



Registered charity 327878

## IT'S PERFECTLY ACCEPTABLE TO BE AN INDIVIDUAL

The common factor that unites us within PINNT is our need for artificial nutrition. Our members are either receiving it, caring/supporting someone either professionally or personally, working within the field that supplies or manufactures the products, supplies or services we receive.

Frequently I receive calls from people who are just starting out on their new treatment. Calls vary and it is rewarding to be able to offer advice that has been gathered from a wealth of useful sources, about how to cope with the initial impact of home feeding along with the adjustments necessary to incorporate it into what is commonly referred to as a 'normal lifestyle'.

When I am asked to talk about life on artificial nutrition I find it necessary to stress that despite our common bond we are all individuals with a unique blend of personal goals. Many people forget that the treatment we receive rectifies the existing or approaching malnutrition but does not eliminate the daily difficulties of living with an illness.

Everyone on artificial nutrition does an amazing job of coping; we juggle a serious and complex treatment with varied and

diverse activities associated with our normal lives. We must **never** feel inferior if our individual achievements do not fall into line with those of other people – each one of us should be proud of our individual successes, no matter how great or small.

Sadly, I've spoken to people who feel they're not making the grade if they're not as active as other people, or feel they are not making the most of themselves if they do not feel the need, nor have the energy or desire, to go out and prove something to the world.

For many artificial nutrition will improve well-being but it will not do the same for everyone. Even those of you with the same condition will have different expectations, outcomes and emotions.

So if you are reading this and have at some stage thought 'why can't I do that' or 'well if they can do it perhaps I should' – don't unless it's realistic for you.

Holidays abroad seems to be an 'expectation' that cause some of you great concern. Sensible people may wish to test the process by holidaying in the UK before venturing abroad - that's okay too!

*continued overleaf...*



**Price £2**  
Free to Members

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I feel slightly aggrieved when I hear some of the comparisons people are given when they may be considering a holiday abroad - 'they told me it was easy to arrange', 'I've been told others manage it perfectly well' – fine, good for them but do not feel under pressure to conform to other people's expectations or aspirations. You will know when the time is right to consider it. Careful planning is the key factor and don't do it because you feel you ought to, do it because want to. For those of

you managing a painful and fluctuating disease there is more to consider than the feeding.

As we progress with our feeding, and time allows us to accept, cope and modify our lives trying new things may be the right thing to do. It's tempting to push the boundaries, defy sound medical advice or insist on getting things our own way. My advice to those facing dilemma's is to discuss, negotiate and question any response you find unacceptable

or do not understand – there may be a logical reason for a 'no' or perhaps the question is not clear in the first instance.

Personally I've known many people achieve 99.9% of their goals – most things are possible with realistic expectations.

**JUSTINE**  
ON BEHALF OF THE  
EXECUTIVE COMMITTEE

## BENEFIT NEWS

# DISABILITY RIGHTS

**We realize that this information on Disability Rights does not affect all members, but PINNT likes to keep you informed with what is happening.**

October 2004 marked a landmark for disabled people. From this date anyone providing a service has to address those physical features which make it difficult for disabled people to use their services. This will mean that service providers - including shops and restaurants, pubs, clubs, gyms, swimming pools and hospitals - will all have to make "reasonable adjustments" to their premises or the way they provide their services to ensure they are not unreasonably difficult for disabled people to use. The Disability Rights Commission (DRC) has launched a campaign across England, Scotland and Wales to highlight what service providers should be doing to make their services accessible.

### Disability Right Commission (DRC)

The DRC is an independent body set up to eliminate the discrimination faced by disabled people and

promote equality of opportunity. When disabled people participate - as citizens, customers and employees - everyone benefits. Disabled people already have important rights under the Disability Discrimination Act (DDA) when it comes to using services or accessing goods. From October 2004 these rights will be extended.

### Disabled Peoples' rights to services have been introduced in three stages:

1. Since December 1996 it has been against the law for service providers to treat you less favorably because of your disability
2. Since October 1999 service providers have had to make "reasonable adjustments" for you, such as giving extra help or changing the way they provide their services

3. Since October 2004 service providers have to make other "reasonable adjustments" to their premises so that there are no physical barriers stopping or making it unreasonably difficult for you to use services.

The Disability Rights Commission (DRC) has produced a Code of Practice for service providers about the DDA. It will be taken into account by the courts where relevant and it guides disabled people and service providers on how reasonable adjustments should be made. It is available by telephoning **0870 600 5522**, priced at £13.95 and is available in a range of formats. You can also buy it from the DRC website: **[www.drc-gb.org](http://www.drc-gb.org)**

**GEOFF SIMMONETT**

## FROM THE CHAIRMAN



It's our final edition with Dawn at the helm and I think we would all like to extend a huge 'thank you' to her for all the hours she has sat poised at the computer editing our magazine. Dawn has been volunteering time to PINNT for more years than I can recall and we've certainly had a few laughs along the way. See the special feature further on in the newsletter.

PINNT continues to offer support as and when it's needed and due to the summer holidays the usual requests for advice regarding travelling have kept the phone lines hot. We are able to provide current advice thanks to the feedback we receive from our regular travellers.

Internally we are still working on the many policies we need to have in place which will be added to our handbook for all volunteers, you would be amazed by the amount of documentation it takes to maintain our charity to ensure we conform to charity law. Please keep your contributions coming - we really do love hearing from you.

**CAROLYN WHEATLEY**  
CHAIRMAN PINNT

## VOLUNTEERS WANTED

PINNT needs more volunteers to help with routine tasks, attend the occasional meeting and to offer new ideas and suggestions. Sadly again this year we didn't receive any new nominations for candidates to join the Executive Committee. Are we really that scary?

