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# Online

June 2006

in association with



The Scottish HPN Managed Clinical Network is a multi-disciplinary group formed by professionals from each of the major centres in Scotland associated with HPN. It was set up to organise the care and treatment of HPN patients in Scotland and here Janet Baxter, Network Manager, talks about its aims and objectives.

*Q: Why was the HPN Managed Clinical Network established?*

A: The network was officially launched in 2000, and I was appointed as manager in 2001. This followed a period when the NHS in Scotland was being reviewed and the concept of managed clinical networks first discussed. The first aim of networking is to allow equity of access for patients to services that are not commonly used in all hospitals. The wide geographic area of Scotland, with only a few centres with sufficient expertise to undertake HPN, means it can be difficult for patients to travel to recognised centres of excellence for their treatment. A managed clinical network means that rather than have care centralised in a few centres, there is support for smaller centres who want to manage their own patients.

*Q: Who manages the day to day business of the network?*

A: The role of manager means running the network on a day to day basis. It is my responsibility to support the nutrition teams who manage HPN patients. To do this I visit the teams and identify patients by providing evidence-based procedures and protocols which I update with other members of the network. I gather audit data from each team and use that to assess their performance against the nationally agreed clinical standards. It is also my responsibility to arrange all network meetings – business, education and clinical. I have regular meetings with Dr Ruth McKee who is the lead clinician to take the network forward.

continued inside. . .

## THE SCOTTISH HOME PARENTERAL NUTRITION MANAGED CLINICAL NETWORK

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*Q: What are your aims and aspirations?*

*A:* The network aims are to enable access, to provide optimal patient care using evidence-based medicine, to audit practice and to encourage multi-professional care.

From a more personal point of view, it is to support nutrition teams to maintain the great level of care already offered to this patient population. I would like to see all patients have quality of life considered as an integral part of their overall care. The network is preparing the first HPN-specific quality of life questionnaire to assess this.

*Q: Who is represented on the network?*

*A:* The network is inclusive – which basically means that anyone involved in the management of HPN patients

Have you often wished you could volunteer to help PINNT but felt unable to make a long term commitment? Then this could be for you: why not become a floating member of our Online editorial board? Working with one of our existing team members, you'll be given all the help and support you need. So why not try us out? Join us for one edition and see how it goes. It's challenging, it's fun and you'll be helping PINNT. So pick up the phone or write to me and we'll get the ball rolling.

Please keep your letters and articles coming in. Following a number of enquiries from members, we would like to confirm that you do not have to have your full name included with a feature or letter – first names or even initials are acceptable – we do not want to miss out on any of your contributions.



*Barbara*

Online Editor

FROM THE EDITOR

is welcome to attend meetings and be involved in network activities. Those involved include nurses, physicians, surgeons, dieticians, pharmacists and biochemists. We are also proud of the fact that patients are also involved – both at committee level and also in that they are welcome to attend annual meetings. We have had great support from patients in terms of their attendance at meetings as well as their willingness to be involved in activities such as the preparation of the quality of life questionnaire.

*Q: How many patients does the network manage?*

*A:* At any one time, approximately sixteen network centres look after approximately seventy adults and about twelve children. As new patients are referred, I register them with BANS (British Artificial Nutrition Survey) so that the network data contributes to the national picture. This represents 14.3 per million of the Scottish population compared to an overall reported UK prevalence of 10 per million.

*Q: What are the benefits to the patients of having the network?*

*A:* Probably the most significant benefit to patients is the knowledge that their HPN is being managed by nutrition teams with recognised expertise and experience. The most important indicators for the care of HPN patients are catheter complication rates, hospital re-admission rates for HPN related problems, and quality of life. Comparison of data from before the network began suggests that catheter sepsis rates have been reduced since the introduction of these protocols. A survey carried out recently demonstrated a high rate of satisfaction amongst patients managed by network members and quality of life will soon be measured as part of routine clinical care.

*Q: Can you tell us about the procedures and protocols you have developed?*

*A:* All of the procedures have been developed using the expertise of nurses, dieticians, doctors, pharmacists and biochemists depending on the protocol. Perhaps the easiest way to answer this question is to list those available for all members:

- Clinical standards for HPN
- Guidelines for patient selection

- Catheter care documents including patient information
- Nutritional assessment and monitoring
- Micronutrient monitoring
- Diagnosis and management of catheter related sepsis
- Diagnosis and management of central vein thrombosis.

All of the above have been developed for adult and paediatric patients and combined into a network handbook.

Most of these are available on our website which is:

[www.show.scot.nhs.uk/shpnmcn](http://www.show.scot.nhs.uk/shpnmcn)

**Q:** *What are your aspirations for 2006 and beyond?*

**A:** Up until now we have concentrated on clinical and professional issues and so I am keen to encourage more patient involvement. My personal aim for the network is to get the quality of life work off the ground. We are also hoping to start some other research projects involving many of the HPN patients. One will look at bone disease and another will involve an analysis of the activity levels achieved by our patients (which I also think affects quality of life, on the basis that the more active you are, the better you feel). We need to continue to develop the audit projects – all centres now have their own audit database so that data can be collected electronically. It is important that we maintain a profile in both national and international settings so I hope to continue to be able to demonstrate the benefits of the network at conferences and meetings.

In 2006 I would like to be in a position to say that we have the best set up for HPN in the world! Am I too ambitious?

Sometimes it's good to heed your own advice. Having booked a holiday to Australia I knew this was not going to be as routine as our usual beach holiday so I carefully read the PINNT literature and paid close attention to the preparation and planning. How wise we were when we wrote those paragraphs advising people to think carefully about the amount of medical supplies you'll need for the duration of your holiday, and also to consider the type of holiday you are embarking on.

