DRIPLINE

PARENTERAL NUTRITION DOWN UNDER

Parenteral Nutrition - Down Under™

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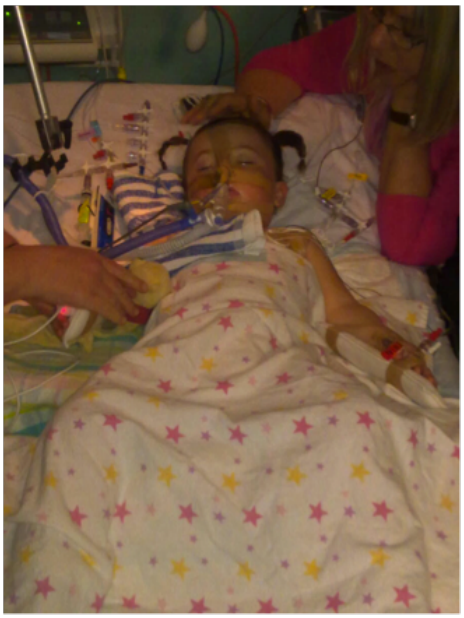
Welcome to another edition of Drip Line! It's hard to believe that the year is half over, as is winter, and this edition sees Drip Line commence its second year! Thank you for your support, and hopefully, you'll have time to sit back, read, enjoy, and learn from this issue's articles. We have two PN-DU members' stories – Emily, a beautiful four-year old, and Reneé, one of our most warm-hearted, sympathetic forum members. We read about our latest Sydney get-together, meeting Gil, from Auckland. We find out a link between hair loss and PN. Baxter pharmacists reveal what happens during their day, preparing our 'dinner'. You might find some ideas for your non-eating child's birthday parties. Find out when HPN Awareness Week is, and when PN-DU will again be appearing at Australian Gastroenterology Week. Read the government's eHealth record brochure for personally controlled, electronic health records. And you might like to follow the link to The Kid's Foundation, a New Zealand based organisation.

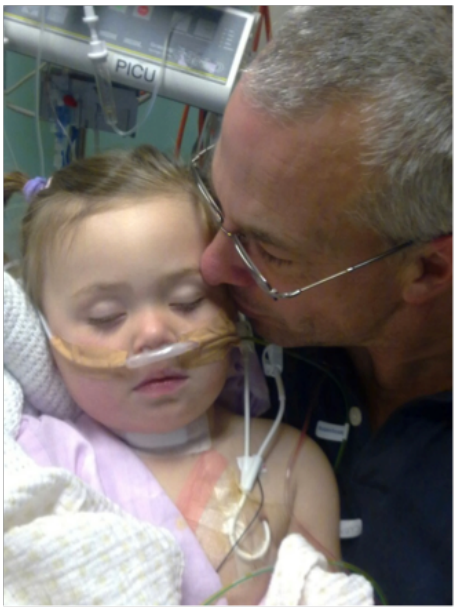
Gillian Anderson
Editor

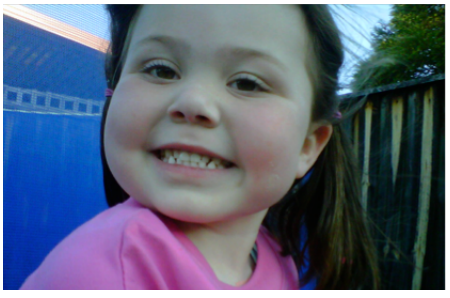
IN THIS ISSUE

EMILY'S STORY

WORDS BY *MELANIE*







When I am asked to write Emily's story my heart often skips a beat as it means going back over the darkest time of my life however, for any other parents struggling with their child's illness, I hope this brings comfort that you are not alone and that in the face of the worst odds, light and love can shine through.

Emily was born on the 31st of March, 2009 at 9:02pm. She was a beautiful, healthy baby who bought such joy to all of our lives and who was never sick. Emily has two older siblings, Tayla (18) and Ryan (16) and a little brother, Matty (2). She is the adored 'first grandchild' and in a large South African family that means a LOT of love!

On June 14, 2011 Emily woke at 1am screaming. We rushed to her bedside and she promptly vomited but continued to scream and arch her back. We assumed a normal toddler tummy bug, albeit extreme and phoned the Children's hospital advice line who told us to wait. Within half an hour Emily had settled back to sleep. Or so we thought. We realise now, she actually passed out from pain. (Yes this is one of my horrific 'guilty mummy' moments).

My husband (Mal) slept with Emily as we always did with the children when they were sick. Mal has a severe eye condition and is unable to see much without his glasses, which of course he wasn't wearing at night. So he didn't notice Emily's colour.

When I went back in to her room at 5am, Emily was grey. Her eyes had rolled back in her head and she was drooling. I don't know why I didn't call an ambulance; I just knew I had to get her to hospital. I picked her up and drove her to our nearest Private Hospital.

She was seen within moments, and around 2 minutes after being placed on the bed, she went into cardiac arrest and 'died' in my arms. (It all sounds very dramatic, and I wish it was just an excerpt from a daytime drama, however I recount Emily's story as I remember it. I have no medical experience so I apologise in advance for any medical errors in this story.)

Emily's body was in such a complete state of shock her vascular system had completely shut down and staff were unable to get a canulla in to her to deliver fluid. She was revived after what seems like hundred of needles were inserted all over her body. This included drilling holes through both her shins to see if they could get fluids in to her bones, rather than her veins.

Emily was terribly unstable and none of the team knew what had happened.

The Neonatal and Paediatric Emergency Transport system (NETS) arrived and decided she was not stable enough for helicopter transport, but was to be taken via ambulance to Sydney Children's Hospital at Westmead, which fortunately is only 20 minutes away from us.

During the trip Emily went in to cardiac arrest again. She was admitted to the Intensive Care Unit rather than the Emergency Department who quickly began all sorts of invasive procedures including placing her in an induced coma. Mal and I were ushered in to a small room and the Hospital's top Intensivists and Surgeons calmly told us our baby was going to die. She may have a chance if they operated however it was extremely unlikely she would survive the surgery. We had no choice. We opted for surgery and we gathered our closest family and prayed.

Perhaps the worst thing was that no one knew what had happened.

After the surgery it was all explained to us. Emily had suffered a 'spontaneous and catastrophic mid gut volulous' where her intestine had twisted around the mesenteric artery cutting off the blood supply to her entire small and large intestine. This catastrophic event is extremely rare and usually occurs in children under 12 months, particularly premature babies. Why it occurred when Emily was 2 years and 3 months is beyond anyone's understanding.

When we were finally ushered in to Emily's room after surgery we were shocked to find out baby girl had her eyes taped shut, over 25 lines travelling in to every available vein in her body, as well cardiac monitors, catheters etc. But perhaps the most upsetting for us was the large 'window' of clear contact covering a gaping hole in her abdomen to allow for swelling after surgeons had attempted to remove the ischemic bowel which was poisoning her body. Staff expected Emily's major organs to shut down and for her to die that night. They said this to us each night for 2 weeks. She had 60cm of small bowel with 7 anatomises in it and 50 cm of large bowel.

