

25  
YEARS

# PINNT

## Annual Review 2012 - 2013

### Adapting to Life on Artificial Nutrition at Home



25 years ago when four people had to adjust to life on artificial nutrition at home, they and their families had to cope with the daily practicalities and challenges of these life-saving, complex therapies by themselves.

These same four people decided that no-one else should have to go through that on their own ever again.

Out of that personal commitment, the support group Patients on Intravenous and Naso-gastric Nutrition Therapy (PINNT) was born.

Today PINNT is a national, independent, not for profit membership charity established for over 25 years providing mutual support and understanding to hundreds of adults and children and their families adapting to life on home artificial nutrition. PINNT provides this support direct via local and regional groups, online via forums and literature and a national telephone and email helpline.

## What is artificial nutrition?

Artificial nutrition is liquid feed that is taken into the body via a tube or central venous catheter (CVC).

There are different types of liquid feeds and these will be chosen by the patients' nutrition team to ensure each individual receives an intake that suits their body's ability to absorb sufficient nutrients and fluids to sustain their nutrition and hydration status. It is well documented that even people with similar conditions may find themselves on different types of artificial nutrition.

All types of artificial nutrition and feeding methods will present individuals with a number of hurdles to overcome. Some may have restrictions on what they can eat and drink due to their personal medical issues, whilst others may have to adapt to no oral intake at all.

From the experience of their members, PINNT knows only too well how much an oral restriction or no oral intake impacts on the daily lives of the patient and their families. Adjusting to the need to carry medical equipment at all times and to all places, to long feeding times attached to a pump – generally up to 12 hours - makes living a 'normal' life a great challenge. This is a particular challenge as food and drink is everywhere, and one of the main social events. Access is easy and it's part of life, a routine way to celebrate, congratulate, commiserate with friends, family and work colleagues. Being unable to eat and drink at such occasions is very challenging.

Life on home artificial nutrition is not normal but is absolutely necessary to sustain life. And if that wasn't enough, it is important to remember that PINNT members will be managing an underlying medical condition as well as their artificial nutrition.

There are two main feeding types: *enteral* and *parenteral*. **Enteral** – where feed is delivered into various parts of the gut to maximise absorption and **Parenteral** – infused directly into the bloodstream.



**'My parenteral nutrition is my fish and chip supper, my steak and kidney pie and my KFC .....**" Norrie McKillop.

Further information can be found on the PINNT website: <http://pinnt.com/Therapies.aspx>

To face life successfully and confidently in the community, all of us on home artificial nutrition need the support of both the medical and nursing professionals and of others also living through the challenges and opportunities of these complex therapies.

PINNT fulfils that second crucial role providing a genuine day to day appreciation of those daily challenges and how they can best be faced and hopefully overcome. PINNT also brings a reality check to the work of health and care professionals who, with the best will in the world, cannot truly appreciate what living on artificial nutrition is like 24/7/365.

PINNT's aim for 2013 is to touch the working lives of more healthcare professionals with that reality check, and to reach out to more adults and children living on artificial nutrition through an expanded local group network.

**Carolyn Wheatley**  
Chair

**Complimentary PINNT membership is currently available. Sign up online at**  
<http://pinnt.com/Membership.aspx>

**During our anniversary year PINNT offered complimentary membership to mark this momentous milestone. This has been extended for a further year. It is our desire that financial restrictions should not preclude anyone from the benefits of PINNT.**

## PINNT's Mission

Patients on artificial nutrition want to live the best lives they can - healthcare professionals want to provide the best care they can. By setting goals together **for the person** rather than solely for the management of the treatment and its consequences, the person on artificial nutrition can be supported to optimise their quality of life at home on artificial nutrition. PINNT's mission is to help patients and professionals reach that mutual understanding to the benefit of them both.

