# INSIDE OUT

# Hello Friends

Just to keep you all in the picture as to what is going on with our group. As you know we had our Quiz night on Tuesday 6th March, it was the best bit of fun we have had for some time.

I thank all those who attended, one table had the brain of Britain and ours had the most knowledgeable but the wittiest answers. I would like to say a big thanks to our quizmaster and to our very friendly Tory, from Convatec. I look forward to seeing as many as possible on our Charity Night extravaganza, which will include a fashion show, casino and much, much more

#### Bob

And finally, many thanks for all the submissions for this issue - don't worry if yours is not here we have plenty more newsletters to come - keep sending them in... Editor

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# Diary dates: -

#### Coffee, advice and chat mornings

Wed 27th June 10am to 12pm
Thurs 26th July 10am to 12pm
Tues 28th August 10am to 12pm
Mon 24th Sept 10am to 12pm
Wed 31st October 10am to 12pm
Thurs 29th November 10am to 12pm
volunteers needed and welcome

Open day - 11th July – for all manufacturers to come and display their wares 2.30 to 5.30pm

Meetings

Charity Night Tues 19th June 2001 Sister Anne Driscol Tues 11th Sept 2001 Dr Max Pitcher (Gastro Interologist) Tues 4th Dec 2001



# Monte Carlo Extravaganza

Tuesday 19th June sees the event of the year!

#### 7pm in Himsworth Hall

Join us for the fashion show, casino with roulette wheel and blackjack tables with music from Northwick Park hospital radio.

Buffet and refreshments - free parking

Tickets £10 (£9 in advance) Contact Bob or Clare Bossom to purchase your ticket! All proceeds in aid of Cancer Research and Inside Out

# Ringing in the Changes

When Susan asked me to write a little something for the newsletter. "What would you like me to write about?" My adventures up the Orinoco river, where I lost my paddle and how my bag saved me from dehydration?"

"No" she answered.

"Oh! How about the year I spent in the jungle without my supply of bags and had to use Yum Yum leaves?"

"No"

"What about when I got stuck up a ...."

" No, why not write about the changes that you have seen since you had yours" Well, it might not be as interesting but I will give it a go.

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I was born at a very early age, I remember it well. I shot out like a bullet from a gun, it was a good job the district nurse was our wicket keeper for the village first XI cricket team. It was a cold April morning in 1948, when we had snowdrifts up to 16 feet high, or was that the year before? No matter. In those days there was no National Health Service, that did not come about until June or July of that year, to the relief of my parents, as they had to pay for everything.

Some four days after I was born, due to the fact that I had not passed anything, it was found that I was born with an imperforate anus and I was a spina bifida and my parents thinking that they had a baby that was so clean and cheap on nappies!

There I was, lying in my hospital cot looking out of the window towards a very big cedar tree, with drips and things in and around me. The gas radio blaring away with the ovalteenies tune. I was dancing and getting in a mess not only with the tubes but with my new colostomy as well.

You see, in those days they did not have bags for children, in fact the first invention was in 1795 by a chap called Daguesceau who made a leather pouch. The next invention was in 1824, Matland constructed a truss to hold dressings in place. It was not until the early forties that things really started to move, first the black rubber bag and then Koenig Rutzen produced the first adherent pouch (the adhesive was a type of latex) and so on until today's modern designs. I digress.

I had to use cotton wool wadding and a crepe bandage to

As you can imagine, I had lots of accidents and had to change my clothes quite a few times a day.

Salts came up with a belt, that had two straps that went under the legs and four holes in the front of the belt for a dome shaped cup to be attached on the inside of the belt. I then had to place a cotton wool wadding over the colostomy and place the belt over the top with the dome encircling the stoma. All I say is, at times, it was not very pleasant.