After 3 weeks where Emily suffered numerous set backs including encephalopathy where the extreme toxin levels in her body from the dead bowel altered her mental state such that she really didn't wake from the coma for 16 days. She would lie on her bed surrounded by machines and just stare in to space. We tried desperately to interact with her and it was perhaps one of the most heartbreaking times. Eventually one afternoon I was playing 'incy wincy spider' on her belly and she looked at me and smiled. I can't tell you how much I jumped for joy.

As staff had little experience with Emily's condition each step was difficult and experimental procedures became a living nightmare for Emily over the next 6 months.

Once her abdomen was closed and a stoma formed, this first stoma prolapsed and a fistula formed. Through the fistula poured the acidic gastric juices, which were not digested at all. Emily suffered constant severe burns and excruciating pain, and staff attempted many different methods of dealing with this fistula all with limited success. Eventually she was fitted with a Foley catheter which when combined with a nasal gastric tube, worked the best. We added liberal amounts of good old Sudocrem® around the fistula to protect her raw skin and changed the dressing several times a day. Eventually we were able to get her skin well enough for more surgery to close the fistula.

In September Emily had the fistula closed and surgeons had hoped the 7 anatomises had good blood supply and they could save the

60cm of small bowel. Unfortunately none of her small bowel was left viable and was all removed.

Emily was sent home in December 2011, with a colostomy and a central line for her parental nutrition which is administered by us over 12 hours each night.

What is life like for Emily now?

Almost 2 years on and Emily is a very bright little 4 year old who has become used to her 'bits and bobs' as she calls them. Pumps and bags are part of her life and whilst she often wishes she was like her friends, I am not sure she remembers a time when she could go to sleep and not be woken every 2 hours to have her nappy changed, or be able to swim at the beach with her friends.

As with all central lines we are vigilant with her care and extremely aware of life threatening infections. Whilst she has only had one central line infection, Emily does get many respiratory and other infections such as urinary tract infections, which was the most recent. For Emily this means another stay in hospital while her temperature, heart rate and other vital signs are stabilised and intravenous antibiotics administered. Emily is now classified as an immune-suppressed child and she seems to pick up every bug going around. It is with great trepidation we send Emily to pre school however our role as her parents is to provide the best care we can and to make her life as normal as possible. We are extremely fortunate to have access to a smaller community preschool with caring staff who adore Emily and who take great pains to ensure she is as safe as possible.

Perhaps the most debilitating aspect of Emily's medical condition is pain. Emily lives with almost constant pain. Sometimes she is able to go to ballet, bike ride, go to Pre School and play with friends. Sometimes all she can manage is to lie on the couch and watch her favourite fairy and princess movies. As Emily has surpassed all expectations, medical staff is unwilling to provide explanations or relief for her pain. She has undergone such horrific procedures that she would rather live with pain than spend time in hospital having more things done to her. When Emily does have investigative procedures they are often inconclusive as to why she experiences so much pain.

As with all children, we treat each day as the most precious gift and relish any time we are able to share with her. Recently Emily celebrated her 4th birthday with a pirate / princess party. The sound of her laughter as she ran around with her friends dressed as a princess still makes all the adults around her shed a tear.

We pray that some day medical knowledge will catch up to where Emily's body is and perhaps intestine transplant will become a reality in Australia with a better survival rate. ✳

MY FIRST PN-DU MEETING

WORDS BY *VERONICA*

I had the pleasure to meet with other PN-DU members on Saturday 18th May at Gillian's house in Sydney.
It was great of Gillian and Ray to open their home to all of us. Thank you very much, most appreciated. It was fantastic to be out of the cold!

It was a bit of a challenge for me to get to the meeting! I had planned that it would be easy to go via train, EXCEPT I found out that there was track work that weekend, which was a major deterrent. Buses were being used between affected stations. I can't stand buses, so instead of aborting the plan of going, I had one other option - to try and drive.

I asked a friend if she knew the suburb where I was going. She said "Yeah, that's where my mother lives". She explained that it was really easy to get there and it was only 20 minutes away. I thought 'no problem'. But just before I left, I discovered that I had given her the wrong suburb name and found out that I was meant to be going past Hurstville! I then panicked about driving, because I get lost just driving to Blacktown! (I live near Westmead Hospital). I got two GPS navigations working, via phone and GPS. I was confused with both of them, and rang another friend, who then advised me the easiest way to go. She knows my poor navigation skills and laughed saying "You will never get there!" Miraculously, things were straight forward and I didn't get lost, but arrived late due to driving at a snail's pace most of the way, due to congestion on the highway from two car accidents! I got lost twice on my way home BUT our group meeting was really worth it!!

When I arrived I had a warm welcome from everyone. I was really happy to be able to meet Jane, Karen, Gillian, Ray and Gil. Thank you all for the effort in coming.

About half an hour after I arrived Miranda and Dave came with Ariel and Eadie to liven things up. The kids were such calm, peaceful children. Baby Eadie slept peacefully a lot of the time in Gillian's arms, and Ariel walked around meeting everyone. I have never met an infant who has been sustained on TPN let alone for over 2 years. It is unbelievable how well she is doing, so a big thanks to her parents for putting in all the 'sterile' hard work and for their healthcare support team.

It really is nice that we have been able to meet in person. It puts a personal approach to our group and we all enjoyed putting faces to the names!

We were able to talk about experiences with each other. I was happy to learn things and hope that others did also. This is the main

point of the exercise: LEARNING from, and HELPING, each other! A very big thank you goes to Gil, for making the huge effort to travel here from Auckland, NZ. The hassles for Gil going to airports, and catching taxis, buses and trains, is heaps compared to our travelling to these meetings. We are all extremely grateful for your presence and especially for your knowledge. It was great to meet you!

Gillian put a big effort into catering for everyone. Drinks and cakes all went down well. Well, they tasted good to those who consumed them and were most appreciated. Thank you.

I look forward to our next meeting and hope to meet more group members (providing, at the time, that we don't have health issues or other commitments)!

Until then, everyone take care, best wishes and hopefully BETTER HEALTH! ✳

L: Ray, Jane, Veronica, Karen with Eadie, Gillian, Miranda, David with Ariel, and Gil, standing.

R: Ray, Dave and Gil

L: Jane, always knitting, Veronica, Eadie and Gillisn

R: Ariel and Eadie with Gillian, Miranda and Ray

HPN AWARENESS WEEK

Home Parenteral Awareness Week is coming soon, from the 4th – 11th August. This is our chance to raise awareness of this complex, and comparatively unknown medical treatment. It's a great opportunity to talk to friends, family and colleagues. And why not write your story for your local newspaper! We will once again have our own YouTube slideshow to circulate far and wide, Awareness Week badges for you to wear, a poster to put up in your workplace or on a community noticeboard, as well as the Awareness Week logo to use as your Facebook profile during the week. So many ways to get involved and help raise awareness!

