



TRAVELLING BY AIR – DISABLED DISCRIMINATION

About 2 years ago the Department for Transport published a Code of Practice: **Access to Air Travel for Disabled People** - with the aim to stop discrimination against disabled travellers. This code is meant for travel agents, airports, baggage handlers and airlines and states that – for example – the airlines should protect wheelchairs from damage, that all employees should receive disability awareness training and that all public areas and services in terminal buildings should be accessible to disabled people. It is interesting to note that the actual aircraft is currently exempt from the Disability Discrimination Act.

The government has warned airlines that, if the voluntary route failed, they would be brought under the Disability Discrimination Act. Certainly the new Disability Rights Bill does make such a move possible should it be considered necessary.

Meantime then, has the Code of Practice made any difference to disabled air passengers? As one might expect there are mixed messages, with representatives of the air travel industry reporting things are all going in the right direction but disabled people reporting that they have not noticed any improvements.

Jo Campion (Policy and Campaigns Manager for the disability charity Leonard Cheshire) does not believe the voluntary approach is working and airlines should be brought within the Disability Discrimination Act: Airlines can literally say **'you are not allowed on this plane because you are disabled'.... legally they are allowed to do that** and that is unacceptable. The airlines, of course, disagree, much preferring a Code of Practice to the law.

Would it be time now for the government to consider legislation? And: will the government want to legislate? Another look at the industry is planned for this year. That means the government is not likely to consider legislating until 2006 at the very earliest. Until then disabled air passengers will have to face humiliation at the hands of poorly trained staff or perhaps being left stranded for hours on board an aircraft or finding their wheelchair mangled.

Finally, a new **draft directive by the European Commission** is expected this year which will make it illegal to charge disabled people for assistance at airports. It is also expected to recommend a centralised structure for assistance run by airports and not by the airlines.

Travel News continued overleaf...



Price £2
Free to Members

in this issue ...

Travel News	1-2
PINNT News	3-5
Regional Reports	6-7
Ringling in the Charges	7
Readers' Experience	8
Information	9
Postroom - Your Letters	10-12

INSURANCE COVER IN EUROPE

With the holiday season upon us it might be useful to check that your E111 is up-to-date as recent changes may mean that you are no longer covered.

A European Health Insurance Card is replacing the form E111 which entitles travelers from the UK, who are eligible, to free or reduced cost emergency medical treatment in the European Economic Area (member states of the European Union (EU) plus Iceland, Liechtenstein, Norway) and also Switzerland. It will also

replace a number of other temporary forms.

The new card is plastic and will hold no electronic or clinical data. In line with the agreed EU format the card will show your name and date of birth and will have a personal identification number. The card will be issued on an individual basis and not on a family basis as at present, therefore children will not be covered by a parent/guardian's card. There will be a small number of processing authorities, which will authorise the issue of a card. This information will then be fed

electronically into a central database. The card will be valid for up to 5 years and there will be no charge. An emergency paper certificate will be available.

A new style E111 has been issued since summer 2004, which will be valid until 31 December 2005. Old Style E111/s ceased to be valid on 31 December 2004. If you completed a new style E111 during the past year you should have been advised to tick the box which provided automatic issue of a European Health Insurance Card sometime in 2005.

BENEFIT NEWS

CHANGES TO INCAPACITY BENEFIT

Readers may have heard about the radical changes to benefits for disabled people that the Department for Work and Pensions (DWP) are planning. These are part of longer term reforms to encourage people into work and were featured in the departments five year strategy which was published in February 2005. It is believed that they will have a significant impact on those people currently in receipt of Incapacity Benefit.

The plans include replacing Incapacity Benefit with a new system that will separate those people with severe medical conditions from people who have medical conditions which are more manageable. Disability and Sickness Allowance will replace Incapacity Benefit for those with severe medical conditions whilst those with more manageable conditions will initially

be put on a holding benefit at Job Seekers Allowance (JSA) rates before undergoing a medical assessment. They will then be put on Rehabilitation Support Allowance (also set at JSA rates) but given more money for attending Work Focused Interviews and steps to get them back into work.

