

10<sup>th</sup> Anniversary Event

THURSDAY 19TH JUNE 2014

@ CARDIFF CITY CENTRE



WALES  
CANCER BANK

June 2014



# WCB newsletter

## Wales Cancer Bank is 10!

### 10 years and over 10,000 patient donations

The official launch of the Wales Cancer Bank was in June 2004, so this month we are celebrating our 10th anniversary!

To mark this occasion we are holding a public event in Cardiff on June 19th. This celebration of WCB achievements over the last decade will showcase the research that WCB has supported. We will also be looking to the future, and the impact of stratified medicine and biobanking over the next ten years.

This event will allow us to share how far we have come with our supporters, partners, patients and the general public.



Prof Malcolm Mason (WCB Director) with Sara Edwards and Nigel Walker at the launch in 2004

This special edition newsletter focuses on our most important asset — our patients.

See inside for patient stories and experiences, the latest update on our sample collection figures and the options available to us in the future to increase the number of patients that donate their samples to WCB to allow us to meet targets set in the Welsh Cancer Delivery plan.

# My Day at the Palace — Keith Cass MBE

My life was turned upside down on Thursday February 9<sup>th</sup> 2006, the day I was diagnosed with metastatic prostate cancer and told that most men with my stage and grade of this cancer only survived for 18 to 24 months. This was the first illness I had ever had in my life. Telling my four children I may not be around for them after the next two years was the worst part of the diagnosis.

After three months of 'why me' and days in absolute fear of what tomorrow was going to bring, I started researching prostate cancer with the full support of my consultant Professor Malcolm Mason. I owe my ability to deal with incurable cancer to him and he continues to give me support whenever I need it. My research took me to Harley Street, Cambridge University, Texas, Boston, Vienna, Bratislava and Toronto.

In 2007 I started the Red Sock Campaign to raise the awareness of prostate cancer in Wales. It was obvious to me that it was only through research that a cure for prostate cancer would ever be found. The ground-breaking work of the WCB is a key element in unlocking the mysteries of how and why cancer cells grow. My life was now dedicated to research and helping those affected by this awful disease. Volunteering at the University Hospital of Wales, Velindre and the Marie Curie Hospice not only added to my experience of how people lived to the end but it also enriched my own life.



Keith with Max Boyce for the Red Sock Campaign

On 15<sup>th</sup> June 2013 the London Gazette announced that Keith S. Cass Esq. had been awarded an MBE by the Queen in her birthday honours as recognition of the Red Sock Campaign research and support of all those affected by prostate cancer in Wales. The shock was similar to that of being diagnosed with prostate cancer but this time the tears of despair were replaced with tears of joy and amazement. I have never looked for praise or accolades; I do what I do because I am passionate about helping men and their families to get as much quality out of life as possible either following their own diagnosis or when caring for a husband, father, partner or friend with prostate cancer.

The journey from Cardiff to London started on Thursday 5<sup>th</sup> December; after completing a check list of everything that was required for myself and my three sons so that we would arrive at the gates of Buckingham Palace on time and in a state of dress that would not embarrass friends and family. An overnight stay followed by a short walk through Green Park at 9am saw the four of us arrive 30 minutes early at the gates. I had already warned my sons that there were 34 remote cameras recording the event so they should be aware that they were being monitored. After two security checks we were allowed into the Palace, my sons following the signs for guests and myself the signs for recipients. It was at this time it was announced that Prince Charles, the Prince of Wales would be presenting the awards on behalf of the Queen. There were approximately 100 recipients of various awards which included three knighthoods. There were no crisps, nuts or canapés, just flavoured water as the recipients waited for the investitures to start at 11am. Gathered in a room full of pictures painted by world famous artists we were all told what was expected of us.

As the band of the Welsh Guards were playing 'Men of Harlech' we were lined up and taken in single file to the entrance of the ballroom where the investiture was to take place. I was 95<sup>th</sup> in line so by the time I arrived at the head of the queue all of my nerves were focused on 'What should I say? How should I answer any questions?' I spotted my three sons all wearing the same design of tie in the second row (arriving early had proved to be a bonus!); a smile and a nod of assurance was all that passed between us. I was told it was my turn to move forward into the ballroom seven or eight paces to the second check point, my left shoulder in line with one of the Queen's household.