Please contact us at contactpndu@gmail.com to obtain a badge, the Facebook profile and/or the Awareness Week poster.

ONE JOURNEY WITH HPN…THE POWER OF LOVE (RENEÉ'S STORY)

WORDS BY *RENEE*

Sydney, Australia

Starting Permanent HPN

I woke up in intensive care on the 6th December, 2011, two days after I was rushed to hospital for emergency surgery. After 46 years of health challenges it had come to this: I was told I had experienced my second volvulus (an abnormal twisting of the intestines causing obstruction), the blood supply to my gut had been cut off by a band of scar tissue and, following another resection of both my small intestine and colon, had intestinal failure. As a result I would be on Home Parenteral Nutrition for life.

My devoted husband, Mervyn, was delighted!! My condition had been critical and the doctors were very doubtful I would survive. Next to death, for him this was a wonderful outcome. I was less sure. I could not speak as I was still intubated. Quietly I felt I had had enough of the struggle and was ambivalent about this outcome.

Unlike most people who are given this news following a health crisis, I understood exactly what it meant: in 1981, a few months after my son was born, I was one of the first patients on HPN in South Africa. After my pregnancy, I was very depleted and experienced continuous serious electrolyte deficiencies. The doctors felt this new treatment was precisely what I needed. At that time, however, it was not intended to be a lifelong treatment and after six months the central line blocked and the PN ceased.

Johannesburg, South Africa

The Beginning
I remember with precision the day my journey with health challenges started in 1965, when I was eleven years old. I was a very active young girl and participated in every sport my school offered – netball, tennis, swimming, cricket, hockey, and athletics. Despite my lack of talent in any of these activities, my enthusiasm was never blunted and every break I could be found on the playing fields. But not this day...I felt ill. As soon as the end of school-bell rang I looked for my sister, Ann, who is five years older than me, to tell her I was sick. Usually we caught a bus together for some after school activity (ballet, piano, Hebrew school and youth groups). On this day she managed to find a mother of one of my friends who was willing to give me a ride home.

For the next three months I was sick with fevers, vomiting, diarrhoea, pain, loss of appetite and weight loss. Despite the best efforts of my doctors, my illness was a mystery. Finally, with all other tests exhausted, they decided I would undergo a diagnostic laparotomy. The diagnosis was then clear: Crohn's disease. Today, children as young as one or two are being diagnosed with Crohn's, but at that time none of the doctors had ever seen a case in a child and this caused great interest among the local medical fraternity. I had a great Aunt who suffered from Crohn's disease and she knew only too well what this diagnosis meant.

Years of struggle
Treatment in those days consisted of Salazopyrin and cortisone - drugs that are still in use in the treatment of Crohn's –and surgery. There was not much else about. For the next eight years I continued on some combination of these drugs but was never able to go into remission. My days were filled with the same symptoms that I experienced during the first three months. I tried to continue with usual activities but it was a struggle. Many times I used to pray "'Please God let me make it to the top of the road" as I walked to catch the school bus. Somehow, I managed to continue with my schooling and keep up with my peers, although many of my activities were curtailed and I often ended up in the sick bay and had to go home early. I was very fortunate in that I had a wonderful GP, Boz, who never let me behave like an invalid and he encouraged me to live as full a life as was possible. He and his family lived in the same apartment complex as I did; his daughter and I were close friends and he was more like a father to me. (My parents divorced when I was three and I lived with my mother. I saw my father regularly but did not have a close relationship with him.) I did not go to hospital very often as a child as there was not much they could do, but Boz sat with me for many nights when I was writhing in pain or vomiting from obstructions. I spent my final year of schooling in a boarding school and to be truthful I actually spent most of the time there in the sick bay...there were gaping holes in my knowledge. Somehow I staggered through my final exams, matriculated at the end of 1971 and applied to go to university the following year.

Israel and Europe

Travels abroad
I had been selected to go to Israel on a youth leadership program following matriculation and left Johannesburg for a period of work, study and touring in Israel. My Dad had other plans for me.

Both my parents were refugees from Nazi Germany. My mother never wanted to return there (although she did when she was well into her 70s as part of the German reparation program) but my father always wanted to show Ann and I the places where he had lived. Since I was already in Israel it was an easy trip to the UK and Europe and he planned a visit to England, Scotland, France, Switzerland and Germany following my time in Israel. It was a very strange experience travelling with a father I did not really know very well but it was a rewarding time too.

I did not know it at the time, but my father also had another motive in getting me to the UK – I had previously seen a Professor from Edinburgh when he visited Johannesburg. At that time he was considered a world authority on Crohn's disease. My father wanted me to see him and have my illness reviewed as I was still quite ill. I spent about a week in hospital in Edinburgh and the doctor was shocked at my condition – he said my nutritional status was so poor he did not know how I was functioning. His recommendation: three months in hospital in Edinburgh and a year of bedrest!!! The theory behind this at the time was that Crohn's should be treated like TB – bedrest would give the body a chance to recover. This was unthinkable. My mother did not even know I was in hospital and besides, I was due to start my university studies. So, the Professor wrote a report for my doctors, and my father and I continued on our holiday (later joined by Ann) and we had a wonderful time despite the bouts of illness.

Johannesburg, South Africa

A year in bed!
I duly returned home in time for university interviews and registration and with much anticipation started my undergraduate degree in social work. Within the first three weeks it became clear that I could not cope. My health was simply not up to it. I saw no way out but to take the Professor's recommendation and spend an extended period of time resting....trying to get my body to overcome the illness. Boz was totally against this decision. He understood only too well that I was more than my body and my illness, and was concerned about the impact on my mental and emotional wellbeing. But I did not have any other options.

So for about seven months I effectively stayed at home most of the time, rested a great deal, engaged in a small amount of activity (I learned to type – a skill I am grateful to have!)...and became very lonely and isolated. My health did not improve. In the second half of that year Boz suggested I see a doctor who had recently returned to South Africa from the USA. Although a surgeon, he had seen first-hand the positive effects of the new wonder drug – Imuran – on patients with Crohn's disease and was having success in treating patients with this new drug. I duly started on Imuran and for the first time in seven years, I started to feel better and to contemplate the future with more optimism. I started going out and seeing friends and began planning to commence university again the following year.

One November night I awoke with excruciating pain. I was used to pain and had a very high threshold. I crawled into the kitchen,

made myself a hot water bottle, and struggled through the night. I did not wake my mother as I did not want to disturb her but in the morning I told her of my pain. Of course Boz arrived and I was off to hospital. X-rays soon revealed the problem – my bowel had perforated. I had an emergency bowel resection but recovered quite quickly, and with the Imuran my improvement continued. I looked forward to the New Year with much excitement.

Falling in Love
I was still recovering from surgery when my mother told me we were going to Durban (a seaside city) for a holiday. I did not really want to go as with my newly improved health I had started socializing and, for the first time in my life, dating!! However, she gave me no choice so six weeks after surgery I was in Durban. On the beach on Christmas day 1972, I met Mervyn and – as they say – the rest is history. My mother was none too impressed as I had just turned 18 – but that is another story!

