



## Rhondda Breast Friends - an Open Invite



Members enjoying a craft session

If you have had a diagnosis or know someone who has, Rhondda Breast Friends is a local Breast Cancer Support Centre in Porth who would like to help and provide support to those who have been affected directly or indirectly by Breast Cancer.

The Centre is a safe haven for those who need it. It's comfortable and inviting with a friendly environment and atmosphere, along with welcoming and approachable staff. Come and meet the most wonderful, resilient and kind hearted ladies in the Rhondda Valleys who despite their own struggles wish to comfort others.

RBF offers a great selection of services to enable a calm recovery and healing process when coming to terms with a diagnosis: counselling, support group network, hypnotherapy, complementary therapies, computer studies, light exercise class and crafting workshops that are run from a weekly to monthly basis. RBF also arranges two monthly support meetings that take place on the second Wednesday evening and the last Friday morning of each month. It allows members to socialise with each other and find out about the latest news and developments both in and around the Centre. RBF also provide a great amount of up to date and accurate information covering a wide range of topics and issues that a person may be faced with when living with Cancer.



Rhondda  
breast friends



Enjoying Coffee and a chat at Rhondda Breast Friends

If you would like to know more about the Centre please contact Tel:01443 687556 or e-mail [info@rhonddabreastfriends.org.uk](mailto:info@rhonddabreastfriends.org.uk) or you can pop in, we are on Eirw Road, Porth.

**Christina Ryan**  
**Rhondda Breast Friends**



Rhondda  
breast friends



## South Wales Cancer Network – Patient Conference at Margam Park on the 1st October



The Third annual South Wales Cancer Network Patient Conference will be taking place on **Wednesday 1st October** at The Orangery, Margam Park. Registration forms are available from Sheila James in the Swansea Office (Sheila.james2@wales.nhs.uk) - Spaces are limited.

If you would like the opportunity to have a display table at the event please contact Eleri (Eleri.girt@wales.nhs.uk) —there are 10 display table spaces available.



### Be kind to yourself

It is very easy to lose sight of what is important to you when you are ill or tired. You alone know what is important to you- make your own list. Then make priorities for yourself. It could be that being with friends, with family, or worship are on your list. Whatever your favourite things are, make time for them. If you are tired, then is it really important that you have dusted every day? Maybe not.

If you need help for everyday things, is there someone you can ask for it? There may be other ways to do things- is there a store that would deliver your groceries? If you can't do an internet delivery, then perhaps a neighbour can help you use their computer.

Be kind to yourself, set priorities, and don't be alarmed if you can't do everything that you want to.

**Jane Barnard**



### Cancer Awareness Dates 2014

#### January

Cervical Cancer

#### February

World Cancer Day

#### March

Prostate Cancer

Ovarian Cancer

Brain cancer

#### April

Bowel Cancer

Orchid Male Cancer awareness

#### June

Carers week.

Myeloma week

#### July

Mesothelioma Day

#### September

Thyroid Cancer week

Lymphatic Cancer week

#### October

Breast Cancer

#### November

Mouth Cancer

Lung Cancer

NET Cancers

#### December

Childhood Cancer Awareness Week

## Greetings from the South Wales Branch of the Net Patient Foundation (NPF).

### Here's our story so far:

We all live in S Wales and we are all automatic, lifetime members of the NPF. In other words, our link is an uncommon type of cancer called NeuroEndocrine Tumours (NETs). They're not something you come across every day and most of us hadn't heard of the condition before we found out we had it. It's a strange, complex cancer that grows in various parts of the body e.g. intestine, pancreas, lungs etc, and ranges from very aggressive to very slow growing. Many of us have the slow growing type which can be there for years before it's diagnosed. Often it has spread to other organs of the body before it's found. Just because it grows slowly doesn't mean it's symptomless. Most of us struggled for years with pain and other distressing symptoms before diagnosis. Many of us received unnecessary treatment for all sorts of other diseases. For some it came as a bolt from the blue when something showed up on a scan for a completely different condition, for instance after a car accident.

However, we all have at least 2 things in common. Firstly, it's with us for life. Many NETs are controllable but only a tiny minority are curable. Most of them have significant ongoing symptoms which need unrelenting hard work to get anything close to a reasonable quality of life. Secondly, either before or after this devastating diagnosis, very few people, including medical professionals, seemed to know much about our condition. Many of them appeared to find it trivial. Only a few of us were given any real understanding of our condition or given the right information. Many of us received conflicting advice from different health professionals. There's a lot out there on the Web, but it's difficult to work out what applies to you. Much of what you find is just plain frightening. For many of us the Macmillan slogan, 'No-one should have to face cancer alone' has a very hollow ring.