Keith and his MBE in Dec 2013

My name was then announced which was my signal to move forward then turn left to face Prince Charles, chin dipped once to the chest then three paces forward until my toes touched the platform. The conversation between us centred around the Red Sock Campaign, the volunteering that I do at Velindre, University Hospital of Wales and the Marie Curie Hospice, and my life living with metastatic prostate cancer. The conversation ended as Prince Charles said with a light prod "I'm pleased you're still alive" to which I replied with a broad smile "So am I". A handshake followed as a signal that it was time for me to take three paces back, nod

my head, turn right and walk out of the ballroom. After the investiture I met up with my family and friends to examine my MBE medal and reminisce about the proudest day of my life and one that I will never forget.

**Keith is a member of the WCB Lay Liaison and Ethics group**

# Cancer Patient Event — Margam Park

In September 2013 “The Patient Voice in Shaping Cancer Services” event took place to showcase how patients have successfully helped to shape the cancer services available across South Wales; how they have influenced models of care and rehabilitation for cancer patients. The audience included patients, carers, representatives from the voluntary sector and NHS Wales health professionals, and they discussed various topics and identified possible solutions.

Suzanne Dolphin, a lead nurse for the WCB based in Swansea, presented “Insight into the Wales Cancer Bank: Y Dechrau (The Start)” which provided a whistle-stop tour of how the WCB came into being – how it was started ten years ago following a conversation over a pint of beer in a pub! Suzanne also asked the audience for their opinion on patient consent; the role of the WCB nurses and the current process, and whether a doctor or a lay person (such as a patient) should do this instead. The consensus was that as the nurses are already employed and trained to do this role then why change the procedure – it allows the patient to ask the nurse questions about the process.

The key message was to celebrate ten years of the excellent work of the Wales Cancer Bank.

Pam Hayward and Sian Roberts, both members of the WCB’s Lay Liaison and Ethics Group, also presented at this event. Pam and Sian both shared their experiences of being diagnosed with breast cancer and how they became involved in various activities to help improve the lives of other cancer patients once their treatment finished.

**Pam** was diagnosed with an aggressive grade 3 tumour, after urging her GP to refer her when she found a lump in her breast in 2007. She was shocked and struggled to take it all in. It was a triple negative tumour meaning she could not have Tamoxifen or Aromatase inhibitors, and as it was HER2-negative this meant she would not benefit from Herceptin either. She donated tissue to the Wales Cancer Bank, and Suzanne accompanied her to her appointments – she was put into the REACT research trial. Pam had a mastectomy in 2007, followed by a sentinel node biopsy. Three nodes were affected but there was no further spread; in 2008 she had chemotherapy. She decided to shave her hair off before it fell out, and then she had radiotherapy. She had a lot of support from her family and friends, and used Maggie’s Centre at Swansea and the Old Mill Foundation – ‘they are both a sanctuary’. She returned to work after her treatment finished and took up a post as a research nurse with the Wales Cancer Bank. She also became chair of the Maggie’s Active Friends committee.



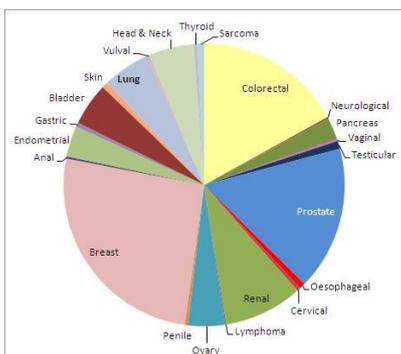
Pam (left) and Sian telling their stories at patient event

**Sian** was diagnosed with a grade 3 tumour breast cancer in 2005 following a mammogram. One of the hardest things she had to do was tell her 93 year old mother. She also worried she would not be able to have any time off work - she was a cancer nurse. Sian needed two operations and contracted MRSA; she donated tissue to the WCB. She then had chemotherapy and radiotherapy. Her chemotherapy was largely uneventful, with the main problems being nausea and vomiting. She had a central line inserted but this developed a clot and an infection so she had to have it removed and another one inserted. She then took Arimadex for five years. Sian declined breast reconstructive surgery, opting instead for a breast reduction. Like Pam, Sian became a member of the Active Friends committee at Maggie’s in Swansea, and she also joined their walking group. Sian feels that 2005 seems a long time ago.