There are a number of projects we would like to start but our few overburdened volunteers are working so hard, this remains impossible. We get offers for IT support which is wonderful, but sadly there are other things we need help with. We are currently looking for volunteers to help patients by working on questionnaires and for people who can carry out some office work – all of which contributes to the overall success of PINNT. Are you a whiz with figures and could possibly offer assistance in relation to finances? With enthusiasm you can help to ensure PINNT's future - if so please contact Justine Bayes on 01933 316399 or email her on: [justine@bayes3721.fsnet.co.uk](mailto:justine@bayes3721.fsnet.co.uk) - **your charity needs you!!!**

“ Don't forget to look on [pinnt.co.uk](http://pinnt.co.uk) where you can access all kinds of PINNT information, some of which is available to download. ”



### EDITORIAL BOARD

- Dawn Carter
- Carolyn Wheatley
- Patrick Hastings
- Prof. Gil Hardy
- Carola McRae

### PINNT LEAFLETS

ADVICE ON CLAIMING DISABILITY ALLOWANCE AND CLAIMS AND APPEALS  
Available free from PINNT to members

## WELCOME NEW MEMBERS

### New Adult Members:

Yvonne Mahase  
Dorothy Smith  
Jayne Paterson  
Nikki Jones  
James Saturley  
Donald McPherson  
Ian Simpson

### New Child Members:

Alice Taylor  
Rhea Talwar  
Damian Simpson  
Kieran Whiteside  
Michael Goldney

PINNT extends a warm welcome to all of you and to your family and friends who have joined as Associate Members.

## FROM THE EDITOR



Recently I was flicking through an old issue of Online when I noticed my first contribution to the newsletter which began with the words 'As a relative newcomer to HPN, having been on it for 7 months'. I read through it with interest and realised how my life had changed since then. In those early days I recalled how difficult it had been to deal with the loss of my health, and how I turned to PINNT to fill some of those large gaps in my life.

Volunteering with PINNT gave me the opportunity to build skills, gain confidence and believe in myself. Some 16 years later, I now work full time as a manager of a busy volunteer development agency, am working towards an MSc degree, have just bought a fast little sports car and during this time met my partner, got a dog, moved into our dream home and have just bought shares in an

aircraft. By the way he's the pilot, not me! So why am I telling you all this? Well, firstly I find we all too often focus on the negativity of life on TPN and not on what it enables us to do but also PINNT was instrumental in turning my losses into gains. Yes, there have been difficulties along the way but back in 1989 I would never have believed I would be writing this letter.

Reflection is a good thing thus, reading that first letter some 16 years later I realise that the gaps are no longer there and so this will be my last issue as Editor of Online leaving it in the very capable hands of my successor who I'm sure will do a wonderful job and be able to give it the time it needs and deserves. It is tinged with a little sadness as I will miss the good friends I have met during my time both as Editor and Chairman of PINNT – you know who you are and please stay in touch.

So, if you are reading this 'as a relative newcomer to HPN or HEN' ...go on take the plunge, fill those gaps and volunteer as you too might be writing a similar letter some years down the road!

**DAWN CARTER**

**Now you've read exactly how PINNT can be good for your health please note the sports car, aircraft and dream home have not been personal rewards from PINNT for Dawn's years of voluntary work – if only!!**

Dawn's first appearance at a PINNT meeting was at our AGM in Birmingham. At first I thought she'd brought along a rather slim friend, but no she was actually connected to her feed via a rather cumbersome pump attached to an old fashioned hospital drip stand. Even in those early days Dawn was determined to build on her situation and although she was rather shy at the time it was apparent that there was an inner strength that would enable her to eventually overcome any dilemmas that she has faced.

Within a short space of time Dawn was an active volunteer. Throughout her time with us she has performed numerous tasks; LITRE Chairman, PINNT Chairman, Online Editor, Executive Committee member, representative at Oley conferences, Bapen council representative – to name but a few! Those in effect could be classed as the 'glory jobs' but she never shied away from the nitty gritty of other tasks such as baking for the children's Christmas parties in my small flat in Essex and even dressing up to entertain the children in a costume she'd never wear in public for any other reason!

During her time on the Executive Committee and in her position as Chairman we worked hard, played hard and learnt lots. Perhaps



I should recall our evening in a pub in Wales on the children's climbing frame ... second thoughts perhaps not!

Combined with her professional role within PINNT, in addition to personal beliefs, Dawn contributed to much of the hard work we undertook to educate healthcare professionals as to exactly what life 'on line' really meant. I recall us doing a double act at the nutrition nurses meeting one year – we left them speechless, but soon recognized that our efforts had contributed to a change in attitude, professionals started to appreciate that we were 'people' not just 'patients' with lives to live and personal goals to achieve.

Without a doubt one of Dawn's proudest achievements must be the very magazine you are reading today. We are commended in many quarters for our quality newsletter and it's fair to say thanks to Dawn it's been one of our least problematic projects.

While it is always sad to lose the support of a stable and trustworthy colleague we are thankful for the years of voluntary work Dawn has given us. We know she will remain a member and hopefully even contribute something to Online to update us on her progress.

So from everyone in PINNT may I extend a huge debt of gratitude to Dawn for her valuable contributions over the years, we wish her well in all her personal ventures and pray she remains happy and healthy.

**CAROLYN WHEATLEY**

## 6060/BAXTER UPDATES ...

You may not have been given any recent updates but please believe us when we say that work continues behind the scenes. The development of the new rucksack is finally complete and the rigorous testing process has now been done. This has been carried out by the manufacturers themselves along with the patient group who put the new rucksack through its paces. Additionally the process required to gain the CE mark has also been completed.

