

Wales Cancer Network

Patient and Carers' Newsletter

Autumn 2016



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Wales Cancer Network Patient and Carers' Conference – 28th September 2016



We welcomed about 76 people to the Patient Conference at The Orangery Margam Park, Port Talbot this year – which was the 5th Year the conference has been held.

The day was chaired by Alun Tandy, Macmillan Partnership Quality Lead, South West Wales (ABMU). The programme was varied with 6 presentations in the morning on the following topics:

Demystifying Anal Cancers – Melanie Mills Macmillan Clinical Nurse Specialist Anal Cancers at Velindre Cancer Centre

Macmillan Framework for Cancer in Primary Care – Peter Gorin Macmillan Programme Manager Framework for Cancer and Sian Howell: Macmillan Communication and Engagement Manager Framework for Cancer

Working with patients, carers and communities to improve healthcare – Benji Williams Macmillan Person Centred Care Manager, Cardiff and Vale UHB

A Patients' update on the development of a NET Service in Wales – Sally Jenkins

A video raising the awareness for patients of Neutropaenic Sepsis – Mark Harvey Media Development Officer at Velindre Cancer Centre

Therapeutic Relationships – Wendy Wilkinson Macmillan Lead AHP, Wales Cancer Network and Macmillan Occupational Therapist, ABMUHB

The lunchtime provided the opportunity to browse the information stands of various organisations and support groups. The afternoon session was facilitated by Gill Knight, Macmillan Lead Nurse Wales Cancer Network who led roundtable discussions exploring what matters most and what needs do to patients have in relation to physical, psychological and social needs during diagnosis/ investigation; treatment; after treatment; living with the impact of cancer and any cancer reoccurrence.

The evaluation forms collected on the day have been analysed and will (as usual) help to shape next year's conference.

A big thank you to all of the presenters and Alun for supporting the conference. Thank you to the organising committee for their continued hard work, throughout the year and on the day. Finally a

big thank you once again to Macmillan Cancer Support for the 'Learning and Development Grant' to fund the conference once again.



CANCER DELIVERY PLAN 2016-2020

Welsh Government's commitment to delivering the best possible care and support to people affected by cancer has been acknowledged by the launch for the Cancer Delivery Plan 2016 -2020. The refreshed delivery plan continues to build on previous progress and successes to date to deliver services and outcomes to our population that match the best in Europe.

The development of the plan has been led by the Wales Cancer Network in partnership with its stakeholders and is structured around key areas of:-

- Preventing cancer
- Detecting cancer earlier
- Delivering fast, effective treatment and care
- Meeting the needs of people with cancer
- Improving cancer information
- Caring for people with cancer at the end of life
- Targeting cancer research
- Cancer service performance and plan delivery

The Cancer Delivery Plan is available on our website via the link below:-

<http://www.swcanet.wales.nhs.uk/document/299783>



Rotary President visits the Macmillan garden in Prince Charles Hospital

On a whistle stop tour of South Wales, Eve Conway, president of Rotary International for Britain and Ireland 2016/17 visited the Macmillan Unit garden at Prince Charles Hospital on July 29th. She was accompanied by Steve Jenkins, Rotary District Governor for South Wales.

On walking around the garden, Eve said: "This garden represents the heart of what Rotary does - making a difference to our communities, helping people and making a difference in the world."

“It is important that the local Rotarians are able to add to something that helps patients and their relatives.”

Members of the Merthyr Tydfil Rotary Club have been maintaining the garden since 2013. Every week a small gang of avid gardeners arrive at the site to mow lawns, tend to flower beds and trim hedges.

The garden, which is used by cancer patients and carers, has been transformed by the Rotarians into a tranquil haven of life and colour.

During her visit, Eve planted a ‘Macmillan Nurse’ rose bush which was paid for by an anonymous member of the public. Eve carried with her a bear wearing a purple jumper which symbolises the Rotary Club’s commitment to **Purple4Polio** and its fight to eradicate polio across the world. The amount of polio-endemic countries has dropped from 125 in 1985 to just two, Afghanistan and Pakistan, with over 2.5 billion children receiving vaccinations thanks to the help of Rotary.

The campaign ties in with the 100 year anniversary of The Rotary Foundation, which has played a key role in making polio eradication become close to reality.

When the maintenance of the garden was taken over in 2013, a diamond of purple crocuses was planted to support the campaign. The colour represents the purple dye used to mark the finger of a child who has been immunised.

Rotarians Keith Jones, 69 and Tony Wade, 71, who regularly tend the garden said: “We think the garden is absolutely stunning. “We get good feedback from patients and their families who sit out here.”

The Rotary Club continue to receive a lot of support from local businesses with materials and equipment and patients have provided gardening vouchers. Lawnmowers and strimmers have also been provided by family members.

