

WALES CANCER BANK
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NEWSLETTER



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'This is such an exciting project -- and a real investment by today's generation for the Welsh people of tomorrow.'

Huw Edwards
BBC

WELCOME

Welcome to the sixth edition of the Wales Cancer Bank newsletter.

This edition's 'spotlight' features an article about three Patient and Carer Involvement groups around Wales, one in South East Wales, one in South West Wales and one in North Wales

HOSTING

The Wales Cancer Bank is continuing to host sample collections attached to clinic trials. Two new trial collections have recently commenced. The Wales Cancer Bank will be storing blood and tissue for both trials.

SCOPE1

SCOPE 1 (Study of Chemoradiotherapy in Oesophageal Cancer Plus or Minus Erbitux™) is a trial in patients with cancer of the oesophagus for whom it has been decided the best form of treatment is chemo-radiation (treatment that involves giving radiotherapy together [or concurrently] with chemotherapy). It will attempt to answer the

question of whether the addition of the monoclonal antibody cetuximab (Erbitux™) improves patient survival compared to standard chemo-radiation alone.

ACTION

The Institute of Cancer Research Clinical Trials and Statistics unit is running the ACTION (Adjuvant Cytotoxic ChemoTherapy In Older Women) trial, recruiting 200 women over 70 for a pilot study around the UK. The trial is designed to question whether giving a combination of cyclophosphamide and adriamycin is an effective treatment for women aged over 70 diagnosed with early breast cancer. The trial will also investigate whether there

are benefits to accelerating treatment (i.e. every two weeks instead of the usual three weeks). If it is found that chemotherapy is acceptable to British women in the 70+ age group and that they cope well with treatment, the information these 200 women contribute will automatically be included in the main ACTION trial. The trial will include 1000 women and will take several years to complete. It will be one of a group of research projects throughout Europe, all aimed at improving treatment for breast cancer patients in the 70+ age group.

Samples also continue to be collected and stored for the COIN and XERXES trials, run by the MRC and UCL trials units respectively

RACE FOR LIFE

A number of WCB staff have dusted off their trainers and volunteered to take part in the 2008 series of Race for Life, organised by Cancer Research UK. The 5km event is staged in various towns around the UK and has grown enormously over the last few years to become the UK's largest women-only fundraising event. In 2007 665,000 women walked, jogged or ran 5km to raise £40 million pounds for Cancer Research UK.

Cath McPhee and Lindy Kirk (pictured right) took part in the Haverfordwest event on 17th May 2008, Janette Gwillim took part in Cardiff on 1st June and Suzanne Williams, Catherine Lloyd-Bennett and Yasmin Friedmann competed in the Swansea race on 22nd June. Well done to everyone who took part and raised money!!



Carol Thomas, Cath McPhee and Lindy Kirk at the Haverfordwest Race for Life



SPOTLIGHT ON: PATIENTS AND CARERS—MAKING A DIFFERENCE

Support groups are an important resource for cancer patients and their relatives but some people want to become more involved and help inform the health care professionals and service providers of the patient perspective. Three groups, representing three geographic areas of Wales, are featured below.

All the groups aim to represent the views of people affected by cancer and their remits include; raising the profile of patient and public involvement within cancer services; providing channels of communication and developing good working relationships between the users and providers of cancer services; increasing the understanding of health care professionals as to the patient and carer; perspectives; to raise issues on behalf of patients and to facilitate training for group members in understanding the NHS and their roles within the group.

CaSE Wales

CaSE Wales (Cancer in South East Wales) was formed in September 2005 as part of the Macmillan User Carer project in Wales. Funding for the group and its facilitator was initially made by Macmillan but in 2008 this funding will be taken up by the Cancer Network.

The group is a patient and carer involvement group that works in partnership with the SE Wales Cancer Network. The group is made up of

around 30 members. There are a small number of health professionals but the majority of the members are either patients or carers with a cancer experience. They come from all over the S E Wales area and have experienced a wide range of cancers.

Over the past 12 months the members of the group, some of whom attend as representatives of various cancer support groups in S E Wales, have represented CaSE Wales on many groups and committees covering a wide range of cancer types. Meetings are held every two months at locations and times convenient to members.