Embracing life
The following year, 1973, was a new beginning for me. I was feeling better than I had my since I first became ill, I started university, I was in love and living life to the full. These were heady times with the rise of social movements – feminism and most importantly in the context of South Africa, the Anti-Apartheid movement. I was studying social work and so was fully engaged in social and political context of the time. Mervyn and I married at the beginning of 1974. I was so very happy.

However, illness was still a constant part of my life. Crohn's was ever present and my classmates knew very well that I frequently had to leave the class to go to the bathroom. There were many days I was ill and I experienced a number of complications including internal bleeds, kidney stones, kidney infections and the ever present vomiting, diarrhoea and small bowel obstructions. But we coped and life went on.

Short-Bowel Syndrome
1976 was a critical year in South African politics. It was the year of the Soweto riots, the oppression of the Nationalist government was at its height and the call to action was very loud. I was in my final year at university and my student practical placement was in Soweto. I was in my office near the university preparing my project when I felt the familiar pain. "Not to worry'', I told my friend who was in the office with me, ''it will pass''. She knew me well and knew how often I had these episodes. After about an hour, however, she could see this was not going to go away. I was lying on the floor writhing in pain. Fortunately she knew which hospital and surgeon cared for me and rushed me there immediately. Mervyn, Ann, my Mom and Dad were called.

At first the surgeon (the same one who had prescribed Imuran) was nonchalant – it was just another little perforation and a minor operation would fix it. Hours later, however, when he finally emerged from the operating theatre, he was ashen. It was not simply a perforation but a volvulus. By the time he operated, most of my small intestine was gangrenous, and he had to remove all but 45cm. At the time I did not know it, but he told Boz how sorry he was – he knew Boz was more than a doctor to me – and he did not know how I would live a normal life. I officially had short-bowel syndrome.

In those days there was nothing like Parenteral Nutrition. The best they could do was offer me Flexical (an elemental oral diet that was invented for the astronauts). I lost weight drastically and was very ill but somehow I recovered enough to complete my studies and graduate with the rest of my class.

The years that followed were once again very challenging. It was impossible to maintain proper nutrition and I had many symptoms of electrolyte, vitamin and mineral deficiencies. We soldiered on.

Cape Town, South Africa

A new start
Towards the end of 1977, there was change ahead. Mervyn's company wanted to transfer him to Cape Town and we were delighted at the opportunity to live in such a beautiful city with an apartment on the beachfront. But it was tough – we were starting again. We had only one friend, and Mervyn had some family, so we needed to make contacts. I began the process of finding work, and enrolled in a Masters degree in social work. We loved living in Cape Town and often had family and friends visiting from Johannesburg.

But creating a new life in a new city is hard enough when you are well but with my health there were added dimensions. I found new doctors. In addition to the ever present symptoms associated with poor nutrition and Crohn's, I had a belly so bloated it looked like I was about to give birth. The doctors diagnosed a 'blind loop' (like a billabong where there is no flow) in the gut (caused by the previous emergency operation) in which there was bacterial overgrowth. As a result I was on Flagyl for eighteen months and constantly nauseous.

A Baby
After a couple of years in Cape Town I began to long to have a baby. It never occurred to me that I should not attempt this because of my health. Only dear old Boz issued words of caution. However, I first had to get off Flagyl, which cannot be taken during pregnancy. So, another operation followed to remove the 'blind loop' and tidy up my gut. As soon as possible after I recovered from surgery I became pregnant and in 1980 we were looking forward to the birth of our child.

I truly had no idea about the impact a pregnancy would have on my body and at the time it seems the doctors did not either as I was given only oral nutritional support. I carried out my usual activities including work (by now we were in the midst of serious political upheaval and the school boycotts in the townships in which I was heavily involved). At seven months pregnant I weighed the same as I did at the start! At one of my regular antenatal appointments the obstetrician's concern soon translated into immediate hospitalisation – there was no discernible foetal heartbeat. What we now understood is that I was not able to absorb sufficient nutrients for both me and a baby. I stayed in hospital for the final two months of pregnancy and was fed a high calorie diet, 24/7 by

naso-gastric tube. To our delight and gratitude, Justin was born on 24th September, thin but healthy. I was exhausted and totally depleted.

The next three years were both a joy and a struggle. Justin was simply wonderful and soon picked up weight (I tried to breastfeed but had to stop very rapidly as I could not nourish him adequately). He was a joy, bright and so amazing to be with. But I was finding life with my baby very difficult and Mervyn was required to be a very hands-on father, day and night. I was constantly in hospital for electrolyte infusions. As a result, after six months I was finally put onto HPN. This was hard with a little baby but much easier than going to hospital. I finally was better nourished and felt much better. However I had complications when they inserted the central line (pneumothorax) and when it blocked it was decided I was well enough to manage on my own. As a result the constant visits to hospital resumed. To illustrate this point: One day, when Justin was fifteen months old, Mervyn was driving to the hospital to visit me. As the hospital came into view, Justin piped up from his baby seat: "Oh, we're at the hospital. Mommy lives there!" Because my problem at the time was mainly with electrolytes, and not absorption of all nutrients, HPN was not considered to be a long term option.

Emigration
This process continued and for us became normal. We then made a decision that could be considered crazy given our circumstances...we decided to emigrate to Australia. The political situation was becoming more fraught and social workers who worked in Black communities were being arrested by Security Police. I actually got through the medical examination required for this process and on Justin's third birthday we left Cape Town.

Sydney, Australia

We have always loved Sydney from the day we arrived and are profoundly grateful for the opportunities this country has given us all. I soon found a new medical team and a wonderful gastro-enterologist. I still had many days when I was ill so we had to organise stable care for Justin, and Mervyn continued to do so much...but we managed and enjoyed life. My gastro tried to give me some additional oral and injected supports but I continued to require hospitalisation for electrolyte infusions.

I started seeking help from alternative practitioners as I accepted the medical profession had little more to offer me. I saw a range of people and collectively they were able to give my body far more support than it had been receiving...at its peak I was taking 100 tablets a day – we won't talk about the cost of this supplementation. My health did improve and from around 2002 – 2010 I enjoyed better health than I had since my diagnosis of Crohn's disease. I still had limitations but the days of illness were far less frequent. An exercise program also helped me to get stronger. Even a diagnosis of breast cancer in 2004 (requiring surgery and radiotherapy) did not have a hugely negative impact on my health (but I did question the level of support offered to people with breast cancer compared with those who have gut problems, but that is another issue).

Back to TPN
2011 was a difficult year. In May I contracted pneumonia which left me feeling quite debilitated for a couple of months. Around October I started with bowel obstructions and was hospitalised three times before the admission in December for my second volvulus. Recovery was very slow...I was very ill. In the first six months of 2012 I had three emergency admissions, two to the ICU, for line infections and sepsis. Gradually in the second half of last year I started gaining weight and feeling a bit better and the first half of this year has seen my health improve markedly.

My life has changed significantly since this last operation. Despite the fact that I have had issues with my energy since I became ill, my life is more constrained. I am no longer able to do the demanding job I had before (managing a service that supports adults with an intellectual disability to live independently in the community) although I do still work two days a week in the same organisation. I have reduced the amount of voluntary work I do significantly and I need to plan how much I do each day carefully.

But I am here to enjoy wonderful times with my precious Mervyn and Justin; I have wonderful friends and am part of a much treasured spiritual community. Ann and I remain close and she visits me from her home in Los Angeles twice a year. The medical team that supports me is superb and I am grateful to live in a country that allows anyone who needs it access to HPN. How fortunate we are!! My early ambivalence about living on HPN has largely dissipated and I am grateful to take each day as it comes, treasuring each precious moment in this amazing world.

Postscript
I was recently reading an edition of the Oley Foundation newsletter and saw a reference to a book Tasting Life by Inalee Koonin. Inalee was one of the earliest HPN patients in the USA. She started the Lifeline Foundation which later merged with Oley and was a tireless worker in spreading the word about the benefits of HPN. Inalee died in 2009. Because of the coincidence of names I was interested in making contact with her family and managed to connect to her husband, Marshall, via the Oley Foundation. We have written to each other and it seems we are from the same family tree but have not yet been able to find the direct connection.

You can read more about her here:
https://itunes.apple.com/us/book/tasting-life/id577939207?mt=11

AUSTRALIAN eHEALTH BROCHURE

Some of you might be interested in registering for the government's eHealth initiative. The following brochure gives some information, and any questions should be answered either on the website (www.ehealth.gov.au), or on the phone (1800 723 471).

Why register for an eHealth record?

Your eHealth record will be controlled by you. It will allow you and the healthcare organisations you choose to access a summary of your important health information.

This could include potentially life-saving information such as any previous adverse drug reactions, or the details of the medications you are taking. Having this information at the point of care will help your doctors, nurses and other healthcare professionals make the best decisions. It will also mean you will not have to remember and keep unnecessarily repeating your medical history.

Benefits for you include:

- Best treatment – As the system grows, healthcare organisations such as a GP practice or local hospital will be able to quickly view a summary of your information, helping them to make the best possible decisions about your care.
- More convenient – You will not have to remember every medication, test or health-related incident, or when a child was immunised.
- Less stressful – Allows rapid access to information in an emergency.
- Better health – You will be able to better manage your health.
- Sharing the load – If you wish, you can share your health information with family members, carers, or other trusted people.

This is just the starting point for eHealth records.

The system will grow — as will the benefits — as more individuals and healthcare organisations get connected.

To make Australia's health system work better for you, register for an eHealth record.

To register for an eHealth record

or for more information

visit:
› www.ehealth.gov.au

or call:
› 1800 723 471

All information in this publication is correct as of September 2012.
D0756 September 2012

Australian Government
Department of Health and Ageing

Personally controlled electronic health records

› www.ehealth.gov.au

National Health Reform

eHealth

Personally controlled electronic health records

Connecting your health records

Technology is a part of daily life for most Australians. We use it for banking, shopping and connecting socially with family and friends.

It can also help deliver better care for individuals and build a more efficient health system for Australia. This is why the Australian Government has developed an eHealth record system.

Registering for an eHealth record will help you take control of your health.

People seeking health care in Australia can register for an eHealth record in one of four ways:

- **Online** – visit www.ehealth.gov.au
- **Over the phone** – call 1800 723 471 and select option 1
- **In person** – visit a Department of Human Services service centre offering Medicare services
- **In writing** – complete a registration form application form, available from a service centre offering Medicare services or from www.ehealth.gov.au, and post it to:

  Personally Controlled eHealth Record Program
  GPO Box 9942
  In your Capital City

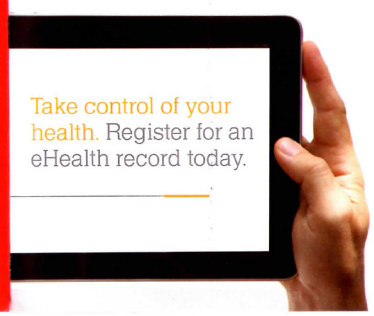
How is this different to the current system?

Until now, health records have usually been stored in different locations with little connection to each other or healthcare professionals and hospitals. Your eHealth record will allow you to access a summary of your important health information online, and share that information with the healthcare professionals involved with your care, meaning you no longer have to remember the detail of every medication, immunisation or treatment you have received.

Your health information travels with you

Your eHealth record will grow over time to contain a summary of your most important health care events. This could include details of a stay in hospital, a visit to the GP or when you have had medical tests.

People who regularly use the Australian health system will be able to manage their care more effectively, even if they travel, need treatment after hours, or see more than one doctor.



What are the benefits when you regularly see a doctor?

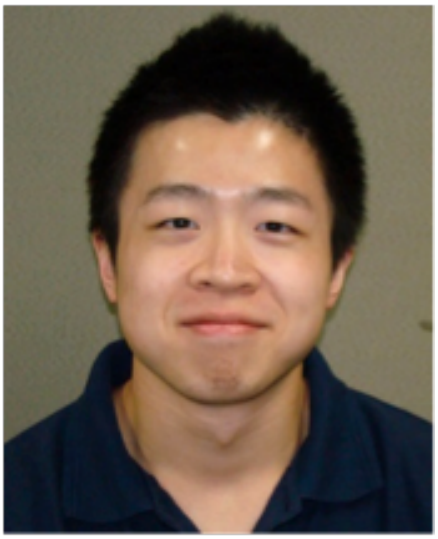
Having an eHealth record will help ensure your GP or your specialist has information about your health. This will help them make the best possible decisions about the care and treatment you need.

Will my health information be secure?

The eHealth record system is protected by existing and new legislation. You will have a login and password to access your eHealth record, and control over which organisations can view your information.

› www.ehealth.gov.au

PREPARING OUR (PN) DINNER



WILLIAM HSIEH, DEPUTY TEAM LEADER, BAXTER AUCKLAND

How long have you been working at Baxter?
I have now been with Baxter for 2 years and 2 months.

What do you enjoy about your job?
I find providing a service that prolongs the lives of our patients extremely rewarding. At Baxter, it is a team effort to provide the best service to our patients from order receipt to delivering the product to the patient's home.

What do you enjoy/find rewarding about sending HPN formulations to HPN patients?
What I find most rewarding is being able to contribute to the wellbeing of patients.

What do you enjoy doing in your spare time?
Running and snowboarding

ANDREW LIM, PHARMACY TEAM LEADER, BAXTER SYDNEY

What do you enjoy doing in your spare time?
Friends and family are such an important part of my life, so I like to catch up over good food and drinks. I also have a passion for photography so when I do get a spare moment, I like to blow the cobwebs off my camera and take a few leisurely shots.

How long have you been working at Baxter?
I have been working at Baxter for three and a half years. Time does fly!

What do you enjoy about your job?
Knowing that the end result of my team's hard work makes a meaningful difference to patients' lives.

