



**Step into Spring with PINNT**

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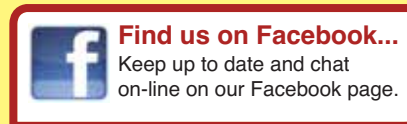
THE PROMISE

BAPEN ANNUAL  
CONFERENCE

FIVE MINUTE  
TELEPHONE  
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and much more ...



**ALL THE LATEST NEWS FROM PINNT**



**Spring 2014**  
**in 2013 PINNT celebrated 25 years**

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## PPP Winners

The last set of lucky PPP winners are:

1st - No.95 - Elizabeth Ward - £113

2nd - No.195 - Brian Corkett - £68

3rd - No.157 - Christine McCluskey - £45

***Congratulations!*** Hopefully you have renewed your PPP numbers for the next year. Your name could be appearing here next time round. Thanks to everyone who has joined; why not recommend it to a friend or family member. The more the merrier.

## Hello from PINNT

Thanks to those who sent greetings and donations to PINNT over Christmas. During the colder months members appear to be turning their thoughts to holidays and travelling. Remember to utilise the information in the members area on the website or request printed material from Steve Brown. His details are on the back cover. See page 18 for a list of what information is available through PINNT.

We are delighted to have enlisted Paula Stewart as our lead for fund-raising. On page 4 you can read about our move into eBay. Paula would love to hear from anyone who had an idea or wants support. Our new sponsor forms are available on the website too now, so it's easy to do something for us; the hardest part may be deciding how to raise the money.

Enjoy the features in this magazine. While you read this one we are already working on the summer edition. It's not too late to send in your feature.

We are also working on our second Home Artificial Nutrition (HANs) Week – watch out for further information. Enjoy your Spring copy of Online.



Carolyn

# Sam Lawday



*Ellis - a few weeks old with liver problems*

Ellis was born on the 25th December 2011 weighing 3.1 kg and admitted to neonatal with bilious vomiting. Ellis was in hospital in Hull for three months, undiagnosed. He was then transferred to Leeds under Dr. Puntis and given more tests; a bowel biopsy and contrasts. Ellis was then diagnosed with Hirschsprung's disease (HD); congenital aganglionic megacolon. Ellis has an ileostomy and mucus fistula, a gastrostomy and a Broviac CVC line. (central venous catheter). He is dependent on parenteral nutrition (PN) as he does not eat at all. From day one of Ellis being born, it was such a struggle. We were told at first that Ellis had only a thirty percent chance of surviving; it was all very hard to take in, not knowing anything about this horrible disease. However, we had total faith in the new medical team our son was under, as after just being there a matter of weeks and a change of PN, Ellis was picking up. His liver failure was not as serious as first thought, as his liver function was improving. Ellis was still seriously dehydrating due to the high output stoma and still vomiting due to a bacterial overgrowth in the gut.

Ellis has undergone many operations since birth; new Broviac lines being fitted, having most of his large bowel removed and a refashioning of the ileostomy. We also had to undergo three months of training for Broviac care and PN training, etc. It was a struggle some days as our boy was very poorly and trying to concentrate on the training to be able to bring him home was immensely difficult and frustrating. Some days I myself just cried but at the age of six months we brought our boy home on PN. We worried at first knowing that all the pressure was on us but we still had the team in Leeds at the end of the phone if we needed them for advice and help. We still have a daily struggle with Ellis dehydrating due to high stoma loss, so we not only have to put him on PN but we have to replace fluids ml for ml if he goes over his daily allowance, using the same sterile technique we were trained to do.

Having Ellis on PN is life changing really; we do sometimes feel restricted in life but on the positive side



*Ellis - 3 months old*

Ellis is here alive and lives a good life. Even though his illness is still up and down we manage. I do believe as he is getting older we are aware of signs of infection and illnesses more than when he was very little. I'd never heard of PN until our boy was put on it but now I say it is a life saver in a bag and thank God for whoever invented it, as I believe our son wouldn't be here without it. We have been told that PN will be lifelong for Ellis as he doesn't eat at all. We're hoping that as he grows he may eat at some point; we still offer meals at meal times but he simply puts it in his mouth and stores it like a little hamster, bless him.

Apart from HD Ellis is a beautiful, bright little boy, who loves being around people, even though for most of his short life he has been hooked up to his machines on PN and fluids. It doesn't stop him one little bit; he still likes the rough and tumble as all little boys do. He always has a big smile; he is our little soldier. Even when we put him on PN he tells us at every little step what's next. When drawing blood back he tells us it's magic blood and he will very happily sit still. I think he has just learned to live with it and knows he is going to be fed when it's PN time. We have always told him he is a special boy and so brave to have gone through what he has, so he now tells us when setting PN up he is a brave boy. I would say to anyone who is going through this situation to research as much as you can and ask lots of questions. I believe knowledge makes it easier to understand about PN and how important it is to be given it correctly.



*Ellis - 18 months old just before major surgery*

Well, our boy has just turned two - on Christmas day - and is going to be starting nursery in a few weeks. That's going to be very hard for us, having to put our faith in someone else to make sure he is looked after correctly; that his daily routine is not changed causing him to become ill. However, I'm sure he will be fine and it's what is best for Ellis. We've been told we cannot allow HD to run our lives; the most important person is Ellis and he deserves to live the best life he can.



*Ellis - 22 months old following major surgery*

Sam - Proud mum

# Fundraising - Your charity needs you

At time of writing this I have just taken down the last of the Christmas tree decorations and tinsel and now the living room looks completely bare. I hope that you are all safe and well following the torrential rain and strong winds which we have had to endure over the start of this New Year. We now look forward to some sunshine in the New Year and hope for continued stability in the health of each of us and perhaps even begin to plan some holidays.

When we think of fundraising many of us immediately think of having to run marathons, climb mountains or having to perhaps get your head shaved. Whilst we applaud those that can do this and raise money for their chosen charities it is not something that we can all do despite wanting to help.

PINNT is a relatively small charity that over many years has relied upon the goodwill of its members and donations to keep going. In recent times we have seen the development of our wonderful website and continue to produce the Online magazine which you are now



reading. All of this along with many other factors incur costs which we continually need to replenish.

Are you able to take a collecting pot from PINNT and place it in a suitable location where friends, family, customers or colleagues can drop in some loose change for PINNT? If so please contact [pstewart@pinnt.com](mailto:pstewart@pinnt.com) or ring 01382 732746 to request one.

In addition to this we are now registered officially on eBay to boost funds thanks to the work of both Steve Brown and Paula Stewart. Paula has a feature below so please read it and help if you can.

If anyone else has any fundraising ideas and would like to put them forward for consideration please contact Paula direct on

details above.

Donations that you are able to make, no matter how small, are always welcome and are much appreciated as we all benefit from them.

Mark

## PINNT is on eBay

**Hello everyone we have some fantastic news for PINNT, we are now up and running on eBay! This is a great way for us as a charity to sell any donations that we receive from companies, hotels, members or other individuals. We can raise much needed funds for PINNT by this means and we are asking everyone if they would like to help. This is a major achievement so let's try and make it work.**

Steve Brown, General Secretary for PINNT can take the credit for setting up our eBay account, with a little help from me. I have managed to advertise a few items that were kindly donated to PINNT and the good news is these have already all been sold, which is great!

We will keep everyone up to date with what we are selling via our Facebook page in case anyone wishes to buy any items we are advertising. Please encourage friends and family to 'like' us on Facebook to find out more.

There is also another option for everyone to donate to PINNT on eBay when you buy something from another person or trader. You can do this by:

1. When you go to the checkout page you see your name/address etc. there is a donation box that you can click on; this will display a default charity
2. then you can scroll down and select the option to choose PINNT charity
3. then you simply select the amount of money you wish to donate and that's it.

We are now able to receive donations from member so we can sell them on eBay, so if you have any unwanted Christmas presents or other items that you know will just go into the drawer or cupboard, please consider donating them to PINNT. If you're attending a PINNT meeting or want to find out more about 'ways to give' items to PINNT then take a look on the website or contact Steve or myself.



