Chamorro says: ‘The campaign, called ‘Voices on the Path’, carried our voices to the medical specialists at the ETA meeting as well as to the general public. This was an extremely successful awareness campaign, with six national and regional TV impacts and more than 19 radio interviews as well as coverage by the medical (21) and general press (over 130 impacts).

‘We presented in Madrid during our National Thyroid Cancer Day, on 28 September, the 20-minute Documentary ‘Voces en el Camino’. It shows the story, in Spanish and English, of these 35 brave patients during the five-day pilgrimage as a metaphor of the five challenges of the thyroid cancer patient’s journey. I would like to thank all of our volunteers for their hard work.’

Judith Taylor, TCA Secretary, says: ‘It was a privilege to take part and to celebrate my own nearly 50 years as a survivor in this way. Although many of the pilgrims spoke little English we managed to communicate with each other. I met some wonderful people and it never fails to move me when I view the video that Luis made. A memory that lives with me is meeting a British nurse in the main square during the celebrations after our arrival, who said she had been moved to tears to see us all walking in to the city together.’
The Camino in pictures...
Claudia Canchaya writes:
In the last twelve months, ACTIPERU has grown from fifty to more than one hundred members.

In prevention we have organised two medical campaigns in order to detect thyroid affections and cancer: one in the National Hospital Edgardo Rebagliati Martins and the second one in the district of Ancon in the boundaries of Lima city. These included sports and dancing activities.

We have given orientation and emotional support to patients and relatives everyday by a virtual group and in a personal way also, such as visits with our own clown.

In order to provide information and empower our patients, the conferences also took place on themes like: Bio-nutrition, Thyroid Cancer Diagnosis, Thyroid surgery, Radioactive Iodine Treatment, TKIs, and New Aspects in Thyroid Cancer.

ACTIPERU has created a new area that brings attention to social cases. Nowadays we are supporting with orientation to a 6-year-old boy who lives in the Amazon, has thyroid cancer with pulmonary metastasis and receives TKI treatment. We are helping his family to get the funds necessary for the medicines and accommodations in the city of Lima.

In August we are going to inaugurate two groups of patients in two hospitals, the National Institute of Cancer and the National Hospital Loayza, called ‘The double smile club’.

For Thyroid Cancer Awareness Month in September this year, we are planning a medical campaign in the city of Trujillo in the north region of Peru, in alliance with the Regional Hospital Belen, and the “Butterflies festival” in Lima.

ACTIPERU’s President elected to JUS Lima

In August 2014, Claudia Canchaya, President of ACTIPERU, was elected as a member of the first JUS LIMA or ‘Junta de Usuarios de Servicios de Salud de la Región Lima’ (Health Services Users Board of Lima Region), where she works ad honorem as the coordinator of the internal committees of the Board. The JUS is a space for an effective dialogue between the users of the health services and the ‘Superintendencia Nacional de Salud’ (National Superintendence of Health) – SUSALUD - which develops a cooperative relationship for the formulation of proposals to improve health services, based on a citizen listening approach.

The activities of the Board includes: give inquiries and opinions as well as informing about matters that may involve health right violations; proposing guidelines for actions that will contribute with the promotion and protection of the exercise of health rights; promoting the civic participation and the dialogue between the users and the health sector institutions; giving opinions on consultations of SUSALUD; disseminating among the public the projects of the Superintendence, and generating feedback in order to enrich the proposals.

The Board is formed by regrouped members, who participated in an election process; and non-regrouped members, who were selected. The regrouped members include representatives of
groups of users that get together because of a common disease or disability, and groups of persons of the same age: young and elderly.

The JUS Lima is formed by representatives from patients organisations of thyroid cancer, breast cancer, kidney failure, sclerosis multiple, tuberculosis and children and teenagers with diabetes.

This is the first initiative in Peru and also the first one with these characteristics in Latin America. There is a second board in the Callao Region and five others in the process of being started in the different regions of the Peruvian coast, mountains and Amazon.

ACTIRA Argentina // www.actira.org.ar

‘Patient journey’ meeting in Buenos Aires

Soledad Rodríguez Perea writes: Actira organised a patient and family ‘journey’ in September 2014.

The room was filled by about a hundred people who gathered on different working tables to talk about issues such as: hypothyroidism, hypoparathyroidism, thyroid cancer, psychological aspects, radioactive iodine treatment, and motherhood and fatherhood after thyroid cancer. One member of each table presented a summary.