What do you enjoy about sending HPN formulations to HPN patients/find rewarding about helping HPN patients?
It's always rewarding to help HPN patients live their lives to the fullest, from overseas trips to seeing and hearing the little ones grow! I always look forward to the meet and greets with the home patients and it's great to put faces to names. It's also a great opportunity for them to share their side of the story with Baxter employees. This really brings everything into perspective and allows us to understand the role Baxter plays in their lives.

HAIR LOSS IN HOME PARENTERAL NUTRITION

'PROFESSOR GIL HARDY PHD FRSC AND "SUZIE DANIELLS APD

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[Modified from Daniells S and Hardy G. Hair loss in long-term or home parenteral nutrition. Curr Opin Clin Nutr Metab Care 2010:13;690-697].

Summary
The phenomenon of unexplained hair loss is multi-factorial. Deficiencies of essential fatty acids (EFA) resulting in alopecia and other symptoms appear to have been eliminated by regular use of lipid-containing parenteral nutrition (PN). Zinc is the most frequently suspected deficiency; marginal biotin status could still be prevalent; alopecia in some infants on PN has been relieved by selenium supplementation and there may also be a relationship between iron depletion and diffuse hair loss in Home PN (HPN) patients.

INTRODUCTION and BACKGROUND
HPN patients are, by definition, reliant on intravenous administration for their macro- and micro-nutrient needs. They are at higher risk of nutrient deficiencies because of malabsorption, increased nutrient losses and increased requirements due to their underlying disease processes.

Much of what is known about nutrient disorders that manifest as hair loss, relates to inadvertent omission of vitamins or minerals from early HPN prescriptions. However, the recommended parenteral dosages have been invariably based on oral requirements of the healthy population, which may in turn be estimates [1]. Assessment of deficiency symptoms are occasionally recommended but are usually not specific for individual micronutrients in PN [2].

Anecdotally, hair loss, or alopecia, remains an infrequent but not uncommon complaint in patients reliant on HPN in Australasia, Europe and USA. This review will focus on some of the key nutritional factors associated with hair loss in HPN.

HAIR LOSS
Abundant, good quality hair signals good health. The hair follicle is a dynamic organ with the ability to regenerate under hormonal regulation. Shedding 100 to 150 hairs per day is normal [3]. Greater losses of scalp or body hair is not life threatening but is clinically relevant in the HPN patient as a possible marker of nutritional inadequacy. Additionally, hair disorders can cause psychological distress adversely affecting quality of life [4].

Alopecia areata (AA) is recurrent, non-scarring patchy hair loss considered to be a T-cell mediated autoimmune process that affects 1-2% of the general population, with equal sex distribution in genetically predisposed individuals [5]. Telogen effluvium (TE), where hairs are shifted into the resting phase after a physical or emotionally stressful triggering event, resulting in diffuse hair shedding, is the most common type of hair loss in adult females [6].

Physiological stress such as surgical trauma, or chronic illness [6] can precipitate TE two to three months after the metabolic or hormonal insult. Hair loss often resolves spontaneously within 6 months, but can also become chronic TE [7]. Nutritional factors have also been noted as causes [1].

PROTEIN-ENERGY MALNUTRITION
Severe protein, fatty acid and energy restriction in chronic starvation, inflammatory bowel disease (IBD) and other malabsorption syndromes can precipitate hair shedding and loss of pigmentation [8]. It may therefore be expected from time to time in HPN patients. Sander et al [9] reported a case of alopecia secondary to malabsorption and increased amino acid excretion, due to a combination of Coeliac and Hartnup's disease. Clinical features resolved with a high-protein gluten free diet, demonstrating the importance of adequate protein and energy input, in cases of PN associated hair-loss. Essential fatty acid (EFA) deficiencies resulting in alopecia, and increased susceptibility to infection were reported in the USA before fat emulsions were widely used [10]. Today, lipids are included in most PN regimens, but EFA depletion can still occur during minimal or fat-free PN.

MICRONUTRIENTS AND HAIR LOSS
Lack of essential trace elements may trigger the onset of alopecia [5] because of the high metabolic requirements of hair production. The most widely cited nutritional causes of chronic diffuse TE include iron deficiency anaemia (IDA) [8], acrodermatitis enteropathica with acquired zinc deficiency, [7] or hypothyroidism (possibly related to selenium status) [3].

Zinc
A component of numerous enzymatic systems, zinc plays a role in the synthesis of protein and nucleic acids, which is why, in the absence of exogenous intake, a fall in serum levels can occur in PN patients, during periods of anabolism when zinc utilisation is greater [11]. Excess losses occur in intestinal failure through diarrhoea, stomal output and GI fistulas [12].

Zinc deficiency is associated with acrodermitis enteropathica, renal disease, malignancy and absorption disorders including coeliac disease, IBD and short bowel syndrome (SBS) [13]. Manifestations include dermatitis, stomatitis, thin, brittle hair with areas of alopecia, and diarrhoea. Disseminated alopecia was reported in a 4 year old girl with repeatedly low serum zinc levels at 48 and 61µg/dl (reference 66-144 µg/dl) [14]. Zinc supplementation (50mg daily) resulted in a cessation of hair loss within 3 weeks. Bhat et al [5] similarly reported decreased serum zinc levels (78 ± 7.45 µg/dl) in 50 patients exhibiting extensive hair loss without other mucosal lesions, varying from 7 days to 120 months duration, and, in another study of PN patients, diffuse alopecia was observed in 3/6 cases allegedly prescribed 37µmol/l zinc, but actually receiving only 3µmol/l. Rapid clinical response was attributable to correction of the zinc deficiency state.

An anorexic patient, with brittle sparse hair that had lightened in colour, diagnosed with hypozincaemia together with a low serum iron and haemoglobin, responded rapidly to zinc supplementation, but the hair changes may have been partly attributable to her low iron stores [15]. This highlights the need to consider coexisting micronutrient deficiencies.

Selenium is a component of glutathione peroxidase, which protects cells from oxidative damage, but hair loss is more often associated with toxicity from excess oral selenium [1]. However, in the 1980's, alopecia was reported in children on long term selenium-free PN [16]. A more recent case study describes a child with cardiomyopathy and anaemia, associated with very low serum selenium after 5 months PN [17]. Supplementation with 100 µg to 200 µg selenite twice daily for 6 weeks, raised serum selenium to 5.3 µg/dl (normal range, 10.6-17.4 µg/dl) and cleared the skin lesions. However neither the cardiac disorder nor the scalp hair improved. Retrospective analysis of six selenium deficient infants in Japan, who had been receiving PN for up to 15 months, confirmed their serum selenium levels were all below normal, and all infants suffered from alopecia [18]. Treatment with 5 µg selenite/kg/day achieved normalisation of serum levels and resolved all symptoms within 1-2 months.