The DWP suggest that Rehabilitation Support Allowance will be for people with less severe impairments that can be usually well managed with support and so need not be a major obstacle for getting back to work whilst Disability and Sickness Allowance will focus on health problems that will for some time be a significant obstacle to getting back to work.

The new measures are planned for new claimants from 2008 and the DWP will be consulting with

stakeholders on the proposals. It is not yet known what will constitute 'severe conditions' but both benefits will be based on a doctor's rather than a personal assessment.

NEXT ISSUE

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

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e-mail: dawn.carter@tiscali.co.uk
- 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.

WELCOME NEW MEMBERS

FROM THE CHAIRMAN



Thanks to everyone who has been in touch with us lately, still popular are requests for advice regarding holidays. Although we have our Holiday Guidelines I think they need amending just to add one or two pieces of

additional information to keep it current. If you are off travelling over the summer then please ensure you have made adequate preparations and that you have a wonderful holiday.

Please remember to pass on any useful pieces of information you feel other members of PINNT would benefit from. My last holiday went really well, no infection problems. Keep well and safe

CAROLYN WHEATLEY
CHAIRMAN PINNT

New Adult Members:

Mrs Jessie Smillie
Miss Faye Talbott
Miss Wendy Stokes
Mrs Irene Brennan
Mr James Presser
Mr Michael Sandy
Mrs Debra Harris
Miss Susan Chapman

New Child Members:

Matthew Guile
Joseph Chapman
Lewis Ransley
Phoebe Wall
Jacob Tidcombe

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

CINEMA EXHIBITORS' ASSOCIATION CARD

Have you heard about the scheme whereby an accompanying person can go to the cinema with a disabled person for free??

To apply for the card, you will need to meet one or more of the following criteria:

- Be in receipt of the Disability Living Allowance or Attendance Allowance.
- Be a registered blind person.
- Be a holder of a disabled person's rail card.

The card is valid for three years and is accepted at 90% of all UK cinemas. A full list can be found on their website or requested in writing. A processing fee of five pounds is charged per card.

You can download an application form by logging onto www.ceacard.co.uk or by writing to: The Technology Centre, Inward Way, Rossmore Business Park, Ellesmere Port, Cheshire CH65 3EN or telephone **0151 3488020**, minicom: **0151 356 7113**.

DID IT WORK FOR YOU?

When we launched our Restaurant Card, we said we wanted your feedback as to how it was received when you used it. In each pack we sent out with the card there was a comment sheet for your positive and negative experiences, and we wanted your sheet back after six months. The time has now come for you to send your sheet back in the stamped addressed envelope you were given in the pack and tell us if the card has been a success.

Please send it as soon as you can, along with any comments you would like to make. If you have lost the stamped addressed envelope, the sheet should be returned to Carolyn Wheatley at PO Box 3126, Christchurch, Dorset BH23 2XS.

We look forward to finding out how you got on!

PINNT LEAFLETS

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

FROM THE EDITOR



With the holiday season upon us you will have noticed that many of our articles relate to travelling, a topic which always stirs a great deal of interest amongst members. I hope by the time you read this you will be enjoying the sunshine and will find time to write in about your experiences.

Once again many thanks to all those of you have contributed to this issue and with many changes being implemented which have an impact on people with medical conditions we are interested to hear how these affect you. In this issue we have included information on the planned new reforms of disability benefits, along with details of how to apply for reductions in council tax and the need to update your E111 forms to ensure you are covered for medical treatment whilst in Europe. Do let us know if you hear of any information that might benefit other members or alert us to subjects we need to report on.

DAWN CARTER

I WONDER WHO THAT WAS...

How many times have you been in the middle of your procedure when the phone rings? You're on your own, you can't possibly answer it, and they don't leave a message. The caller may be someone you want to talk to but on the other hand it might be someone who is unwelcome.

You can put a stop to telemarketing calls if you register with the Telephone Preference Service. Registration will also prevent organisations who regard you as a customer from calling you again, unless you have previously told them that you have no objection to them calling you. You can also register mobile telephone numbers.