If you have any queries or questions regarding any part of eBay or you are unsure if your donation would be suitable please contact myself [pstewart@pinnt.com](mailto:pstewart@pinnt.com) or Steve Brown at [sbrown@pinnt.com](mailto:sbrown@pinnt.com) and we will be only too happy to help. Our phone numbers are on the back cover.

Thank you for all the support and fundraising events that you already do for PINNT. It is very much appreciated, but I feel this is a golden opportunity for more of us to be involved. So please do not think your item is too small; we will be most grateful for any donations.

Paula Stewart  
Fundraising lead

# The promise



**Our son Tarun was born with a rare genetic condition that has seen him fight for life on five occasions during his short life. He was born at thirty two weeks and we were told that he was not going to make it. We held a vigil at his bedside. Tests revealed he had Noonan's Syndrome, a disorder that causes abnormal development of many parts of the body and a rare form of leukaemia. Tarun fought to stay alive. Since then, Tarun, whose twin Kian is perfectly healthy, has spent most of his short life in hospital, undergoing numerous operations to keep him alive. He has been unable to eat or drink and has been fed through tubes to ensure he gets the nutrition he needs to survive.**

Joja, now my husband, and I made a promise to our premature son as he lay in intensive care fighting for his life in 2010. If he pulled through and made it to his third birthday, we would get married and he, along with his twin brother Kian and older sister Tia, aged six, would go down the aisle together.

When Tarun was two I knew it was time to start planning the wedding although Joja didn't want to tempt fate.

On 28th December 2013 the family kept their promise. To our amazement and joy we walked down the aisle as a family; Tarun, his twin brother Kian and Tia. We had 'Ave Maria; by, Beyonce, to accompany us, as this song had got us through all the heartbreaking trips to hospital.

It was one of the most amazing days of our lives. To have all our children there together on our special day when we had been through so much meant the world to me. We had 200 guests there to share these special moments too.

Having Tarun with us is a miracle. I'm the proudest mum in the world and I truly never thought I would see this day. We thank God every day when we wake up with him. Having Tarun walking down the aisle with us was so overwhelming and our day was made extra special. He is truly our little miracle.

Tracey Chungh



## Glossary of terms

**Hirschsprung's Disease** - A disease in which all or part of the large intestine have no nerves, resulting in an inability to function.

**Congenital Aganglionic Megacolon** - Another name for Hirschsprung's Disease

**Noonan's Syndrome** - A genetic disorder which can cause congenital heart defects, short stature, learning problems amongst others.

**Sinusitis** - Inflammation of the lining of Sinus cavity, caused by a viral or bacterial infection.

**Lumbar Puncture** - A medical procedure in which a syringe inserted into the spinal column to collect cerebral spinal fluid. This can be analysed to detect the presence of bacterial infection.

**Tarsorrhaphy** - Eyelids are partially sewn together to narrow the opening of the eye in order to protect the cornea in cases of corneal exposure which can result from conditions such as Grave's Ophthalmopathy or after corneal surgery.

**Clostridium Difficile (C.Diff)** - A bacterial infection that affects the digestive system, which causes diarrhoea, fever (temperature above 38°C) and abdominal cramps.

## Save the date

**Our annual get-together will be on Saturday 31st May 2014.**

The meeting will be hosted by our group in Southampton. Full information will be available directly to members by post along with updates on our website and Facebook. The day will have time set aside for the formalities of the charity followed by fun for all to enjoy. Please put the date in your diary; we would love to see as many of you as possible.





# BAPEN annual conference

**In November 2013 PINNT was invited to attend and exhibit at the annual British Association of Parenteral and Enteral Nutrition (BAPEN) conference in Harrogate. BAPEN were marking their 21st anniversary and PINNT has been involved since its inception.**

For us it is an excellent opportunity to see what the healthcare professionals are discussing as well as providing us with a forum to catch up with our friends in industry and individuals who support PINNT. Our role is to keep the patient voice at the top of the agenda in a constructive way.

There is a lot of talk about having patients at the centre of healthcare, with patients being involved with their care more than just being the end user. Given this it was fitting that PINNT was asked to be part of the opening session at the conference. Steve gave a patient focused presentation in response to both the Francis and Berwick Reports on patient safety. We utilised this opportunity to explain that in most cases patients want to be involved in their healthcare and that through building mutual trust, respect and honesty between patients and their healthcare team, then patients can feel valued and take more responsibility for their care and treatment. The feedback after the presentation was very encouraging. Many healthcare professionals believed that if this could

become a reality across all healthcare settings then this would be beneficial for both patients and professionals. After the success of the opening session, the rest of the conference was split into different symposiums, which covered an array of subjects. One session was of particular interest to us which is outlined below (liquidised feeds).

For us the exhibition is what we enjoy the most. We have the opportunity to reach out to healthcare professionals from across the United Kingdom who are not usually easy to reach and explain how PINNT works. We are following up offers for potential local groups which is exciting.

Our attendance at the conference was certainly beneficial. We utilised the opportunity to give the patient perspective, we gained insight into the work of the healthcare professional, along with the chance to liaise with industry and homecare companies and increase the awareness and profile of PINNT.

## The Liquidised Enteral Feed Debate

On the second day of the conference a symposium was held discussing the growing interest and use of liquidised foods administered through enteral feeding tubes as an alternative to the standard formulations that are currently prescribed in the UK.

It was explained that the use of liquidised foods down enteral feeding tubes involves preparing and making a meal as normal before placing it into a blender to puree the meal. This requires the addition of fluid to lower the viscosity of the puree to facilitate it in its administration down tubes.

Many of PINNT members are aware of this practice as it is widely used in the USA, mainly due to the expense associated with prescription medications and feeds and the way the healthcare system works in America.

Despite standard feeds being available on the NHS in the UK, there are a growing number of people who now want to know more about this method of feeding and

some now want to switch to this method entirely.

Dr. Susie Lepwood, a specialist doctor working with children who have life limiting neurological conditions gave an interesting presentation on the experiences of a number of patients in her care at the Helen & Douglas House Hospices for children and young adults in Oxford. She explained how for some children they found that using a standard enteral feed that some children experienced gastrointestinal symptoms such as diarrhoea, discomfort and general feed intolerance, but when they were switched to liquidised foods they found the frequency of the gastrointestinal symptoms was reduced and in some cases the nutritional status of the children improved. The results were varied, but she highlighted that for some this was a positive move, despite the extra time taken to prepare and administer the liquidised feeds. She explained that a number of parents of the children in her care who are

in need of enteral feeding often express a wish to feed their child the same as the rest of the family and so a liquidised diet administered through the tube would facilitate this.

She went on to highlight a number of drawbacks to the use of liquidised foods, which was echoed by Professor Kevin Whelan, a professor of Dietetics from King's College in London. He highlighted the pros and cons of liquidised foods versus standard enteral feeds, which included the increase risk of tube blockages; making tube changes more frequent, an increased fluid intake; as the liquidised food needs to be watered down to enable it to pass through the tube without blocking. This results in a greater volume, which may be too much for some people to manage, although it is sometimes suggested that using milk would increase the energy density of the food and mean a lower volume was needed.

Professor Whelan explained that one of the major issues for healthca

professionals when discussing using liquidised foods instead of standard enteral products is that of the increased potential for microbial contamination. Standard feeds are manufactured in sterile conditions and safe to be left hanging for up to 24 hours without the risk of contamination becoming a concern. This is not the case for liquidised foods, as the exposure to microbes is far greater and must be administered immediately after being prepared. This requires administration by the bolus method, which can be difficult for some patients to tolerate.

Finally it was highlighted that there may be nutritional differences

between standard feeds and liquidised feeds, although he couldn't state that all pureed diets were nutritional inadequate, as many of them could be well balanced with proper preparation, he did highlight that when using the standard enteral feeds, it is clear exactly what nutrients are being given; this is far more difficult with liquidised foods.