A bench has been donated by the Rotary Club and the well-cared garden is now in full bloom and enjoyed by patients, carers and staff at the unit.

Cathy Barker, Macmillan clinical lead/manager at the unit said: “I would like to thank the Merthyr Rotary Club who has maintained our garden to a very high standard over the last few years.

“It gives our patients a lovely relaxing view to look out on during their chemotherapy treatment.”



Wales Cancer Research Centre (WCRC) - An Innovative Approach



Welsh Government and NISCHR - National Institute of Social Care and Health Research - in 2015 commissioned this innovative approach to research, namely to establish a centre for research excellence. The WCRC is commissioned to deliver research in collaboration with the NHS, Higher Education Institute (HEI's), Scientists, Researchers, Clinicians, Patient and Public and the Third Sector Charities involved with cancer. A budget of £4.5 million was allocated from an overall £18 million budget for Health and Social Care Research. The WCRC is funded for three years to include three universities in Wales.

The WCRC is seen as an innovated project as its overall aim, is to work collaboratively with all these bodies/organisations to deliver research that will improve the whole process and pathway for the patient; namely the prevention of cancer, the diagnostic process, the treatment journey and improve survival. It intends to facilitate a closer supportive working relationship with the NHS and HEI's in the development and delivery of cancer research in Wales. This strategic role will bring together all aspects of research to include four main areas: Pre-clinical, Translational, Clinical areas and Community research. Funding issues are paramount to this research work and the strategic role will aim to improve and sustain the support required for continuation of the work of all these organisations involved with research, under the overarching 'umbrella' of the WCRC.

This initiative is unique because of the involvement of the public and patient's voice. Many organisation, previously have asked for patient's opinions and perspective on work within the cancer field and in cancer research. However, the WCRC's initiative has included the patient's involvement at the onset of this project. It has been built into the organisation structure; initially setting up an Advisory Group to include PPI (Public and patient involvement) in a consultancy capacity last year when the Lead Consultant John Chester (Director of WCRC) and Deputy Peter Barratt-Lee formulated a bid to the Welsh Government/NISCHR to identify an action plan, which is now being implemented.

Patient involvement is incorporated into Research Themes with each of the four Themes being allocated a Theme Lead with support from two Research Partners, namely Patient/Lay people. The Pre-Clinical Theme will look at areas of cancer genetics and cancer causing mutations, cancer immunology looking at the activity of the immune system, cancer stem cell and identifying targeted therapies and ultimately leading to drug development these are the 4 work packages. The Translational Theme will look at stratified medicine - a precisely tailored and effective treatment plan for patients and will be facilitated by the Wales Cancer Bank. The Clinical Research Theme will be looking at two work packages namely Early Phased Trials - to develop innovative therapies to improve access to the latest treatments and Randomised Clinical Trials - where people being studied are randomly allocated to one or other of the different treatments under investigation. This trial design allows for the effectiveness or side effects of different treatments to be compared and is seen at the 'gold standard' in trial methodology. Under the Community Theme the three work packages will look at cancer prevention, palliative care and the link between primary and secondary care particularly social factors leading to late presentation of patients symptoms/patient reporting and

screening programme uptake i.e. programmes like breast and smear test screening, bowel screening (are people taking up the opportunities for different screening programmes?) and joint professional education between NHS staff/physicians, GP's and Oncologists.

The vision of the WCRC is active involvement with the general public "where people are not just the subjects of research but are working with researchers to plan, manage, carry out and present research" (Involving People 2014). In using the term 'general public' it means potential patients, patients, carers who use the health and social care services.

The WCRC have now set up a web site and produces a newsletter, an annual report has been submitted to the Welsh Government and they are organising a conference to present their current activities in November.

Pam Parkhouse (Lay member) October 2016

SAVE THE DATES:

Date for your diary: Clinical Research Facility Open Day

On the 31st of January the Clinical Research Facility (CRF) at the University Hospital of Wales will open its doors to the public.

The CRF provides a high quality clinical environment in which patients can undergo research programmes safely and effectively according to scientifically robust, ethically approved studies, including both clinical trials and other forms of clinical investigation. At the facility, 14 diseases are treated, and around 60% of the clinical trials run at the facility are cancer trials. Vital facilities like these allow new treatments to be assessed, and without them we would not see modern breakthroughs in cancer treatment.



The event will run from 2 – 8pm, with guests invited in for two hour sessions. Each session will involve a self-guided tour of the facilities where you will have the opportunity to see some of their cutting edge equipment demonstrated. You will get to hear directly from researchers and data managers and learn the intricacies of how a trial is run and how each patient's participation contributes to improved cancer treatment for the future. Each tour will culminate with three of four short talks given by the leading researchers behind the trials conducted in the building.