There is no charge for registering; the direct marketing industry funds the service. It is good business sense for them to only contact those individuals who wish to hear from them.

If you have been troubled by calls where the phone rings but on answering there is no one there, you may wish to register your number on the Silent Callgard Service on **0870 4443969**. These calls are generated by automatic dialling equipment which dials more numbers than there are operators available to take the calls.

The Telephone Preference Service can be contacted on 0845 070 0707 or you can register and find out more information on their website www.tpsonline.org.uk

TREASURER'S REPORT



Welcome once again to the money section of Online. It has been a very busy few months with all the membership monies coming in with many visits to the local bank to be sorted out. Trust me although time consuming it's always a nice thing to be doing when you work for a charity. Thanks to all of you who also take this opportunity to donate to PINNT at the same time. I have yet to collate the final figures but have received large numbers of donations with membership fees. Some separate large donations have been received and once again we would like to thank those members and friends of members who donate in this way.

PPP continues to be very strong and I will update the Executive Committee at the next meeting in a few weeks time but we have now a large number of members taking part in this activity.

Thanks again everybody for your contributions and I look forward to talking to you all again in the next Online and at the AGM where I will reveal the accounts to everyone.

KEITH NURCOMBE

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.



EDITORIAL BOARD

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

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

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, Whetstone, Leicester LE8 4PB or e-mail Geoffsimmonett@aol.com



GENERAL SECRETARY'S REPORT



First of all, a big thank you and good luck to those of you who have signed up to participate in the PINNT Prize Pot. We have had a very good response, which meant we held our first draw on the 16th April and the winners were:

First Prize: Pamela Michie
(179) £143

Second Prize: Mrs K Matthews
(177) £86

Third Prize: Wendy Stokes
(191) £57.

The next draw will take place on 16th July at our Executive Committee Meeting. All the lucky winners will be announced in Online, and will receive a cheque for an amount pro-rata to the number of participants. If you haven't signed up yet, do so – you never know, the Prize Pot could be yours!

I'm pleased to report that the PINNT Executive Committee members and Regional Co-ordinators have now undergone their Criminal Records Bureau checks with regard to working with children, and our Child Protection Policy is now in place.

Those of you with naso-gastric tubes may be aware that there have been some incidents where the tubes have been misplaced. The National Nurses Nutrition Group and the National Patient Safety Agency have prepared some guidelines for patients and carers to ensure correct placement of the NG tubes, which can be found at www.npsa.nhs.uk/advice. The title is 'Advice to the NHS on reducing harm caused by the misplacement of naso-gastric feeding tubes', issued on 22 February 2005. Alternatively you can ask your healthcare professional for a copy.

I hope you all have a healthy and sunny summer.

JUSTINE BAYES

REGIONAL REPORTS

NEWS FROM SCOTLAND

We had a wonderful meeting in the Southern General hospital, I am delighted to see how well all of our members get on, and enjoy spending these hours together. During our meeting I spent a short time updating everyone on what is happening within PINNT. We were asked by the Scottish Managed Clinical Network to view a video made by an intestinal failure unit on Home Parenteral Nutrition. We found it very interesting and we can now feed back to the Network what we feel would be needed in Scotland for a video for patients going home on HPN.

For the last few weeks Samuel and I have been trying out the new

2 litre Rucksack that is currently being developed for the Baxter 6060. We have had the test run and everyone at our meeting was thoroughly impressed with the new rucksack and only suggested a few minor changes. Other members have been testing the 4 litre size it will be very interesting to hear all the views when they go back to the manufacturer.

On the 11th June, we are travelling to Ninewells Hospital, Dundee and hope to see some members from that area, I am sure you will enjoy the meeting if you managed to come along.