## PINNT's Aims

- To provide practical information, support and advice for all on Artificial Nutrition
- To encourage contact between patients and their families
- To establish a network of local branches across the UK
- To raise funds and receive donations to support and maintain PINNT's services
- To create understanding among healthcare professionals of the impact on the patient of Artificial Nutrition and its consequences
- To increase public awareness and understanding of Artificial Nutrition treatments
- To promote international exchange of views on living on Artificial Nutrition

### 2012 – 25 years of patient support

On Friday 25th May 2012 we celebrated our 25th anniversary by hosting a special evening event at the Donnington Valley Hotel and Spa, Newbury. Carolyn Wheatley gave a heart-felt welcome.

She said PINNT was a charity run by patients and carers that benefitted from the support of a wide range of people. Carolyn felt it was a wonderful time to show our appreciation.

Everyone invited had either inspired, supported, donated personal time or believed in PINNT and it was hoped that this would continue.



PINNT grew from the belief of two people, Andy Lumb and Anne Pick, who had a dream about a patients support group; along with Sue Saunders and Carolyn Wheatley they made that dream a reality.

PINNT is so much more than a patients' support group – it's a community where life-long friends are made. PINNT has contributed to so many lives; through the good times and the bad. Information shared is sometimes very personal and honest; heart to heart conversations make a difference and enable people to cope.

PINNT has been supported by some eminent healthcare professionals and none more eminent than Professor John Lennard-Jones. Sadly he was unable to attend the special event but Carolyn closed with a message from John "Bravo PINNT on so much achieved during your first 25 years - best wishes as the Association continues to gain in stature and mutual self help as your second quarter century begins."



# Highlights of 2012

**Regional groups:** Our expansion continues and in line with members' requests we are supporting the establishment of smaller local groups within regions. For many travelling long distances due to illness and their feeding needs we have introduced 'local' groups, bringing the support even closer. We have made inroads in Ireland during 2012 plus additional groups across England and Scotland.

**Networking:** During 2012 we continued to promote the needs of our members via professional forums. We attended the British Dietetic Association (BDA) meeting, the annual meeting of the National Nurses Nutrition Group (NNNG) as well as many one off study days where contributing to key debates is crucial to keep the patients view in the forefront of future planning and care pathways. Liz Evans, Chair NNNG, "I have been a member of PINNT for a year now. I consider this one of the wisest moves I have ever made in my professional carer. The patient is at the heart of what we do and is the most important person. PINNT gives hope, help and life, along with a good sense of humour, to so many."

## **Oley:**

PINNT and the Oley share a common goal; supporting people on home artificial nutrition. PINNT attended early Oley conferences during which they learnt the tricks of the trade and were able to apply this newfound knowledge in the UK. Despite the distance we continue to share information and offer reciprocal support networks for visiting patients and their families. Attending the Oley conferences enables our special bond to continue to develop; sharing knowledge and gathering new ideas is a tremendous way for us both to continue our work. Joan Bishop, Executive Director, Oley Foundation said "We welcome members of PINNT at our conferences with open arms. We truly appreciate the amount of effort it takes to travel the distance with HPN in tow."

**Oley Conference:** PINNT was able to maintain its international relations by attending the Oley Conference in June 2012. PINNT remain a 'contact group' for patients visiting the UK from America; it's a mutually respective arrangement. We know how daunting any travelling can be; offering a genuine support network away from home provides reassurance. PINNT representatives were able to bring back new ideas in relation to products, which we pursued upon our return. We are delighted to see these products now being available to patients in the UK.



**Online:** We maintain a patient focused quarterly newsletter bursting with patients' stories and experiences. This is widely circulated and is even distributed to our sister group in New Zealand. Our membership consists of a large number of healthcare professionals keen to hear it from the patient's perspective; an excellent medium in which we both educate and support.



