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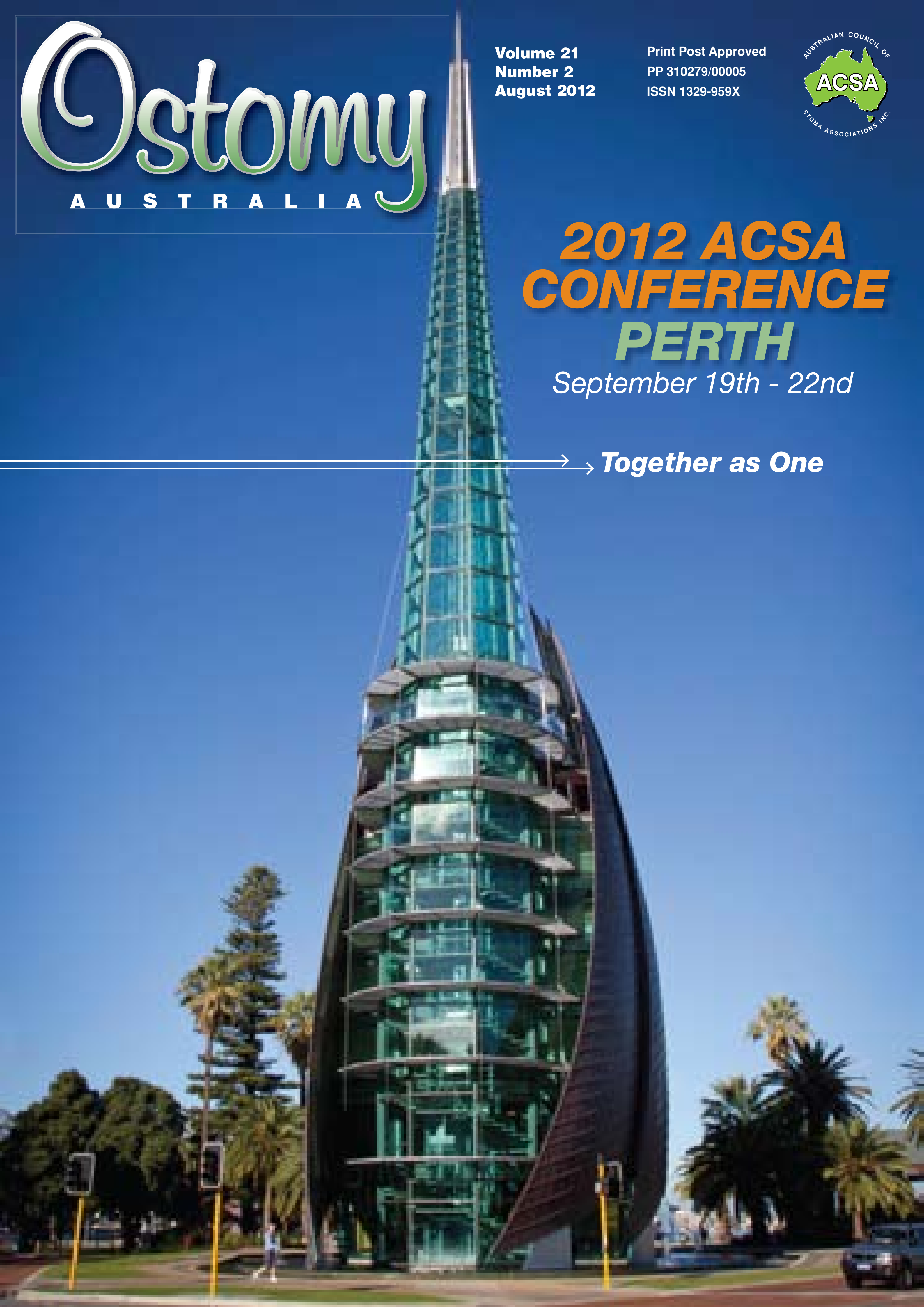
AUSTRALIAN COUNCIL OF STOMA ASSOCIATIONS INC.
ACSA



2012 ACSA CONFERENCE PERTH

September 19th - 22nd

Together as One

National Directory of Stoma Associations

Please contact your association (from the list below) for all ostomy issues relating to membership, appliance supply and/or *Ostomy* AUSTRALIA journal distribution.