Visiting three places in Australia gave us plenty of food for thought. I spoke to all the relevant people and between us we planned it down to the last detail. I knew exactly how many feedbags I needed to take and when the next supplies would be delivered to me. I had contact numbers both in Australia and the UK just in case there was a hitch – never needed them once. The best reassurance I had was the back up of medical teams in Australia. A fantastic gastroenterologist in Melbourne provided 110% reassurance that my needs would be met if an unexpected medical problem arose – again, thankfully, I never needed to use this support network.

So why am I telling you this? It's not to boast about where I've been (although it was fantastic!) but to reinforce that the PINNT Holiday Guidelines really do make sense and even if you travel frequently, certain types of holiday need a little more thought. I now know that the best jab you can have before travelling is the boost of confidence that good planning gives you.

I had actually gained advice and support from fellow patients who had already travelled to Australia – none of us know it all and we can always learn from others. So if you are planning a holiday this year and could do with a refresher course on travel arrangements, dig out your Holiday Guidelines and spend a few minutes reading them just to ensure you've planned it to perfection.



Enough of my holiday news – it's about time some of you out there told us all about your travel adventures, no matter how near or far. . .

*Carolyn*

**Chairman PINNT**

# PINNT NEWS

## WOULD YOU BE INTERESTED IN AN INTERNET FORUM?

We would like to gauge how you feel about having a forum on our website [www.pinnt.co.uk](http://www.pinnt.co.uk). I'm sure many of you will have tried these out and may be regular users of some.

It is an idea we are considering, but we would like to know that there is sufficient interest from you, our members. It will need resources from us in terms of time, and so we want to know the level of interest before we proceed any further.

If you feel that it is something you would use, please can you fill in a 'contact us' form on the website and tell us.

Our site has undergone some changes so please take a look!

## CAN YOU HELP?

Do you suffer from pseudo-obstruction or have a problem related to a motility disorder? Your experience could be helpful in order to support a new research group that is currently being formed to promote research and raise awareness of the problem. If you are happy to share your story then please email it to Sue Stewart on

[sue\\_stewart\\_pseudo@hotmail.co.uk](mailto:sue_stewart_pseudo@hotmail.co.uk)

## PINNT PRIZE POT

The winners of the PINNT Prize Pot draw for January 2006 are:

- |     |                            |
|-----|----------------------------|
| 1st | 105 Jeff Gibbons – £143    |
| 2nd | 158 Graham Arnold – £86    |
| 3rd | 195 Gillian Hamilton – £57 |

## PORTABLE PUMP UPDATE

Just to keep you up to date with the current situation as far as we are aware. There are currently four possible replacement pumps being evaluated by various centres and companies to identify suitable replacements for the Baxter 6060.

LITRE carried out a review on two pumps: the Hospira Gemstar and the Fresenius Kabi IVantage. Their conclusions can be found on [www.bapen.org](http://www.bapen.org).

Since that evaluation was carried out another potential pump was identified: the Bodyguard Portable pump. LITRE will have reviewed this pump at their meeting on 8th May and hopefully a report will be available via the same source stated above.

The one pump which has not been revisited is the CADD portable pump. This pump is still used by some patients and could also be an acceptable replacement for some people.

As Baxter have agreed that the 6060 will be fully supported until 2007 this provides ample time for detailed evaluations to take place to ensure that pumps that are then offered to patients fit in with safety criteria in addition to enabling the end user to have the ability to feed on the move. PINNT and LITRE still advocate that where suitable pumps are identified, patients should be given a choice as to which one fits more easily into their personal lifestyle - of course taking into account all safety parameters.

## STOP PRESS

PINNT have just learnt that following detailed evaluations of the IVantage it has been withdrawn by its American manufacturers because of an unlikely but possible condition of under-infusion in the PCA mode, and software improvements are required to prevent this. Sadly this doesn't affect the PN mode but as patient safety is everyone's concern then it's not looking like a feasible option in its current position.

We will keep you updated if we hear of any modifications to this pump



## NEW EDITORIAL BOARD MEMBER

I'd like to introduce myself. I'm Chris Turner and I have been a PINNT member for two years and have been on a PEG feeding system for two years and three months. I live near Cambridge and have been to two PINNT meetings at which I managed to chat to people mainly on HPN and found it very helpful to share experiences.

Like those on HPN, infections have been a major problem for me. After nine months on a PEG I started to suffer chest infections which have left me with bronchietasis and I have found that I have to have my PEG food in the daytime whilst in an upright position. Looking back I wish it had been made clear to me that whilst being fed at night I should have had the top end of my bed propped up 30 degrees or more - easily done with a hospital bed but not so easy at home with a standard bed. The problem is we are still on a learning curve with PEGs and HPN and most ward staff and district nurses are not accustomed to the procedures.

That said, I am very grateful for the time my PEG has given me with my family and for the way they have coped with me not being able to eat or drink. I know my wife finds it very hard not being able to feed me and being unable to go out very much for meals as a family is also difficult. In some ways it seems easier for me as I have become used to being fed via my PEG and just accept it. I feel I have been able to complete a few useful tasks and have been of some support to my family. We also managed an extended family holiday with our children, their wives and husbands, and the grandchildren all mucking in together. They all want a repeat this year.

I have an eighteen year old daughter still in full time education and would say that my strokes and PEG have hit her hardest and resulted in a loss of confidence, but time is a great healer and I think she is slowly regaining some of it.

Chris Turner

**Ed replies: Thanks Chris – your story will hopefully encourage others to share theirs too!**

This has been as always a very busy quarter for the Treasurer and Assistant Treasurer as we process all the membership fees and donations that come in from you all. It is hard work but always a pleasure to see the funds coming into the bank as I then spend the rest of the year taking them back out to pay the bills.