Laura Rodero talked about her experience of the taking part in the ‘Camino de Santiago’ (The way of St James) last year with AECAT and TCA members.

Dr Fabian Pitoia and Dra Sandra D Licht answered questions from patients for an hour. We are very grateful to them for their time.

People from other cities assisted with the meeting. Groups are also growing in other cities in the Republic of Argentina.

Introducing ‘Panambi’

‘Panambi’ (‘Butterfly’ in Guarani language) is a group of thyroid cancer patients who live in Chaco, North Argentina.

Marisol Díaz Oliva and others have started up a group of patients who have been meeting together once a week since 2012.

During the Thyroid Week, they inaugurated a place near the endocrinology clinic in the J. Ferrando Hospital. Relatives and patient volunteers painted the walls and made the curtains and they now have a specific place to meet together.

The endocrinology clinic help and support the group and its meetings. Panambi is very helpful for the endocrinology clinic too because new patients can be more confident and less stressed when they have the chance to meet another patient who has lived the same experience.

Actira is planning a Shiatsu massage day there in November 2015. Panambi grows up together with ACTIRA.
Cristina Chamorro writes: This last year has been a very busy one for AECAT’s team, after the success of the Voices on the Way Campaign during the 2014 ETA Annual Meeting in Santiago de Compostela, Spain (see article in this issue).

The ETA Meeting gave us the opportunity to record interviews with the very best specialists in thyroid cancer. Twenty video interviews can be seen now in our website: www.aecat.net.

‘The butterfly effect’

From Christmas 2014 on we focussed on celebrating AECAT’s ten-year anniversary, with the campaign called ‘The Butterfly Effect’ that aimed to involve more partners, volunteers and supporters as well as honour the volunteers. As small actions can give great results in the AECAT family

In 2015, AECAT organised a training school for volunteers and expert patients: the “Butterfly Effect” with 25 patients registered in the attended classroom though out the year. Our aim is to promote our local presence through senior members and zone groups, in an attempt to go beyond its virtual presence and get closer to the patient, and we may say that it has been successfully accomplished though the year with new awareness activities in different regions of Spain and the creation of six local delegations.

We have also planned four conferences and round tables for thyroid cancer patients with the goal of promoting well-informed and empowered patients.

‘Cancer makes a life-long mark’

On 7 June AECAT participated in GEPAC National Cancer Survivor’s Day, with an exhibition of photos and testimonies illustrating that cancer makes a life-long mark, by showing patients with the name of the type of cancer they have had to face, ‘tattooed’ by their own scar.

‘It could be your thyroid’

During International Thyroid Week AECAT launched a public awareness campaign called ‘It Could Be Your Thyroid’ on the health effects of thyroid dysfunction and the importance of an early diagnosis. The campaign was supported by the Spanish Endocrinology and Nutrition Society (SEEN).

The centrepiece of the campaign was an educational video and a shorter TV spot showing the impact that a thyroid disease may have on health such as depression, cardiac disorders, osteoporosis, hypercholesterolaemia or infertility. The spot was shown on a wide range of national and local TV over three weeks at least four times a day, and the press releases resulted in personalised interviews for TV, Radio and the press.

www.youtube.be/tyBe864fLYo

AECAT also organised webinars and interactive online courses for patients on the AECAT website where expert endocrinologists are invited to respond to the questions posed directly by patients. The campaign was backed with local activities in the regions such as informative stands and seminars. In Valladolid, a charitable/sports day was organised with almost 800 participants.

‘Loud and clear’

During 2015 AECAT took another step to defend the interest of thyroid cancer patients in the eyes of Government Institutions with two campaigns: #timeislife against bureaucratic obstacles for the Rare Disease Day and ‘Loud and clear’ Campaign during the Thyroid Cancer Week.

The ‘Loud and clear’ campaign seeks to speak out against the injustices and inequities that are being generated in the Spanish health system, while providing proposals to improve treatments. Our main goal is always the same: making our experience useful to future patients.

We held a survey to uncover the needs, met and unmet, of thyroid cancer patients and their treatment improvement priorities. Simultaneously, a social and audiovisual media campaign was launched, based on patient testimonials.