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Telephone/Fax: (02) 6205 1055
Website: www.actstoma.org.au
Operating hours:
1st & 2nd week of each month Mon, Tues, Wed. 10.00am - 1.00pm
Office Manager: Lindsay Foster
Email: actstoma@alphalink.com.au
Secretary: Carole Forsyth

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CANCER COUNCIL OF THE NORTHERN TERRITORY INC.
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Fax: 08 8927 4990
Email: ostomy@cancernt.org.au
Web: www.cancercouncilnt.com.au

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Office Manager: Mrs Jenny Kemp
Secretary: Norma Toohey
Telephone: (02) 9565 4315
Email: ostomy@iinet.net.au
Website:
www.ColostomyNSW.com.au

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Kirrawee NSW 2232
Postal Address: PO Box 3068
Kirrawee DC NSW 2232
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Website: www.ostomynsw.org.au

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Secretary: Barbara Myles
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P.O. Box 198 Moorooka 4105
Operating hours: Tues & Thurs 9.00am – 3.30pm
Secretary: 07 3848 0138
Fax: 07 3848 0561
Email: admin@qldcolostomy.org
Web: www.qldcolostomy.org

QLD STOMA ASSN INC.
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Fax: (07) 3350 1882
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Emergency No: (07) 3359 7570
PO Box 370, Chermside 4032
Email: admin@qldstoma.asn.au

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Fax: (07) 4636 9702
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Secretary: Bob Schull
Telephone: 0418 717 199
Email: bob.schull@bigpond.com

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88a Crofton Street, Bundaberg West, QLD 4670
Operating hours: 8.30am - 3.00pm Tue, Wed, Thurs.
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Fax: (07) 4153 5460
Appliance Officer: Trina McRae
Email: wbostomy@bigpond.com

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Distribution of supplies:
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Secretary: Bruce Harvey

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Fax: (08) 8234 2985
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Telephone: (08) 8268 3645
Email: ileosto@bigpond.net.au

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OSTOMY TASMANIA INC
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St. Johns Avenue, Newtown 7008
P.O. Box 280, Moonah 7009
Telephone: (03) 6228 0799
Fax: (03) 6228 0744
Operating hours:
Mon 9.00am – 3.00pm
Tues 9.00am – 1.00pm
Sec/Treas: Sue Hoyle
Email: admin@ostomytas.com.au

VICTORIA

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PO Box 404, Golden Square. 3555
Ostomy Rooms: (03) 5441 7520
Fax: (03) 5442 9660
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Tues, Wed, Thurs 10.00am - 2.00pm and second Tues of each month from 9.00am - 3.00pm
Secretary: PO Box 404,
Golden Square, VIC 3555

COLOSTOMY ASSN OF VIC.
Suite 221, 2nd Floor, Lift 3,
Block Arcade, 98 Elizabeth Street
Melbourne 3000
Telephone: (03) 9650 1666
Fax: (03) 9650 4123
Email: colostomy@mail2me.com.au
Operating hours:
Mon - Fri 9.00am - 2.00pm
Stomal Therapy Nurse
Tues 9.30am - 2.00pm
Contact: Kathleen Allan

GEELONG OSTOMY INC.
Geelong Ostomy Inc.
6 Lewalan St. Grovedale Vic 3216
Postal Address: P.O. Box 1069,
Grovedale Vic 3216
Telephone: (03) 5243 3664
Fax: (03) 5243 6335
Email: goinc@geelongostomy.com.au
Website: www.geelongostomy.com.au
Operating Hours: Monday, Wednesday, Friday 9.30am to 2.30pm
Administrator: Joanne Holmes

ILEOSTOMY ASSN (VIC) INC.
Suite 322, 3rd Floor, The Block,
98 -100 Elizabeth Street,
Melbourne VIC 3000
PO Box 32, Flinders Lane. VIC 8009
Telephone: (03) 9650 9040
Fax: (03) 9650 1723
Email: ileovic@three.com.au
Web Site: www.ileostomyvic.org.au
Operating hours: Appliances
Mon to Thurs 9.30am - 2.00pm
Emergency Contact: (03) 9311 5658
Contact: Terry Carver