We have another donation from Vygon totalling just over £600 and some other donations from bequests and wills.

I look forward in the next month or so to totalling up all the membership donations and membership fees so I can see what we are going to be able to do with PINNT and its members over the coming year.

Let's get our thinking caps on and if anyone can come up with some great new fundraising ideas for 2006, I and the rest of the Executive Committee would love to hear your ideas for fundraising so we can do more for you, the members.



Keith

# UPDATES FROM THE EC

I hope you've all got the date and venue for our AGM in your diaries – it's Saturday 3rd June, New Hall, Cambridge. We have a varied and interesting day planned and are looking forward to seeing as many of you as possible!

I would like to thank those of you who have returned your nomination slips and voted for the Executive Committee.

Thank you to those who have sent feedback regarding the new look Online; you seem to like the change and we will endeavour to take into consideration your comments in future issues.

We have been encouraged by the letters of support we have received regarding the introduction of the membership fee. As you know it was done at the request of our membership, and many of you have asked why it wasn't done sooner.

The National Institute of Clinical Excellence (NICE) published their 'Guidelines for Nutritional Support' on 22nd February. Carolyn was asked to sit on the panel which launched the guidelines and an interview with her was featured on the radio. The guidelines have generated an immense amount of interest and can be found on the following link if you have access to the internet:

<http://www.nice.org.uk/page.aspx?o=293228>

We and LITRE are still involved with the withdrawal of the Baxter 6060. You can read a report on two possible replacements on [www.bapen.org](http://www.bapen.org). At our next meeting in May we hope to have another presentation of a potential replacement. We will keep you updated on the situation.

Until next time



Justine

# WELCOME NEW MEMBERS

## Adult

Heather Morris  
Judy Jolly  
Gloria Barrett  
Brigitte Southwell  
Sonia Roston Johnson  
Kathleen Cook  
Darren Bray  
David Tuck  
Barbara Lowe  
Caroline Campbell  
Wendy Leonard  
Valerie Chatfield  
Maureen Prince  
Gordon Richards  
Robert Lander  
Jacqueline Farley  
Susan McGlone  
Alec Bennett  
Nona Jones

## Child

Georgia Child  
Niamh Pymont  
Michael Humphrey  
William Milne  
Teshar Hart-Edmonds  
David Oliphant  
Callum-Benjamin Lucas

- **Does your family member receive nutrition via PEG?**
- **Are you interested in NHS service development for families like you?**
- **If you answered yes, we would love to hear from you. . .**

PEG feeding in the home has become a common way of supporting people with medical conditions. Therefore the numbers of families involved in caring for relatives with a PEG has also increased. Health professionals are aware of the extra responsibility that PEG feeding can cause individuals and their families.

Whilst the government wants to support family members who care for their relative, we do not have a full understanding of how using a PEG in the home actually affects family life. We hope to gain a greater understanding of this in order to inform and improve future services for families who support a relative using a PEG.

I would be interested in hearing from any family member aged over 18 years and who is involved in their relative's PEG procedure. I would like to take up about 30 minutes of your valuable time (more if you wish to chat to me) to complete some brief questionnaires on what you think and feel about the PEG. You can opt to have the questionnaires posted and a stamped addressed envelope will be included for return. However, I would be pleased to call on you and complete these questionnaires with you.

If you are interested in being involved I would be grateful if you would contact me on **07841 819 490** or at **[alex\\_legge@hotmail.co.uk](mailto:alex_legge@hotmail.co.uk)**

Thank you for your time and support.

THE UNIVERSITY OF HULL

## NICE to hear it!

PINNT are pleased to announce the conclusion of two and a half years of work that our chairman has been involved in. Carolyn recently took part in a media launch which was well received and gained good coverage. It also gave one of our fellow organisations, BAPEN, whom PINNT is closely involved with, the opportunity to discuss their concerns with the media:

February 2006 saw the launch of the 'Nutrition Support in Adults' guideline from NICE.

The objective of this guideline is to improve the practice of nutritional support by providing evidence and information for all healthcare professionals, patients and their carers so that malnutrition, whether in hospital or in the community, is recognised and treated by the best form of nutritional support at the appropriate time.

The guideline advocates that patients and carers should be informed and involved during the decision making in relation to their nutritional support, without losing sight of their medical needs, as well as their personal and cultural beliefs.

In addition to the full version of the guideline and the quick reference guide there is a booklet that was primarily written for people who are malnourished; but it may also be useful for family members, carers and anyone interested in nutrition or in healthcare in general.

The user friendly format will enable people to feel more informed about good nutrition in general which leads on to discuss the signs and symptoms of malnutrition and treatment options available to them. Early warning signs such as unintentional weight loss or a change in personal well-being should not go untreated. Hopefully the guideline will educate healthcare professionals to respond accordingly too.

It is our belief that each person should be vigilant and seek appropriate care which should then result in the right support being offered. We do not wish each person to be fed via a tube - other contributing factors to weight loss may be corrected which prevent tube feeding - this is reinforced by our belief that the right treatment should be given at the right time.

Hopefully by explaining in the booklet the treatment options, people will feel more informed if the need arises for them to receive nutritional support via a tube. The reassurance that his or her nutritional intake can be appropriately delivered, thus preventing or correcting the effects of malnutrition, may be comforting to know, in some cases more so for carers.

The guideline advocates standards of good nutritional care across a variety of care settings which is good news for patients. The earlier changes are recognised and reported, the better care people should receive.

Patients should welcome this guideline as it clearly puts nutritional support high on the agenda and will benefit patients from within the hospital setting and extending out into the community.