Iron
Iron deficiency (ID) is frequently cited as a contributor to diffuse hair loss [19,20], however a causal link has not been established. Whilst hair loss is not found in all patients with severe iron deficiency anaemia (IDA) [19], a number of studies have found higher rates of iron depletion or lower iron stores (as assessed by serum ferritin) in patients, particularly women, presenting with otherwise unexplained hair loss . White et al [21], noted increased prevalence of IDA (14%) and ID (71%) in female, but not male subjects with alopecia. Other researchers, using different definitions of ID have not confirmed this correlation [19,22,23].

Nearly 50 years ago Hard [24] demonstrated cessation of hair loss with iron supplementation in non-anaemic ID women. There has been limited data since, but assessment of iron status and supplementation for those with suboptimal iron stores is a common recommendation in the management of unexplained hair loss [4,19]. However, the target ferritin level considered 'normal' is controversial. Trost [19] notes that whilst many laboratories use a serum ferritin cut-off of 10-15 µg/L this has a low sensitivity for ID and treatment for hair loss is enhanced when serum ferritin levels are above this threshold. This is borne out by the experience of White et al [21] who failed to correct hair loss with supplementation to ferritin levels of 20 µg/L, and Rushton [20], demonstrated a significant 39% reduction in hair shedding, with an increase in serum ferritin from 33 to 89 µg/L, after 6 months of treatment with 72mg/d iron in conjunction with 1.5g/d of L-lysine. Consequently, commencement of iron therapy in cases of unexplained hair loss when serum ferritin is below 70 µg/L has been proposed [20].

These different clinical experiences may in part be due to the impact of inflammation and diurnal variations in iron binding mediators. Because ferritin is also an acute phase response protein, interpretation of iron status is best carried out in conjunction with C-reactive protein (CRP) levels. The HPN patient may be at a higher risk for IDA due to ongoing bleeding or active GI disease, and iron is not a routine additive to PN regimens because of perceived stability issues. Iron dextran can certainly de-stabilise lipid emulsions in PN admixtures [25] but in Australasia and Europe , the levels of iron contained in the available multi-trace element formulations (as ferrous gluconate or ferric chloride) have short-term compatibility with lipid containing PN (providing approximately 1-1.2 mg iron per PN bag). The latest ASPEN recommendations suggest maintenance supplementation of 1mg/d and 1.5mg/d to maintain iron stores for menstruating women on HPN [26].

Biotin
Biotin is obtained from the diet and bacterial synthesis in the intestine. Clinical features of biotin depletion resemble zinc or EFA deficiency and include alopecia, skin rash, and central nervous system dysfunction [1].
During the 1980's biotin was the most commonly reported vitamin deficiency in HPN. Khalidi et al [27] reported alopecia associated with SBS 6 months after commencement of HPN without biotin. New hair growth was evident within 5 days of biotin supplementation at 60 µg/day. A later series of patients exhibited alopecia, skin rash, and low plasma biotin levels associated with use of biotin-free PN for more than one month [28] then, Forbes and Forbes in 1997 [29] reported 3 cases of hair loss and dry eyes in patients on biotin-free PN for up to 9 years, which resolved after intravenous biotin treatment.

PN-associated biotin deficiency has not been reported since biotin has been a routine addition to PN formulations.

However, reports of marginal biotin deficiencies occurring in adult female smokers, in pregnancy and decompensated liver disease in children and at times of increased metabolic demand (such as infection or illness) suggest that marginal deficiency during HPN may be unreported [1].

Although the recommended biotin dose for adult PN (60ug/d) [26] is double that for normal dietary intake, measures of biotin status are not routinely undertaken in HPN patients and its assessment is not specifically advocated in any of the current PN guidelines [26,30-33]. Thus, it is possible that marginal deficiency resulting in mild or intermittent alopecia occurs during long term HPN but is unreported.

SUMMARY QUESTIONS and RECOMMENDATIONS

Does hair loss occur in PN patients at rates greater than the general population?

There are many anecdotal observations of hair loss in HPN, but its prevalence is ill-defined. This poses difficulties for clinicians who may not notice hair loss symptoms, associated with marginal micronutrient deficiencies in the few HPN patients they manage each year.

Why are micronutrient deficiencies in PN no longer reported?

Recommendations for monitoring micronutrient status in HPN vary from annual assessment [30] to 3-6 monthly [31], but the ESPEN Home Artificial Nutrition Group reported [34] only 19% of centres routinely measured trace elements and only 14% analysed for the vitamins A, D, E, B12 and folate, on average 3 monthly. Thus inadequate monitoring, rather than absence of deficiency symptoms may explain the lack of data.

What should a clinician do with a HPN patient reporting hair loss?

Given the complexity of the diagnosis a clinical examination is of paramount importance. The scalp should be examined for degree and pattern of hair loss, inflammation, erythema and scaling. Collections of more than 100 hairs per day suggest effluvium [8]. Nutrient deficiencies can coexist in individual patients with changes in hair, skin and mucous membranes [1]. It would be prudent to consider overall nutritional status with regards to protein, energy and EFA and to ensure the PN prescription meets current recommendations for zinc, selenium, iron and biotin (Table 1).

CONCLUSION

New biomarkers for micronutrient status that are simple to conduct and interpret need to be developed. Guidelines are needed for interpreting signs and symptoms that may be due to increased nutrient requirements and for correction of any manifestations such as hair loss by routinely adjusting individual micronutrient dosages.

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Table 1. Key Micronutrient's in Hair Health and Recommendations for Parenteral Intakes

Micronutrient	Status assessment	Deficiency symptoms	Biomarker levels associated with alopecia	Acute doses to reverse hair loss	Daily recommendations for parenteral intakes	ESPGHAN 2005 [33]	ESPEN 2009 [30]	ASPEN 2012 [26]
Biotin	Urinary biotin and 3-OH isovaleric acid excretion.	CNS dysfunction, skin rash, alopecia	Plasma biotin 0.33 μg/L	1-2 mg/d (oral) 60-200 μg/d (i.v) in adults	Adults Infants Children	 5-8 μg/kg/d 20 μg/kg/d	60-69ug/d	60 μg/d 20 μg/d
Iron (Fe)	Hb, serum ferritin + CRP, serum transferrin receptor	Fatigue, dry skin, anaemia, alopecia	Serum ferritin <70 μg/L	24-72 mg/d (oral) 1.0-1.5 mg/d (i.v), in adults	Adults Infants Children	 50-100 μg/kg/d (0.9-1.8 μmol/kg/d) 50-100 μg/kg/d (0.9-1.8 μmol/kg/d)	1.0-1.2mg/d (18-21 μmol/d)	1.0-1.5mg/d (18-27 μmol/d) 0.85mg/d (0.015 μmol /kg/d) 0.5-0.95mg/d (0.009-0.017 μmol/kg/d)
Selenium (Se)	Plasma/whole blood Se, RBC GPx	Cardiomyopathy, anaemia, alopecia	Serum Se 2.0-3.3 μg/dL (0.25-0.41 μmol/L)	100-200 μg/d (oral) 5 μg/kg/d (oral/i.v) in infants	Adults Infants Children	 2-3 μg/kg/d (0.025-0.04 μmol/kg/d) Not discussed	30-70 μg/d (0.4-0.9 μmol/d)	60-100 μg/d (0.75-1.25 μmol/d) 2 μg/kg/d (0.025 μmol /kg/d) 2 μg/kg/d (0.025 μmol /kg/d)
Zinc (Zn)	Plasma or serum Zn + CRP, albumin and ALP in conjunction with clinical parameters	Stomatitis, diarrhoea, brittle hair, alopecia, dermatitis	Serum Zn 13-61 μg/dL (2.0-9.3 μmol/L) ALP 15-25 U/L	50 mg/d (oral) 8 mg/d (i.v) in adults	Adults Infants Children	 100-250 μg/kg/d (1.5-3.8 μmol/kg/d) 50 μg/kg/d (0.8 μmol/d)	2.5-6.6mg/d (38-100 μmol/d)	2.5-5.0 mg/d (38-76 μmol/d) 250μg/kg/d (3.8 μmol/kg/d) 50 μg/kg/d (0.8 μmol/d)