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Axxess Business Park
71/170 Forster Road
Mount Waverley Vic 3149
Telephone: (03) 9543 1224
Fax: (03) 9543 1994
Email: enquiries@oam.org.au
and orders@oam.org.au
Manager: Sue Read
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Mon to Fri 9.00am - 4.00pm
STN by appointment only - Tuesday only: 9.30am-2.30pm

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Secretary: Alexandra Terdich
Email: poainc1@bigpond.com.au

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Coordinator: Mrs Jacque Harrison

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279 Koroit St, Warrnambool 3280
Telephone/Fax: (03) 5563 1446
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warrnamboolostomy@swh.net.au
Operating hours:
Friday 12 noon - 4.00pm
Secretary: Lois Thwaites

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IN THIS ISSUE

Index to Advertisers:

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Please take this advice into account when responding to company promotions and competitions.

From The Editorial Desk

First of all, a hearty CONGRATULATIONS to Michael Letch, Liz English and Professor Garry Egger, who each received awards in the Queen's Birthday Honours this year. Each has contributed in their own way to the benefit of Australian ostomates. Well done and thank you all!

New Email Address
Journal@AustralianStoma.com.au

Many ostomates around the world will be celebrating ***World Ostomy Day on Saturday 6th October*** later this year. The theme this year is "Ostomy surgery is life-saving surgery so ***"Wear Lilac for Life!'"***. Please help raise awareness of ostomy in your community and show your support by wearing a ***lilac ribbon*** on World Ostomy Day.

In this issue we focus on a couple of very positive ostomates. The first item from Gillian Anderson, will hopefully assist in raising awareness about Parenteral Nutrition with our readers. Gillian's *"Living with a Drip"* article explains how she came to rely on this life-saving treatment. Our second story is from Sarah Larcombe, a young adult ostomate who tells of her difficulties in *"Sarah's Story - Appreciate the Life You Have"*. Both Gillian's and Sarah's positive outlook in adapting to life with an ostomy and their refusal to let their condition limit a zest for life and travel is an inspiration to me and will hopefully be to others.

This issue we also feature an invitation to the annual ACSA Conference which is to be held in Perth during September this year. I know first-hand how hard the WA Ostomy Association have been working over the past 12 or so months to ensure a successful event. Delegates from most of the associations will be attending and I am sure will return with more contacts and many great ideas which they can utilise to further improve their service to members.

A big "thank you" must go to Brian Hunter for relating his very interesting flight experience in *"Turbulence at 36,000 feet"*; to "Barbara, the Bag-Lady" for again sharing with us her next travel story in *"Have Mojo, Can Go (to Borneo)"*; to Ruth Horne for her *"9th Biennial WCET Congress – Adelaide"* report and *"CASA Goes International"* item; to Harry Ashton for another good *"Smile-A-While"* item; and to new ostomate Walter Soroka for his *"Stoma Ditty"*.

Our regular "Ask Kylie" column explains the regulations about requesting more goods than the Stoma Appliance Scheme (SAS) permits, what members can expect with the new Body Scanners now operational at all Australian international airports, and the maximum support garments entitlement that a member can obtain through the SAS.

We welcome two new Ostomy Support Groups - **Sunraysia / Riverland** in Victoria and **Wide Bay** in Queensland which are now listed in the National Directory of Support Groups page. This section is now spread over two pages, allowing us to increase the font-size and hence improving overall readability, particularly for people like me who often struggle to find their reading glasses. This change also allowed us to add a new section which provides the contact details for the ostomy product suppliers. We hope this will assist members that don't use the internet.

Please also note that the *Ostomy* AUSTRALIA email address has been changed due to recurring problems with our old address. On several occasions during May and June we were unable to send/receive emails but this problem became significantly worse in late June when no emails could be received by us. If you sent any emails to the old **ostomy-oz** email address after June 25th, please resend them to the new **Journal@AustralianStoma.com.au** email address.

Once again, thank you for your letters, helpful hints and stories, as well as the articles from Ostomy Associations. Keep sending in your stories and helpful suggestions for our upcoming Journals.

Remember that all contributions must include your name and address. However, if you do not wish your name published, please say so in your letter, and only your initials and State will be printed in the journal. Also note that an electronic copy of this journal is available to non-ostomates via the ACSA and other internet websites.