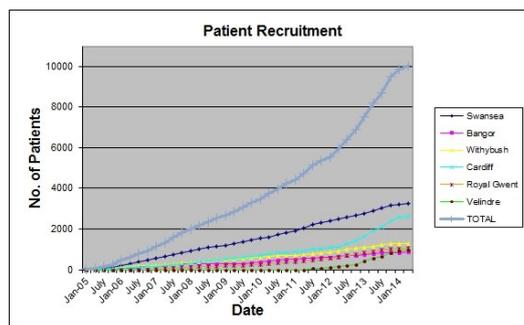
**The key message was that** if you feel there is something wrong then keep nagging your GP.

## Collection Update

We have met the target that we previously set of recruiting 10,000 patients before our 10th anniversary this month.



Patients in the Cwm Taf Health Board are now being consented at Prince Charles hospital in Merthyr Tydfil and Royal Glamorgan hospital in Llantrisant.



This patient consent is being carried out by a combination of our existing research nurses and clinical teams.

# The future of patient consenting

The Welsh Cancer Delivery plans sets a target for LHBs that 20% of cancer patients across all Welsh NHS Health Boards should be consented to donate samples to WCB by 2016. Currently the majority of patients are consented through research nurses employed by WCB who visit clinics and wards where patients are being seen as part of their cancer diagnosis and treatment. They provide information about tissue donation, answer any queries, complete the necessary consent forms and take a blood sample. Severe financial constraints mean the need to make savings and reduce costs, so there will be no extra money to employ more research nurses. In order to meet this target alternative approaches to patient consent must be considered alongside the existing research nurses. Below are some of the options:

**Clinical teams** – the team that is caring for the patient during their diagnosis and treatment takes the WCB consent. This is currently being done in a number of Welsh health boards including Cwm Taf at the Royal Glamorgan hospital. This model requires the co-operation and commitment from busy clinical teams with input from WCB central office to co-ordinate paperwork and sample collection.

**Electronic consenting** – the consent is recorded using an electronic system rather than on paper. However it must still be witnessed and have the continued involvement of a health professional to support the patient. Donation information can be provided to patients online at an alternative time to their hospital appointment. This approach expands the scope for providing information to patients in a variety of ways, and continuing communication with them via email after their appointment or procedure, sending regular newsletters or updates. Once certain aspects have been confirmed (ethics approval, data retention process) then it would need to be trialled.

**Lay consenting** – this involves a trained volunteer consenting patients. They would provide information to each individual as they attend clinic and give them the opportunity to ask any questions, complete paperwork and obtain the patient's signature – the patient would then take the paperwork to their appointment and blood would be taken by the clinical professional to complete the process.

This model has been introduced by the Nottingham Health Sciences Biobank at their breast clinics. Staff from the WCB visited the clinic last November to see lay consenting in action. Patients arrived at the reception desk for their appointment, and were then directed to an area of the waiting room where the lay consentor was at a table. Since this visit, there are plans to set up a sub-committee to look at this process and set up a pilot at a suitable clinic.

**Opt-out model** – this would involve blanket consent for all patients, and anyone not willing to donate their samples for research would have the ability to opt-out by withdrawing their consent.

There will be a debate at WCB's 10<sup>th</sup> anniversary event on 19<sup>th</sup> June where several of the consenting options will be discussed and attendees will vote on their preferred model both before and after the discussions take place. This may help us to understand individual preferences to be considered as we expand our consenting capability. Other factors will also have to be considered, and we are likely to get differing agreements from each health board. We will need to be flexible and have a number of options available if the Welsh Government targets are going to be met.

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