SHARON BELL

REGIONAL CO-ORDINATORS:

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Jackie Huff 01767 225631

North West

Rosemary Martin 0161 998 6201

Scotland

Sharon Bell 0141 959 6701

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Raymond Toulson 028 9260 4705

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John Sturt 0191 565 8651

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Trent

Justine Bayes 01933 316399

NEWS FROM THE NORTH WEST

Our meeting in April went very well although we were disappointed to have only 8 in attendance despite invitations being sent to over 70 people. However, not to be deterred we exchanged our usual pleasantries, caught up with news and discussed many issues that had arisen in the last Online. We were fortunate to have Bill Strettle attending our meeting; he is the co-ordinator of the Patient and Public Involvement Forum and represents the research and development side. Bill agreed to give an impromptu talk on his role and also to write an article for Online which will appear in the next issue.

Whilst on the topic of meetings, I wonder if any PINNT members may be interested in running the North West Group; it may help to bring in some new ideas as a way of revitalising our group and increasing attendance. Please let us know if you are interested.

On Thursday 31st March 2005, I attended the Royal Liverpool University Hospital for a Gastrostomy Study Day and was presented with a cheque for £645.00 by Derek Edwards from Vygon (UK), for PINNT. The money was raised from the registration fees that delegates paid to attend. There is more cash to come for the Liverpool day as well as from three other study days organised for 2005.

ROSEMARY MARTIN

NEWS FROM WALES

I am on HPN and was sent to the Hope Hospital from University Hospital of Wales in 1998 to be trained. After 3 weeks I wanted to go home and nurses were sent from Manchester to Swansea to put me on and take me off feeds until they trained a nurse in Swansea. This nurse was Sarah Squire and she looked after me until I was fully trained but we remained good friends and she was always at the end of the phone for me. Sadly, Sarah died last November after being diagnosed in 2003 with bowel cancer. She ended up with an ileostomy and had to have a line in for chemotherapy. It seemed so ironic that she had looked after so many patients, teaching them how to look after their lines, that she should need one herself. She was always cheerful though and (I say this with affection) bossy!

I am sure all her patients in South Wales will remember her and be thankful for everything she taught us. She will be greatly missed not only by her husband and three children but the patients she helped.

LETTY JOHNS

RINGING IN THE CHARGES

Over time it's amazing how trends start to affect those who can least afford to incur additional costs. It's not designer labels or a new make of car we are dealing with on this occasion – we have now entered the '08 zone'.

0844, 0845, 0870 numbers, which are apparently introduced to provide companies with a more professional image and enable them to move location without disruption to the calling customers, are now widely used. While researching these numbers I have even discovered that they are encouraged by phone companies to adopt an 0870 number to generate income - 'your incoming calls can turn into a significant revenue stream for your business'. Apparently they pay to have the service then depending upon the level of incoming calls they receive 'cash back'.

0845 numbers allow you to call a number from anywhere in the UK at the cost of a local call sounds good.

0870 numbers allow you to call from anywhere in the UK which could cost up to 10 pence per minute.

My concern over this new trend has increased because everyone I need to telephone in relation to my medical treatment has either an 0845 or 0870 number. Trying to arrange a holiday meant playing telephone tag around a company whose contact number was 0870, 10 per minute and 20 minutes later, still unable to resolve my query, I hung up. Eventually after a further game of tag, I managed to sort my travel needs out but yet again incurred a considerable cost for being on the phone for more than an hour.

Resentment of this trend has accelerated because my income has greatly reduced since retiring from work. I also recently switched to an 'inclusive landline calls phone package' and although I was aware that 0844, 0845, 0870, or 0871 numbers were not included in my



'free minutes' allocation I did not realise my need to use them would be so great.

Over time I have also needed to phone my homecare company and it's turning out to be a costly exercise each time and I try to minimise calls to save money. I can email them but the response time is not ideal and on some occasions I need to speak to them 'now'.

It's unfair that companies are making money out of us although I can see why a more professional image appeals to the companies. In a true business world they carry on, but please can we do anything to encourage companies who provide a homecare service to think again?

If any of our readers have similar concerns then please either contact PINNT with your views or make them known to your own homecare company.