Please ensure that your contributions do not specifically name any doctors and nurses, unless they have agreed in writing to his/her name being published. Just refer to them as *'my surgeon'* or *'my doctor'*. Similarly, try to avoid specific use of an appliance company's name when it may suggest advertising in articles and letters.

Take care and stay healthy.
Kim Lyell EDITOR

Like to be on the front cover of this journal?

We are keen for the front-cover of our journal to better reflect the resilience, achievements and enthusiasm of Australian ostomates – babies and children who are not only cute but brave and resilient; young adults who are coping with rigorous daily routines; older adults who are out there making the most of life.

Readers are invited to send in their digital photos along with a narrative relating to the photo subject.

Photos must be high-resolution JPEG files and preferably in portrait aspect (i.e. vertical format).

Please note that we are unable to use hard-copy photos as scanning does not deliver images with sufficient clarity and sharpness for the front-cover.

Written permission from all people shown in the photos should also be provided.

> *"Volunteers don't just do the work – they make it work!"*
> Carol Pettit

Help! *Ostomy* AUSTRALIA needs your stories, experiences, helpful hints, etc
Please send your submissions via Email, Word or PDF documents to **Journal@AustralianStoma.com.au**
Hard copy submissions may be posted to:
The Editor, *Ostomy* AUSTRALIA, PO Box 195. Frenchs Forest. NSW 1640

President's Message

In this message I would like to focus on the role that partnerships play in the rehabilitation and support of ostomates within our community. While these partnerships can vary in nature, they will involve some or all of the principal stakeholders in the Stoma Appliance Scheme (SAS) in one way or another. SAS stakeholders include the Australian Council of Stoma Associations Inc (ACSA), the 22 National Ostomy Associations who provide a local support network for ostomates, health care professionals who fulfill the healthcare needs of ostomates, product companies who supply ostomy related appliances through the SAS, the Department of Health and Ageing who are responsible for administering the SAS and, of course, ostomates themselves.

Australia has one of the best stoma appliance schemes in the world and we may, at times, assume that the support we enjoy just happened. Sadly, this is not the case but rather is the result of hard work and persistence shown by many dedicated and influential people who have paved the way for the development of the Stoma Appliance Scheme as we know it today.

The Stoma Appliance Scheme in its present form began in 1974. While some pharmaceuticals were available to ostomates prior to this, the introduction of the scheme saw a full range of appliances become available to Australian ostomates at no charge. Being that there was already a distribution network of sorts in place in the form of Stoma Associations who had been complimenting their self help activities by operating as buying groups on behalf of members, a special act of parliament was introduced to enable Associations to continue with this activity and be reimbursed for appliances supplied through the SAS plus a 2.5% rebate to assist with administration costs. This scheme that began 38 years ago is now the envy of ostomates internationally and it is the responsibility of all stakeholders to work together as partners to ensure that the SAS remains cost effective and viable.

While the Department of Health and Ageing has administrative responsibility for the SAS, it is carried out in partnership with ACSA and its affiliated associations. The ACSA Executive maintains an ongoing and open channel of communication with the Department concerning SAS related issues and works with associations to ensure that the operational management of the distribution of SAS products is carried out in accordance with the SAS guidelines.

The partnership between ostomy appliance companies and Associations is maintained on a number of different levels. Associations have commercial arrangements in place with appliance companies for the purchase of SAS listed products for distribution to ostomates, collaborate with appliance companies on behalf of members during appliance trials, and work with appliance companies in jointly arranged member support initiatives and information seminars. Despite the commercial nature of appliance companies, their ongoing support of the Australian ostomy community helps to ensure that associations can continue to provide local networking opportunities for member ostomates and participate in ostomy related matters at a national level through attendance at the annual ACSA conference. In addition, research and development programs carried out by appliance companies ensure that we as ostomates have the benefit of an excellent range of appliances.

We now arrive at the most important partnership of all: the partnership between the ostomate, the ostomy association and the stomal therapy nurse (STN). Today, many ostomy associations not only have STNs on their staff but also on their management committees ensuring a professional viewpoint is considered when developing support programs to assist ostomate members. This close working relationship between STNs and ostomy associations also plays an integral role in the rehabilitation of new ostomates. The STN has the vital role of assisting the new ostomate to select the most appropriate appliance for him or her and then training the new ostomate in the correct use of that appliance. The ostomy association then has the responsibility of providing these appliances in a timely manner when requested by the ostomates and in accordance with SAS guidelines and association distribution policies. In addition, associations provide an ongoing support network for the ostomate through the provision of stoma related information and opportunities to meet and interact with other ostomates. Support which has been proven to be a critical factor in the ongoing wellbeing of the ostomate.