People should not be afraid to mention any concerns they have about themselves or a relative - if we do not speak up then the problem will only get worse. We advocate that people should use this guideline to raise the profile of good nutrition, and where necessary seek out the right type of nutritional support and feel better informed about treatment options.

We do not want to hear stories of people starving - it's not necessary when there are effective solutions available.



# MEDICAL MATTERS

## Intestinal Transplantation – A Brief Overview

by Dr Jeremy Woodward, Consultant Gastroenterologist,  
Addenbrooke's Hospital, Cambridge

Body parts occasionally fail prematurely and when they do we usually have just two options:

- Use a machine or technique that can take over or support the essential functions of the failing organ. For instance, a dialysis machine works as an artificial kidney, and home parenteral nutrition is supportive therapy for intestinal failure.
- Replace it with an organ that is no longer needed by its previous owner. (Just as kidneys can be transplanted, so can intestine).

There are of course downsides to both approaches. Using artificial life support can mean being attached for long periods of time to a pump or machine with tubes (catheters) permanently dwelling in large blood vessels. Despite medical advances, it is never quite as good as nature intended. Transplanting an organ generally results in much better function, but the body's defensive immune system can recognize the organ as 'foreign' and will attempt to destroy it in a process known as 'rejection'. For this reason, patients receiving transplanted organs need to take powerful drugs ('immunosuppressants') to reduce the body's defenses. These can cause side effects, not least of which is a tendency to pick up infections.

Organ transplantation has now become accepted practice and over the last ten years nearly 15,000 patients have received kidney transplants but still only about 50 people have received intestinal transplants in this country. There are several reasons for this difference:

- Intestinal failure is relatively uncommon – only about 600 patients in the whole UK receive home parenteral nutrition.
- Home parenteral nutrition is an excellent form of life support for patients who have intestinal failure and severe or life threatening complications are rare.

- Intestinal transplantation is quite difficult – it requires very potent immunosuppression in order to prevent rejection. This has been associated with major side effects although recent developments have made this much safer.

Because home parenteral nutrition support is so effective and because the intestine is one of the most difficult organs to transplant, it was thought for many years that there was no requirement to develop techniques for intestinal transplantation. However, there are a small number of patients who do run into problems and are no longer able to continue on home parenteral nutrition – it is these patients who could be helped by an intestinal transplant. The main reasons for considering the operation are:

- Running out of veins in which to insert a feeding catheter due to clots or blockages
- Severe irreversible liver damage due to parenteral nutrition (this is commoner in children than in adults)
- Recurrent or life threatening episodes of line sepsis
- Patients who have to undergo major operations to remove most of the abdominal organs (for instance due to trauma or rare fibrous tumours)

In some cases other organs need to be transplanted along with the intestine – for instance the liver – and some patients require multi-organ or 'cluster' transplants that may include the stomach, liver, small intestine, pancreas and kidney. Because it is the intestine that causes the most difficulty, patients who have undergone multi-organ transplantation are usually looked after by the intestinal transplant team.

Until recently, intestinal transplantation was perceived as being a desperate act of last resort. This became a 'self-fulfilling prophecy' as patients would be referred very late in the course of their illness and too unwell to cope with a



major operation. Recognising this, patients are now being considered for intestinal transplantation much earlier. Along with significant recent technical advances the reported outcomes are now very good (and continue to improve). In some centres as many as nine out of every ten patients receiving an intestinal transplant are alive at the end of the first year, and about half of the patients who receive an intestinal transplant (with or without other organs) now survive beyond five years. This may not sound particularly encouraging until you realize that these patients have been selected for transplantation because of life threatening problems.

For kidney failure, transplantation can be considered as an alternative and even preferable to dialysis. On the other hand, intestinal transplantation cannot yet be considered a routine alternative to home parenteral nutrition that is working well. However, when there are serious complications associated with the parenteral nutrition, then intestinal transplantation can now provide an excellent chance of long term survival.

There are three centres performing intestinal transplantation in the UK – Addenbrooke's Hospital in Cambridge and St James' Hospital in Leeds for adults; and the Children's Hospital in Birmingham for children.

This is only a very brief overview of intestinal transplantation and we aim to provide updates over time. If you have any specific questions relating to intestinal transplantation please feel free to write in and your questions will be answered personally via Online – general questions not relating specifically to personal issues may be used in future updates to help inform others.

Please send your responses for Dr Woodward via email or post to Barbara Berry (contact details on page 19) marked 'Dear Dr Woodward'.

## Sponsor's Feature



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We are committed to working as part of a team alongside other healthcare professionals to provide the best possible service to our patients. As all patients are individuals we believe in tailoring our services accordingly.

Calea recognises the wonderful organisation and support provided by PINNT and pass on our best wishes to all Online readers.

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PINNT would like to thank Calea for their support with this edition of Online. In addition to this sponsorship, we work closely with Calea throughout the year and always welcome their support with projects and events.

**The following article, which was originally published in The Times on 15th February 2006, has been reproduced with kind permission of The Times/NI Syndication.**

## **GP asks hospital users to rate performance online**

By Nigel Hawkes, Health Editor

**P**atients are being encouraged to rate hospitals on a website set up with support from the National Health Service as a forum for their judgments.

The new website, [www.patientopinion.org.uk](http://www.patientopinion.org.uk), was the idea of Paul Hodgkin, a Sheffield GP. "There's lots of official information about the NHS available on the internet," Dr Hodgkin said. "But people also want to find out what patients thought of services."

Yesterday he urged patients to use the site. "Patients have a huge collective wisdom about how to make the NHS better," he said. "But for Patient Opinion to work, we need stories from patients about their experience – what was good? What could have been better?" The NHS has in the past been wary of the opinion of patients. Community Health Councils were abolished by the present Government and replaced by Patients' Forums, whose own future is now in doubt. But official policy is that public views matter, and that information should be available.