A few of the lucky ones made contact with the NPF, the only charity in the UK dedicated wholly to NETs. From that initial contact, the current, 50 strong, NPF patient support group grew in S Wales. In less than 2 years we've mushroomed from nothing to 2 larger groups, based in Cardiff & Swansea and a number of smaller 'Natter' groups. And what an exciting journey it's been so far. At first, it was enough just to meet others who were going through the same harrowing experiences. It's hard to describe how the burden lifts after sharing it with someone travelling the same road. Everyone contributed: fundraising, circulating newsletters, arranging meetings, researching NETs information, by just being there. And we laughed. And we talked. And as we shared our experiences, common threads started to emerge. Unhappily, none of us could report a uniformly good experience of the NHS. Very late diagnosis, long waits for hospital appointments, lack of access to appropriate therapies and drugs, no one-stop co-ordinator to contact (key worker) and little understanding of the condition were just a few of our issues. The picture grew of a patchy, post code lottery. We realised our service fell well below the criteria set out in the Welsh Assembly's Cancer Delivery Plan.



So we decided to do something about it. We went to our Assembly Members for help. Julie Morgan, AM for Cardiff North, gave us our first break by sponsoring an awareness-raising meeting in the Senedd in November 2013. NET patients and their AM's turned out in force, thanks to a vigorous letter-writing campaign by the patients. A few very supportive health professionals also piled in. This was a turning point because it put us on the cancer radar. At last we were visible and we had a voice. We were included in many events and surveys including the official inquiry into the progress of the Cancer Delivery Plan. As a result, within the next few weeks, the Health Minister, Mark Drakeford, is scheduled to submit a report on the provision of services to NET patients to the Health and Social Services Committee. This is a huge step forward.

Unfortunately, in reality, the service we receive now is no better than it was when we first started, if anything it's worse. BUT now we are visible, vocal and very active and feel some large wheels are in motion. We are not unreasonably demanding, we understand resources are a problem in these difficult times, but many improvements can be achieved by re-organisation of existing services, co-operation with cancer charities and a big dose of ordinary common sense.

Several charities have been crucial in helping us to get to where we are today. Truly, we can't thank them enough. In the order in which we encountered them, they are the NET Patient Foundation, Macmillan and Tenovus. Between them have given us vital support. They have included us in the formal & informal cancer networks in S Wales, the UK and worldwide. They have genuinely proved that we aren't alone. They are supporting us as individuals and as a group, they have been our lifeline.

While we have found the care from the NHS as a whole to be fragmented, uncoordinated and deeply unsatisfactory, there are some outstandingly shining examples of dedicated health professionals who always go the extra mile. They make our lives bearable and we will never be able to thank them enough. They know who they are and they should be proud of themselves for their compassion, warmth and professionalism.

What does the future hold? Sadly, we have lost three of our members already. In their memory and for the sake of all NET patients everywhere, we are determined to continue supporting each other as friends and to working as a group to improve NET services.

Our message to other cancer patients, especially those with unusual or rare cancers is – don't think that you are helpless. There are people out there to help you and make your voice heard. Go and find them.

Onwards and upwards.....

**Sally Jenkins - The South Wales NET Patient Foundation Local Support Group**

NET Patient Foundation: <http://www.netpatientfoundation.org>

Tel: 0800 434 6476

Macmillan Cancer Support: [www.macmillan.org.uk](http://www.macmillan.org.uk)

Tel: 0808 808 00 00

Tenovus: [www.tenovus.org.uk](http://www.tenovus.org.uk)

Tel: 0808 808 0101





## The development of a Macmillan Metastatic Spinal Cord Compression (MSCC) project

Metastatic Spinal  
Cord Compression



WE ARE  
MACMILLAN.  
CANCER SUPPORT

### What is MSCC?

MSCC is a highly complex debilitating complication of cancer which **affects 5 - 14% of cancer patients** (most commonly those with breast, prostate, and lung cancers).

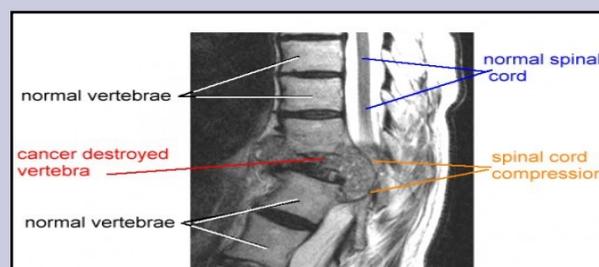
People who have cancer, whether they have a known primary cancer diagnosis or not, are at risk of it spreading to other parts of their body including the liver, lungs or bones. When cancer spreads it is known as 'metastatic'.