Two rucksacks have been developed, one which will be able to hold up to 2 litres of fluid and the other up to 4 litres. Just about all the original complaints have been addressed and we are delighted that this project has been led by the UK.

The final process has been slightly delayed by some reorganisation within Baxter in the USA. As this is a US product the final process must be completed there by their engineers and marketing department. The UK contingency has worked tirelessly to ensure they have all the necessary paperwork and equipment to complete the final phase. There has also been a slight delay due to the supply issues with some of the parenteral nutrition bags

which are required for the final testing process. We are assured that this project is a high priority and that November will be the month when we see the fruits of our labour, thanks to our 'testers' who have responded very quickly on numerous occasions to our cries for help.

We haven't always had as much time as we would like to post samples on and give a long trial period, but we have worked within the minimum time scale to ensure we keep to our deadlines. Obviously many of you will be wondering how you will be able to get or have the opportunity to look at one, watch this space and we'll keep you posted.

**UPDATE** - Whilst on the subject of the Baxter 6060 we would like to inform you that the 'old style' giving sets are no longer available. These sets were the ones we used prior to the round disk being introduced which is used to help insert the set into the feedbag. Limited supplies of the old style set were available but supplies have now been exhausted. We have an assurance from Baxter that the new set which was tried and tested by a panel of patients from PINNT will be available in November (believe that if you dare ...!!!!)

## LITRE Looking into the requirements for equipment

Got something to say about a piece of equipment you use?

Something you could pass on to someone else?

Questions you need answering?

If so contact Geoff Simmonett, 4 Loughland Close, Blaby, Leicester LE8 4PB or e-mail [Geoffsimmonett@aol.com](mailto:Geoffsimmonett@aol.com)



# GENERAL SECRETARY'S REPORT



## Hello Everyone

You will see elsewhere in Online the report from our AGM. These are some of the other activities PINNT has been and continues to be involved in:

- We have contributed to the British Society of Gastroenterology guidelines for the 'Management of Patients with a Short Bowel'.
- The second draw of the PINNT Prize Pot has taken place – you will see the lucky winners elsewhere in this edition.
- We are carrying out a review of the workings of our Regional Groups, following on from the survey that we did. Our first step was to send out a form asking if people wanted to be kept on the mailing list for regional meetings, only be notified of ones in certain areas, or to be taken off the mailing list. This was sent out with the meeting invitation to the Trent region members and associates, along with a stamped-addressed envelope for their reply.
- In November there will be a new Chairman of BAPEN (British Association for Parenteral and Enteral Nutrition). Alastair Forbes is stepping down to make way for Marinos Elia; PINNT voted for Professor Elia and is confident that the patient's voice will be heard loud and clear under his Chairmanship.

- A new approach has been established for attendance at BAPEN Council meetings. Geoff Simmonett and I will attend on a rota basis, supporting Carolyn our Chairman.
- I have agreed to sit on the BAPEN Communications Committee, so relieving Carolyn of one of the numerous committees she is on.

**You will see an announcement about the introduction of a membership fee. Please continue your membership - we can only strive to make life better for those on artificial nutrition with the backing of a strong membership.**

**JUSTINE BAYES**

## AGM REPORT 2005

Following an industrious executive committee meeting on Saturday 11th June we rolled straight into our AGM. We were confident for a healthy turnout. RSVP's were returned to Justine, our General Secretary, with many sadly unable to attend but many sent thanks and best wishes to the EC, PINNT and all those who continued to strive with PINNT's best interests at heart.

It was lovely to see some familiar faces along with a couple of new members. We were astounded, what a turnout - yes we mean exactly that: what turnout? With EC members I think we stretched the total of attendees to 15! Where were you??? We've always been told

that London is a popular location and 'if you held it in central London we'd definitely attend'.

Are we down hearted - No! This obviously indicated the level of satisfaction with the work we continue to do, the support we continue to provide and the information we tirelessly toil over to produce. Everyone on the EC contributes to the AGM but I would like to thank Sarah and her family for dedicating a lot of time to the preparation and distribution of the AGM notices.

People cry out for 'parties' or 'special events' - sadly we need to be able to justify the costs of these and if we cannot rely on support for the one event where we have the opportunity to take time out

to pat ourselves on the back and extend a heartfelt thank you to all our volunteers for the amount of time and dedication they provide to PINNT, then it's little wonder that they feel unenthused to commit more time to events when we cannot guarantee your support.

Having said all of this, the AGM went really well. Excellent contributions, suggestions and comments from those present have given the EC some questions to ponder over. Many of you said you'd love a special event to mark our 20th Anniversary in 2007. Please show your support before then because without a guarantee of members' support, it is futile to think of celebrating in 2007.

**The Executive Committee.**

## INTRODUCTION OF MEMBERSHIP SUBSCRIPTIONS IN 2006

At our 2004 AGM we raised the issue of a membership fee following numerous questions received by the Executive Committee as to why we do not levy a fee for full membership. We detailed why we had never done so in the past but respected the communications we'd received and therefore felt that it was not a charge the EC wished to apply without consent of the membership. Members in attendance unanimously voted in favour of the introduction of a subscription of £5.00 and this comes into effect from next year, January 2006.

As you can see from the following list of benefits of being a member, PINNT offers exceptional value for a fiver:

- Four free copies of our newsletter Online per year (list price £2 each)
- A free copy of our acclaimed and invaluable Holiday Guidelines (list price £5)
- Our extensive range of literature

- Our Restaurant Card
- Direct access to support and information, by telephone and email
- Access to Regional Meetings
- Being part of a unique network where people genuinely understand and support your concerns
- And if we know your birthday, we'll send you a card!