The session concluded with an expert panel being asked questions from the audience, most of which were dietitians who were interested in understanding more about what to tell their patients and their families if asked about using liquidised foods. This is clearly

something that is going to be ongoing and of greater interest in the future but at the moment the general consensus is that the decision should be on a patient by patient basis, taking into account the needs of the patient, their families wants, the wishes of the patient and the support available.

Using liquidised feeds in enteral feeding can be a big commitment, but that said, enteral nutrition in itself is a big commitment.

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## Nutricia event

On Tuesday 26th November of last year (shocking to think that we're already in 2014!) I attended a workshop run by Ebee Digital Healthcare in London on behalf of Nutricia. The aim of the workshop was to gain first-hand information about those of us who are home tube-fed, with a view to establishing a website providing case studies and useful information. Prior to this workshop Ebee had held similar sessions for healthcare providers and parents of tube-fed children thus covering the whole spectrum of people involved in the realm of tube feeding.

The day was carefully planned out by the staff at the agency who were clearly interested in what we had to say. There were various agency members who were in attendance along with four patients and three carers. I wasn't sure quite what to expect, yet as the day progressed, I realised simply being asked about my own experience and listening to those of others, was quite therapeutic. Tube feeding is something different to everyone. The day to day essential practicalities are one thing, but how it impacts upon your life is another.

We were asked about how we ended up requiring tube feeding, how we became trained to do it ourselves at home, and what kind of support we received whilst in hospital as well as at home in the community. We were also asked to reflect upon what would have been useful to know before being sent home from hospital as well as any tips on dealing with various aspects of home enteral feeding. Whilst the core training may remain the same, the impact of dealing with tube feeding is different for each and every one of us. We're affected physically,

emotionally – and logistically. Going away for the night is no longer a simple overnight bag – add on a pump, feed bags, syringes and giving sets.

During the course of the day we worked both as a whole as well as in small groups. We were videoed answering various questions about how our lives had changed as well as the lives of our loved ones. Having carers on board was very insightful – I'm used to seeing my situation from my perspective, but hearing about a mother tube feeding her son and children looking after their parents, well, it was quite emotive. It became clear that the level of care we have received has varied from hospital to hospital, with some being far more supportive than others. The day reinforced the obvious – that you don't always know what to ask when you're given a diagnosis and sometimes you're unsure as to whom you should direct your questions. As a group we came up with several useful tips and pieces of advice for new patients, and we offered our own experiences as video testimonies. We were also shown a YouTube video clip providing guidance on how to use the pumps and administer the feed, and we then critiqued it with suggestions for improvement.

I felt quite empowered at the end of the day. Nothing had changed in my own circumstances but I was glad to have been offered the opportunity to have a voice and to have been part of the information-gathering stage for improving the training and support for patients facing and dealing with tube feeding. Hopefully Nutricia's end product will be a user-friendly website.

Lisa Eland



**money giving**

**via Virgin Money Giving. It's an opportunity to reach people in order to engage their interest in your event and hopefully make a donation.**

**Remember if you are organizing a fund raising event/activity for PINNT you can promote this**

# My Story (So Far!)



My name is Peter age 53, born in the North East; I'm single, my parents are deceased but I have one brother and two sisters. I live alone in Stirchley, South Birmingham. I always worked in catering and hotel management.

Back in January 2007 I thought I had flu; family and friends suggested I should see my G.P. I self-medicated with paracetamol but during the night, when I tried to take the tablets with water, I began to choke and couldn't swallow them, so I rang the 'out of hours' service. I was told they were very busy and could I make my way to the Badger Clinic at Selly Oak Hospital? I told the doctor I would go in the morning as I didn't drive and I lived alone.

Next day, the doctor on duty took one look at me and admitted me to the Medical Admissions Unit, as my face and tongue had started to swell alarmingly! So I rang my sister, who was a nurse there, but was off duty at the time.

I was transferred to the Queen Elizabeth Hospital in Birmingham diagnosed with sinusitis; little did I realise it was for a year and my life would be changed completely!

As I was Warden at Wesley International House and there were numerous overseas students, they queried TB. I was scanned and they found I had meningitis, so I had several lumbar punctures! (Not a nice experience!)

In the scanner, I had a respiratory arrest as I had an abscess on the brain stem, which controls breathing. Luckily the crash team revived me. I was given a tracheotomy and moved to Intensive Care, where my family were told by doctors I would probably die!

I had a stroke which caused paralysis down the right hand side of my body and a catheter was fitted. I was given lovely, long elasticated socks to wear and Warfarin injections in my lower abdomen to prevent blood clots from forming. Daily blood samples were taken from numerous locations due to collapsing veins. I couldn't talk, so I used an alphabet card to spell out what I wanted to say.

Due to nerve damage I couldn't swallow, so initially I was fitted with a naso gastric feeding tube. I then went to theatre where a PEG was fitted.

I was transferred to Moseley Hall Hospital in South Birmingham, where my rehabilitation would take place. The psychiatrist on the team asked me how I felt about not being able to eat or drink; I replied "Well it's better than being dead!"

Thankfully, movement came back in my arm and leg, however I can't tell the temperature with that side, my balance is affected and I can only walk slowly with the aid of a delta frame!

I have a carer who comes every morning to help me wash and dress. I also have a support worker where I live, who calls several times a week plus a volunteer from Focus Birmingham (for people with vision problems).

I am completely deaf in the left ear with tinnitus and I don't make any tears in my left eye or close it fully when asleep. I am under an Eye Consultant (at the local Eye Hospital) and due to numerous infections, was given a Tarsorrhaphy operation, (it is a surgical procedure in which the eyelids are partially sewn together to narrow the

opening). It is often done to protect the cornea in cases of corneal exposure. I have a scarred cornea which results in blurred vision which needs a District Nurse to call each night to apply eye ointment.

Due to ill health I could not return to work and I lost my job and accommodation. You can imagine I was devastated and my confidence was at an all-time low!

Whilst in hospital, I caught Clostridium Difficile known as C.diff and pneumonia!

My social worker in the last hospital told me about the Sheltered Housing Community I currently live in, owned by Sanctuary Housing.

Sounds all very negative at this point doesn't it? Despite all these medical issues and problems I am determined to try and continue life in a positive way.

I go to Headway West Midlands and I attend the 'Brain Injury in the Community' group, where we go on various visits. Also, I go to 'Conductive Education and Headway Lifestyle' and as recommended by my physiotherapist, due numerous falls, I also go to the 'Extend/Goya Exercise Class'. (For the last two years we've done an exercise display at the King's Norton Festival.) I went to my nephew's wedding and reception in Stockholm last year. I have also been to my sister's house in Spain flying from Birmingham airport to Girona.



*Girona, Spain - with my Sister* ➤





*Collioure, France with my Niece*

I have done two sponsored walks for the Stroke Association, 'Step Out', with my support worker from 'Headway Lifestyle', whereby I raised hundreds of pounds. In addition, I went to the Durham Lumiere 2013 for the first time, courtesy of my sister who drove me there. I stayed with my brother. Big thanks to the police and stewards, who were very helpful to me when my scooter got stuck on the cobbled streets.



*Durham Lumiere 2013 - Durham Cathedral, with the Sanctuary Knocker projected on it.*

My confidence has increased so much, that in the summer I went to Norway on a cruise from Southampton; I booked an accessible cabin. Royal Caribbean International provided an extension cable and I took a travel adaptor for my pump. I enjoyed it so much. I have booked a Baltic Cruise, with my sister next summer from Stockholm. I am limited on the number of days I can travel by the amount of feed I can place in my travel trunk, provided by Nutricia, my homecare company, (who by the way are very good and reliable!)



*Kjosfossen Waterfall, Aurlandsfjorden, Norway.*

I have been several times on my mobility scooter to the Birmingham Frankfurt Christmas Market and the Nature Centre. I've to Birmingham Hippodrome, Repertory Theatre, National Indoor Arena and National Exhibition Centre, Symphony and Town Hall, L.G. Arena and Cineworld Cinema. I am also a member of the National Trust.

I was talking to my Support Worker from 'Headway Lifestyle' recently and I said to her "There is no point being angry about the situation as it changes NOTHING! Despite not eating or drinking for seven years, I still love watching programmes about food and cooking.