Later this year, the Australian ostomy community will be presented with another opportunity to develop these partnerships through the celebration of World Ostomy Day on October 6, 2012. The aim of World Ostomy Day is to improve the rehabilitation of ostomates worldwide by raising awareness of ostomy within the general community and bringing attention to the needs and aspirations of ostomates and their families. This year, the theme will be “Let’s be Heard”.

We anticipate that all associations will participate in World Ostomy Day celebrations in some way and so invite all member ostomates to join in supporting their local association. Activities to promote awareness may include educational programs, seminars, support meetings and demonstrations/displays; electronic information networks, newspaper and magazine announcements/advertisements and articles. Other initiatives may include publication of informative handout materials and brochures, audio and video announcements and films; personal visits and lobbying activities; official government proclamations and joint activities with allied agencies and professional health Associations.

Until next time, keep well and
be involved.

Peter McQueen PRESIDENT

Letters to the Editor

Dear Editor,

After receiving my April copy of *Ostomy* AUSTRALIA, I was delighted to read your request for pictures of us ostomates out there living it up! Attached is a photo of me on my horse, Robert aka The Whole Shebang, hunting last year with the Clare Hunt Club. At the time, I had had my stoma for 3½ years.

Since having my large bowel removed at age 22, I have had people marvel at the things I still do. I ride, ski, hunt and have completed my Certificate 4 in Veterinary Nursing. What they don't realise is that I am healthy now but I was sick before my bag. With the love and support of my family (hi mum!) and friends, I have found that my bag is liberating whereas my Crohn's was debilitating!

Thank you for taking the time to read my email, I now hope you find my photo good enough to grace the cover of this terrific magazine!

Kristy Pearn

ED: *Thanks Kristy for the great photo and letter. Your picture is just the sort we are looking for but unfortunately we couldn't put it on the front cover as the resolution was too low (when enlarged it becomes grainy / fuzzy). Please send in more photos!*

Dear Editor,

Thank you for printing the article on Erectile Dysfunction (E.D.), a major problem for me, and I suspect, many male ostomates. As you will appreciate I do not want my full name printed.

Like others in this article, I suffer from E.D. as a result of a successful colorectal cancer operation, chemo and radiation therapy. Very soon after the operation my late wife was diagnosed terminally ill, so E.D. was not a priority.

Having passed the grieving stage I found a desire for a female companion. I had no trouble finding such people up to the point where E.D. became a problem. My G.P. tried pills and injections to no avail and then referred me to a specialist who prescribed other pills and injections with no success. It would appear there is an operation which might succeed, but since all these things are most expensive it seems I must remain celibate.

This prospect is most depressing.

Smaller co-payments or a higher Medicare/Private Health Insurance payment might help. Maybe post-operation counselling might forewarn us of the likely problem.

PLEASE endeavour to keep us informed of any developments in this field of medicine and any new products which may become available.

W.G. NSW

Dear Editor,

This photo of Brooke (my grand-daughter) and I was taken in May 2011 just five weeks after my ileostomy operation.

Brooke was 7 years old, so I decided to educate her on an ileostomy and she said she would like to wear a bag to see what it was like.

After about an hour she wanted it removed, which we did, only to discover that Brooke had a severe reaction to the adhesive and required medical attention. She had a severe reaction to latex which we had no idea of so our ostomy education lesson turned out to be a positive outcome as we are now aware of her allergy.

Thanks for a great magazine.

Nancye Turner QLD

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NOVALIFE

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Are there better ways of learning how to manage a loop ileostomy?

Submitted by Mary Ellis, Victoria

My story began on 28th November 2011 with a right-side loop ileostomy. Before admission to hospital I was interviewed by the hospital's stomal therapy nurse and given pamphlets and general information. On the morning of surgery I met a relieving stomal therapy nurse who drew lines on my body marking my waist and a suitable site for the ileostomy. After surgery a different relieving stomal therapy nurse assisted with the first bag change. One of the ward nurses supervised my own first attempt at bag changing before I was discharged.