“ I was very interested to read a letter in Online about managing without TPN, as I am trying to do the same. I thought I'd share my experience. ”

I have a condition known as Essential Thrombocythemia, which means that my bone marrow produces far too many platelets, making me prone to thrombosis. This was first diagnosed in 1990 when, at the age of 40, I suffered a portal vein thrombosis following a flight to Mauritius. I was lucky to survive that, but I recovered well and with the help of drugs to suppress the platelet production and I was able to live a near normal life for about the next 12 years.

Then in August 2001, following a day trip to Sydney (I used to work for British Airways) I had another problem, this time with a blockage forming in my small bowel. I was admitted as an emergency to my local hospital (the Royal Berkshire Hospital in Reading) and had most of my bowel removed and now have only 40cm remaining. I was not expected to survive, especially when my condition was complicated by contracting MRSA, but after time in Intensive Care and several months in hospital I managed to pull through. St Mark's Hospital had been advising the Royal Berkshire on my care, but despite heavy eating I was becoming emaciated and suffered other problems associated with malnourishment so they admitted me to St Mark's in March 2002 to try to sort me out.

They did a really great job. I was given a Hickman line and trained in how to manage TPN and was sent home in May 2002 to manage the

new regime. I was on TPN every night to start with, which provided about 1200 calories a day to supplement the calories I was able to absorb through my normal (heavy!) eating. My weight started rising and before too long I was back close to what I had been before Aug 2001. They then gradually started to reduce the number of nights that I was on the TPN and about 15 months later I was down to just 2 bags per week. At that point my weight had stopped rising, so St Mark's were nervous about reducing the TPN any further, but also tempted to do so to see if I could manage. I was very keen to give it a try as I had had a line infection, causing septicemia, which occasioned another trip to Intensive Care and life hanging in the balance.

So in January of last year I stopped taking TPN "as an experiment". I was prescribed three cartons of "Peptamen" per day to try to compensate somewhat. As had been expected, my weight dropped markedly over the coming weeks, from around 12st to 11st 3lb, but then it leveled out and I seemed able to keep it at about that weight. To do this I was eating about 4500-5000 calories per day. I felt good and had about as much energy as before. St Mark's were very pleased and in April of last year felt they could remove my Hickman line.

Since then things have continued to go pretty well. I do find that I really have to keep at the eating or the

weight just drops off me - I lost 7lb in one week at New Year because I neglected my eating regime. I am not terribly good at following all the advice I have been given on eating - I eat too many fruit and vegetables and drink too much liquid but, despite this, I have generally managed okay. I do now try not to drink at meal times, and I think this has been beneficial (though I don't like it), but there is remarkably little that I don't seem able to eat. The sheer volume required is an issue, though luckily I do like my food. Aside from a hearty breakfast lunch and dinner each day, I try to have a cake mid morning and a sandwich or equivalent mid afternoon, and always end the day with a large bacon roll or similar.

The major down-side in this for me is that with such a huge volume going in, and less than 50% getting absorbed, a large volume needs to come out of the other end. This is the main factor that now limits my activities, as I tend to need to open my bowels six or more times per day, so I get nervous if I am more than about one hour away from a loo. But otherwise I feel good and am back into running and visiting the gym. And it is so nice to be able to conduct one's daily life and go on holiday without worrying about the line. I feel very fortunate in this, as it seems to be quite rare for people to come off TPN once they have been found to need it.

DAVE RUTHERFORD

'COPYING LETTERS TO PATIENTS' INITIATIVE



The 'Copying Letters to Patients' initiative was set out in the NHS Plan. NHS organisations were to have implementation plans in place from April 2003 onwards with full implementation from April 2004; however it is not currently complete across the country. The initiative will build on the existing legal provisions for patients to access their medical records under the Data Protection Act (effective 1 March 2000); however there are exceptions and these are summarised at the end of this article.

It is believed that copying letters is an effective way of keeping patients up-to-date with their diagnosis and treatment and demonstrates a commitment to good communications and valuing patients. The NHS wishes to see a shift to 'concordance' from 'compliance'; the traditional method of 'compliance' – follow the doctor's orders and take your medicine - has been proven not to work as effectively as 'concordance', in which patients understand and negotiate with clinicians the best course for themselves.