We hope you will continue to support your charity and the work we do on your behalf by continuing your membership when the small fee is introduced. Many members at our 2004 AGM felt that this amount was too small, but the Executive Committee felt that £5.00 would be an appropriate amount, given that many of our members have a limited income. We would encourage anyone who wishes to pay a higher level to do so by giving an additional donation. Our Associate rate remains at £10.00 and the corporate rate at £50.00.

## TREASURER'S REPORT



No major donations have been received since my last report; however, some individual donations are still coming in. Subscriptions and memberships have been coming in thick and fast, although donations are lower this year than in the past few years. Thanks as always for your contributions and gifts to PINNT, as always we try and make sure they go to the best causes and services that we can.

We would like to express sincere thanks to Phil Hinckley at Point One Print for his generous donation to PINNT. This has been given in various ways and we are indebted to him for his consideration and support of PINNT.

I look forward to talking to you in the next edition in more detail, I'm moving house at the moment and it is very trying and taking a lot of time.

Kind Regards

**KEITH NURCOMBE**

### PINNT PRIZES & POT ENQUIRIES

The second draw of the PPP took place in July and the winners were:

Victoria Bailes - 165 ■ Alexis Wolfe - 184 ■ Paul Glicker - 104



### NEXT ISSUE

Articles and letters to: Barbara Berry, 53 Leicester Street, Long Eaton, Nottingham, NG10 1FJ or e-mail [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.

# LITRE'S CATHETER OCCLUSION SURVEY

One of LITRE's projects in 2003 was a survey to assess the prevalence of line blockages in Home Parenteral Nutrition (HPN) catheters and the methods used to try to prevent and resolve the problem. Below is the abstract of the results which have caused a lot of interest and hopefully this project will be the basis of further work. Thank you to everyone who helped by completing the questionnaire.

Blockage of a HPN catheter is a common problem reported to the LITRE committee. The aim of the survey was to determine if catheter occlusion is more common in HPN patients infusing lipid, flushing the catheter with saline (rather than heparin), or having no heparin in the parenteral feeding bag.

A questionnaire was sent to all PINNT members having parenteral nutrition and to the two Intestinal Failure Units at Hope Hospital and St Mark's. The questions were about line blockage, lipid infusion, line flushing, the addition of heparin to the PN bag, and methods to treat line blockage.

Of the 360 questionnaires, 103 (29%) were returned. Line occlusion was reported in forty-five (44%).

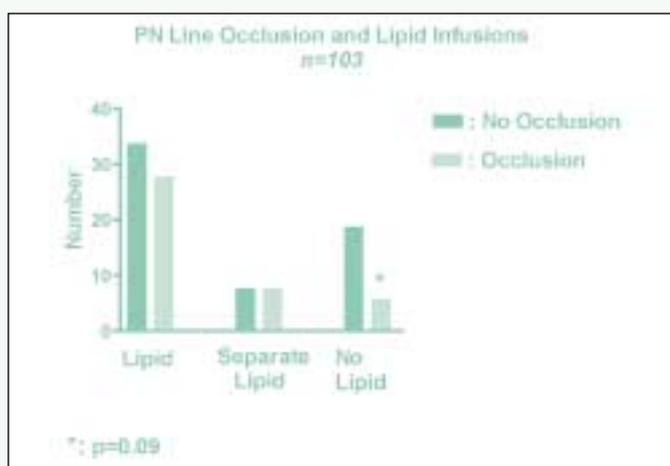
	No Occlusion	Occlusion
<b>Lipid</b>	<b>30</b>	<b>27</b>
<b>Separate lipid</b>	<b>9</b>	<b>11</b>
<b>No lipid</b>	<b>19</b>	<b>7*</b>

The table shows the effect of lipid on line occlusion.

\*p=0.06

Line occlusion occurred in 5, 13 and 24 patients using heparin, using saline or a saline then heparin flush after the PN infusion respectively, compared with 12, 14 and 25 without. Of thirty-two who had heparin added to their PN bag line occlusion occurred in ten compared with thirty-three of sixty-five (51% having no heparin in the bag (p=0.05)). Of those forty-five who had a blockage, thirty-five (78%) took no precautions to prevent blockage though six out of ten used an alcohol flush.

In conclusion, occlusion of an HPN catheter is common and patients who do not infuse lipid may have fewer line occlusions than those who infuse it separately or in an all-in-one bag. Patients who have heparin added to their PN bag may also have fewer line occlusions. Randomised prospective controlled studies are needed to further investigate the role of lipid infusions, non-heparin flushing of the catheter and the addition of heparin to PN bags.



Flush	No Occlusion	Occlusion
Heparin	12	5
Saline	18	16
Saline + Heparin	23	19

# DISABLED COUNCIL TAX REDUCTION

**This article has been written by Sharon Jacobsen as it is several years since we last informed members of this reduction**

Did you know that as a disabled person you may be eligible to a reduction in your council tax? Unfortunately, information about financial benefits available to disabled people isn't always common knowledge and Disabled Council Tax Reduction is no exception.

## Who Can Claim?

Claimants must prove that the property meets their needs as a disabled person. Your local authorities will have specific guidelines that need to be fulfilled, usually one of the following, although the actual wording may differ from one local authority to another.

The property must have one of the below and being used specifically to meet the needs of the disabled person:

- an additional bathroom
- an additional kitchen
- use of a wheelchair inside the house
- any other room used mainly by and required by the disabled person

Although the fourth requirement appears to be open to interpretation, a bedroom that's used to store supplies and needs to be kept scrupulously clean because of 'hooking up' routines won't be accepted if it's still being used for its intended purpose – to sleep in. In order to meet this requirement, the room must be used for something other than its original purpose. A spare bedroom used as a 'clean room' will be accepted if a clean environment is essential for medical purposes and nobody ever sleeps in there.