The campaign was accompanied by a public event in the very centre of Madrid, in the presence of the local and regional health authorities: a karaoke of patients together with the performances by famous singers. Between the songs there were short testimonials by patients defending with their own story a proposal or denouncing an injustice. Each song is dedicated to one patient, and flew loud and clear for one of our campaign hashtags.
AMeCAT is the organisation for thyroid cancer patients in Mexico. The main activities of AMeCAT in recent months are:

Café Thyroid are regular meetings held between members of the association and newly diagnosed patients, they share their experiences and resolve doubts about the disease in a way that can only be possible between people who have had the experience. In these talks it is made clear that the information and support we provide should only be considered as emotional support to share experiences from patient to patient, and that the sole purpose is to facilitate the understanding of the treatment and communication with the doctor. Under no circumstances do we intend to replace the advice, diagnosis or treatment from specialists.

In February the First AMeCAT Patient Workshop took place, with the participation of medical specialists (who are part of the medical advisory committee within the association) where an extensive question and answer session between patients and doctors took place and was of high interest and value for patients and their families.

In May 2015 after eight months of legal procedures, the association was registered before a notary public as AMeCAT.

In July 2015 we were invited to a radio station with a national reach to talk about the disease and the activities carried out in the association, in the same month an interview and news reporting was done with the chain Mexico Media Services. (www.youtube.com/watch?v=uwpnPxX9jIQ)

We also attended the Walk for Thyroid Cancer Survivors in Mexico City, where we participated in different activities with patients, doctors and other organisations.

New patient support materials

Judith Taylor writes: The British Thyroid Foundation (BTF) launched four short films about thyroid cancer at the end of 2014. The films are part of a series called ‘Patient Journeys’. Cory, Glenda and Beth each share their stories and in the fourth film, Dr Mark Vanderpump of the Royal Free Hospital, London, President of the British Thyroid Association (BTA) and a BTF Trustee, provides an introduction and overview. The films are an excellent introduction to thyroid cancer for people who have been newly diagnosed and their families and send out a message of hope.

The BTF thyroid cancer group consisting of Judith Taylor, Carole Ingham, Janet Prentice and Glenda Shepherd (patient representatives) and Mr Richard Bliss (surgeon) and Dr Kate Newbold (oncologist) has met a number of times over the year by phone to plan and execute new activities. The group has produced two new documents to support patients and their families: Targeted Treatments for Advanced Thyroid Cancer, and Travel and Travel Health Insurance.

Judith Taylor represented the BTF on four submissions to the Scottish and Welsh health authorities about access to new drugs, along with Kate Farnell of Butterfly and (when relevant) Jo Grey of AMEND. Not all of these submissions were successful but the process has resulted in two ‘wins’—sorafenib for Scottish patients, and cabozantinib for Welsh patients.

To access the films and these two documents please visit the BTF website thyroid cancer page.
This year Hypopara UK celebrates its tenth anniversary!

Liz Glenister, Founder and CEO of Hypopara UK, writes: The first website and online forum went live on 15 July 2005. We are now starting to see the culmination of ten years’ work campaigning and awareness-raising about patients’ needs by us and our supporting health professionals.

Today we have over 1,400 members and we are a recognised name throughout the hypopara world, the only official source of information about parathyroid conditions in the UK, and proud to be helping to establish other groups around the world too.

In 2005, our goals were to support patients, provide information to patients and health professionals, to raise awareness about hypoparathyroidism, to bring a replacement hormone to market and to establish clinical treatment guidelines.

We began to raise awareness about hypopara, then barely known about even in the medical world, and sought out and brought together a group of doctors interested in hypopara in the UK, as our advisory team, and published the first patient information leaflet as the first step towards flagging up the need for guidance. In 2008, we highlighted the urgent need for a consensus statement, bringing together an international group of doctors and got people talking.

From this, grew the first global clinical trial on parathyroid hormone PTH 1-84 in which we were proud to participate. Natpara was approved by the FDA in January and the first patients are beginning treatment in the USA this month. Our grateful thanks go out to the ten members of Hypopara UK who took part in this trial (and were the second largest cohort bar one, after the USA).

This news marked an important milestone in the treatment of hypoparathyroidism and we now hope for a positive outcome in Europe. In December last year, the European Medicines Agency (EMA) validated and initiated its review of NPS Pharma’s (now Shire) application for Natpar, as it is to be known in Europe.