**SHCA:** PINNT is a member of the SHCA – Specialised HealthCare Alliance – which has over 80 charity and patient support group members that are involved in specialist health areas or rare diseases. The SHCA works hard to ensure that the patient voice is heard by national Government, Department of Health and National Commissioning Board as well as at regional and local levels with commissioners and providers of health and social care. It has kept that clear focus throughout the negotiations around the new arrangements for the NHS. The SHCA keeps its member organisations up to date with developments and provides opportunities to meet with key players in the Government and the NHS.

**Forum:** Social media is ever growing and PINNT offer a 'private' forum in which they can talk openly to share their experiences and seek true support from people in similar situations. No question or concern is ever deemed silly; life on line is challenging and we are delighted to provide a private place where people can support each other.

**Facebook:** Our Facebook page is growing; it has general discussion and we are happy to facilitate this. We do know that many people opt to share privately on the members only forum on PINNT's website. We move forward with various media to encourage contact in diverse ways which appeal to individuals.

**Videos:** – Home artificial nutrition can be daunting for all concerned. For many, as the treatment corrects signs of malnutrition, there are no obvious signs of anything wrong. Much of what happens takes place on or within the body; all covered up! People report frustration as all too often we form an opinion on what we see; learning how to manage this can be challenging. Members requested some visual stories to try and get across to the wide world just how much thought goes into many aspects of their lives. In May 2012 we brought together a number of our volunteers to film a series of short videos which form part of our education programme and self-support to offer hope and reassurance to those embarking on their treatments. In addition to the impact this has had on patients and carers, these have been warmly received by healthcare professionals. Liz Evans, Chair NNNG said "Watching PINNT's videos should be compulsory for every healthcare professional who cares for people on home artificial nutrition support. Sometimes we need a reminder that there is a person attached to the tube." These videos will stand the test of time and be a resource for all new patients as the core principles of managing treatments at home will remain the same.

# Highlights of 2012

**LITRE:** LITRE is a sub-committee which runs on an ad-hoc basis in response to products and services. We work closely with manufacturers and suppliers and are proud of the high regard that LITRE is held in for being impartial and the voice of the patients. Historically we have looked at a wide range of items that impact on patients' day to day lives.

Our LITRE user assessment in relation to ambulatory parenteral nutrition pumps that are available on the market has gained been a marvellous tool for informing both patients and healthcare professionals at to the options they have when deciding about an extremely key component in relation to parenteral nutrition at home. During 2012 LITRE assessed an additional two pumps that will be available during 2012/13. LITRE has been able to work with the manufacturers to enhance their products and add those extra touches that will aid patients and carers. Historically feeding pumps were designed for use in hospital, the evolution of homecare means that different aspects need to be taken into account – LITRE has certainly been able to contribute to positive outcomes for both parties.



The LITRE assessments were also recognised by the Department of Health and acknowledged during a review of Homecare Procurement for HPN in England that only ambulatory pumps assessed by LITRE could be supplied by homecare companies. LITRE continues to be the voice of the homecare patient specialists.



**BAPEN:** PINNT – providing the Patient Voice for BAPEN and the healthcare professionals it represents in nutritional care

“Hearing the patient voice is vital to the delivery of safe and quality care across all care settings. PINNT has an important role to play in all BAPEN's work by providing the patient perspective on how nutritional services, care and treatment can be constantly improved and monitored. BAPEN endeavours to ensure that PINNT has every opportunity to contribute effectively across all our areas of work.

As a core group of BAPEN, PINNT has a seat on our Council, has a representative on each of the BAPEN internal standing committees and meets and works with BAPEN's other core groups – National Nutrition Nurses Group (NNG), Parenteral & Enteral Nutrition Group (PENG) of the British Dietetic Association, British Pharmaceutical Nutrition Group (BPNG) and BAPEN Medical.

During 2012, PINNT has worked alongside BAPEN both internally to refresh the strategic direction and priorities of the Association and has joined BAPEN clinicians and associated healthcare professionals to represent patients on numerous national committees discussing the improvement of the design and delivery of nutritional services, including NICE (National Institute of Health and Clinical Excellence) and HIFnet (Home Intestinal Failure Network) in England.