When the website was piloted in South Yorkshire more than half the postings praised the NHS or thanked individual members of staff for their care. About a third of the postings were critical, but tended to be constructive. Hospitals in the area found the feedback useful.

The costs of the service are to be covered by charging healthcare providers for access to data. "Patients need to be able to trust Patient Opinion," Dr Hodgkin said, "and I also wanted Patient Opinion to be really useful to staff – not just another stick to beat them with."

"So we made Patient Opinion into an independent, not-for-profit, social enterprise. It is separate from the NHS, but funded by subscriptions from hospitals and PCTs (primary care trusts) who want to access feedback to improve services."

The website is not an alternative to the NHS complaints procedure. It forwards any such complaints to the Patient Advice and Liaison Service.

The system is free to patients and is confidential. Postings are previewed before publication, to eliminate defamation and to cut overlong contributions. Patients are asked to comment on medical and nursing care, cleanliness, parking, whether they were treated with respect and dignity or had a proper share of information and decision-making, and whether services were provided punctually.

Each is rated on a five-level scale ranging from very good to very poor and the overall rating worked out from all the contributions made. Anecdotes and comments are encouraged.

Because the service has just started, there are gaps, but it covers all acute hospitals in England and will be extended to the private sector and mental health providers from March.

### **The brickbats ...**

#### **Leeds General Infirmary**

'I dislocated my shoulder playing football and had to go to Leeds A&E. It was one of the most depressing places I have ever been in. The staff were grumpy and short-tempered and treated patients like annoyances'

#### **GP services**

'Whenever I ring up my doctor's surgery to make an appointment, if they don't have any slots within 48 hours they refuse to book me in for a later slot, telling me I have to ring back tomorrow ... it's ridiculous'

## ...and bouquets

### Wharfedale Hospital

'I've just returned home with a FIRST CLASS experience of surgical and nursing care. But the experience was spoiled by some of the worst food I have ever had. The omelette was rubbery and the chips rock-hard'

### Diana Princess of Wales Hospital, Grimsby

'I had a pacemaker inserted a couple of years ago. I have to attend check-ups ... and every time I have been dealt with quickly and competently. I wish other parts of the health service could follow their example'

© The Times, London 15th August 2005



# HOLIDAYS & TRAVEL



If you enjoy holidaying in this country we are pleased to announce that

as a member of PINNT you are entitled to a special discount from Haven's Privilege Holiday Club. You can save up to 50% during off-peak dates, 35% during early summer and 20% during the main school holidays. If you'd like to take advantage of this offer, please contact Rebecca Lee by email at – [rebecca.lee@bourne-leisure.co.uk](mailto:rebecca.lee@bourne-leisure.co.uk) or telephone her on 01442 868001. Please let her know that you are a member of PINNT – Rebecca will then verify your details with our membership secretary. Bookings can only be made by members, for members and their immediate family and friends, and the PINNT member must be included in the booking.

If you have previously been to one of the Haven or British Holiday Parks we would love to hear from you.

## NEW 'TALKING POINTS' LEAFLET

Travel insurance is always of great concern to our members. Many healthcare professionals also look to us for guidance. Changes in the market have meant that it is increasingly difficult for our members to obtain an insurance policy which covers their needs without having to pay an exorbitant price. Being able to define 'fact' from 'fiction' helps considerably in order to gain appropriate cover. To assist them we have up-dated our Travel Insurance leaflet and have compiled a 'Talking Points' leaflet for patients in conjunction with healthcare professionals which aims to ensure that all aspects of travelling are considered, especially 'fitness to travel' and its implications. Full members of PINNT will receive a copy of this leaflet with a future edition of Online.

# READERS' EXPERIENCES

**M**y name is Kate Bainbridge and I would like to share my story with you. I am enterally fed through a PEG and I have five Fortisip feeds during the day. I am unable to have my feed at night as my muscles can't keep feed in my tummy when I lie down.

My problems began when I had ADEM encephalitis (my brain swelled up), then my immune system attacked my mid brainstem so all my muscles stopped working. Therefore when I try to eat, food can go into my lungs and when this happens it makes me very ill. Video X-rays also showed that my muscles were weak and that food would go into my stomach and then bounce back up, so eating is far too dangerous for me: PEG feeding is much safer. I have been on it for nearly eight years and it keeps me active and well. I am a great fan of it – it solves so many problems.

I can't smell or taste anything. I am nil by mouth but I never feel hungry so it is not hard to cope with, although I find I do miss the social side of eating. This can be hard to deal with but I just remind myself of how much safer my PEG feeding is for me. Once I remember the fact that it is keeping me alive and well I don't mind what I'm missing.

I was in a coma, so when I regained consciousness I did not know about the tube in my tummy and for a while I wondered why I did not eat. After a few months I worked it out but this was not a nice time and it would have been helpful if someone had explained what had happened and shown me how my PEG worked.

I am unable to work as my illness has made me very disabled, but I do get out and I take my feeds with me. I have found a great hotel for my holidays called Park House. It is near Sandringham and caters for disabled people and their friends and relatives. There is always a nurse on duty and they are very friendly and deal very efficiently with my feeds.

I am very grateful for my alternative way of feeding. It's hard to put into words how much it has helped me, but without it I would be dead. I became very ill trying to eat and I can now see that it is not worth the worry. PEG feeding throughout the day is just like making a meal, but

easier – I just have to open a box! After spending two years in hospital I can now lead a normal life and get on with things without the extra worry of food.

Writing this has helped me as it has made me think about the way I feed and how good it is!