In the mid to late '50s, Salts produced a one piece bag that was about 18 inches long and for a small boy with short trousers, well I mean, it never left anything to the imagination. It was about this time I was introduced to irrigation by the nurses and doctors of the Children's Hospital in Ladywood, Birmingham. Unlike today's methods I had to put a rubber catheter into my stoma that was connected to a rubber tube and glass funnel. I would then have to put a pint of warm water and enema soap in. Once in, I had to pull a catheter out and then throw myself over an enamel bucket to empty my stoma.

In the late 50's a company in Denmark called Translit produced a two-piece appliance, which, when I look back, I am amazed it even worked as well as it did. It was a plastic bag with an elastic band around the neck so that it could be attached to the flange. The trouble was, every now and then, the elastic band would snap and fall off, or too much motion

would push off the bag and there was no odour control.

The other important event of the late 50s was the set up of the distribution and manufacturing companies that had done a lot of research over the years and the developments produced have helped to improve our quality of life, and long may it continue.

Now the problem I had with the Yum Yum leaves.....

Robert Azevedo-Gilbert

# Letters to the editor

I thought I would share my travelling tales of Thailand to other stoma wearers. I am 32 years old, have been in and out of hospital for 12 years and have had an ileostomy for 2 and a half years. I had only ever been to Europe so this was a big adventure.

Myself, my boyfriend and 4 friends had planned the 2.5 week holiday for months. We'd had our jabs, I'd had a check up at St Mark's, stocked up on all my supplies (bags, wipes, flanges etc), seen Clare and had been given some really good advice in case of dehydration (crisps, marshmallows, diorlyte). I was all set; I had been packed for weeks! I was very excited but also anxious, I had been told the toilets were just holes in the ground, I was worried about the food and I don't like spiders or anything that moves very quickly!

The 11-hour flight was not a problem, I managed to sleep for 7 of them, the food was fine, the toilets were a bit small. I had taken all my supplies in my hand luggage plus a change of clothes and a wash bag. It was lovely to be able to clean my teeth and wash properly. We flew direct to Bangkok and had a 2.5 hour wait for a connecting flight to Koi Samui. We were told that if we wanted we could get an earlier flight as the previous one had been delayed, we jumped at the chance! They said our luggage would be transferred. On arrival we waited and waited for our luggage but it did not show. A friend who was already there and travels there every year said it would be on our next flight, so we might as well go to our hotel and relax there. The hotel could pick it up later. I was now very grateful that I had all my medical supplies in my hand luggage!!!

It was about 7.30pm so we went to the hotel and had some dinner, the restaurant to the hotel was on the beach and the food was fantastic. Our luggage arrived at the hotel at about 9.30pm so we put on our swimming costumes and went for a swim in the sea.

We had arrived in paradise!!

We stayed there for 2 days so that we could acclimatise before getting on a ferry for 40 minutes to go to Koi Paeng Yang. On arriving, we got a taxi boat for about 20 minutes to take us further down the island. We were staying with a family who have about 10 bamboo beach huts, when they are full they put up tents, when they are full they let you sleep in their house!! Fortunately we all had huts with their own bathrooms, hot and cold water. The shower was only cold water (very refreshing!). The sea was only 20 metres away. We put a hammock up on our balcony and deciding what sarong to wear was the most taxing thing I had to do.

The place was run by a lady called Noc, she lived there with her son, 4 brothers, 4 sisters and 1 grandmother. There was a little restaurant where they cooked for you, the food was fantastic, fresh fruit, vegetables and fish caught daily. My boyfriend even helped catch the crabs one evening. Everyone does as much or as little as they want to. A lady comes in to give massages so of course we had one every day. I explained to Noc about my tummy problems and how and what I ate. She was very accommodating and gave me a key to the kitchens so I could go at night and rustle something up if I was hungry. We stayed in this beautiful place with these warm people for 7 days before getting a ferry back to Koi Samui.