ALP, alkaline phosphatase; CNS, central nervous system; CRP, C-reactive protein; GPx, glutathione peroxidase; Hb, haemoglobin; RBC, red blood cell.

PN-DU TO EXHIBIT AT AGW

AGW (Australian Gastrointestinal Week) 2013 will be held in Melbourne from the 7th to 9th October. At this 3 day conference, held by the Gastroenterological Society of Australia (GESA), gastroenterologists, physicians, surgeons, oncologists, radiologists, nurses and various other health professionals meet to learn about various issues related to gastrointestinal disorders. PN-DU will again have an information stand to promote our support group to clinicians involved in the care of HPN patients. We thank GESA for once again welcoming our involvement and providing us with a free stand, and Karen for her willingness to travel to Melbourne in order to 'man' our stand

This was our stand at AGW 2012…..

And this is how tiring the days are!

HOSTED BY: GASTROENTEROLOGICAL SOCIETY OF AUSTRALIA (GESA)

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Participating Organisations:

- Australian Gastroenterological Society of Australia (GESA)
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- Australian & New Zealand Gastrointestinal Oesophageal Association (ANZGOSA)
- Colorectal Surgical Society of Australia & New Zealand
- Gastroenterological Nurses College of Australia (GENCA)

Program Format Mon-Wed:

- Concurrent sessions
- State-of-the-art lectures
- Clinical updates
- Symposia
- Free papers
- Poster sessions
- Debates

Featuring:

- NETI Live Endoscopy Workshop with gastroenterologists and surgeons
- Hepatology and IBD clinical updates
- Multidisciplinary symposia
- State-of-the-art lectures
- Meet the experts breakfast sessions
- Trainee and supervisor workshops
- Advances from the bench to bedside for the physician and surgeon
- Research: oral and poster presentations
- The Great Debate

Critical Dates:

31 May 2013
Close of sponsorship exhibition bookings

7 June 2013
Close of submission of abstracts

31 August 2013
Close of applications for travel grants/ early registration

AGW Secretariat: C/- GESA, PO Box 508, Mulgrave VIC 3170 Direct Call: 1300 766 176
Ph: +61 3 9001 0279 Fax: +61 3 9802 8533 Email: gesa@gesa.org.au Website: www.agw.org.au

IT'S TIME TO PARTY!

WORDS BY *GILLIAN*

All children love the excitement of a birthday: adding a number to their age, anticipating presents, and sometimes looking forward to a party. But it's difficult when the birthday child can't eat, or has limited ability to eat. How can this be overcome so it doesn't place a dampener on the festivities? I asked for some ideas on our forum, and I've collated responses from parents of HPN dependent children, sharing their party plans.

One member suggested lots of singing, dancing and games. Having a treasure hunt, without food treasures, was an idea.

Another mum involves her daughter in the preparation for the party, deciding what food to provide for her friends, even though she doesn't eat much herself. She also loves choosing her cake design, and even though she doesn't eat it, she still enjoys the candle ritual. At the party, she focuses on the games and face painting and fun activities, rather than the food. At night, after a family dinner (where she is served the same special meal as everyone else, even though she just plays with it), the family spends time doing puzzles or playing games with her.

Yet another mother has a theme party, with costumes and food designed around the theme. Games can be adapted to this, as well. Although her daughter hates food, she loves the cake and candle ritual, so she chooses a cake design to match the theme, and they sing happy birthday and blow out the candles about 4 times, as that is the bit that interests her, not the eating part! The goody bags never have food for any of the children - just novelties related to the party theme. It's a pretty normal kids' party – the mum caters for the other children, and her daughter understands that they want to eat and just sits with them happily while they do. In her case, it's easier because her daughter doesn't want to eat, as opposed to can't eat.

As another mum says, 'It's really not about the food, it's about having fun with her friends that matters most'. Her daughter would be consulted about food, to feel special, and they would have standard party food of fairy bread, chips, party pies, lollies, etc, with her daughter licking, rather than eating. They would have an ice-cream cake with 'girly' decorations.

Another idea is to spend some time decorating a room or the house with balloons or streamers, or even paper chains that the child can help to make. This makes for excitement even before the party begins!

For children who are very sensitive about the fact that they can't eat, maybe a foodless outing to a special place for a short time would be an idea. The friends would understand the reason behind this. Maybe a small group taken to the movies, or on a bush walk, or to the beach could be a party replacement. Or a sleepover, commencing after dinner, with DVDs or music and dancing might be welcomed by some.

Hopefully you might gain some ideas from these suggestions, so that your child can have a HAPPY BIRTHDAY, no matter what their circumstances.

THE KIDS FOUNDATION WEBSITE

The Kids Foundation (NZ) website www.idfnz.org.nz might be of interest to parents of children and teenagers on HPN in New Zealand. IDFNZ and the Kids Foundation were founded in the late 1980s by a group of concerned parents, and today they care for hundreds of families coping with chronic illness relating to Primary Immune Deficiency (PID). The KIDS Foundation is the youth section of the Foundation, specifically supporting New Zealand's chronically ill children affected by PID conditions (including PID bone marrow transplant and plasma IVIG/ SCIG recipient patients). In addition, KIDS Foundation also supports chronically ill liver transplant, gastro and bowel transplant children facing secondary immune problems.

DONATIONS

If you feel able to contribute to our support group, you may wish to make a donation. Donations are currently only tax deductible in New Zealand. We are grateful to our sister charity IPANEMA (Charities Commission Registration CC21178) which receives donations on our behalf.

Cash, NZ cheques or International Money Orders made payable to:
"IPANEMA TRUST" and sent to:
PN-DU Treasurer, c/o G Hardy, Massey University, Private Bag 102 904, Auckland 0745 New Zealand
On-line donations:
directly to IPANEMA's bank account with the notation "PN-DU":
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If you have an experience with Parenteral Nutrition that you would like to share, or if you have questions please email these to **contactpndu@gmail.com.**
Visit the website at **www.parenteralnutritiondownunder.com**

Designer: Carla