SOUTH WEST WALES

The views of people of South West Wales are represented by a forum that was established in Swansea in September 2005. The forum meets every two months in Singleton Hospital and is a patient partnership group with the South West Wales Cancer Network.

The forum is run according to the needs of the members and a number of site specific groups have been set up to discuss issues relating to particular cancer sites, eg. Breast groups, colorectal groups etc. Consultant surgeons, oncologists, radiologists and nurses all contribute to the groups, as do pathologists and network management staff. Patients and carers are full members of the group and are encouraged to participate fully in the

discussions. The forum also gives a means of getting involved with other official bodies and groups such as CSCG (Cancer Services Co-ordinating Group) which is an advisory group to the Welsh Assembly Government with patient/carers representation.

Training is available through Macmillan 'CancerVoices' and two days of training give insight into working on a committee, understanding the NHS and building confidence. This training is free for all forum members.

NORTH WALES

The North Wales Patient and Carer Liaison Group was one of the first 'user involvement' groups of its kind in Welsh Cancer Services. The group began in 1998 when the North Wales Cancer Treatment Centre in Bodelwyddan was just a set of architect's drawings. Dr. Audrey Champion, Director of the Centre, brought together a group of patients to 'have their say' in the design process. Their views did indeed prove invaluable and made an important contribution to creating a Cancer Centre which is sensitive to the needs of the people who use it.

On completion of the Centre in 2000, the patient group, reluctant to disband, became affiliated to the North Wales Cancer Network. Cancer services throughout the UK are organised into Networks - 3 in Wales and 27 in England. Each Network brings together

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the people responsible for cancer care in a particular region and aims to ensure a good and equitable standard of service for all.

The Group, with the backing of the Cancer Network Team and Macmillan Cancer Support is growing in strength. Members meet for a couple of hours once every six weeks. It is an opportunity for different aspects of cancer services to be discussed and for patient/carers views to be shared with health professionals. It is often the small changes, perhaps costing very little, that can make a big difference.

New members are always welcome. The only qualification needed is a personal experience of cancer, as a patient, friend or relative.

'Wales is once again showing the UK the way.....'

Professor Alex Markham

commenting about the Wales Cancer Bank at the launch of the Wales Cancer Institute in January 2005.

CONFERENCES

ISBER

The 2008 Annual ISBER (International Society for Biological and Environmental Repositories) was held in Bethesda, Maryland in May 2008.

Professor Gerry Thomas was invited to take part in a workshop event, that was run twice during the meeting, to highlight how biobanks can promote themselves to institutions, researchers and the public.

WCC



Sarah Phillips at the WCC

The Wales Cancer Institute and the Wales Cancer Alliance jointly organised a Wales Cancer conference (WCC) on 30th April and 1st May 2008.

The event was held at City Hall in Cardiff and WCB took the exhibition stand

to help raise awareness amongst the groups attending the conference. Professor Malcolm Mason gave an update on the work of the WCB in the translational science session that was chaired and organised by Professor Gerry Thomas and Dr John Pritchard from Cancer Research Wales.

The event aimed to bring together researchers, clinicians, nurses, policy makers and patients to promote the excellent research being conducted in Wales and to highlight issues relating to policy-making, resources and services for people affected by cancer in the Principality.

A question and answer session on Cancer policy in Wales involved Welsh Assembly Members on day one and day two saw a lively debate entitled 'All Effective Treatment should be free' with Professors Gordon McVie and Richard Sullivan successfully speaking for the motion and Professor Sir Michael Rawlins and Dr Fergus Macbeth speaking against the motion.

“The Wales Cancer Bank is looking to the future – our children and grandchildren deserve the best chances we can give them. Supporting this project will help ensure they receive them.”

Katherine Jenkins

COMINGS AND GOINGS



Alison Davies

Since the beginning of 2008 the WCB has welcomed five new members of staff and said farewell to one. Sameer Jha, MLA in Wyllybush, left the project in January and has recently been replaced by Helen Jones.