Unfortunately the day before leaving Koi Paeng Yang I somehow managed to catch the flu!! I became very weak, lost my appetite and began to lose weight very quickly. The day after getting back to Samui there was only one thing for it, I had to go to hospital. I was expecting cockroach infested corridors, dirt and no English speaking doctors.... Basically the worst. It was, of course, the complete opposite, I was seen very quickly, they knew about Crohn's and stomas (as if they wouldn't) and everyone spoke English. They did lots of tests for infection but it was just a case of very bad flu. I was told to rest and not to sit in the sun as I was dehydrating very quickly, to drink 3 litres of water a day, not to eat red meat, dairy or fish for a while and to drink diorlyte. I couldn't believe this, I had come all this way and couldn't do anything. I was quite upset for a while. The best thing for me to do was sleep and rest for a few days.

After 2 days I was getting bored, I hadn't come all this way to sit in my hotel room, so we went to a spa in the middle of the jungle. We were pampered for 5 hours – facials, massages – the works, it was just what I needed. It was amazing to be lying out with all the sounds of the jungle around me. The next day we went elephant trekking in the jungle and through the waterfalls, this is where we saw our first and only spider!! I was still quite weak so I sat and watched while everyone else went swimming but I wouldn't have missed any of this for the world.

The day after we flew back to Bangkok for the last 2 days of our trip. As a birthday surprise my lovely boyfriend had booked us into a 5 star hotel and organised a car to drive us around. I was even more grateful because I was still getting tired easily and the heat in Bangkok is very intense. We did all the sights and I felt like the Queen.

The flight home was fine, again I managed to sleep for about 7 hours (I think long stays in hospital have given me the ability to sleep anywhere!) A small part of me was glad to be coming home, as I knew that I wouldn't feel 100% until I was back in the UK but I was sad to be leaving this

beautiful country.

If any of you fellow stoma wearers have doubts about going to far flung places, don't worry, just be prepared. I am already planning another trip to go back and explore some different islands. It's just the flu you've got to be careful of !!

Catriona Smith

## **Banns of Marriage**

Spare time at sea was either spent studying or reading books supplied by the "Seafarers Education Service". The company supplied a dartboard and a set of darts for the crew and another set for the officers. This was in the days before the advent of television. Cricket was played at sea, the bat being made from a piece of scrap wood and roughly shaped out by the carpenter. The ball was made from a nut and bolt wrapped around with rope yarns and then soaked in water to tighten the yarns before painting the ball white. The rule was that if you knocked a ball over the side then it fell to you to make a new ball. Deck quoits were also played but not golf.

On one ship the Master's hobby was cine photography and he had a large supply of printed silent films. His Kodascope 8 projector together with the films were loaned to the apprentices whose duty it was to give a show to the crew each Saturday evening. The stewards supplied a white sheet, which was used as a screen. Darts competitions were also started up by the by the Master with the crew versus the engineers and the winners playing the officers. A prize was given each week by the Master to the winning team which consisted of a case of beer if the crew won or if it was the apprentices then lemonade. The apprentices were forbidden alcohol. Each voyage the Master made a newsreel with his cine camera of various events and these were then shown the following voyage as a newsreel.

When the Master each week presented the prizes to the winning team he made a short speech. After his first speech, further speeches were left to me to write for the Master. When in Albany, New York State, the second steward whilst ashore had too much to drink and returned to the vessel with a toy parrot in a cage. The following morning he did not remember what had happened the night before. I found out that he had been drinking with a girl the previous evening. Much was made of this in the speeches by the Master and it was also arranged with the Radio Officer (Sparks) for the steward to receive fictitious telegrams from the lady concerned, much to the steward's amazement.

Eventually all was revealed when the Master read the Banns of Marriage for the steward, the marriage supposedly to take place on board when we reached the next port. He then realised that it was all a joke and everyone had a good laugh.

John Lindsay

#### **Useful Contacts**

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**NACC** 01727 830 038



**British Colostomy Association** 0800 328 4257

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# Want to join a support group? If you have a colostomy, ileostomy or a urostomy and would like more information, please complete the form below and send it to: c/o Stoma Care Department, St. Mark's & Northwick Park Hospital, Watford Road, Harrow, Middlesex HA1 3UJ Name: Postcode: Telephone: