



PACIFHAN celebrates World Home Artificial Nutrition (HAN) Day 15th October 2019

‘HANs around the world’

“The more we share, the more we have” Leonard Nimoy

We are delighted to share introductions from PACIFHAN directors who introduce people on HAN from their country:



Hi, my name is Chris and I live in Australia. I am the President of PNDU representing Australia and New Zealand on the board of PACIFHAN.

For the past 20 years, I have been a primary carer for 3 family members living with Intestinal Failure requiring Parenteral Nutrition. Our family carries an X-Linked genetic defect causing Intestinal failure, carried by the females and usually fatal in males. Thankfully with the advances in Home Artificial Nutrition, two of my grandchildren Jordan and Logan, aged 10 and 7 years respectively, are able to survive on Home Parenteral

Nutrition. There are complications and restrictions of course, but as a family we always encourage the boys to engage in social activities and lead as normal a life as possible.

Parenteral Nutrition down Under (PNDU) is a not for profit organisation who support, research and inform consumers, carers and providers of Home Parenteral Nutrition (HPN) for Intestinal Failure (IF) in Australia and New Zealand. Membership is open to Adults and Children on HPN and their carers, associate membership extends to clinicians, industry partners and anyone with an interest in HPN. PNDU is a founding member of PACIFHAN and believe that we can learn from other HAN organisations around the world, in doing so we can work together to improve the quality of life and standards of care for all HAN consumers. Working collaboratively together, we can help and support HAN consumers to travel internationally and connect with others living with HAN.

Chris Walker, PNDU - Australia and New Zealand

My name is Monika, I am from the Czech Republic. I am the vice president of Život bez střeby, the Czech national organisation for patients on home parenteral nutrition. I have also been representing my country in PACIFHAN from the day it was formed.

Eight years ago, following a sudden abdominal catastrophe, my very active and very healthy life turned upside down and I became dependent on parenteral nutrition. For the first two years of my treatment there were no portable pumps available in my country and I was infusing up to 16 hours every day. This



meant I was condemned to virtual life imprisonment in my own home tied to a static pump on a stand.

Our patient organisation Život bez střeva (Eng. *Life without Intestine*) together with the HPN doctors worked very hard on making portable pumps available to all who would benefit from it. We succeeded and since then the quality of life of Czech HPN patients, adults as well as children, has improved immensely. Although I still need long hours of infusion, I can now leave my home whenever I need to even if I'm connected to my feed.

Raising worldwide awareness of home artificial nutrition and improving the quality of life of those who need it is the very reason why our Czech national organisation joined PACIFHAN.

Monika Malíčková, Život bez střeva - Czech Republic



My name is Laetitia, now 32 years old. I was born with multiple malformations (bones, digestive system, neurological and so on). The result is multiple disabilities, I have many education sessions such as physiotherapy, speech therapist, psychomotor skills and medical care.

Due to many surgical interventions, I require a wheelchair even though I can walk a little bit and especially do the transfers, from bed to wheelchair for example. I have beautiful purple splints with purple flowers and seahorses and big hiking shoes. My chair has been adjusted so that I can ride with it in a pedal mode. I'm the queen of 'running' in the hallways.

My major digestive disease is a short bowel syndrome (SBS) which means I need home artificial nutrition. I have enteral nutrition. I cannot eat or drink nor can I speak. I cannot use my mouth. I'm never thirsty or hungry. But with this artificial nutrition, that has no aseptic rules, I can be plugged to my pump everywhere and go out as I want and visit anything I want. My SBS is just on the edge of not needing parenteral nutrition. So my lab values such as digestive absorption and blood composition are closely controlled. I know my feeding systems very well and let the nurses or others know when my care is not well done.

I've a wonderful family who make me live as other "normal" people. I've visited many museums, exhibitions, monuments, castles and French regions. I've made many experiences like horseback riding, sidecars, paragliding, boating, summer sledding, hiking in the mountains... I've got kind of a temper: that's what keeps me alive, with the help of my family. But I really like to laugh, make jokes, see lots of different people and things. I love life! I wish such a good life to all other children and adults on HAN, and it's the role of PACIFHAN to help them all around the world. I believe in that!

Laetitia, La Vie Par Un Fil - France

Luisa is a 17 years old girl and comes from Italy. She is a home artificial nutrition (HAN) patient since she was born. At the age of 7 days, after a rectal haemorrhage, we discover she has an intestinal volvulus. She usually has 14 hours of parenteral nutrition and 12 hours of enteral nutrition, but she also eats normally, nevertheless she is a happy and strong teenager.

HAN therapy is a beautiful invention because allows people to live life "normally" even if it is a very demanding procedure and, sometimes, create time restrictions both for patients and for



caregivers. Thanks to Luisa we created a National Patient Association named “Un Filo per la Vita Onlus” as to guarantee the same rights to all patients coping with HAN.

We believe that being part of an International Association, such as PACIFHAN, is a great opportunity for HAN’s patients to travel all around the world always finding safe help and guidelines.

Interview with Luisa’s mother and caregiver Michela Caponi, Un Filo per la Vita – Italy



I am almost 40 years old and live in Cracow, Poland. Since 2002 I have suffered from Crohn’s disease. At the beginning the disease was taking its normal course, but this was not something I could expect for my future. I had surgery in 2005. I got married, became a father, and worked.