Alison Davies (left) started in January as the WCB nurse in Cardiff and has quickly initiated the collection in the gynaecology department in Llandough hospital and her infectious enthusiasm for the project has increased the awareness of the project in Cardiff as well as increasing the number of patients consented in Cardiff.

Claire Alford also started in Swansea in January as the new Information

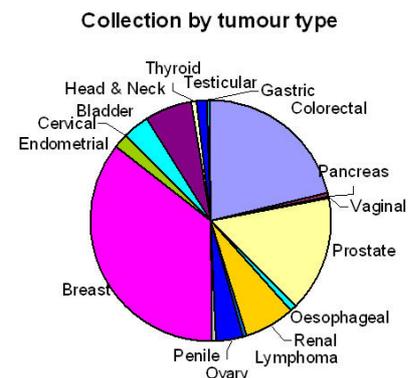
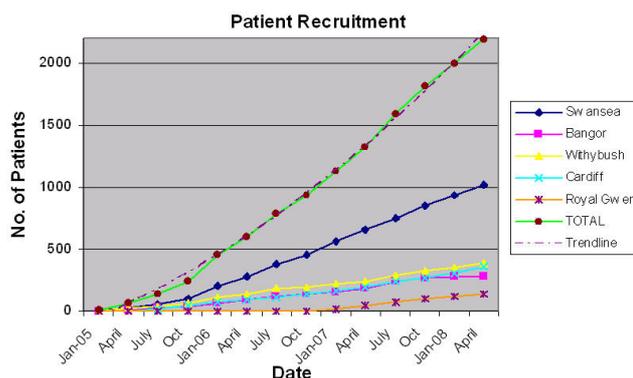
Assistant and has already made a huge impact on data entry tasks, especially her work populating the database with follow up and clinical outcome data.

Debbie Way took up the part time position of clerical officer in the central office in Cardiff during March 2008 and has gradually taken over all the clerical duties allowing Sarah Phillips to concentrate on her new role as project officer. Sarah now co-ordinates all the applications for samples.

Yasmin Friedmann joined the project on a placement scheme during 2007 and successfully applied, in June 2008, for a Developer post to help rewrite the database to a web based application.

COLLECTION UPDATE

The collection continues to flourish in all centres and the range of tumour types being collected is expanding. Three years and three months after collection started 2189 patients have consented to donate tissue and blood to the Wales Cancer Bank.



FORTHCOMING EVENTS

The Wales Cancer Bank will have a presence at the following conferences/events:

CaSE Workshop

8th July 2008

Glamorgan Cricket Club, Sophia Gardens, Cardiff

WCB & Cancer Research Wales will be presenting to members of the Three Welsh Cancer Network Patient Groups and CHC Vale of Glamorgan to update on the work being undertaken by both organisations.

National Eisteddfod of Wales

2nd–9th August 2008

Pontcanna Fields, Cardiff

WCB will be exhibiting at the National Eisteddfod for the first time in 2008. The stand will be alongside the Cancer Research Wales stand and we hope to meet the public and raise awareness about the Bank and its uses in medical research

NCRI Annual conference 2008

5th–8th October 2008

National Conference Centre, Birmingham

Nurse Clinics 2008

15th October 2008

Central Convention complex, Manchester

UPCOMING CANCER RESEARCH WALES EVENTS

Pink-a-Blue Walks

Mumbles, Swansea

Sunday 13th July 2008

Cardiff Bay

Sunday 7th September 2008

The 4.5 mile walks start at 11am (from outside Verdi's Ice cream parlour in Swansea and outside the Norwegian Church in Cardiff Bay) and walkers are encouraged to wear pink or blue to show their support for Cancer Research Wales' breast and prostate research projects

Fashion Show

Holland House hotel

Monday 6th October 2008

The Cancer Research Wales Fashion show will be held in conjunction with the Capitol Shopping centre, Cardiff where next season's high street fashions will be showcased.

To register for the Pink-a-Blue walks please contact Cancer Research Wales on: 029 2031 6976

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Llywodraeth Cynulliad Cymru
Welsh Assembly Government



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