I was signed up with the nearest Ostomy Association and my first supplies were ordered. They were mailed to me at home and were there when I arrived. With them was a note to the effect that the Association would be on holidays from 19th December to 5th January, to give the volunteers a well-earned break. I could not place another order until after the first week of January.

I had an appointment for a week after discharge to see the original stomal therapy nurse, a round trip of 110km. She changed the bag for me and introduced a new technique, using a seal around the aperture in the bag.

On the Tuesday of the following week I had leaks - 3pm, 7pm, 10pm, 1.30am and 5.30am. I tried both with and without seals. The seals tended to spread too far or rise against the stoma allowing leaks underneath. The skin was sore, red and oozing. I contacted the district nursing service and finally met the local stomal therapy nurse. However, she was only available briefly before having two weeks' annual leave. The district nurses called three times a week and, because I was running out of supplies. they scrounged bags, seals, barrier wipes and adhesive removers. The stomal therapy nurse also provided Mercurochrome to help heal the skin lesions.

In January I ordered a month's supply of the original style of bags. I had another appointment to see the local stomal therapy nurse and she assisted with the order for supplies in February, including a change of bag style to one that was pre-cut to size, the stoma having settled to a diameter of 25mm. By this time I was using additional adhesive strips to secure the bags.

I was following a strict routine when changing a bag. Cleaning the stoma with warm water, drying the skin around the stoma thoroughly, removing all adhesive, drying, applying mercurochrome, drying, applying no sting barrier wipe, drying, meantime warming the bag under my arm. When ready I put some lubricating deodorant into the bag, peeled the cover and applied, holding the bag to my side with my hand. The additional adhesive strip was applied, then I would lie down for ten minutes to allow the adhesive to stick properly.

Throughout January, February and March I had unreliable attachment of bags with leaks. Sometimes I managed to get more than 24 hours, more often less. Then in the middle of March I had a series of bad days having to change the bags after 22, 25, 23, 13, 6, 2, 5, 9, 31, 25, 3, 23, 2, 4, 16, 7 and 5 hours. In desperation I decided to try a different type of bag on Sunday 25 March at 2am! The stomal therapy nurse had given me a few of each type of bag to try some time previously. This one lasted until Monday 26 4pm (38 hours), when I saw the stomal therapy nurse and we completed my April order for the new type of bag.

This new style of bag proved reliable, changed every other day without leaks until I had the closure of the loop ileostomy on 16 April 2012.

It took 4 months to reach a position where I could choose the time of day to change the bag, that it would last 48 hours and where I no longer had to be anxious about unexpected leaks. Unfortunately, the experience of the previous 4 months meant that the anxiety didn't disappear immediately. During those months I had two long trips to visit the surgeon and to have a barium enema X-ray, on both occasions fortunately without leaks. The whole experience was demoralising, depressing and isolating.

It is clear that the patient has to manage the application of bags alone - leaks do not occur to order when the district nurse is visiting or when you have an appointment with the stomal therapy nurse. There is no possibility of failure because the ileostomy is going to continue to discharge. There were times when I thought it would be simplest to just stop eating.

From reading advertisements for bags claiming solutions to leaks, I have to assume that my history is by no means unique, that others have had similar problems. Therefore can we collectively find a better way to learn how to manage bags?

It seems to me that the keys to managing an ileostomy successfully are:

- The stomal therapy nurse - backed up by the district nursing team. They provide both experience and moral support. The patient probably needs almost daily support initially to try different bags and a variety of techniques. Establishing a leak-proof system early would make an enormous difference to the patient's morale.
- The ostomy association for supplies - could a variety of bags and more information be supplied to new ostomates. While it is crucial that the efficiency of the Associations be maintained, as mentioned in the President's Message (*Ostomy* AUSTRALIA April 2012 issue), new ostomates need a more flexible approach.

The new patient is under pressure to use only 30 bags per month. This does not allow for leaks or trying different styles of bag and the order for each month must be sent in at the end of the last month, meaning that the patient is confined to one type of bag for the next month. Once established with a successful style of bag, the patient probably does not need 30 bags in a month. How can a new patient know which style of bag will best suit their body?

I hope that the Association will consider adopting a more flexible approach to new ostomates in the future.