Registration is not currently open, but if you would like to express your interest in attending, please contact Zoe.Boult@wales.nhs.uk

Save the date: Where cancer drugs come from

On the 9th of February, join the Wales Cancer Partnership for an event that explores how new cancer medicines are developed.

The event will feature short and easy-to-digest talks from researchers working in Cardiff on developing the medicines of the future. You will also have the opportunity to get hands on with activities that explain some of the exciting work that takes place in local labs. Not only this, but you will also be offered the chance to have a tour of a laboratory and learn more about the work that goes on behind the scenes.

The event will take place in line with World Cancer Day to celebrate the successes made to date and the aspirations for future treatment. The event is free to attend and will run from 6:30 – 8:45 and light refreshments will be provided. If you would like to know more or register your interest in attending, please contact Jodie Bond at BondJ@Cardiff.ac.uk



JANE'S CORNER

Watch and Wait

A small number of cancer patients are not treated straight away, we are put into 'watch and wait.'

Some cancers, like lymphoma, grow slowly. So patients will be carefully monitored in watch and wait. It is no advantage to you to have chemotherapy, or other treatment, until the time is right. "Watch and wait" is very hard to accept, you feel no one is doing anything while the cancer is left to develop. This is actually the grim truth, but the reason for this is very real and sensible. Chemotherapy can be harsh on the system, and there is a balance between when the treatment gives you an advantage and when it does not. Your doctors will know when the time is right.

It is difficult to understand, because we have been told all our lives that early treatment is best. This is true in many diseases and many form of cancer, but not all.

From our point of view, the patient, it is often called 'whine and worry'. The cancer is out of our control, and we don't know how many months or years it is to treatment. Many of us find this very stressful. Family and friends understand less than we do, and can make unhelpful comments.

So what can you do to help yourself?

- Talk to a friend. You aren't looking for solutions, just a friendly ear.
- Manage your general health. Treat your aches and pains the same you always would.
- If you are ill and need treatment, go to the doctor. Just because you have cancer does not mean, sadly, that you can't get arthritis or heart disease like anyone else.

- If you think that the symptoms of your cancer are getting worse, ask to go back to clinic. Even if your next routine appointment is months away. They will be happy you checked.
- Eat a good diet and get what exercise you can to keep moving. We can't all run marathons, or go to the gym, but most of us can walk, or climb stairs. Just keep it normal.

You will have good days, and bad days, we all do. You can feel that you are the only person in the area that has this problem. But there are thousands of people in Britain in watch and wait. You are not alone.

Going to the clinic is always stressful. Do I need treatment now? Are there signs I will need it soon? The staff will understand how you feel. Ask what questions you need to; don't worry if you have asked the questions before.

There are many support organisations for cancers that you can contact to talk to people with the same problem. Ask at the Clinic, your GP, or the local library.

Jane Barnard

Cancer Patient Voices Wales - Event at the Assembly 17th January 2017

Come and join us and have your say to help ensure cancer diagnosis, treatment, support and survival is the best it can be for patients in Wales. You are invited to the second Cancer Patient Voices event, to be held on Tuesday 17th January from 11:30am to 1:30pm in the Senedd.

The event is kindly sponsored by Andrew RT Davies AM and will be attended by Cabinet Secretary for Health, Vaughan Gething AM. It is open to all people affected by cancer in Wales and all AMs.

This follows on from the highly successful first Cancer Patient Voices event, organised by cancer patient Annie Mulholland at the Welsh Assembly in February 2016. People affected by cancer in Wales are now returning to the Assembly to share their views of cancer services in Wales and to ask AMs what they have done to improve cancer services since the last meeting and what they plan to do.

Annie Mulholland cared passionately about cancer patients being kept informed and having a say in ensuring Wales delivers the best possible cancer care for all. Sadly Annie passed away earlier this year but as cancer patients in Wales we would like to carry on her legacy. Please do come along to hear what is happening regarding cancer care in Wales and to have your say. If you are able to attend, please email CancerPatientVoices@outlook.com.

Please feel free to share the invitation with anyone else you know who is a cancer patient in Wales, but impress upon them that it's important they let us know they're coming so we can manage

numbers.

If you are planning on coming and want to ask your AM to be there, you can use a [template email](#) which is hosted on the Target Ovarian Cancer website (but open to people affected by all types of cancer).

Finally, this event is being organised and led by cancer patients, so if you would like to take a more active role in making it happen please let us know at CancerPatientVoices@outlook.com

Cancer Patient Voices Wales

This newsletter has been produced by the Wales Cancer Network. If you wish to place an article in the next issue, please contact Eleri Girt via e-mail:

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