Unfortunately, my life changed when I had a disease flare-up in 2008. Due to abundant intestinal haemorrhage, I had four operations, which resulted in multiple enterectomies. After a month-long struggle to stabilize my condition, I was left with approximately 80cm of small intestine and a stoma.

In the beginning after the surgery, functioning was very difficult. Daily eighteen-hour parenteral nutrition (PN) and the need to live with a stoma caused changes in my life. It took me a long time to accept the situation. Then I started to focus on things that I could do, while trying to forget the obvious limitations resulting from my poor state of health.

Fortunately, the coming months brought a gradual improvement of my health, so after one and a half years of treatment I could undergo another operation. Its aim was to restore intestinal continuity. This step enabled me to look optimistically into the future.

It’s unbelievable, but in six months after this surgery, I managed to put on over 10kg of weight. This has strengthened not only the need to consume more food taken orally but has also allowed me to feel the proverbial “appetite for life.” Since that time, I decided that I would try—to the maximum possible extent—to realize my life plans regardless of PN.

HPN doesn’t make me happiest person in the world and often requires a lot of effort and organization from me and my family. Often it is associated with the pain and discomfort that accompany Crohn’s disease and PN. Never, however, will this outweigh the satisfaction and joy drawn from life on the rightful basis. I think that for all of us it is important to fight with the limitations, and as far as possible to prevent our disease from dominating our lives in any aspect.

That’s why in 2012 I set up an association - Appetite for Life for home parenteral and enteral (HPEN) consumers in Poland. On a daily basis we empower, educate and support home artificial nutrition (HAN) patients in our country. We also appreciate the possibility to cooperate with patients’ groups from other countries under PACIFHAN umbrella, as we believe that together we are stronger.

Marek Lichota, Appetite for Life - Poland

To be informed that your newborn child has a serious rare disease completely rock your boat. You are no longer on your way to the destination where you thought, the compass of life has turned around and you are sailing in uncertainty, towards destinations you had never imagined.

But we never thought that the destinations would be so fantastic and life as good as it has become. Today Svea is 9 years old, and ever so healthy!

When Svea was born, it was pure joy, we had had a daughter, Erik had had a little sister, but already that first day came that feeling that something was wrong. Once back at the hospital, a paediatrician came and confirmed our fears. Svea has not received a clear diagnosis: but she has intestinal failure, short bowel syndrome, and a condition like pseudo obstruction. She has a stoma with high stoma flows. She has a Port-a-Cath® and gets most of her nutrition from total parenteral nutrition (TPN).



At the hospital we received a solid education on how to manage TPN and replace ostomy bags. The staff was extremely supportive and gave us both the strength and courage to go home and assured us that this is the best for us all.

What we didn't know was that when you become a parent of a child with severe intestinal failure, you are not just a parent. You become a nurse, coordinator, lawyer, psychologist, educator and a warrior.

In all sadness about how life was not as we imagined, we came in contact with a patient association. The Swedish HPN Association. We gathered and went on a summer meeting organized for the whole family. The happiness of seeing these wonderful HPN children of all ages, running around and playing, and enjoying life became a turning point. We learned to accept the disease, no diagnosis was the solution, we were the solution.

We are to live like a normal family, that is our motto and something we have worked hard to achieve. We started traveling, first within Sweden, but later also abroad. The power of traveling has given us the feeling that we can handle everything. Some days are obviously heavier than others. Days when it is so obvious that you cannot do everything there as everyone else does. Or days when someone said something stupid at school, that's when the big challenge comes. As a parent, you just want your child to have a good time, a happy childhood and you want to remove everything that hurts, but you can't. But we could do better, we bought a dog. The dog has become the one who comforts the bad days, and the friend who does not exist otherwise, the dog has also led to taking responsibility for someone else, and for a moment forget their own problems.

When we look back on everything that has happened, the patient association has been the most important bit for us and now with PACIFHANS formation we feel a great hope for the future.

Jennie, mother to an amazing girl, Svenska HPN-Föreningen Barn & Ungdom – Sweden



Finding out that despite all my personal efforts to eat and drink, 34 years ago I faced the dilemma of life on parenteral nutrition (PN). Years of ill health and hospital admissions, I thought my life was over, PN was the only hope I had to regain some independence and normality. Granted, I would still suffer with pseudo obstruction, but my nutritional status would be improved and give me strength to cope.

It wasn't easy to start with, it took a lot of effort to understand how my life would change but looking back, I can now see all I achieved thanks to PN. The support from my medical team, family and friends gave me the

courage to face the future. I quickly learnt that there was little understanding of how people lived with PN in the community. This resulted in some patients starting a patient support group, designed to share information and remove the isolation of the home treatment. I became involved and we work as a team. PINNT supports people on home enteral and parenteral nutrition. It's an inclusive group and we network with all those who support and share our cause for education, patient resources and a greater awareness among all those who govern and manage the overall provision of home artificial nutrition (HAN).

HAN benefits so many people and PINNT continues to actively support people to live their life on HAN in the best way that works for them as an individual. We share the common treatments, but everyone needs to be an individual and cope with the individual needs and lifestyle choices.

I am personally eternally thankful for my PN, it has presented many situations over the years that have meant some difficult decisions or choices to be made, I try to live the best life I can thanks to PN. Through our membership with PACIFHAN we have already learnt so much, we look forward to continuing our evolution to a wider network of patient groups with a united voice and offer more people to showcase life on HAN.

Carolyn Wheatley, second from right, PINNT - UK



#WorldHANDay