There are many potential benefits of copying letters between professionals and patients, including:

- More trust between patients and professionals.
- Better informed patients.
- Better decisions – patients are more informed and better able to make decisions about treatment options.
- Better compliance - patients who understand the reasons for taking medication or treatment are more likely to follow advice.
- More accurate records – errors can be spotted and corrected by the patient.
- Better consultations – professionals confirm that patients understand what is said during the consultation.
- Health promotion – the letters can be used to reinforce advice on self-care and life styles.
- Clearer letters between professionals – will help understanding.

Not all correspondence and test results will be copied to the patient. The range of letters will inevitably be varied as will the circumstances and patients are advised to discuss the arrangements for copying letters with their healthcare professional. 'A letter' refers to any correspondence between health professionals including hospital doctors, GPs, nurses, dietitians and therapists. Due to the nature of the letters there will be technical terms, but there should be nothing in the letters that has not already been discussed.

Under the Data Protection Act 1998, access may be denied or withheld, where the information may cause serious harm to the physical or mental health or condition of the patient, or any other person, or where giving access would disclose information relating to or provided by a third person who had not consented to the disclosure.

Further information on this subject can be obtained from your hospital, or from the Department of Health website www.dh.gov.uk (this article was prepared with information from this site).

LIFE ON TPN

Reading a recent issue of Online I noticed a request for people using a port for IV feeding to send in their experiences. I am a 54 year old female with a history of Crohn's Disease and have had several operations and have had a port for four years after previously having two central lines with external connections.

Around eight years ago I had my last operation which left me with a metre of bowel, as well as problems absorbing calcium and magnesium along with weight loss. I was on TPN for a while but eventually I was able to absorb some nutrients but to the present time still cannot absorb calcium and magnesium.

I had my first central line for a year and this only failed when the clip broke. Another central line was then inserted but after many infections it was removed after six months. I then had the venous port inserted and although it is a slightly more complicated procedure, I am very pleased with it.

I infuse three times a week for about 20 hours each time – Mondays a normal saline and a calcium/magnesium bag, Wednesdays a lipid and then a calcium/magnesium bag and Fridays a normal saline and a calcium/magnesium bag. I have a nurse who comes to my home to insert the needle into the port for me – purely because it was sited under my right breast and is difficult for me to access. She puts the needle in on Monday and it is left in place until my Wednesday infusion is completed. I then remove the needle and it is then reinserted for my Friday infusion. The only downside that I can see to having a port is one of access. I have only had the confidence to holiday in the UK where a nurse can insert the needle for me and I would be thrilled to be able to travel further afield. However, if the port had been placed in a better position I can't see any problem.

I hated having the tubing from the central line continually reminding me that I was medically dependent on it and because I also have a stoma felt that the front of my body was a sea of tubes and dressings. My port means that on the days I am not infusing I can literally forget it, which for me is invaluable. The surgeon did say that it can be quite a difficult procedure to remove a port compared to a normal central line but I will face that when the time comes. It would be interesting to hear from other people who have been through this procedure and whether they had another port inserted at the same time?

Because of geographical problems and ill health I have been unable to attend any of the meetings that PINNT has organised – so far! Therefore, my only point of contact is through Online and I really look forward to each new edition. Please keep up the good work. I have got a few queries of my own and I wonder if anyone could help me with them?

I do not get supplied with any spare infusion bags because of their instability the shelf life is only a week. Does anyone else have this problem and how do they get around the problem if one of the bags is faulty?

I have for the past year (learning of its existence from PINNT) been using a Baxter 6060 pump but for some reason it has now decided that it doesn't want to infuse the last 30 mls of the lipid bag. Are they ever serviced and if so how is it achieved? My homecare company doesn't seem to know the procedure for servicing and say that the pump probably has to be sent away for this – how do others cope?

Lastly, please can you perhaps print an article detailing the procedures necessary to holiday by air, I have no idea how to organise this and Healthcare at Home seem unable to help. I need to take stoma supplies as hand luggage, and medication. How can I make sure that all my other medical supplies travel with me and in the right conditions? Do you get any help with the sheer amount of luggage that all this involves as I don't think that my husband and I could cope with it all? At the moment a week away by car means that the car is full to bursting with bags, pump, cool boxes etc.