A garage used for storage purposes may be accepted but only if so much storage space is needed that there's no longer room to park a car there. Similarly, an outhouse could be accepted as long as nothing other than medical supplies are stored there. A living room that has been transformed into a bedroom for a person who isn't able to use the stairs will be accepted but only if the family no longer use it for recreational purposes. The living room has to have been lost. The same goes for dining rooms or any other reception room. Few of us have houses with second kitchens but a second bathroom isn't such an unusual feature. If one is used as a 'clean room' and for this purpose only, your application may be accepted.

For an application to be successful, your disability must be substantial and permanent. If there's any doubt

as to the severity or permanency of the disability, most local authorities will, in addition to accessing your home themselves, require supporting evidence in the form of a doctor's letter.

As every application should be accessed on its own merits, it may still be worth applying even if your particular requirements differ from those covered by the guidelines. If in any doubt, contact your local council tax office to discuss your situation.

## How Much Reduction Can I Expect To Receive?

Successful applicants will be charged council tax at one band below the band they belong to. Should you already be in "Band A" then you'll usually be offered a reduction equivalent to the difference between "Band B" and "Band A". Please bear in mind, however, that some councils work this last reduction differently.

## How Can I Apply?

Most local authorities have a special application form, some of which are available to download from the Internet. However, if you 'phone your local Council Tax Office (your local council will be able to give you the number), they'll be able to advise you.

# REGIONAL REPORTS

## NEWS FROM SCOTLAND

I want to share with you what a wonderful meeting we had in Dundee. I was worried as it was the first time I have held a meeting in this part of Scotland although I have been eager for some of the members from this area to be able to attend, I know that travelling to Glasgow is not always possible for everyone.

The meeting gave me an opportunity to meet 13 members that I have been corresponding with but have never met. The event went very well and we had Janet Baxter from the Scottish Clinical Network attending who talked about a Quality of Life questionnaire that she is currently

working on and was keen to seek the views of PINNT and the patients. Well she came to the right place and we shared the points that we all thought would help the medical staff improve the quality of life for patients on HPN.

The rest of the time we spent chatting, getting to know each other and I can say we are looking forward to holding another meeting in Dundee in the near future. I want to thank all of the members for attending and showing their support to myself and PINNT.

**SHARON BELL**

### REGIONAL CO-ORDINATORS:

#### East Anglia

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#### Wales

Letty Johns 01792 521618

#### Trent

Justine Bayes 01933 316399

## NEWS FROM THE SOUTH EAST

Our next meeting will be held on Saturday 10th September 2005, in The Spa Lounge of the Ebbisham Centre in Epsom, Surrey. It is a year since our last gathering and we should have lots of news to catch up on.

One of our regular members will be talking about his holiday in South Africa. We will also have some children's activities and afternoon tea. I will send invitations nearer the time but if anybody would like to attend and does not get a personal invitation please get in touch with me on the telephone number provided and we will make sure that you are added to our mailing list.

**CARMEL LAVERTY**

## NEWS FROM THE TRENT REGION

Unfortunately the planned meeting for 9th July at Queen's Medical Centre in Nottingham had to be cancelled due to only two acceptances. I would like to thank those of you who returned the mailing list form as this will enable PINNT to plan our meetings in the Trent region and only send invitations out to those who have indicated that they wish to receive them.

Our next meeting will hopefully be in the autumn.

**JUSTINE BAYES**

## NEWS FROM WALES

A meeting was held at the University Hospital of Wales in Cardiff on Saturday, 2 July 2005. Around 50 invitations were sent out so I was rather disappointed when only 15 people turned up. Many members sent their apologies as they were from mid or north Wales and it was too far to travel to Cardiff. Also I had specified that the main subject of the meeting would be of interest mainly to HPN patients.

However, Dr. Barney Hawthorne, the gastroenterologist at the University

Hospital of Wales, kindly gave us an interesting talk on what is happening to HPN patients in Wales. As Dr. Hawthorne explained it will all take time but it is being looked into and beginning to take shape and I have included his report in Online. Many questions were asked and Winnie Magambo who is the TPN nurse at the Heath Hospital and Dr. Hawthorne responded.

Two representatives from Calea attended, Ms. Beverley Young and Mrs. Moira Kallis, and they very

kindly donated a cheque for £50 to PINNT. We also managed to get £40 from the raffle. In fact I think everyone went home with a prize.

We hope to have the next meeting around Christmas time and this one will be held in Swansea. So, everyone get out their party dresses and funny hats and get ready to celebrate. Until you hear from me then, have a great summer, a good autumn and we will make it a fun Christmas.

**LETTY JOHNS**



## HOME PARENTERAL NUTRITION IN WALES: PAST, PRESENT AND FUTURE

### Background

There are two centrally-funded intestinal failure units (IFUs) in the UK. These are at St Mark's Hospital and Hope Hospital, Salford. They have been funded by the Department of Health to provide treatment for intestinal failure, and as a consequence of this, have built up expertise in Home Parenteral Nutrition (HPN), as many of these patients need long-term intravenous feeding.

### Problem

Over the past 10-15 years, surgical expertise has been steadily improving throughout the UK. The level of care in intensive care units has also risen. This means that many patients previously not surviving have recovered from catastrophic illnesses. These patients often need HPN. The numbers of patients living long-term on HPN

is also rising, so overall numbers of patients on HPN are going up.

In the past, many of these patients would have been sent to the intestinal failure units, but it is not always convenient or acceptable to patients to travel long distances, particularly for long-term follow-up. In addition, the IFUs cannot meet demands for care of patients on HPN, and have difficulty in meeting the needs of patients requiring treatment for intestinal failure. The funding arrangements for long-term parenteral nutrition are very unclear in England, and there is no **central** funding for regional centres to provide HPN.

