



Special update sheet

Autumn 2014

Regional/local group reports:

In the Autumn edition of Online two extremely important reports were omitted, accidentally, from the main copy of Online.

To ensure that these reports are enjoyed by members we have produced a special update sheet to share the group updates.

South Wales PINNT Group Report July 2014

Apologies once again that this didn't appear as promised in the Autumn edition of Online.



PINNT was delighted to work in partnership with Nutricia, organising a get together for the benefit of people in South Wales.

22 from the local area came along including some family and friends and Nutricia representatives. Most were familiar with PINNT but were not yet members; all expressed an interest in joining and attending future meetings.

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Autumn 2014
in 2012 PINNT celebrated 25 years

It proved to be a great opportunity for people to ask questions, converse and receive reassurance through the experience of others in a friendly, informal environment. Holidaying abroad was a particularly hot topic.

Letty Johns provided invaluable practical advice around available benefits and how to source information.



We did not know that you can have medicines etc sent to your destination abroad

We found the meeting friendly and helpful and would like to come to further meetings, especially pleased to hear that deliveries of feed to hotels abroad are successful



Our Nutricia Nurse, (Richard) is brilliant. If we have a problem, he is there as soon as he can get to us

On line stock checking is great

If you are only receiving syringes and tubes on your deliveries, it would be good if you only had them delivered 3 monthly, and would save you money

We look forward to seeing you at future meetings and would welcome suggestions or advice. For Letty's details see Online, PINNT's quarterly publication.

Bristol May 2014

Bristol Home Management Services (Community Dietetic Department), PINNT and Nutricia put our heads together to host the first Bristol PINNT Group in May. We met over a cup of tea where ideas on getting away on holiday were discussed, but best of all was the opportunity to meet with others as shown by comments from some of the 25 people who came along.

Pat "I attended the meeting not knowing about PINNT but the information given was very interesting and helpful. At 78 I was the oldest person and have only been on artificial feeding for 3 ½ years. Meeting parents of a four year old and a baby of 10 weeks made me realise how fortunate I have been."

Raymond, 33 "I have an illness called Gastroparesis which has required me to be jejunal fed for 18 hours a day for the last year because my stomach is unable to empty. It has its ups and downs. I know I'm getting everything I need to keep me going in life, but the downside is that I feel this illness has taken away most of my social life. It's my ambition to have the best quality of life that I can under the circumstances. Meeting other people with problems needing tube feeding made me realise that one is not on one's own in life."

Sara, 34 "I too have had symptoms of Gastroparesis for just over ten years and been tube fed for around eight. I've been a PINNT member for a few years and it was lovely to be able to go to their first meeting in Bristol, as I was able to meet fellow long term tube feeders and share experiences."

Lisa with Rosie aged 10 months "In February 2014, after 8 ½ months of a happy and healthy pregnancy, I excitedly waved goodbye to my work colleagues to have my first baby. In March (2 weeks overdue) Rosie was born."

Within her first few days it became evident that something wasn't quite right. She was having difficulties feeding amongst other issues. My husband Iain and I spent the first seven weeks by her hospital bedside watching her being prodded, poked, injected, scanned and x-rayed. Now at 11 weeks old we are still

waiting, waiting to hear if and what is wrong with our beautiful Rosie.

Meanwhile, Iain and I have been getting accustomed to arm ache as we hold her milk in a syringe waiting for it to empty down her NG tube every four hours. Feeding my baby is certainly different to how I'd expected and imagined it to be – breast feeding as I sat in my new rocking chair, cradling her in my arms watching the 'breaking bad' box set! However, this is how it needs to be for a while so my theory is to just embrace it and all that comes with it. Rosie is putting on weight and is happy. At the moment I can't ask for anything more.



PINNT was a new acronym for me but one which I am now so happy to know. When I was invited to attend a local support group in Bristol, eager to find out more and connect with others in a similar situation; that was exactly what I got. With a warm welcome, information available, stories shared over a cup of tea and an unexpected serenading from the brass band playing the theme tune to 'Dad's Army' in the room next door, it was a relaxed and enjoyable get together and the time flew by."



I was surprised at how many people came to the group and the age range – from Rosie the youngest through to Pat, a lovely chatty 78 year old whom I sat next to. I took much comfort in knowing that I am not alone and that however long Rosie requires feeding in this way that it is not to be feared.

I was glad to learn about Half PINNT too – designed for children and babies -which is more appropriate for Rosie. I am hoping to meet more parents within this category at the next meeting and learn more through the Half PINNT membership that Rosie's now

signed up too. I'm so glad that we went to the group and already feel part of a new circle of friends at a time we need it most. We'll look forward to seeing you again soon!

We met successfully in again in October; so now keep the next date free – Tuesday 17th 2015, revenue to be advised.



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