Kate Bainbridge

**Ed replies: Thank you for writing this Kate. Hopefully your positive outlook will offer encouragement to other readers.**

**H**ello. My name is John Capstick. I am forty-two years old and I have been on HPN seven nights a week since I was twenty-seven, due to a blood clot. I had to have half of my small bowel removed because of a duodenal ulcer, but unfortunately I got another blood clot shortly afterwards and surgeons had to remove all of my small intestine. Pulling through this illness was a turning point in my life and I now live life to its fullest.

I go on holiday in this country most years. I usually go self-catering so that I can put my HPN in the fridge, although if I stay in hotels they are very understanding and also accommodate my needs. Whenever I go away I always take extra supplies of everything to be on the safe side.

I think it is important to try to go out every day and I enjoy doing all the normal things like having a meal out, going to the pub and I enjoy gardening in the summer. I also do voluntary work for a cancer charity, driving patients to hospital appointments and day centres.

It is essential for me to keep well as I am also a carer for my mum who is disabled and my advice to others regarding staying healthy is to do as you have been told by your hospital and never cut corners.

I cope very well with my HPN, treating it as just a normal part of my life: it's the way things are and I just get on with it. It helps if you can see the funny side when things don't go as planned. A few years ago I was going to a



Christmas party and set up my HPN so that I could go straight on it as soon as I arrived home. I came in and connected up my feed as normal. I was a little tipsy and went to sleep. When I woke up the next morning I noticed my feed bag was still full and to my horror I realised I hadn't switched on my pump! Very annoying as I then had to stay hooked up all day, but it wasn't long before I was smiling about it.

I think it is very helpful when new patients are given the chance to contact other patients who have been feeding for many years and can share their experiences. Doctors and nurses do a great job, but it's not like living with it all the time, and as patients we can be of great help to each other.

John Capstick

**Ed replies: I couldn't agree more John - patient contact has proved vital to many of us and we hope that through PINNT we can help facilitate this. Forgetting to switch the pump on made us smile too, as we all do small things that thankfully make us laugh – laughter is a good tonic.**

**M**y name is Wendy Davies and I have a daughter, Anna, who is severely disabled and has been on enteral feeding for nine years. She is bolus fed Nutricia Multifibre Fortisip during the day, seven days a week. Before this Anna wasn't eating and was losing weight as it was taking several hours to feed her even a small amount of baby food.

The turning point in our lives was when Anna had her gastrostomy. This built her up again and the feeding fits into her daily routine very well. Artificial nutrition has had a positive effect on our lives as it has reduced the time it takes to feed her from several hours to about 45 minutes, and bolus feeding works better for her as she cannot tolerate large amounts of feed through the pump. Being artificially fed has given us hope because in the end Anna would have died without it.

We are well supported by our hospital. The nutrition sister and dietician visit Anna at home and are always at the end of the telephone if we need them.

We manage to travel quite frequently, visiting France several times as well as travelling around England, and we have stayed in different types of accommodation including cottages, hotels and camping.

The best piece of advice I could pass on to others is 'don't worry': work around the feeding and try to make life as near to normal as possible. As long as Anna maintains the quality of life she has at the moment she will be happy. Our aim in life is to keep her as healthy as possible.

Wendy Davies

**Ed replies: A wonderful story of encouragement and determination. There are many beautiful places to visit in Europe and in our own country – it is great to hear you are making the most of this when you can.**

## Half PINNT

### PARENT POWER

by Jo-Christa Taylor

**I** am often asked by doctors and nurses if I have a medical background when I am talking about my baby Alice's bowel condition and her requirement for home parenteral nutrition. My response is always to say no because prior to Alice's arrival I had had very little to do with the world of medicine.

This all changed when on day five of her life we found ourselves in an ambulance hurtling towards intensive care and I was thrust onto a crash course in nursing, human biology, pharmacology, gastroenterology and much more, with not so much as an NVQ offered along the way!

Some of the biggest lessons, however, have come from our relationships with parents of children who face similar challenges and these relationships are as precious now as they were to us in the early months of our journey. Alice's condition is rare and so these parents are few and far between but thanks to Great Ormond Street, PINNT and the internet we are now in touch with parents in

Scotland, Ireland and Canada, as well as with those whom we have met during the months we have spent on hospital wards.

Some parents are trained in the 'non-touch technique' and some in the 'aseptic technique', some of our children receive their HPN from one homecare company and some from another, some of our children swim and some do not, some stay largely infection free while some do not. By talking to each other we can all improve the way we do things and feed those improvements back into the NHS. In our case we were trained in two different techniques by two different hospitals and now do a version of 'aseptic' and 'non-touch' that works for us. But it was the support and information we received from another family that ultimately gave us the confidence we needed to fight for the change we wanted. I think that healthcare professionals should be encouraged to put parents of children with similar conditions in touch with each other whenever possible. The benefits to the NHS and to us as families in terms of improving the care and treatment of our children are huge and issues of confidentiality can be overcome by talking to each family individually first before putting them in touch.

The timing must be right, however, as in the early days of our journey with Alice my husband and I believed that a cure may be just around the corner and did not want to meet people coping with parenteral nutrition at home as we were still fighting against this as the solution for Alice.

And although HPN has been the solution for Alice and is now part of our everyday routine, which also includes all the other normal baby activities like mother and toddler groups and family holidays, it is still a great responsibility and the support we receive from other families continues to be invaluable.



Jo-Christa Taylor is mother to Alice, a seventeen-month old baby who is currently HPN dependent.