The funding comes from local primary care trusts, and this can be difficult to arrange. The other problem has been a lack of expertise in centres around the UK. This is gradually changing, as most hospitals build up nutrition support teams, with team members from dietetics, nursing, pharmacy, biochemistry, medicine and surgery.

### Solutions

It is clear that the solution is to build up skills in regional centres,

particularly those with active nutrition support teams, and for them to provide training and support for HPN. It is important that these centres provide the same high standards of care that the IFUs provide. An example of this has been the Scottish Regional Network.

### Welsh Adult HPN Network

In Wales, we have been discussing for some time the concept of an HPN network to provide training and support for HPN. This is now gradually evolving. It is proposed that there are three centres providing care within reasonable distance from most Welsh patients. These centres are in Cardiff, Swansea, and North Wales (Wrexham). Like the Scottish Network, the initial task has been to agree shared standards of care. These are agreed protocols, in line with best practice in centres of excellence. We are able to audit the outcomes of care to check that there is a high standard.

The challenge has been to improve funding arrangements for HPN. This falls into two parts:-

1. The most expensive is the cost of home care companies. Health Commission Wales (HCW) is the

central body who have a duty to fund HPN treatment. We have now tendered for a single home care provider for new patients in Wales. This is to be agreed over the next two months. This will provide better value for money, and HCW have agreed to fund this routinely for all new patients.

2. Hospital-based costs of supporting patients. In the intestinal failure units in England this is somewhat easier, because of the large numbers of patients. This means that a ward-based team can provide 24 hour support, and this is cost-effective. The challenge is to provide this in

smaller centres for a few patients. The way forward is to initially fund extra individual staff according to need and numbers of patients. This initially helps to provide working hour support for patients, and HCW has funded a nursing post in Cardiff.

The next step is to provide training and teaching for other hospital-based staff to raise standards of care in specialist ward areas. There is now a TPN training course for nurses being run every few months. As this takes effect, we aim to have ward-based staff able to provide 24-hour advice and care for HPN-related emergencies. This will gradually roll out across other Welsh

centres, and funding will increase as numbers of patients rise.

At present therefore, there are three Welsh centres that can provide training and support for new and established HPN patients. There are still problems with 24-hour hospital-based support for HPN, but we hope that this will gradually improve over the next few years. The funding arrangements are now in place, with HCW having a duty to fund care of a high standard, although of course there is never as much finance available as we could wish for.

**A B HAWTHORNE**

## READERS' EXPERIENCE

### Things they don't tell you at Antenatal Class...



How many times have you heard a pregnant woman say "I don't mind whether it's a boy or a girl as long as it's healthy"? I said it myself but looking back

I realise that I did not have the slightest understanding of what not having a perfectly healthy baby could mean. Until Alice was born that is and my husband George and I were thrust onto the emotional and physical rollercoaster-ride that parenting a child with complex medical needs can bring.

Alice was born with too few nerves in her bowel to co-ordinate the muscle action necessary to move food through. Her condition is so severe that she is dependent on PN for 100% of her intake and has it infused for fourteen hours a night, seven days a week. She also has an Ileostomy and a Gastrostomy too.

At three-days old, however we were blissfully ignorant of all of this. All we knew was that our new baby had begun

to vomit a lot. And when the vomit turned green a kind and efficient midwife packed us off to the local children's Emergency Department. Within hours we were looking at our lovely baby through the perspex walls of an incubator in the Neonatal Intensive Care Unit at the Queen's Medical Centre in Nottingham.

For several months Alice remained a medical mystery. Her bowel appeared to be normal but attempts to feed her even the tiniest amounts of milk, a depressing two mls an hour, resulted in more green vomiting and impressive volumes of NG aspirates.

A diagnosis of Pseudo-Obstruction as a result of Myenteric Hypoganglionosis (too few nerves) finally came in January of this year following an operation at Great Ormond Street Hospital to create a much-needed Ileostomy.

Alice was discharged from hospital in mid-February on Home PN after four-months in hospital but was back in two-weeks later with a suspected line infection. Then another bowel operation and yet another to re-site the central

line. This pattern has continued and to date Alice has never spent more than two consecutive weeks at home without being rushed back in to hospital following a high temperature or a problem with either the central line or her bowel. Why do these things always seem to happen at three in the morning!

Despite all this Alice is a happy little girl with an amazing ability to bounce back from any knock she takes. In between hospital stays she enjoys 'Music Time' and 'Soft Play' sessions with her friends. She gives us the strength we need to carry on when things are tough.

The journey we are on with Alice is not an easy one and the future is unclear, and whilst it is hard to live with the threat of liver damage and the risk of sepsis which PN brings it is also the thing which keeps our little girl well and growing and for that we are profoundly grateful.

So now when we are out with friends whose babies are eating and a well-meaning stranger asks if Alice wants some food I say "No thanks she's already been fed." And its true, she has.

**JO-CHRISTA TAYLOR**

MUM TO ALICE EDIE TAYLOR –  
AGED NINE-MONTHS

## WOULD YOU LIKE TO BECOME A RESEARCHER IN THE NHS?

The North West Regional Group invited Bill Strettle to speak at their Regional Group meeting on this subject and wanted to share this with other members of PINNT.

### SOME TRUTHS AND FALSEHOODS:

**All researchers are highly qualified and trained scientists, doctors and nurses. False**

Certainly, a researcher requires some training but if you are interested and can commit some of your time, there is nothing to stop you becoming adequately trained as a researcher.