Watch out world – my scooter and I may be coming your way!

Peter



*Stroke Association - "Step Out" 2013 Kings Heath Park with my support worker from Headway.*

## JustTextGiving™

by  **vodafone**

**A Quick and easy ways to donate to PINNT –  
Just Text Giving, give it a try.**

It really is simple – text the word **TUBE25** and then an amount (don't use a £ sign). You have a few choices with the amount; it can be £1, £2, £3, £4, £5 or £10. You then send it to 70070. So for example if you want to donate £2 to PINNT type the following into the message - Tube25 2 - and then send it to 70070.

You will then get an automatic text message receipt. There will be instructions about applying Gift Aid to your donation; everything helps. It's that simple and easy so don't forget PINNT this year especially as we approach the end of our anniversary year. We still have lots of exciting projects and we depend on your generosity to help us achieve our goals.



# National tender for Home Parenteral Nutrition

## Outline of home parenteral nutrition (HPN) homecare

As we know HPN care is the process through which feeds and fluids are provided directly to patients at home, along with any care that may be needed to administer feeds/fluids safely. The NHS has provided HPN for many years, albeit through different processes across England as each local NHS region has until now made its own decisions regarding the best way for care to be provided.

## The need for change

Following a review of the provision of HPN it became evident that while services were good there was a need for all companies providing homecare to patients to improve in certain areas.

An in-depth national tender was undertaken where all companies wishing to provide homecare to HPN patients in England applied and were taken through a rigorous process. Each was required to meet a number of quality standards, the outcome was that six companies were approved to provide HPN services in England (adults and children).

## How will I know what is meant to be happening?

During this process it became clear that those on the receiving end of this service should be able to measure the service being provided. A Patients' Homecare Charter is being produced so you can see the standards that homecare supplies must meet. You too have a role to play in relation, to your, or your child's, homecare so the charter will outline important information from both perspectives. We will update you when the charter is ready.

## How will this affect me?

Many of you will not be aware of any changes as a result of the national tender process. However we are aware that some of you noticed changes during the initial introduction period. We recommended then that any unexpected changes you saw were reported to your healthcare professionals/nutrition team. This advice still stands; anything unfamiliar to you must be reported as soon after the event as possible. Your own healthcare professionals/nutrition team are responsible for all decisions relating to your homecare and not the homecare company.

As already stated no aspect of your, or your child's, homecare should change without your knowing in advance. Under the terms of the framework there is flexibility for the individual needs of each patient. The

stock/ancillaries, feeds, pump, deliveries, etc should not change; however, where improvements in the provision of the service have been applied, changes may occur but you will be notified.

**Stock (ancillaries)** – there is no need to fill your house with large volumes of stock items. A regular and appropriate flow of stock should arrive with you at timely intervals. If you find yourself worrying about low or no buffer stock then please contact your own healthcare professionals/nutrition team.

**Feeds (PN)** – this should not change unless for medical reasons the PN prescription changes. If you notice a change; in the PN bag itself and were not aware of the change or have any problems physically using a PN bag do let your healthcare professionals/nutrition team know.

PN feeds should be delivered in a sealed light-protective outer bag with a label on the front as well as an inner bag and label. If you are not receiving covered sealed PN bags then please contact your own healthcare professionals/nutrition team. Over time products may change, one homecare company is introducing PN bags which have the light-protective layer built into the bag itself. Letters have been sent out so please ensure that any communications you receive from your homecare provider are read. It's in your, or your child's best interest.

**Pump** – your healthcare professionals/nutrition will decide which pump you will use. It is a clinical **not** a corporate decision. Different people may have different requirements due to lifestyle choices or abilities. All pumps that have been accessed by LITRE are part of the framework and must be supplied in line with your healthcare professionals/nutrition team's instructions.

**Deliveries** – you should be seeing a regular driver along with notification of expected deliveries.

**Holidays/travelling away from home** – before making any holiday/travel arrangements you should enquire as to the holiday service your homecare company has in place. You may be able to locate this information in the patient manual/information they provide you with. Depending on what you will be asking them to do permission may be necessary from your healthcare professionals/nutrition team if there is a change from your normal homecare package, extra delivery or stock/ancillaries ... Remember to consider your usual delivery during any travel plans. ➤

# (HPN) Services in England (adults and children)

**Pharmacy fridge** – this is possibly one of the significant changes patients will see. While domestic fridges are adequate a pharmacy fridge is designed to keep PN in the right environment maintaining an even and more accurate temperature throughout the fridge. Should a problem arise with the fridge then this can be detected straight away. No change should take place without you being informed in advance.

**Phone numbers** – each homecare company must provide free phone numbers for your use. If you are not aware of these then ask your homecare provider. Please be careful when using both the office free phone numbers and out of hours numbers – if using a mobile they may not be free. Ensure you know what your phone packages permit you to do.

Some patients may change companies; it may be better for some patients to be with another company due to their personal needs. Nothing should change without you being informed, you may even be part of the

decision making. Where a change of company is deemed necessary full written information will be provided to you in advance of any changes being made. You must have a complete understanding of how and when changes will take place.

We know that many patients are extremely happy with the HPN service they receive and this should not change. The national procurement exercise aims to ensure that all key aspects of good quality HPN care remain and to make that care available for all patients across England.

## Finding out more about your own homecare

PINNT are pleased that homecare services are being so well regulated. The best place for you to get information about your own homecare is from your own healthcare professional/nutrition team/consultant.

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## Running is good for my health and PINNT's wealth

I was lucky enough to get three months paid leave when I changed jobs at the beginning of 2012, so was keen to use my time to do something other than catch up on TV and sleep! I decided that I would try to get fit, so rather than join a gym, I thought I would take up running to capitalise on the fact that we're lucky enough to live by the sea. I have to say at this point that when I first started, I struggled to run to the end of the street and nearly gave up as I thought I wasn't built for running. A friend recommended a 'run 5k' app which was amazing, and by the time I went back to work, I was able to complete 5k which I was delighted with and never thought I would ever achieve!

Now with a busy work schedule I soon realised that I missed my regular running so decided to keep it up; to motivate me to keep going I signed up for a 10k run that November. The 10k was probably one of the toughest things I've ever done. I remember saying to myself as I was running the last kilometre to the finish line 'never, ever sign up for something athletic again'.



*Mary in the middle with her friends and medal*

Then Christmas came and I was seeing an old school friend; we jokingly started saying we should run a half marathon (she had also done a 10k but nothing further). Before we had time to think through what we were doing, we'd signed up for the Bristol Half Marathon. We managed to sign up Adam's brother in law to do it as well! I knew this was going to be a huge challenge, so decided that to keep myself motivated I would use it as a good excuse to do some fundraising for PINNT! I cannot begin to tell you how tough the training was, especially motivating myself to run miles and miles when the weather

was bad. It was worth it though. Through the truly humbling generosity of family, friends and work colleagues, I was able to raise over £1800 for PINNT! As some of you may know, Adam was in and out of hospital for the best part of the summer with three line infections. He was not able to cheer me on that day, but I had great support from family and friends. To be able to go to the hospital that night to give him my medal made it all worthwhile! And if my knees hold up, who knows ... I might even run the Brighton Marathon next year.

Mary Duncombe

Wife of Adam, HPN patient

# Calea Day in London 2013

During the earlier part of 2013, Calea, one of the major care companies providing homecare packages for the NHS to home parenteral nutrition patients, experienced grave difficulties in their provision of parenteral nutrition (PN). Deliveries were incomplete, occasionally missing altogether for some days, with erratic and unsocial timing. I have been a Calea patient since I went onto PN in 2010 but only had the slightest inkling that things were wrong from my own experience but knew of more serious breaches in their service from the PINNT website forum. Messages posted there are automatically sent to my email address. I was quite concerned and when I had a hospital clinic appointment I agreed that perhaps I should change my care company. However, soon after, I received a massive new pharmacy fridge and changed to fortnightly deliveries which although not a totally problem free transition made life easier for me, so I contacted the hospital and said I would stick with Calea for the moment. I foresaw that if many people changed all at once there would likely be problems with any of the other care companies too.