As well as that long awaited news, there were exciting developments on the guideline front. Last year we saw the first emergency guidelines for hypocalcaemia published and we were also delighted to have input into the British Thyroid Association Thyroid Cancer guidelines and related patient information. The PARADOX study was also published, the first piece of research to look at the burden of illness experienced by hypopara patients, in America.

This year, we were also involved in the development of not one, but two sets of guidelines to emerge, on the treatment of hypoparathyroidism.

‘History in the making’

In May, Liz attended the First International Hypopara Conference in Florence, Italy.

She writes: this was a truly momentous occasion bringing together world experts and, for the first time, the leaders of the first three Hypopara patient organisations (Liz Glenister UK, Helen Dahl Hansen, President of the Nordic Hypopara Organisation, and James Sanders, President of the USA Hypoparathyroidism Association) were able to meet in person having worked together online for ten years – an emotional event!

From left to right: Helen, James and Liz, leaders of the first three hypopara patient organisations meet in Florence

The conference details and abstracts are on the Fondazione Menarini website. From this fascinating conference will emerge three papers and one guideline/commentary which will be out soon.

‘This was hypopara history in the making and I felt honoured to be there,’ says Liz.
The end of 2014 and the first half of 2015 have been used to rebuild the thyroid cancer group within the general thyroid patient organisation Schildklier Organisatie Nederland – SON.

Marika Porrey writes:

This fall we are organising two big patient information meetings in Rotterdam and in Nijmegen. The goal is to have an open atmosphere for patients to obtain information about thyroid cancer, the medical process and the experience of a thyroid cancer survivor.

The idea is that these meetings can be organised in any hospital in the Netherlands and that SON can support with the patient leaflet which will be out soon.

The guidelines were drafted by an international group of authors who are Jens Bollerslev (Norway), Lars Rejnmark (Denmark), Claudio Marcocci (Italy), Dolores M Shoback (USA), Antonio Sitges-Serra (Spain), Wim van Biesen (Belgium) and Olaf M Dekkers (The Netherlands). These have now been published in the European Journal of Endocrinology.

You can read the ESE Guideline here: www.eje-online.org/content/173/2/G1.full.pdf

World Hypopara Awareness Day

World Hypopara Awareness Day is celebrated each year on 1 June. There is a new website to make our global presence known and to help patients to find support and to raise awareness, featuring the logos and linking to the websites of hypopara patient organisations around the world, at: www.hypopara-awarenessday.com

Schildklier Organisatie Nederland (SON)
The Netherlands // www.schildklier.nl

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We have a blogger Anke van Haften who has written about her personal experience with thyroid cancer treatment and the acceptance, physical and psychological discomforts, for the SON website. She also writes a regular blog for a national newspaper. Anke’s story has been published as a book called Goede Kanker Bestaat Niet! (‘Good’ cancer doesn’t exist!). It is of course in Dutch, but news has just come out that it is now going to be translated into English and will available for a worldwide public.

We are so proud of her!
Helen Hobrough writes: Once again it has been an extremely busy year for TCSGW. We have been involved in many awareness and fundraising events.

It is always an enormous privilege to be able to help and support thyroid cancer patients and their families. We appreciate the generosity of people with their time, money and commitment to the challenges that we have set ourselves as a group.

Our gardening group continues to meet regularly to look after the gardens outside the isotopic rooms at the Velindre Centre, and patients undergoing radioactive iodine treatment comment what a difference this makes to their stay.

In May 2015 we participated in the Genzyme summit held in Amsterdam. This was an excellent opportunity to liaise with other representatives from the thyroid cancer support groups throughout Europe.

Our new website - kindly funded by a grant from TCA - was launched and is proving to be extremely popular and successful in raising awareness and supporting patients.

Patients and supporters have held various events on behalf of the group including a sponsored walk, a 140KM Velothon by the Usk Vale Wheelers, and our 7th Seashore Party night.

All of these events make such a huge impact and raise awareness of TCSGW and the work that we do!

We were able to have a stand at the Royal College of Surgeons’ International Thyroid Forum and also at the 2nd Royal Marsden Thyroid Cancer Conference in June 2015. Both of these events were a fantastic opportunity to showcase the work of our patient support group and highlight the work that we do. We greatly appreciate the opportunity afforded to us by the organisers of both of these conferences.