**There are a number of training programmes which will show me how to do research. True**

There are now many research training programmes for members of the public covering all aspects of how to carry out research. For more information contact Health R&D North West or [www.lancs.ac.uk/fss/ihr/hrdn/users](http://www.lancs.ac.uk/fss/ihr/hrdn/users).

**As a member of the public, I can get involved in any research project which interests me. True**

If you have a particular interest in a medical condition, treatment or medical/nursing service you can become involved as a researcher, once you have been appropriately trained.

**Because I am neither an academic nor NHS professional my contribution to the research will be less valuable. False**

This statement is false. As a member of the community, a patient or ex-patient, all research in the NHS is undertaken for your benefit. This means that your ideas about topics for research and your views into researching the medical/nursing services that you use will be essential, if that research is to be worthwhile.

**The world of research seems very different to the world of the general public; I would never fit in. False**

At first, you may feel as though you do not belong to the world of research but this feeling is true of any new enterprise that we engage in. However, the more experienced you become, the more

confident you will feel. Many members of the public who have undertaken successful research projects say how much the experience has boosted their confidence, self-esteem and sense of doing worthwhile work. For more information about people's experiences as researchers, contact 'INVOLVE' [admin@invo.org.uk](mailto:admin@invo.org.uk) Tel: 02380 651088.

**My local hospital is far too busy to be bothered with helping me to become an effective member of the research team. False**

This is another false statement. The government now insists that all hospital Trusts should have patients and public involved with all aspects of hospital services and this includes research.

If there is an issue about any aspect of health which concerns you and you would like to explore its possibilities for research, please do not hesitate to contact Bill Strettle at Hope Hospital Research and Development Unit on 206 5585 or Email [William.Strettle@srht.nhs.uk](mailto:William.Strettle@srht.nhs.uk). Your interest will be keenly appreciated because we are here for your benefit.

**Once involved in research training or project, I will be expected to commit myself and my time to it until it is completed. False**

You will not be bound in any way to a training programme or a research project. You may leave at any time you wish.

**I can decide to what extent I wish to be involved in a research project. True**

There are three kinds of research project so you can decide which one is the most appropriate for you. For instance, you may wish to become involved in a research project which requires you to be consulted from time to time throughout its progress; this would take the form of a one-off interview. The second kind of research would require

you to be continuously involved. This means that you would collaborate as a full partner in the research project. The third kind of involvement is one in which you, usually as a member of a group, would lead the project, making all the decisions regarding what you wanted to research and how it would be done.

**There are organisations which will advise me and support my decision to become a researcher. True**

Apart from Health R&D North West and INVOLVE mentioned above, there are numerous organisations which can help you in your role as a researcher. These include: 'Ceres' (Consumers for Ethics in Research) an independent charity set up in 1989 to promote informed debate in research and help users of health services to develop and publicise their views on health research and on new treatments. Email: [info@ceres.org.uk](mailto:info@ceres.org.uk)

**If I am under 18 or under 16 I am too young to take part in research. False**

The government is very keen to encourage young people to become researchers. They may need more support than adults but they can make very valuable contributions. For instance, young people can identify research issues and questions that professional researchers may miss or not prioritise. Also, young interviewees may open up more to their peers, depending on the topic and the skills of the young researcher.

**As a young researcher, I am more likely to be manipulated and/or condescended to. False**

Good Clinical Practice, which is a legal requirement in all research, will ensure that young people will be supported to get involved in ways that suit their needs and availability rather than expected to fit into adult structures. Young researchers views will be listened to and influence decisions along with the views of other members of the research team.

## PROBLEMS WITH TUBE FEEDING

I wondered if members of PINNT have experienced any of the problems our 15 year old daughter has been having with enteral feeding?

She has Gastroparesis and was fitted with a Jejunostomy tube in January 2005. This moved in and out continuously for three months causing infection, intense pain and necessitated several hospital visits. It was replaced but eventually it had to be removed. In April 2005 a Vygon MIC transgastric double lumen gastro-jejunosomy tube was fitted. Since this has been fitted the tube sucks in and out and it also tries to disappear inside her stomach, despite having an external disc fitted to it, again causing severe pain.

Another problem that she is experiencing is tube blockage. The Jejunal Lumen is 8F and Fresubin Energy is being infused at 30mls per hour. The slow speed is because the faster the rate is the more the tube sucks in and out. The tube has blocked on many occasions and has needed hospital intervention because we have been unable to unblock it using conventional methods. This tube has now completely blocked again and the Clinical Nurse Specialist in Nutrition Support says it will probably have to be changed yet again for a different tube.

We wondered if the small jejunal lumen together with the slow infusion rate could be part of the problem. The tube is flushed before, during and after feeding with sterilised water to try to alleviate the clogging problem but this has not worked. The Nutrition Nurse suggested that we contact PINNT to see if anyone else has experienced similar problems and can offer any advice.

**ELIZABETH TALBOTT**

**Ed replies:**

**If anybody can help with ideas then please send your letters to PINNT and we will ensure that they are passed on to Elizabeth.**

## STORAGE SOLUTIONS

As someone who is new to TPN, I'm still getting myself organised and thought other people might be interested in the set of drawers I bought recently to put all my requisites in.

It's plastic with 5 drawers; 2 deep and 3 shallow with a flip-up cover on top that has 3 compartments. The compartments are ideal for small things like end caps, filter straws, rolls of tape etc, the shallow drawers will happily take gloves, syringes, dressings and even full boxes of Heparin and saline. Giving sets and dressing packs go in the bottom two deep drawers. It's fitted with castors and all the drawers have catches so they don't slide open when you move it around. It costs a very reasonable £29.95 from B&Q.