## Starting School on HPN

I have been asked to write about my son Lucas starting school, an experience I'm happy to share if it can help other parents in a similar situation. Lucas was born six weeks premature with gastroschisis, a condition where a part of the small bowel is exteriorised outside of the body through a small hole in the abdominal wall, and subsequently lost almost all of his small bowel. He spent almost eight months in Birmingham and Great Ormond Street Hospitals before we finally got him home. By the time Lucas started pre-school, he no longer had his NG tube, and was eating some solids, but was still dairy and wheat-free. He was on HPN seven nights per week, and to make things worse, the last VQ scan had revealed that Lucas had pulmonary embolisms, so he was on Warfarin to thin his blood!

By the time Lucas started 'proper' school, he was no longer wheat and dairy-free, and was able to have two nights per week off his HPN. However, the days after a night off, Lucas often had hypoglycaemia, and therefore had to have his blood sugars monitored regularly. It had been suggested to me that Lucas should attend a special needs school due to all of his medical requirements, but I was adamant that Lucas attend a mainstream school, in keeping with his normal development.

Here are some of the things that we did to ensure that Lucas's school experiences were as successful as possible:

- The community nurses and an HPN nurse from Great Ormond Street Hospital were happy to come and do some training with the school staff, but to make it more personal to Lucas, we did our own training too.
- We printed out a clear 'Problem Solving' sheet, detailing what should be done in case of any eventuality, i.e. temperature, chest pains, a damaged line etc.
- We also made our own 'Grab Sheet' and had it laminated for the school to keep: this contained all of Lucas's vital information, such as name, address, date of birth, allergies, blood group, main medical problems, list of medicines, number of the local hospital and emergency contact numbers. If they did

have to take Lucas to hospital, they had all of the information they needed!

- We got Lucas a 'Medic Alert' band to wear: again, in case there was an accident, the paramedics would have some idea of what they were dealing with.
- We gave the school an 'emergency pack' containing gloves, line clamps, gauze etc, and showed them how to use it.
- At pre-school, I stayed in the classroom with Lucas for about the first term, I was so nervous! But the staff were great, and I finally felt confident that they knew what they were doing with him, and by his second year there, I was even happy for them to take him to Legoland without me.
- When starting school, our educational psychologist was great, and attended many meetings at the school we chose in order to determine what Lucas's needs would be. There was also the long, drawn-out process of applying to the LEA for the 'Statement of Needs' which gave Lucas an extra 10 hours per week of one-to-one attention, which they use at playtimes and lunchtimes.
- All of the staff at school attended the 'Lucas Training', as they all take turns to supervise lunch and playtime, so they all needed to know what to do in an emergency.
- As well as having the 'Problem Solving' sheet, the 'Grab Sheet' and 'emergency pack', Lucas also takes his thermometer and his blood sugar monitor to school with him.
- I stayed with Lucas for the first week at school, to ensure that everyone was confident about Lucas's needs, and knew what to look out for.
- The school were great about not rushing Lucas to go full time. He got incredibly tired at first, so we built up the hours gradually, starting with mornings only, then staying for lunch, then one whole day. He only started full time in the new year, and if he's tired and not coping very well, the school just gives me a call and I collect him.

- To minimise the risk of Lucas's line getting pulled at school, we put his bath dressings on in the morning so that his entire line site is completely covered up.

I could go on! On the whole, we've been very lucky indeed with Lucas's schools, and have found them to be more than happy to help and oblige Lucas's needs. Lucas loves school, and when the children ask him why he has a 'big plaster' on his tummy, he just tells them that it's to stop him from getting an infection! No one seems to take any notice of Lucas's 'differences', and he's treated just the same as all the other children, which is just what we wanted. I believe that with so many things in their lives being 'different', it's important that children on HPN or NG feeds have as close to a 'normal' school career as they can. It seems to be working well so far, and watching Lucas as an angel in the Christmas nativity play just summed it all up for me! Good Luck!

Lia Moran

**Ed replies: Some great tips Lia! If anyone else has a story about any aspect of school and feeding, please write in – we'd love to share your story.**



# REGIONAL REPORTS

## WALES

Unfortunately, it wasn't possible to arrange a meeting around Christmas as I had hoped as I had to go into hospital for a few weeks before Christmas. Then I had arranged a meeting for March 2006 but once again I was feeling under the weather and when I went to clinic I found that quite a few of the patients had picked up some bug or other so we cancelled the March meeting.

Now we are all looking forward to spring and our next meeting will be in Swansea on the 13th May 2006. However, the patients in Wales are quite spread out and many of the patients in north, mid and west Wales find it too far to travel to Swansea or Cardiff. If any of you have problems please contact me and they can be discussed at our meeting and another patient may have an answer or suggestion that might help. I try to keep in touch with you all though and hope that one day soon I will be able to meet you personally.

So until I have more to tell you after our May meeting, happy holidays to you all and 'hooray', summer won't be long arriving.

Letty Johns

## WEST MIDLANDS

Our first Dudley Half PINNT meeting in January went very well with two parents and two children attending together with two workers from pre-school services. After coffee we all went and enjoyed the sensory room at Kids Orchard Centre while chatting.

Our following monthly meetings were affected by illness or other commitments. However, Hazel Blackmore, a nurse from Homeward, came and saw the Children's Centre and had a chat about artificial nutrition. Homeward kindly provided me with a pack of Patient Advice Sheets which hopefully patients and carers with this company should have received with their starter packs.

The next two Half PINNT meetings will be on Friday 26th May (Speaker from the Citizens' Advice Bureau) and Friday 23rd June (speaker to be confirmed) from 10am – 12 noon and everyone is welcome. Please let me know of other venues in the West Midlands where I could arrange a PINNT meeting.

You can contact me by telephone on 0121 5207179 or by email on [teresa\\_culverwell@yahoo.co.uk](mailto:teresa_culverwell@yahoo.co.uk)

Teresa Culverwell

## EAST ANGLIA

We have been busy working hard with the arrangements for PINNT's Annual General Meeting which East Anglia is hosting this year on Saturday 3rd June 2006, in Cambridge. Please put this date in your diary, in red! More information will be with you soon.