Currently, the chair of PINNT, Carolyn Wheatley, is co-chairing, with Professor Marinos Elia, one of BAPEN's most important pieces of work for 2013 – the BAPEN Patient and Carer Initiative, which is gathering the views of up to 20 national patient and carer groups on their patient or population group's experience of nutritional care and services, to ensure the patient voice is heard in the agenda for change. This is particularly important following the publication of the Francis Report, which highlighted failings in nutritional care, and the need for the NHS to redesign its services to meet patients' needs to ensure this failure never happens again.

BAPEN cannot thank PINNT enough for its major contribution to BAPEN's work now, in the past and in the future. We must thank members of the PINNT Executive team, who give so freely of their time, to constantly remind the BAPEN membership and the professionals we represent, of our core 'customers' in everything we do – the patients, their carers and families.

Together we can drive through a new mind-set in the delivery of nutritional care that always puts the patient centre-stage.”

**Dr Ailsa Brotherton** Honorary Secretary, BAPEN



## Donations



**Steve Flanagan**  
Managing Director

### Bupa PINNT partnership: Bupa Walk for PINNT

**£5696.28** - Bupa's purpose is to help people live longer and happier lives and support people and families through illness and challenging times. Through 'Bupa Well World' a Walk for PINNT event was held during September 2012. There was mutual benefit as those taking part were challenged to walk 5000 miles while raising money to support the work that PINNT undertakes.

We were delighted to donate the proceeds of our Challenge to PINNT and hope this contribution helps PINNT continue to grow its unique support network and united voice to campaign for a better, flexible and safe service for all HPN and HEN patients.



### Vygon – Study Days for PINNT



**Graham Milward**  
Technical Support & Product Realisation Manager

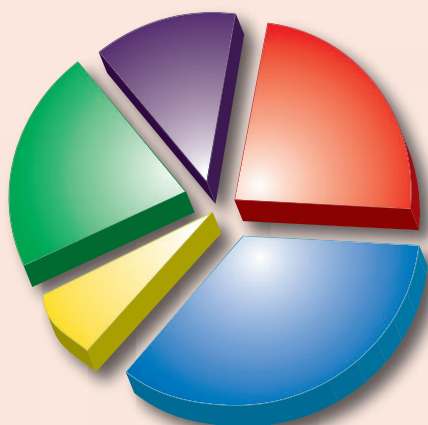
**£6,230 in 2006 – 2012 exceeds £25,000** - From our earliest encounters, Vygon were always impressed with the enthusiasm, focus and drive of the representatives of PINNT. The level of support offered to members, and non-members, is always evolving to ensure that patients are given up to date advice and guidance that might not be readily available from their clinicians. The willingness to engage and work with industry, offering a practical perspective gained from personal experiences has enabled quicker and better development of products and services for patients and carers.

When deciding upon a charity to benefit from the proceeds of our gastrostomy study days, there was only ever one choice and that remains the case, ten years later.

Without PINNT, there would be a huge gap in the support of many patients receiving artificial nutrition and Vygon are proud to be able to support such an important charity.



## Statement of financial activities



### Receipts:

- Donations
- Fund Raising
- Events
- Subscriptions
- Other Income



### Payments:

- Meeting costs\*
- Online (print, design and postage)
- Other
- Fundraising
- IT and website

**Total income £48,032 Total expenditure £38.853**

\* these costs include all Trustee meetings, sub committees and regional/local group meetings where charges apply. Travel, refreshments, accommodation and other costs incurred are included here. All expenses related to trips abroad are possible due to separate sponsorship. No money from PINNT funds are used.