**IAN SIMPSON**

**Ed replies:**

**As readers can see from the photo it looks really useful and I'm sure will offer a suitable solution to storing all the equipment necessary for home feeding. No doubt there are other suggestions for storage, let's hear them!**



## RINGING IN THE CHANGES

I thought the following information may be useful regarding the 'Ringing In The Charges' article in the last issue of Online

Most numbers beginning with 087 and 084 simply redirect to a 'normal' number. There is a web site - <http://www.saynoto0870.com> - that maintains a list of known alternative

geographic numbers for a whole host of 0870/0845 numbers.

If that doesn't help, my preferred course of action is to see if there's another 'real' number for the company (or even better, a sales number - they're usually 0800 so they're free) and ring that; I don't care if it's not the right department because once I'm connected

I turn on the charm and ask to be transferred. It usually works.

**IAN SIMPSON**

**Ed replies:** **Thanks for the useful information and I'm sure those of us who have access to the internet will find it useful.**

## SUPPLY PROBLEMS

Recently due to a problem with supply, I have had the feedbag I normally use substituted for another type. I had mixed reactions to this, of course it served the same purpose and contained the vital solution I need but the appearance and configuration of the ports were different which I knew would be problematic when used in conjunction with my equipment.

Having no choice other than to use the new bags I quickly realised that in fact the 'new' bags were much better than the ones I had been using for years. The shape was different; instead of being long and thin the 'new' bags were shorter thus making it easier to fit into my portable system. For some reason I had convinced myself that no other bag could possibly be as good as the one I have used for many years. I am pleased to report that I am pleasantly surprised by the 'new' bag. Having used it for the duration of my fortnightly supply I surprised myself by hoping the next delivery had the 'new' bags too. My homecare company has now sent out information about the changes which has been extremely helpful but the timing could have been better. My point is that of course we should know about important changes however before dismissing things, give them a try. Obviously we all have our own preferences but for those using the portable system I'm sure they also found the shorter bags easier to fit into the rucksack.

**Ed replies:** **I guess this depends on the quantity of TPN inside the bag, as mine were substituted and won't fit in my rucksack because they are too wide! However, I guess I am not alone as the letter below demonstrates!**

## THE OTHER SIDE OF THE STORY

Recently my usual feed bags have been substituted with a different kind which makes me wonder if the pharmacists/medical staff truly think of us when making changes. If my usual bag cannot be supplied then okay there is not much I can do about that but does anyone have regard for the issues this leaves me to face?

I have 2 litres of TPN which usually comes in either a 2 or 3 litre capacity bag. Of late it has been supplied in a 4 or 5 litre bag which causes me logical nightmares when trying to fit and fold it into the rucksack. For the initial hours of feeding I need to have it laid on the bed and I am unable to be mobile. Can we please ask homecare companies to show some consideration? I'll always do my best to appreciate the supply problems but please apply logic. Most importantly please inform us in advance of any changes and if possible give us a choice.

**S FEDRICKSON**

**Ed replies:** **The new feed bag is only manufactured in sizes of 4 litres and above thus it may not be suitable for everyone. We would welcome your comments as to how you've found them. We have received several letters with positive comments, such as they store more easily in the fridge and that the integrated handle is a useful feature. However, some users find the larger size, especially if they are on 3.5 or 4 litre feeds difficult to fit in the back pack....write in and let us know.**

# ENTERAL FEEDING AND DIABETES

I suffer from Systemic Sclerosis (Scleroderma) and for the past 6 years have been on enteral feeding, first via a PEJ and then via a jejunostomy. In March last year I developed severe Type 1 diabetes (which you are not supposed to do at my age!). The Systemic Sclerosis has severely affected my gastro-intestinal function, particularly the oesophagus, stomach and colon. I am on insulin for the diabetes but am finding it almost impossible to balance blood sugars and insulin – they will be far too high for several days at a time and then suddenly drop – causing ‘hypos’. As the feeding regime is the same from day to day it’s quite difficult to understand what happens and to keep things stable.

It would be helpful to know if any PINNT members have similar problems and how they deal with them. I am in the care of both Diabetic and Gastroenterology Consultants but so far they have been unable to sort things out.

## ANNE PECK

### Ed replies:

Once again please write in if you are able to help Anne and we will forward all replies to her.

## REQUEST FROM BAXTER

I am writing on behalf of the Parenteral Nutrition (PN) Compounding Unit at Baxter Healthcare in Thetford. We currently produce around 75,000 bags of PN a year, some for hospitals and many for home patients both in the UK and abroad. We work closely with homecare companies supplying the bags for their patients.

To date I have been working at Baxter for about 5 years but believe that in the past we had close links with some of the patients we supplied. As the compounding takes place in specialised facilities and the patients are known only to us by name it would be really nice to personalise the work we do by being able to put faces

to names. Many of our operators (those who compound the feed) show an interest in the patients. They sometimes ask why feed manufacturing may be put on hold, ask how old people are and say they wonder what the person behind the name is like.

We were wondering whether any of you who have your feeds made at Baxter would be willing to send us a picture and a brief note about yourself for a patient board I would like to set up. You’ll know if they are made at Baxter as the company name will be clearly displayed on the over pouch. If you would like to support this venture then please send a photo of yourself or your child, along with a brief outline (no more than one side of A4 paper) to PINNT, PO Box 3126, Christchurch, Dorset BH23 2XS - marked with BAXTER on the

envelope. PINNT will then forward any replies to us, you may be asked to sign a form giving permission for this information to be passed on and in return we would like to offer you the opportunity to visit the facility and see how your bags are made. We look forward to hearing from as many of you as possible and hopefully we can have a really large patient board.

## CLAIRE RUDLING

BAXTER



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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.