Soon after this I was rung by a member of Calea's administration team to say that they had indeed been going through a very difficult time but problems were being solved and the company was keen to explain in detail to their clients what the problem had been and how things would improve. Was I interested in a meeting in London, to hear at firsthand what caused the breakdown in service and how they would provide for their patients in future? I said that I would indeed be very keen to attend such a meeting.

Very soon after, I was invited by Calea to the meeting on 20th November 2013. On the day I set off to what I thought would be a very interesting day. Sadly Southern Railway had major problems that day and I was held on a stationary train for forty minutes outside London Bridge station waiting for a place at a platform, which made me late for the meeting. Unfortunately I missed the short film at the beginning of the meeting which showed how the feed is made in the laboratory in Runcorn but was assured by everyone later that it had been very brief. The next part of the meeting consisted of explanations of why there was a staffing issue, which caused the difficulties in meeting their supply obligations. I could see that there were indeed very good reasons why they had had difficulties; though it did not help that there was rather too little communication with patients at the time and people were left not knowing when or if they would receive their correct deliveries at a time convenient to them. However, it was good to hear from those at the top and to meet with many of the staff whom we as patients regularly speak to but don't see.

There was ample time for questions and one to one conversations with Calea employees. As far as I was concerned it was a good day and I felt much more reassured by the face to face explanations than I could have been by a faceless phone call. I understand that there were other meetings of a similar kind in other parts of the country. The only disappointment for me, apart from missing the film, was that relatively few PN patients attended, but I gather that the travel disruption wasn't just for South London and that some of those who intended to come were unable to get there because of traffic or train hold-ups. If anyone else feels they want answers and an opportunity to ask questions and your hospital instigates one of these meetings then I strongly encourage you to attend.

Molly

**PINNT response:** We were aware of the difficulties some Calea patients were experiencing from a number of sources. As a support group we were able to listen and empathise with people who found their usual homecare service had become unreliable. This is where the uniqueness of PINNT comes into play – we truly understand! As Molly points out lack of communication or misinformation contributed to an already difficult time. We conversed with Calea to try and offer support which would in turn benefit our members.

PINNT encouraged everyone who had problems to inform the people responsible for their clinical care, i.e. their unit or hospital. It is those who have clinical responsibility that purchase this care package for their patients. We completely understood the stress this placed on some of our members but sadly we are not in a position to affect change for anyone's individual homecare service or package.

PINNT supported a patient face-to-face meeting in the Midlands last year which was arranged by the nutrition team at the hospital. Since then Calea have been working with trusts and units who have asked Calea to attend a meeting which allows their patients the opportunity to listen to Calea and seek answers or assurance in relation to their individual concerns. PINNT is actively supporting these meetings and we know of a few more being arranged around the country.

If you are invited to a meeting and feel you have unanswered questions or concerns about your homecare package with Calea then do try and attend. PINNT welcomes these meetings as so many people preach that everyone should 'listen to patients' – this could be your chance to be heard and hear firsthand about the situation. ➤

**Calea response:** At Calea we take our responsibility to provide a reliable homecare service very seriously. We are working very hard to ensure our service both now and in the future remains at the very highest standard. Nothing is more important to us than hearing about our patients' experience of our homecare service and being able to describe first-hand the improvements we are making. Following consultation with your hospital clinical team we are running a number of events as described above. On the day, we will cover the following topics:

- Explanation of our service performance
- Understand what we could do better
- Explain how we are making improvements
- Give you an opportunity to ask any questions you may have face to face

We would love to see you at one of these events. It is your chance to let us know how we can help you with your homecare service.

Patient Days already confirmed are as follows:

Newcastle – 5th February

Nottingham - 6th March

If you attend clinic in these Trusts, you will have/ or will be shortly receiving an invitation from us. We are also planning additional meetings in other locations – details of which will be communicated by us or your clinical trust or PINNT asap.

## Overage in parenteral nutrition fluid and nutrition bags

**The title of this feature says it all. We are asked about this on a regular basis. Jackie Eastwood, Pharmacy Manager, St Mark's Hospital has kindly provided information to address the subject.**

Are you one of those people who sometimes find there seems to be a lot of fluid left in your feed bags once you have finished infusing? For some bags does this seem to be more than in others? Or do you find that your bags have exactly the right amount in them?

### **Have you ever wondered why?**

Parenteral fluids and nutrition can be made up in a number different ways and this can affect the actual volume in your bag. Some hospitals like the PN bags to have extra volume for a number of reasons; either so that you can continue to infuse at a low volume until the bag can be disconnected, or so that the volume could be increased slightly if it was needed by the patient without needing to change the prescription.

When intravenous fluids are made by pharmaceutical companies, they will often have some overage in them. This is allowed and can be up to 5% extra volume.

Feed and fluids that are made up for you can be made in two main ways.

1. The first method used is by filling the bag using gravity. The volume of the bag is made up with the bags and bottles that contain the protein (amino acids) and the calories (glucose and lipid). The larger the number of separate ingredients the larger the amount of overage will be transferred. For example if you were prescribed a 2500ml bag, the extra fluid can be up to 125ml from the main ingredients. On top of this, the extra small ingredients (vitamins and minerals) will be added, further increasing the volume. This could mean that in total you have 200-300ml extra. The larger the volume of your bag, the larger the overage is likely to be.

2. The second method of making bags is to use a machine to pump through the exact volume of the ingredients into the empty PN bag. In this situation, unless your hospital has asked for overage in the bag, you will have the exact volume you need to infuse. These machines use concentrated ingredients and so use part bags and bottles to get the correct content. This is then made up to the final volume with water if needed. The small ingredients (vitamins and minerals) will often also be incorporated into the final volume to be infused.

Your hospital should tell you what volume that should be infused; this may be a rounded up value such as 2500ml or the total volume of the bag. Whether there is overage or not, you will not be missing out on your nutrition as your hospital and nutrition team will be monitoring you and your bloods and amending the feed as required. If you are unsure of what to do, it is best to confirm with your team.

Jackie Eastwood

Pharmacy Manager

St Mark's Hospital, London



PINNT members qualify for a £5 discount on the first years annual subscription to MedicAlert.

Your personal medical details are stored on a database only retrievable using your personalized membership number.

**MedicAlert - 0800 581420**  
**www.medicalert.org.uk**

# My first holiday abroad on TPN

**In August 2012 my parents asked if my hubby, daughter and I would like to go on a family holiday abroad the following year, of course we all said yes immediately. Then it hit me! I had never been out of the country since starting parenteral nutrition (PN).**

Typically for me it was then that I started questioning everything in my head. Would I be able to go? What would happen if I became unwell or had a problem with my line whilst I was on holiday? How would I get the PN and all the equipment abroad... the list went on. This made me feel a little disheartened as the more I thought about it I was convincing myself it just wasn't going to be possible.

I thought about it some more and posted some of my concerns on the PINNT forum. I got replies and they were all positives which gave me the boost I needed. I wasn't going to let all this stop me from going on a holiday abroad.

We all decided that we would go Fuerteventura and stay in the villa that we had stayed in twice before. The couple that own it are very accommodating, I knew what the villa was like and that it had everything we needed and we loved it.

I spoke to my nutrition team and asked if I was ok to go on holiday. They said they couldn't see why not as everything was now stable. They asked where I was going and when and said they would give me a 'fit to fly letter'. I came out of clinic so excited and couldn't wait to start planning everything. That evening I rang my mum so she could start looking at flights. (Note-to-self – contain excitement).

The planning started, I used the PINNT checklist as a guide for my 'what to do list' to make sure I didn't miss anything and probably drove Carolyn mad?! Sorry Carolyn. I contacted Bupa about five months in advance to notify them that I would be going on holiday for a fortnight and gave them the dates and asked

them if they could give me a rough estimate for the weight so we could speak to the airline about taking the PN and the other equipment. They gave me an estimate and I thought no way is the airline going to take all this free of charge. Thankfully the airline proved me wrong and agreed to take it all. (Note-to-self – have faith!)