It would also be interesting to get members to write their case histories as I would be interested to hear how members get to the PINNT stage!

GEORGINA WESTERN

Ed replies: Thank you for writing in with your experience of having an implanted port and we would welcome any letters from readers regarding their own story of ending up with us here at PINNT. Regarding your questions, I suggest you request a copy of the PINNT Holiday Guidelines as it should provide you with all the information necessary for travelling by air. As for the Baxter pump it should be regularly serviced and would recommend that you discuss this with your hospital or insist your homecare company makes further enquiries.

THE ANSWER TO DISAPPEARING BAGS

I noticed in the past issue of Online that someone was wondering why her PN bag seemed to empty earlier on warm days than on cooler days when using the Baxter 6060 pump. As I couldn't see an answer in the following issue I thought I'd look into it.

A quick check on the Web unearthed the technical specification for the Baxter 6060 pump which stated:

Volume Accuracy: +/- 6% at 15° to 32.2° C (60° to 90° F), 0 to 55.1 kPa (0 to 8 psi) back pressure. +/- 10% at 40° to 100° F, 9 to 18 psi back pressure i.e. the hotter the ambient temperature and / or the higher the back pressure on the pump, the more inaccurate it becomes.

You might say that your house temperature is always in the range 15° to 32.2° C, however it may be that the pump isn't if it's on its

stand next to the radiator beside your bed.

IAN SIMPSON

Ed replies: I've passed on your information to Justine who told me that she will now make adjustments to the volume to be infused in hot weather. Isn't it good to know that some of our members are interested enough to find out the answers!

HOLIDAY MATTERS

I am writing in reply to the letter in the last issue referring to charges being made by airlines for excess baggage in the form of medication. Some readers may recall the problems I had 3 years ago when I travelled with South African Airlines. Well, in February this year we decided to visit South Africa again and this time I negotiated charges with the airline before I left the UK, but they would only agree to reduce excess baggage charges by 50%.

However, they were offering a good deal on Business Class fares, which meant we could increase our joint total baggage allowance by 20 kilos and by keeping personal luggage to a minimum we were able to stay within the baggage allowance and travel in luxury.

However after 3 weeks into our trip I developed a line infection and

immediately went to a private clinic. Like Carolyn described in the last Online, you need to have a credit card and pay a large deposit, in my case it was the equivalent of £1,000 before even a pill was given! The treatment was excellent, professional and effective and of course there was no language problem. On my return I submitted a claim to my insurer who paid in full; I was most impressed. I have an annual travel insurance with my credit card company (HSBC) who pass on liability to Norwich Union at a cost of £85 per year for my wife and I. The policy has no age limit and the only 'constraint' being that you have to have an HSBC credit card.

On a totally different matter, I am having some problems with the shelf life of compounded TPN in relation to holidays.

I booked my trip to South Africa for a proposed stay of 4 weeks, however when I contacted my hospital to arrange extra feed I was told that the bags would only last 3 weeks and despite lots of pleading they would not give an extension to the expiry date. In the end as I am not totally dependant on TPN and can eat as well, I was able to infuse saline only for the last 5 days of my holiday, which meant that I was not getting the additives, trace elements etc but at least I could stay for the planned time. I would be interested to hear if anybody else has encountered this problem as it would suggest that we are now limited to holidays of less than 3 weeks.

PATRICK HASTINGS

Ed replies:

The problem with airlines charging excess baggage seems to be increasing, yet it comes at a time when there is greater emphasis than ever before on disability discrimination issues.

It would be interesting to find out if people with other disabilities such as those needing dialysis are charged. Please write in and let us know if you have any information.

DISCLAIMER: 'PINNT has made every reasonable effort to ensure that the content of this newsletter is accurate, but accepts no responsibility for any errors or omissions. The views expressed are not necessarily those of PINNT and no reference to any product or service is intended as a recommendation'.

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.