Jackie Huff

## TRENT

It is with regret that I am stepping down as Regional Co-ordinator. I feel that I no longer have the necessary time now that I am Chair of LITRE and taking a greater role within BAPEN.

If you feel that you would like to do this job for PINNT, then please contact either myself or Barbara on the numbers given in the Contact Us section.

Hopefully one of you will be enthusiastic and will give our Trent region members some enjoyable meetings!

Justine Bayes



**East Anglia**

Jackie Huff 01767 225631

**Scotland**

Sharon Bell 0141 959 6701

**South East**

Carmel Lavery 01372 275420

**Northern Ireland**

Raymond Toulson 028 9260 4705

**North of England**

John Sturt 0191 565 8651

**Wales**

Letty Johns 01792 521618



# POST ROOM

I just had to respond to Jo-Christa Taylor's features in the last edition of Online, particularly 'Unwritten Rules', which had me crowing with laughter!

We always used to joke about these problems that no-one tells you about when you leave hospital with your child on HPN. Lucas was on both HPN seven nights a week, and NG tube feeds overnight, and we'd often find him in the middle of the night in a complete tangle! And as Jo-Christa said, not funny at the time, but looking back, it is amusing. Obviously, parents are still having just the same problems.

Our son Lucas has short bowel, and finally left hospital after eight months. Amazingly, he's now 5! The advice I would like to give to parents with young children on HPN (and all the extras), is that it does get easier with time. We always made an effort to get Lucas involved, and talked to him about what we were doing to him, and why. He now has a very good understanding of what's going on, and knows when it's vital that he doesn't touch.

Having said that, as time goes on some problems lessen, but others appear that we hadn't even considered. Lucas is now on just HPN, but desperately wanted his independence during the night to go to the toilet (he has chronic diarrhoea, so this is a frequent need). The problem was that I was worried about his giving set getting caught up on something, and pulling out his line as he dragged his 6060 rucksack along the floor (too heavy to carry). Our solution was to buy a length of clear, plastic tubing from B&Q (about the width of a Smartie tube), cut a slit all the way up the side, and wrap this around from the rucksack and up along his giving set. This enables Lucas to get to the loo with very little danger of getting the line stuck anywhere, as the tube is too big to get caught up. Lucas is overjoyed with this development, but has now realised that he's free also to drag his bag into my room and get into bed with me – something we'd never experienced before as he was always tethered to his bed!

It's been a long, hard struggle, and it's not over yet, but Lucas has surpassed all of our expectations about what we thought he'd be able to do. He's now at a mainstream school full time, and loves it. With a positive attitude, we

don't let the HPN take over our lives. Lucas isn't defined by his illness, he just happens to be a bit different, and we only panic about him now when we need to, rather than all the time like we used too!

Good Luck.

Lia Moran

Well done everyone. The new look Online is extremely eye catching and the features are just as good – keep up the good work.

Jean

The new Online was definitely worth the wait. Although I missed the December edition it was lovely to receive such a colourful magazine. I have written in the past but feel I must contribute more now as there are so many people doing a lot for PINNT – we just don't realise it!

Janet

Improved imagery without compromising on content – onward and upwards, a good magazine just got better. Thanks.

Thomas

Congratulations to you all regarding the latest Online magazine. It was a great read, very well put together, and what a 'look' it has now. Well done.

Rosemary Martin

**Ed replies: Thank you for your generous comments - you obviously like the new look Online. We promise to keep putting in the effort if you continue to contribute the feature!**

I am a forty five year old woman on an enteral PEG with jej extension. I currently use a Clearstar portable pump which is housed in a slim rucksack. I have encountered some problems whilst out shopping with the rucksack on my back. Unfortunately some shops do not allow large bags or rucksacks to be carried in store, especially places of interest such as pottery shops and antique establishments. I was recently refused admission to an antiques fair, even though I explained that it was needed for medical purposes.

Is there a card available which explains that my condition requires this bag to be carried with me at all times? It's so embarrassing to stand there and explain in front of other customers. I feel if it was possible to produce a card with a brief explanation, it would be far more dignified.

Please could you let me know if such a card exists?

Barbara Lowe

**Ed replies: There's no such card at the moment Barbara, but perhaps this is a project that PINNT could look into. If any of our readers think they could make use of such a card, please let us know and we will follow it up.**

I am a new member of PINNT and have just received my first copy of Online which I thought was a very good magazine given the specialised readership. Thank you for all the work done in producing it.

I am also writing to request a copy of the card you can show in restaurants. I hope in the foreseeable future to be able to eat a limited amount and this card would be very useful.

Sr Caroline Campbell

**Ed replies: You should have your card now Caroline – please do let us have feedback on how useful you find it in the future.**

## PINNT LEAFLETS

### ADVICE ON CLAIMING DISABILITY ALLOWANCE AND CLAIMS AND APPEALS

– available free from PINNT to members

## 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.



## 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 to receive an application form.

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## NEXT ISSUE

## Online

Please send letters, articles and suggestions for future features to:

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Email: [barbara.berry3@ntlworld.com](mailto:barbara.berry3@ntlworld.com) – please put PINNT in the subject line.

Please remember when responding to letters, that other members may appreciate your advice. All letters will be printed unless we receive notification that you do not want it reproduced in Online.



Registered charity 327878

**Online** June 2006

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## LIMITED SPACE NOTICE

Thank you to everyone who has written in.

Please remember that we have limited space, so if you are not featured in this edition of Online then you will be in the next.

Please do keep the stories and letters coming.

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