So far everything was going fine, until I rang Bupa to give them the flight details. Due to the time of my flight and having to be at the airport for 4 a.m. they couldn't meet me at the airport with the PN, uh so how was I going to get five PN boxes and all the luggage to the airport I don't own a lorry !?! Bupa did give me the option that if we were going to stay in a hotel the night before departure at the airport they could deliver it there for me. I said I would discuss it and get back to them.

During this time I had attended a PINNT get-together in London and heard somebody mention multi-chamber bags. (Note-to-self – always attend PINNT meeting, most useful!) so I contacted Bupa again to find out more. They said they did do them but they would have to contact the hospital to find out if I could have them, the hospital agreed but said I would need extra fluids four days a week as the bags were smaller than what I would normally have. I was happy with this; it also reduced the number of feeds that needed to be part of the cold-chain process. Another benefit was that I could have them delivered a few days before travelling and if there was any issue I had some breathing space to sort it out. (Note-to-self – I love it when a plan comes together).

Everything on my list was complete from a fit to fly letter, insurance, what ancillaries I needed etc. All I had to do was pack and double check I hadn't missed or forgotten anything. The weekend before I was due to go I was all ready to go and actually impressed I'd managed to do it all and was ready to go well in advance. I did feel a little nervous as 6 weeks before we were due to go I



was discharged from hospital, as I had been admitted with sepsis from a kidney infection, even though I'd had my line changed and my cultures were clear it still played on my mind.

The big day finally arrived, we were finally going on holiday so we set off for the airport.

When we arrived at the check-in desk we found the luggage belts had broken down. We had to go to another dedicated area and leave our luggage there. I wasn't concerned about my clothes I was more concerned about the PN. I had visions of it not making it onto the plane. Luckily my dad works for an airline and explained to me where it goes and what happens; I then felt more relaxed. (Note-to-self – always trust your dad).

We finally arrived at our destination and we stood waiting at baggage reclaim, I was rather nervous. I didn't see my PN boxes; again dad explained that they may have another belt further down where the heavy or fragile luggage comes through. My daughter and I walked further down while the family collected the rest of our luggage. We found another luggage belt and stood there waiting. A Spanish lady approached me and asked if I was waiting for boxes, to which I replied yes and didn't think anything of it. She asked me what was in the boxes, even though they were all marked up as medical fluids. Instead of trying to explain I gave her the letter which the hospital gave me. She glanced at it and asked us to wait so we did. She then appeared with the boxes and the Spanish civil police at which point the colour drained from my face!

His English wasn't great and my Spanish leaves a lot to be desired. He wanted to know what it was for and kept telling me it was far too much, he obviously couldn't understand the letter and I just stood there trying to explain but he just did not understand. I thought any minute now I am going to get arrested and they are going to destroy my PN. I needed to think fast, how could I explain so he could understand? I had an idea. I undid the top three buttons on my shirt so I could show him my Hickman line. His face was a picture he must have thought I was going to strip or something in front of him! I showed him the line and explained the best I could and finally it sank in, PHEW! They handed my letter back, then gave us the boxes, smiled and shook my hand. We then made our way out of the airport to start our holiday. (Note-to-self – get letter translated next time, read PINNT Holiday guidelines properly!)



I am happy to report we had no more dramas during the holiday and all had a fantastic time.

Has my initial experience put me off doing it again? No, I am already planning for next year.

Final comment – (Note-to-self – believe in what you can achieve).

Kym

## 5 minute telephone interview



**New Feature: Many people want to contribute to Online but don't always feel they have anything of value to say or share. Features do not have to be epic and detailed. From this edition we're introducing a new five minute interview. Thanks to Michael for taking part.**

**Background:** Michael is on HPN and feeds seven nights a week. He lives alone and has multiple serious health issues including severe breathing problems and restricted mobility. He had an extraordinarily long stay in hospital and has been dependent on help from others since 2008.

**Michael you sound really well today, how are things?**

Well Carolyn I must say I'm feeling rather positive. I went away for Christmas and stayed with family, which was lovely, but being around all those energetic and capable people really put the focus on just how disabled I actually am! In the mornings I'd wake up full of all my usual aches and pains to find they were already out... and running... 10 kilometres along the river! ... sometimes at 6.00 a.m! And the stairs... they killed me and my slow painful ascents were in full view of everybody - I **REALLY** felt disabled.

**That sounds awkward!**

Well, every cloud has a silver lining! The contrast between their lives and mine was stark and that made me determined to act. Each day I ignored my pains and dragged myself to a nearby riverside bench which was VERY rewarding and just the tonic I needed. It wasn't easy but it paid dividends as I brought the habit home.

**That sounds promising; how's it going?**

Well, I still have very disturbed nights and my mornings are always wretched. It still takes me until about 2.00 p.m. to feel remotely human but I've made a resolution... to put ME before anything else.

I've used pain as a reason to avoid difficult things. The simple task of getting washed, dressed and ready for anything exhausts me and because of that I've lived housebound and mostly in pyjamas for six years, avoiding 'real life'. I used what little energy I had on mundane computer orientated tasks like 'health admin' or social networking and kidded myself that those things were my priorities but this year I'm turning things on their head... My priority is ME... Getting up, washed, dressed and OUT even if it's only a taxi to sit in a park.

And as for my 'health admin' and social networking, that can wait! If I've enough energy at the end of the day I do it then.

**That's quite a change, was it easy Michael?**

No, there are many challenges, but I'm determined.

Two years ago I did some sessions with a life coach and was taught a five-a-day programme to improve mental wellbeing... a recipe for happiness! It recommends that people should: - be Active (do stuff every day), Connect (with others), Notice (surroundings, beautiful things etc.), Learn (stay curious and engaged) and Give (something to others, a compliment, help, time etc.). Google "five a day mental well being" to learn more.

I'm finally putting the last piece in place... the Active bit and I'm finding my efforts VERY rewarding. I'm building confidence and feeling positive about the future.

**How are you going to keep the momentum going during 2014 Michael?**

I know there are so many things I cannot change. I know I will always wake every 90 minutes to urinate, I know it's unlikely that I will ever wake up feeling refreshed. I know I'll always require TPN and I know I'll probably never run or swim or find physical love again BUT I've never felt sorry for myself; in fact I can almost find the challenge of reinventing myself exciting.

There are SO MANY things I can do and so many things I'm grateful for, in particular my great friends and my faith. I have inner peace and I count my blessings. I don't think I'll have a problem keeping this momentum going.



# Regional/local group news

All contact details are listed on the back cover of Online for all groups even if no report is given in this edition.

## East Anglia Region

**Winter 2013** – We met up in Cambridge in November; we were really happy to welcome a number of new faces this time from as far as Bishops Stortford and St Ives Cambridgeshire; a good mix of all ages. Of course we enjoyed meeting up with old friends too, though missing several who were unable to come due to poor health; hope you will soon have recovered.



Our thanks to Calea, Fresenius and Nutricia for helping us send out the invitations and to their nurses who came along to meet you on the day.



Tracy's Christmas Quiz acted as an icebreaker, while reminding us of the festive season. As always, there was plenty of chatter going on and clearly a good exchange of ideas whenever groups of people got talking. This was interspersed with the raffle to which everyone contributed generously, making £51 towards PINNT funds.



We'll meet again on Saturday April 26th, note a return to 12.00 to 3.00pm, back in the David Dunn Suite in the main hospital block; hope to see you there.

**Tracy and Sylvia**

## Essex

**Kelvedon, October 2013** - If you weren't, why were you not here with us for our first PINNT meeting? We had a great time; especial thanks to Fresenius Homecare and Calea for their support.

We met at the Kelvedon Labour Club; just the place for an informal get together. John dealt with our every need; billiard table, TV and soft play area kept the older and younger children out of trouble, some even challenged their skills at climbing the stairs, while tiny ones were content in pushchairs. The rest of us relaxed for 2 hours over coffee and biscuits. From the Essex area, we were adults and children (aged one to twelve) including parents, a grandma, siblings, a community carer and a dietitian plus associate PINNT members. What a good mix, exactly right. So if you are tempted when we meet again, anyone interested or involved in artificial feeding is welcomed.