Cancer that has spread to the spine is known as 'spinal metastases'. Spinal metastases can be painful and if not treated can lead to metastatic spinal cord compression. MSCC is when the spinal metastases press on the nerves in the spine that carry messages between the brain and the rest of the body. If it isn't treated quickly, MSCC can lead to serious disability, including permanent paralysis, and early death.

Signs and symptoms of MSCC include;

- back pain, which is the most common presenting feature and may be associated with referred pain to the torso or limbs;
- reduced muscle power;
- sensory abnormalities;
- bowel and bladder dysfunction.

MSCC is a complication of cancer and is deemed an oncological emergency due to the devastating effects it can have on people. Research has shown that 77% of patients diagnosed with MSCC had an established diagnosis of cancer whereas 23% presented with MSCC as the first presentation of malignancy.



This newsletter has been produced by the South Wales Cancer Network if you wish to place an article in the newsletter please contact Eleri Girt via e-mail:

Eleri.girt@wales.nhs.uk

The network newsletters are available on the South Wales Cancer Network website : <http://www.cancernetwork.wales.nhs.uk>

Cont'd

## The project:

This Macmillan and South Wales Cancer Network Project is funded for two years. The aims and objectives of the project fulfil and set standards against Macmillan's 'Value Based Standards', Macmillan's long-term consequences of cancer and its treatment agenda and Macmillan's survivorship agenda.

The two main aims are:

- To develop a long term strategy to standardise the management and care of MSCC patients and implement across South Wales

- To provide and deliver a standardised education package for use by all Health Care Professionals

Macmillan is honoured to be at the forefront of supporting a project which will make a colossal change within MSCC services across South Wales. In addition, the Project will have a positive impact on the lives of people affected by cancer by implementing best practice and patient centred care. Macmillan acknowledges the demand and importance of the MSCC Service Improvement Project within South Wales.

NICE, 2008 Metastatic spinal cord compression: Diagnosis and management of adults at risk of and with metastatic spinal cord compression

### Contact details:

**Kate Baker: Project lead, [kate.baker@wales.nhs.uk](mailto:kate.baker@wales.nhs.uk)**

**Kathryn Elias: Project lead, [Kathryn.elias2@wales.nhs.uk](mailto:Kathryn.elias2@wales.nhs.uk)**

**Tel: 01792 530845**

## Calling all support Groups—Are you out there?

I am currently updating and revamping the directory of self help and support groups that the South Wales Cancer Network has on its website (<http://www.cancernetwork.wales.nhs.uk>) - click on Patient Engagement tab on the left hand side and scroll down to 'Directory of self help and support groups'

If you know of, or run a support group that isn't included in the directory and would like it to be please contact me and I will add the group to our list.

**Please contact me either by phone 01792 530849 or by email: [Eleri.girt@wales.nhs.uk](mailto:Eleri.girt@wales.nhs.uk)**





## **The Patients Voice at the Heart of the Hospital**

### **Who are we?**

A mixture of **Velindre Cancer Centre** patients, carers, management and staff who work together to improve the lives of patients and carers.

### **What do we do?**

Patient Information Bags – over 11,000 produced since Jan '04.

Provide the patients view on a wide variety of subjects from Transport to Catering to Dignity.

Help out at Radiotherapy Open Evenings.

Help with annual audits at the Hospital.

Discuss all your comments, suggestions and opinions.

**For Further Details Email: [plg@wales.nhs.uk](mailto:plg@wales.nhs.uk)**

**or ring Helen Davies on 029 20 316278**

## **WE ARE ON THE WEB:**

[http://  
www.cancernetwork.wales.nhs.uk](http://www.cancernetwork.wales.nhs.uk)



## **South West Wales Cancer Centre Patient Forum**

### **DO YOU HAVE OR HAVE YOU HAD CANCER?**

We are setting up a South West Wales Cancer Centre Patient Forum and we are looking for patients and carers to join the group

If you would be interested in getting involved then please come along to our meeting

If you are interested in joining the Forum then please contact:

**Mandy Town**

**Specialty Manager - Cancer Services**

**Abertawe Bro Morgannwg University Health Board**

Tel: (01792) 205666 Ext 8389

Email: [mandy.town@wales.nhs.uk](mailto:mandy.town@wales.nhs.uk)