

Celebrating 10 years of TCSGW



THYROID CANCER SUPPORT GROUP WALES

TCSGW begins!

The group was formed under the guidance of Dr Laura Moss, Consultant Oncologist at Velindre Cancer Centre and Tenovus Specialist Nurse, Heidi Trotman, following enquiries as to whether patients would be interested in forming a self-help group. A very positive response was received and so TCSGW was "born" !

Founder Members

Throughout the ten years that TCSGW has been in existence we are thrilled that founder members Cy Davies, Georgina Miller and Dave Woolven are still doing a fantastic job in supporting patients with this rare form of cancer! Well done to them - we really appreciate all that you have achieved and Happy Anniversary!

Projects

Throughout the ten years TCSGW has been involved in a large number of projects - all aimed at making a difference to existing and new patients. To read more about these please visit our website: www.thyroidsupportwales.co.uk



Secretary and founder member of TCSGW Cy Davies doing a great job of raising awareness of our recipe book in the outpatients' department at Velindre.

TCSGW Recipe book cooks up a storm!

Funding the NATT project at Velindre Cancer Centre

As part of our commitment to raise £10,500 to fund the NATT project at Velindre we produced recipe book containing recipes from the "Famous and not so famous".

This has proved a great success and three runs of books have been ordered.

The book took nine months to research and compile - our first reply was from the legendary Sir Tom Jones who wished us success with the venture.

People have reported back their favourite dish - with many sending photos of the end products - all very mouth watering!

Copies are available to purchase at £5 per book .

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Raising Awareness!

As part of Thyroid Cancer Awareness month (September) the group always tries to raise awareness in some way.

In 2011 the group distributed information leaflets in the centre of Cardiff.

This was a very successful occasion and over 1000 leaflets were given out throughout the afternoon.

2012 saw the group providing information leaflets to local doctors' surgeries as their awareness event and again this was very well received.

In 2013 our awareness raising campaign included working with a local radio station - Bro Radio who invited Helen in to be interviewed on the subject of thyroid cancer from a patient's perspective and the work of TCSGW.



A photo of Brenda and Helen in discussion with a visitor to the stand.

Also in September Cy, Brenda and Helen attended the Patient and Carer conference sponsored by the South Wales Cancer Network Patient Forum. This 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 were also fortunate to be allocated a stand to showcase the group's work.

Throughout the ten years we have had tremendous support from various businesses, groups and individuals. The Usk Vale Wheelers presented Cy with a cheque following their fantastic 100 mile sponsored bike ride. They rode from Pontypool to Swansea in aid of our group funds - an amazing effort by all who were determined to make a difference!



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The Green Fingered gardeners!



Some of the volunteers who have helped with the gardens over the years - a project that is really appreciated by patients in the isolation rooms



Tell us Diane - How does your garden grow?

The gardens which have been developed outside isotopic rooms A and B were created from a patch of waste ground. The volunteers met for the first time in March 2006 and have been hugely successful in making a difference to the terrain and the views from the two rooms. A special vote of thanks should be extended to Mrs Diane Fletcher who is the driving force behind our garden project. Her great passion, enthusiasm and guidance makes all the difference to our group. The gardens have also won a number of prizes in the "Cardiff in Bloom" competitions - providing a splash of colour whatever the season.

Thanks team - you really do an outstanding job!



As a group we would like to thank our many supporters who have helped us throughout the ten years. The many businesses and individuals without whom our goals would have been impossible to achieve!

Your kindness and generosity enables us to achieve our goal of making a difference!

We are there because we truly care!

Future Plans!

We have several events planned for 2014 - some are our regular fundraising events and others are awareness raising events.

We also have a number of events to mark our 10th anniversary along with our regular meetings.

All of these are detailed on our website and all are welcome to come along and join us in our efforts to make a difference in the lives of those who are diagnosed with thyroid cancer and their families.

We have received a generous grant from the Thyroid Cancer Alliance - an international network of thyroid cancer patient support organisations to which TCSGW belongs - to enable us to have our website redesigned and we look forward to this very much.

We will continue to provide the financial support for the NATT project - a world first! This project is of extreme importance and you can read more about it on our website.

A Message From Our Honorary President

Dr. Laura Moss

It's hard to believe that TCSGW has now been in existence for 10 years. I don't think I fully appreciated what we were about to embark upon when I first suggested trying to get a support group off the ground. I hoped that we may be able to provide valuable support for local patients and their families but beyond that I hadn't really planned or dreamt.

The Group are not only invaluable at providing support through their buddy system to newly diagnosed patients who are about to embark on treatment but they have made no end of improvements to the experiences of patients undergoing treatment in the isolation cubicles by brightening up the rooms and enhancing the facilities on offer. The work undertaken to provide attractive, tranquil gardens outside the rooms has been fantastic and it's been great to have this hard work acknowledged with Garden in Bloom awards. Funding has been provided by the Group to purchase additional patient information booklets and to produce a DVD to demonstrate what radioactive iodine treatment involves here at Velindre Cancer Centre. Both of these additions have significantly helped to improve what can be a daunting experience.

As well as the local work that the Group undertakes they also have a national and international presence which is invaluable. They have provided consumer feedback to clinicians involved in the development of national guidelines, clinical trial protocols and patient information resources.

By attending conferences they help to promote the importance of patient support and by having representation on the committee of the Thyroid Cancer Alliance they can ensure that patients in Wales have a voice and a presence on the wider stage.

In 2013 the group kindly agreed to support and fund a research project I was trying to launch across the UK and without them this would not have got off the ground.

Anaplastic thyroid cancer is a rare and aggressive form of thyroid cancer which is very difficult to treat and to research. The National Anaplastic Thyroid Cancer Tissue Bank and Database project (NATT) launched in October 2013.

NATT aims to invite all patients with this diagnosis to donate a sample of their thyroid cancer tissue along with a blood sample and information on their disease. The information obtained will then hopefully allow us to develop new therapeutic interventions that may slow the rate of disease progression, improve quality of life and prolong what is often currently a very short survival. To date there are 7 UK centres involved with additional UK centres in the process of being opened and 2 international centres hopefully going to be welcomed on board soon.

I would just like to say how proud I am of the Group and all the hard work they have put in over their first 10 years. It's been a pleasure to be involved and I wish you every success for the future.