As a brand new group, almost all were unfamiliar with PINNT, so we used short video clips from the website to describe the role of local groups and Half PINNT.

All of us gelled, immediately finding common ground for discussion - topics included disabled parking; as there may be few outward signs of being fed or of disability, members of the public often look accusingly as though we're abusing the Blue Badge Scheme. Several expressed indignation that they'd never been given information about PINNT even during seven and twelve years of feeding respectively, amazed that their own healthcare professionals seemed unaware. This led to offers by all to raise the profile of PINNT locally, taking fliers to give to their local care teams and offering to spread the word on Facebook.

Before ending, we held a raffle for PINNT funds, prizes donated by members and local businesses; thanks to all.

Essex intends to put PINNT on their map; and Terry would really appreciate not being outnumbered by children next time! **Come along and support us; as always, the group is open to adults and children on both enteral and parenteral feeding.**

**Looking forward to seeing you on Thursday April 10th 2014.** Further information on the PINNT website [www.pinnt.co.uk](http://www.pinnt.co.uk) and email [lclover@pinnt.com](mailto:lclover@pinnt.com).



**Laura Clover mum of Zachary,  
Amy Rudd Dietitian Broomfield  
Hospital,**

**Sylvia Cottee PINNT Executive &  
Regional Groups co-ordinator**

## Nottingham

We are pleased to be co-hosting a meeting at Queens Medical Centre on 6th March. Tara and Lesley will be meeting local patients and hopefully working towards establishing the group to meet on a regular basis. Both ladies can be contacted via their emails shown on the back cover.

## Ireland

We are looking forward to confirming and hosting a meeting on 20th March. As this copy is being prepared the full information is being finalised. The website will have full information.

## London

The leaders who run London are meeting to set out what the plans are for 2014. Watch this space, more information to follow soon.

**We are receiving more enquiries about setting up regional or local groups; we are busy supporting these people in the hope that they feel able to take this on in the future. We fully understand that people do not want to do this alone; ideally if a couple of people get together then it makes the whole process easier. If you are considering getting a group started please email: [scottee@pinnt.com](mailto:scottee@pinnt.com) for further information or ring 01223 880616.**



## Reading

**October 2013** - The first Reading Group get together was a runaway success according to those who were there.

Jo Wakeling Nutrition Nurse Specialist facilitated the afternoon which was held at the Education Centre at the Royal Berks Hospital Reading. Thanks to the support of the companies who provide nutritional homecare services locally, we enjoyed light refreshments, the fun of a raffle and also got to know them in an informal setting; good for all of us. Abbott's invitation mail-out to our local tube fed patients was invaluable. Oh, and we mustn't forget the amazing nutrition themed cake presented by Natasja from the Dietetic Department.



We welcomed a number of parents whose children need tube feeding, those who came along behaved immaculately while their parents gelled immediately, finding lots to discuss. The adults were evenly split, half tube and half intravenously fed, so an excellent mix of experiences to share.



For 'entertainment', since this was the very first time we'd met, and for the benefit of non-members, a brief overview of PINNT was presented, and Mia Small from St Marks Hospital London informed us of several practical issues pertaining to patients on both tube and intravenous feeding.



On a lighter note, David gave us all a fascinating overview of the ups and downs of his home life on parenteral nutrition. He went on to describe his own patient passport; documentation he carries with him, detailing the essentials of his own case, should he need medical attention away from home; it seemed like a very sound idea. But most of all we wanted to chat, and meet up again... soon!

Plans are afoot to meet again sometime around Easter in a community setting nearby, where we can make a cup of tea, the small children won't be imprisoned in their pushchairs, and older ones will have space; siblings welcome.

All ages adults and children welcome of course. Look out for further information on the website [www.pinnt.com](http://www.pinnt.com)  
Tel: 01223 880616  
or 01183 225111 ext 8342

**Sylvia Cottee PINNT Executive Committee and Regional Groups, Jo Wakeling Nutrition Nurse Specialist Royal Berks Hospital.**

## Dundee

On Saturday the 9th November 2013 our first Dundee get-together meeting was held at Ninewells hospital, Dundee. I was overwhelmed with the turnout it was amazing. There was a mixture of TPN and enteral patients but not all in attendance were PINNT members. I'm signing them all up so they don't miss out on future meeting notices. We are also lucky in Dundee to have the support and good communication between the hospital and the group itself too.

I did a welcome speech to the group, then Steve Brown, general secretary of PINNT, did an overview of PINNT. The day went really well; everyone seemed to be enjoying themselves. We had a fun quiz which created a good atmosphere, then we held a raffle where the prizes were generated from companies and people's kind donations; we managed to raise £61 for PINNT. We had light refreshments followed by a general discussion on various matters. We then all had a good chit-chat and before we knew it the day was over.

I would like to say a special thank you to Steve Brown, Margaret Macdonald and finally to Dr Janet Baxter, Head of Nutrition at Ninewells Hospital for all their help and support for our first meeting. My special thanks goes to everyone for attending the meeting as I know that quite a few people travelled a

long distance to be there on the day. It was everyone's effort and time that made the day so thank you. Details of the next meeting at Dundee to follow in 2014.

If you're reading this and think you would like to come along and join our group then please do not hesitate to contact me. Full details on the back cover.

**Paula Stewart**

## Norwich

On Saturday November 16th 2013 the Norwich Group planned an evening to raise funds for PINNT. It was a fun filled evening, with our PINNT duo 'Back to Back' entertaining us with some great music. We had a fantastic raffle, with some wonderful prizes from holiday voucher, a night in a B&B, beauty vouchers and many more. We raised £510.00 and it was lovely to see some PINNT members too.



I'm hoping our next get-together meeting will be in March sometime and I hope as many of you as possible will be there, as well our normal features, I would like to arrange another fund raiser in the summer, where you can all have a say and be involved.



Hope everyone had a great Christmas, and I wish you all a healthy and brilliant new year.

**Jackie Riseborough**



**Continued on Page 18** ►

## ► Continued from Page 17

### Southampton

Chatter and laughter filled the room on 25th January. We talked about holidays, homecare, aches and pains. We also debated how to help new members in the area and are investigating putting together some basic information to be used when people are asked to come and say 'hello' to new families going home with children on PN. It's that initial period that is daunting, we hope to help.

Delighted to be hosting the annual PINNT get-together on 31st May 2014. The fun team will put together a programme of fun and interaction for all those who are able to attend, we hope to see lots of new people! There will be the formalities of the day but once these are done we will get on with providing a fun afternoon.

Be good to hear from anyone who wants to join our group.

Jasmine Cheesman

### PINNT literature

All our information is available in the members area on our website – [www.pinnt.com](http://www.pinnt.com)

If you do not have access to the internet then please contact Steve Brown who will send out printed copies for you. There is a charge for postage but initial copies are free to members.

- Welcome to PINNT
- PINNT information exchange
- Talking points 1: Considering travel
- Talking points 2: Travel insurance
- Talking Points 3: Introduction to peg feeding
- Holiday guidelines
- PINNT fund raising guidelines + sponsor forms
- Restaurant card
- PINNT A5 Flyer
- LITRE Report
- HANs Document
- Annual Review

## Ever thought about helping PINNT?

### Two voluntary vacancies

As we grow and expand our services we are obviously getting busier. Often people offer to help but without an idea of what's needs or involved it can be difficult to identify a role and purpose. We really need some support in two key roles, do either of them appeal to you? Could you fill some spare time during the week to help PINNT? If you're interested or keen to find out more contact the person shown for each role. If you want to ring them you'll find phone numbers on the back cover.

#### Admin support

PINNT are seeking the support from someone who could offer some admin support. Basic requirements are the ability and confidence on the phone and using a PC.