As always, we held awareness events in September - these included a radio advertisement, a radio interview, items in local newspapers and also awareness leaflet distributions at local stores. Once again we had a stand at the South Wales `Cancer Network Patient Forum’ held annually at Margam - we have been invited as speakers in the 2015 event at the end of September. We also had a stand at the Newport Well Being Roadshow which was very successful indeed.

People are always very keen to find out more about the work that we do and are most kind and supportive in their feedback to the group.

We continue to support the interNational Anaplastic Thyroid Cancer Tissue Bank and Database Project (iNATT) - see the update from Dr Laura Moss in this issue.

TCSGW small enough to care - big enough to make a difference!
15 years of patient engagement!

The French patient organisation ‘Vivre sans Thyroide’ (‘Living without a thyroid gland’) will be 15 years strong in October!

VST started with a small private web forum created in 2000 by Beate Bartès. Beate is German, but has been living in France with her French husband and three daughters since 1978 – she works as a technical translator. After being diagnosed with thyroid nodules in 1999, she searched the Internet for understandable information. She discovered a small German web forum, created by a former cancer patient, ‘Ohne Schilddrüse Leben’. In the six months between the discovery of her nodules and the decision to do surgery, Beate, learned a lot about her disease and the possible issues, which helped her to undergo her surgery and radioactive iodine treatment without exaggerated fear.

Having found so much help from the German patient community, Beate decided to create a web forum in French, following the example of the German forum and with some technical help from its owner.

“Vivre sans Thyroide” went online in October 2000. As the first French website specially aimed at thyroid questions, it was visited not only by patients concerned by thyroid nodules, surgery and cancer, but also by patients with autoimmune diseases (Hashimoto’s, Graves), and parents of children born without a thyroid gland. It has now different categories, a huge list of articles answering ‘frequently asked questions’ in understandable terms, and contains links to medical websites, official guidelines, and patient literature. In 2007, Beate and some fellow patients created an official non-profit organisation, so that forum users could become members and pay a fee to help finance its activities.

‘We are proud to help patients become true ‘e-patients’: Empowered, Equipped, Enabled and Engaged in their health and health care decisions,’
– Beate Bartès

The main activity of the organisation is the web forum in French language, used by French-speaking patients all over the world totally free of charge. There are also some local groups with regular patient meetings such as the monthly ‘thyroid coffee’ meetings in Paris, approximately four information events a year for patients in different towns in France. VST cooperates with cancer institutions such as Ligue Contre le Cancer and the Institut National du Cancer, and works closely with doctors for articles and patient literature. It also participates in medical congresses such as the French Endocrine Society, the TuThyRef network for refractory thyroid cancer, and the European Thyroid Association.

At the international level, VST cooperates with thyroid and thyroid cancer patient organisations all over the world within the Thyroid Federation International and Thyroid Cancer Alliance. As one of the ‘pioneers’ of online patient communities in France, VST also participates in various events dedicated to Health2.0, patient advocacy etc.

The forum and association are managed by a small group of volunteers, all thyroid patients. There is a medical advisory panel of thyroid specialists.

Beate Bartès says:

‘When creating a small ‘private’ web forum to exchange with fellow patients, we certainly did not expect that 15 years later, there would be such a ‘big’ organisation with several thousand website visits per day, but still run by only a handful of active members and a dozen moderators for the website, and on a very small budget.

‘It needs a lot of time and energy to answer so many questions, to encourage and support all those who need help, to advocate patients’ needs again and again. But the enormous positive feedback shows that there is a true need, and makes us go on! ’

‘There is also growing recognition by the medical profession, who are more and more aware that ‘an informed patient is a better patient’. 
Member Organisations

Associate Members

We are grateful to Genzyme and Bayer for their generous support

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Multikinase inhibitors – the patient perspective

The Thyroid Cancer Alliance will be hosting a meeting on Tuesday, 20 October at 4pm during the International Thyroid Congress, Orlando, Florida. The purpose of this meeting is to discuss the provision of information and support for patients on MKI treatment and the present situation concerning global access to MKI drugs, and to present the outcomes from the 1st international workshop on ‘Tyrosine Kinase Inhibitors and What This Means to Patients’ held in Paris, September 2014. Please visit our stand in the exhibition hall for more information.