# Quotes

## Paul

*"PINNT has provided me with a safe environment to discuss aspects of my HPN that I don't necessarily want to worry my family with. I've gained confidence through PINNT to face the challenges my treatment presents and to face the future."*



## Adam

*"Finding PINNT was the best thing I ever did in relation to my treatment. Gaining the confidence to travel and see my treatment as a positive part of my life has enabled me to move forward in a positive way. I enjoyed being part of the PINNT videos. Being able to share my experiences will hopefully inspire others as PINNT members before inspired me."*

## Tracy

*"Hosting a regional group for PINNT allows me to give something back to PINNT in return for all the support I received when I started life on home artificial feeding. Offering words of comfort and support to fellow members is gratifying. Everyone feels part of a family knowing we can turn to each other in times of needs or on a day to day basis. Each meeting welcomes new people and as we progress we will retain our open door policy."*

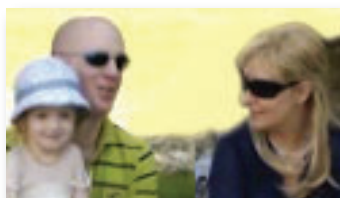
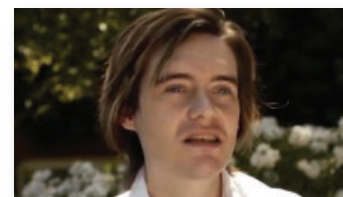


## Sylvia

*"As a retired nutrition nurse I spent a number of years viewing home artificial nutrition from the healthcare professional's perspective. Having never lost sight of the patients' needs, I am now able to offer more time ensuring a support network is available for their benefit. Many patients find huge support from talking to other people in similar situations. The exchange of ideas provides valuable help in accepting and adapting to the need for home artificial nutrition."*

## Steve

*"PINNT allowed me to feel valued as an individual on home tube feeding. I offered my time to PINNT as a volunteer as I wanted to share that feeling with others; I enjoy contributing to PINNT's support network and have grown in confidence thanks to their ongoing support."*



## Jasmine and Ian

*"Our daughter has been on home artificial since an early age and cannot tell us things we desperately want to know; how does it feel and does anything hurt! Through the contact we've had with PINNT we have gathered a wealth of knowledge that has given us a better understanding of our daughters' treatment. We strongly advocate that parents and families benefit from mutual support and understanding that can be gained from the PINNT family."*

## Plans and events for 2013

We will continue supporting and hosting regional and local meetings. PINNT's support network is growing but more importantly it is moving towards being where it's needed – closer to them. We are networking with other groups to determine where we have common factors such as specific underlying condition plus home artificial nutrition. Together we hope to offer additional meetings so we can not only support our members but support fellow groups with link minded aims.

## Benefits of membership

Not only does membership to PINNT offer support on a personal level but it offers a wide range of dedicated support literature. Four quarterly newsletters, Holiday Guidelines, Literature in relation to Considering Travel and Travel Insurance, a free Restaurant Card (a visual communication to explain inability or limited oral intake), access to meetings and the members' private forum plus so much more. Our members benefits evolve in response to the members' requests. We go the extra mile to deliver on information or support they need.

## Donations - how we will use them

We receive two types of donation; 'time' and 'money'. Monetary donations enable us to fulfil our aims and objectives and meet the needs of our members. We are extremely fortunate to receive regular donations from members and one off donations from companies and individuals. Due to the current climate fewer people have spare money to donate to good causes. Usually the larger charities which hit the headlines are worthy, of course they are but so is PINNT. Our work relies on good will from our team of volunteers.

Partnership working - PINNT welcomes enquiries from other support organisations, potential sponsors and Trusts, to explore how we can work together to improve the lives of those people dependant on home artificial nutrition. We recognise the boundaries this may cross in both care setting and disease statuses. Good nutrition and hydration have a major impact on all outcomes; PINNT strives to make life easier to manage on home artificial nutrition.



# PINNT

A SUPPORT GROUP FOR PEOPLE  
RECEIVING ARTIFICIAL NUTRITION



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