Ideally the applicant should be available during the day. The role will actively support current projects and day to day business and may include the following:

- Communicating with other PINNT volunteers either by phone or email
- Contributing to general mailings, supporting the organisation of regional/local meetings
- Gathering information for website updates and Facebook
- Responding to general enquiries

This role will vary in accordance with day to day business but the hours are flexible although deadlines will exist for some projects. If you'd like more information on the role please contact Carolyn on [cwheatley@pinnt.com](mailto:cwheatley@pinnt.com)

#### Financial support

PINNT are seeking the support from someone who could offer some support in relation to financial matters within PINNT. Ideally the applicant should be available during day. The role will actively support existing processes within PINNT but would ideally be available to provide updates, breakdowns for specific projects as well as supporting the day to day donations and expenses processes.

If you would like more information on the role please contact Richard on [rshawyer@pinnt.com](mailto:rshawyer@pinnt.com)

#### Regional/local opportunities:

Still thinking about it, still hoping someone else will volunteer and there will be a group close to you? Well it won't happen unless you take the next step and contact PINNT. So many of you ask about groups but sadly we have to say 'sorry' we're willing to support them but someone in the locality needs to take the lead. It is really disappointing when we are unable to offer essential support in your locality.

**Are you able to offer a small amount of time in setting up and running a PINNT group? Only 3 things required:**

**1. Willingness to volunteer your time, 2. A commitment to helping others, 3. Be a paid up member of PINNT**

**It's as easy as 1, 2, 3 ...** Why don't you pick up the phone and give us a ring, we would be delighted to hear from you and you never know - you would probably enjoy supporting other members. You can contact PINNT on 01202 481625 or email [info@pinnt.com](mailto:info@pinnt.com)

# Letters to PINNT

## Dear PINNT

Does writing to PINNT for the letters page qualify as making an effort to contribute? I am someone who enjoys Online but just doesn't feel able to write a feature. Please keep up the good work and thanks to everyone who ensures the magazine is packed with such good features. Initially many are sad and heartbreaking but I am overwhelmed by the way people turn their situations into such positive and inspirational stories.

Mick

**Ed replies:** One day we'll be printing your story! Our members are truly inspirational and it's rewarding to know they help other members.

## Dear PINNT

Excellent holiday information, well done PINNT.

Jill

**Ed replies:** Glad you found it useful. It is all available in the members area on our website. If you do not have access to the internet and wish to receive copies of holiday information please ring Steve on 0191 499 0582. Anyone travelling, home or abroad, please think about telling us if anything needs updating or amending in the information. Additionally consider writing a feature for Online to say where you went with your feeds.

## Dear PINNT

Recently I switched from enteral feeding to intravenous feeding. My weight was not improving and I was generally struggling with my health. My previous pump and rucksack were lovely, neat and discreet. What a shock when I had the intravenous feeding rucksack delivered. Given I'm rather weak at the moment I find it difficult to manage and extremely heavy and indeed cumbersome. Do these come in different sizes? I have attached it to a set of luggage wheels which has helped with mobility but I would prefer a rucksack more suitable to the size of my intravenous fluid bag. Can PINNT help?

John

**Ed replies:** Hope you start to feel stronger and better on your intravenous feeding. I can imagine how the difference in size could impact on your mobility. Glad to hear you have used luggage wheels which have improved things for you. Some of the portable parenteral feeding pumps come with accessories which include different sized rucksacks. Some even have wheels on. You'll need to raise this issue with your hospital/unit. From what I know the pump you are using does not have alternative sized rucksacks. You may wish to discuss a different pump with your healthcare professionals if this continues to be an issue for you.

## Donations

- Adeyfield Church **£242** • M A Healthcare **£108** • Holme United **£397** • Mary Duncombe **£1833.75**
- Lord Provost, Dundee **£100** • In lieu of birthday presents - Molly Wickert friends and family **£360**.

### Donation from Dundee Lord Provost

I have some good news I wish to share with everyone concerning a donation I have recently received for PINNT. While setting up the first Dundee group get-together I sent out some letters asking for support and donations for PINNT in the hope that people would respond favourably. I decided to write to our Lord Provost in Dundee (this is the equivalent to the Lord Mayor in English towns and cities) to ask if there were any funds available within the city to donate to PINNT.

My first meeting took place which was an amazing day for everyone and I never heard any news from the Lord Provost so I thought I was unsuccessful. To my surprise I received a telephone call a few weeks ago from his secretary to say that on this occasion the Lord Provost would like to offer a donation of £100 to PINNT. I was overwhelmed with this gesture of goodwill and kindness to say the least! So it just goes to show you, if you don't ask for any donations we might be missing out on vital funds needed for PINNT.

I'll be discussing with Sylvia Cottee, who leads on regional/local groups for PINNT, how we can work with other regional/local group leaders to discuss how they may seek similar donations. I am not claiming to be the best at this but if anyone wishes to discuss how they may seek support for PINNT, please contact me at [pstewart@pinnt.com](mailto:pstewart@pinnt.com).

Paula Stewart  
Regional co-ordinator, Dundee

Those shown are up to end of November 2013. **If your donation is not listed here then keep an eye out for the next edition.**

**If you have a donation to send to PINNT please send it to:** PINNT, PO Box 3126, Christchurch, Dorset BH23 2XS. Enclose a short letter or feature saying how this money was raised or why it has been donated and we will ensure you get a mention in Online.

# CONTACT US:

# Online

## REGIONAL / LOCAL GROUPS:

### East Anglia:

Tracy Hill. Tel - 01945 780909  
Email: [thill@pinnt.com](mailto:thill@pinnt.com)  
Sylvia Cottee. Tel - 01223 880616  
Email: [scottee@pinnt.com](mailto:scottee@pinnt.com)

### South Wales:

Letty Johns. Tel - 01792 521618  
Email: [ljohns@pinnt.com](mailto:ljohns@pinnt.com)

### South:

Jasmine Cheesman  
Email: [jcheesman@pinnt.com](mailto:jcheesman@pinnt.com)

### Norwich:

Jackie Riseborough. Tel - 01263 710774  
Email: [jriseborough@pinnt.com](mailto:jriseborough@pinnt.com)

### London:

Molly Wickert. Tel - 0208 7783 475  
Email: [mwickert@pinnt.com](mailto:mwickert@pinnt.com)  
Clare Argent-Hall  
Email: [cargenthall@pinnt.com](mailto:cargenthall@pinnt.com)

### Nottingham:

Lesley Carmichael  
Email: [lcarmichael@pinnt.com](mailto:lcarmichael@pinnt.com)  
Tara Bettison  
Email: [tbettison@pinnt.com](mailto:tbettison@pinnt.com)

### Scotland (Dundee):

Paula Stewart. Tel: 01382 732746  
Email: [pstewart@pinnt.com](mailto:pstewart@pinnt.com)

## EXECUTIVE OFFICERS:

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General Secretary - Steve Brown  
0191 499 0582  
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Chair - Carolyn Wheatley - 01202 481625  
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## HALF PINNT CONTACTS:

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Email: [info@pinnt.com](mailto:info@pinnt.com)  
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## PINNT:

PO Box 3126, Christchurch, Dorset BH23 2XS  
Email: [info@pinnt.com](mailto:info@pinnt.com)  
Website: [www.pinnt.co.uk](http://www.pinnt.co.uk)

## PINNT PRIZE POT ENQUIRIES

If you would like to sign up to be included in the PPP - PINNT Prize Pot, then please contact Sarah on 01322 383507 ([sgreen@pinnt.com](mailto:sgreen@pinnt.com)) to receive an application form.



## WEBSITE ADDRESS

Don't forget to log on to:  
**[www.pinnt.co.uk](http://www.pinnt.co.uk)**  
where you can access all kinds of PINNT information, some of which is available to download. Our new website is full of new and exciting items - pay a visit and provide us with your feedback.



## Leaflets

Talking Points 1 & 2 Considering Travel and Travel Insurance ....

Talking Points No.3  
An introduction to PEG feeding

+ other information and publications.  
All available in the members area on the websire. Copies can be posted to you upon request

Free to PINNT members.

Contact: Steve Brown

Tel: 0191 499 0582

or mobile: 07500 871547

Email: [sbrown@pinnt.com](mailto:sbrown@pinnt.com)  
or [info@pinnt.com](mailto:info@pinnt.com)

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