



# PINNT

A SUPPORT GROUP FOR PEOPLE RECEIVING ARTIFICIAL NUTRITION

## South Wales group

### Update Winter 2012

#### Keep in touch

Register your email address with your regional coordinators to be kept updated

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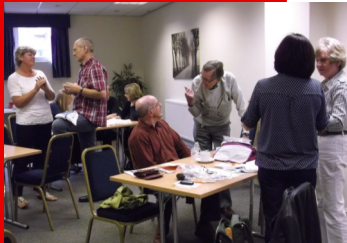
### South Wales group meeting

The first meeting of the reformed South Wales group took place on Saturday 15<sup>th</sup> September at the Sports & Social Club, University Hospital of Wales Cardiff.

PINNT Chair, Carolyn Wheatley travelled all the way to Wales to join us and as well as giving an overview of PINNT, gave us ideas about what the other regional groups like to do when they meet up. Ideas ranged from inviting guest speakers, visits to places of interest, and going to the theatre.

Sarah Mew, Calea's Business Development Manager was available to discuss individual queries and concerns relating to homecare provision.

Consultant Gastroenterologist Dr Barney Hawthorne and Nutrition Nurse Sian Tracey from **UHW's nutrition team** kindly joined us, and were able to chat individually with those present. The potential lobbying power of a patient-led support group was highlighted by Dr Hawthorne. As a regional group we could have an influential input by raising issues of concern directly with the hospital.



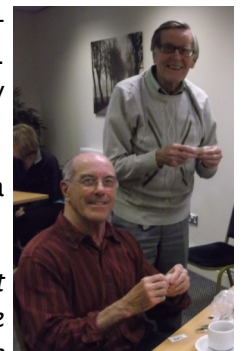
It was great to welcome new and familiar faces as the meeting room began to fill up. An informal discussion raised subjects of concern and enabled sharing of useful information. This included how to reduce Water charges and getting a water meter, Council Tax band reductions, ambulances and hospital admissions, treatment by medical professionals unfamiliar with HPN, and the RADAR NKS (National key scheme) which enables people to gain access to disabled toilets.

**How to be an expert patient.** The relatively rare and specialised nature of HPN means that we can find ourselves in the position of having more knowledge and expertise than a medical professional. Dr Hawthorne made an excellent suggestion for UHW's Nutrition team possibly providing guidance on 'How to be an expert patient'. The importance of patient information and protocol sheets that look official and can be carried around easily was also raised.

A new '**Patient Passport**' scheme being developed in partnership with Calea is currently being piloted at another hospital. The possibility of a Welsh Passport being launched was very encouraging and we look forward to hearing more on this.

**Raffle** We raised £52 for PINNT with donated prizes including a Marks & Spencer voucher, wine and chocolates.

*Thank you to everyone who joined us, we really appreciate it and hope the group can develop and grow. If you weren't able to make this meeting we look forward to welcoming you to the next one!* **Letty & Heather**



*The RADAR and NKS key is available to buy for £2.25 from RADAR's website and gives access to the 9,000 locked public toilets around the UK. A toilet guide and smartphone app are also available*

[www.radar-shop.org.uk](http://www.radar-shop.org.uk)

## BUPA Walk for PINNT



The South Wales regional PINNT group supported Bupa's Global Challenge 2012 which started in September and hopes to collectively walk a 5000 mile route.

Bupa have partnered with PINNT in celebration of the 25th anniversary of the charity, and created a virtual map connecting people, patients and customers.



**BUPA Challenge 2012**

**Save the date!**

**Next meeting:**

**Saturday 16th**

**February 2013**

*Details to follow.....*

## News from your coordinators

### Letty's Hickman line repair

I have been on HPN for 15 years, and manage to plod along quietly without having too many emergencies, so I had never heard about the possibility of a Hickman line repair. Recently I noticed that the thicker covering on my line where the clamp is, had a cut right through it and was only joined by a small piece. My husband did offer to use his 'bicycle puncture repair patch' but I declined this kind offer! At UHW Sian Tracey explained that a sort of super glue was used I thought she was pulling my leg, but no, Sian cut off the broken end, and very carefully replaced the broken end with a new piece. Marvellous, I hope to have many more anniversaries with my 11 year old line, thank you Sian.

### Heather's holiday plans

I have been busy organising a holiday to Las Vegas USA. After much research I decided to go with Virgin Atlantic because they are one of the few airlines who have a direct flight from the UK, and they have previously waived my excess baggage and helped me at the airport. I am very lucky that I can use off the shelf bags for a week which do not need to be kept cold and will have my box of PN delivered to the airport before I check in. Thank you Calea, for enabling me to plan such a wonderful trip which I'm so looking forward to. Providing a service to patients who want to go on holiday is so important and means that we have that choice in life to use the service and enjoy holidays like everybody else.

Letty's Welsh cakes were so popular she agreed to share her recipe!



### Letty's Welsh Cakes

Ingredients: 8 oz. self-raising flour, Pinch of salt, half teaspoon mixed spice, 3 oz. butter, 3 oz. sugar, 2 oz. currants, 1 egg, milk to mix.

Sift flour, salt and spice into a bowl. Rub in butter lightly then add sugar and currants. Mix (by hand) with beaten egg and sufficient milk to make a stiff dough. Roll out to about quarter of an inch thick on a floured board and cut into rounds. Cook on a lightly greased hot griddle (or in a heavy strong frying pan), turning until golden brown both sides. Sprinkle with sugar or serve hot with butter.