Response from Peter McQueen (ACSA President):

Thank you for sharing your story with us Mary and I must say that I was saddened to read about the problems experienced by you during your time as an Ostomate. As you may be aware, while our associations do advocate for the continuing wellbeing of member ostomates, they need to balance this advocacy with their obligations as a Stoma Appliance Scheme service provider to the Federal Department of Health and Ageing. Accordingly associations need to comply with the maximum product allowances as prescribed by the Stoma Appliance Scheme. They also cannot recommend products to member ostomates.

Thankfully there are provisions in place within the scheme to assist

Continued page 10

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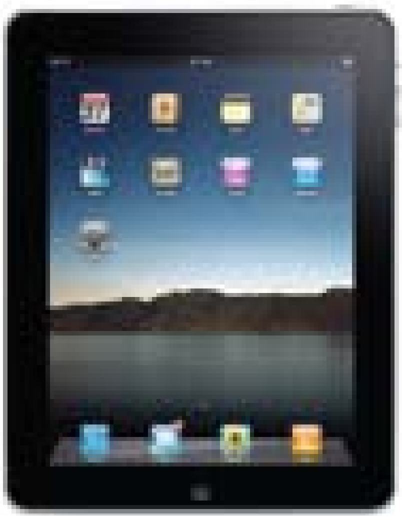

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† Omnigon data on file 2012

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Congratulations - 2012 Queen's Birthday Honours

From Wendy Taylor, VIC

Michael Letch (Mentone, VIC) received a **Medal of the Order of Australia [OAM]** award for his *"service to people with a disability through the Disabled Divers Association Victoria."*

Mike founded the Disabled Divers Association five years ago, which came about as a result of him receiving a Churchill Fellowship and researching similar programs overseas. Over these years, he has encouraged many disabled people to discover the wonders of scuba diving and to experience the freedom as well the breadth of their own abilities. The association's scuba and snorkelling classes are organised through the Royal Talbot Rehabilitation Centre and community groups.

He became a paraplegic in 1970 following a motorcycle accident and is a former wheelchair marathon champion (representing Australia overseas) and is also a three time winner of the Melbourne Marathon. Mike is a member of the **Ileostomy Association of Victoria.**

Regular readers of *Ostomy* AUSTRALIA will recall the fascinating article Mike wrote for the journal several years ago about his own positive experiences as a disabled person who dives and of his conviction that there be the same opportunities for other disabled people to participate through the support of the Disabled Divers Association Victoria.

To quote Mike (as stated in the Herald Sun, Monday 11 June, 2012): *"For me, it's all been about redefining that negative attitude towards disability."*

Elizabeth (Liz) English (Largs Bay, SA) received a **Member in the Order of Australia [AM]** award for her *"service to nursing, particularly in the field of stomal therapy clinical practice and education, and through executive roles with national and international associations."*

Elizabeth (Clinical Nurse Consultant, Stomal Therapy at Royal Adelaide Hospital) is a past President of the World Council of Enterostomal Therapists (WCET) and also the WCET 2012 Congress Liaison and Conventions Adelaide Ambassador. The WCET is an international organisation for stomal therapy nurses (STNs) with over 1,000 members from more than 50 different countries. Elizabeth has also addressed an ACSA Annual Conference in Adelaide.

Professor Garry Egger (Fairlight, NSW) received a **Member in the Order of Australia [AM]** award for his *"service to medical education as an administrator and teacher, particularly in the area of health promotion and research, as an author, and to professional organisations."*

Garry is currently a Professor of the School of Health & Human Sciences at the Southern Cross University in Lismore. He is also an author having written over 30 books, including (with Professor Boyd Swinburn) 'Planet Obesity: How we are eating ourselves and the planet to death'. He also wrote for the *Ostomy* AUSTRALIA journal some years ago.

Professor Egger developed the world's first men's 'waist loss' program (Gut Busters) in 1991 and has run training programs in lifestyle medicine and chronic disease management for thousands of Australian clinicians and allied Healthcare professionals. ■

Continued from page 8

ostomates who are experiencing difficulties and under the care of a stomal therapy nurse or medical practitioner to access a greater quantity of product than that normally provided to the Ostomate through the scheme. This enables the Ostomate to change their appliance more frequently or to change to an alternative product as is deemed necessary by the practitioner when the monthly issue has already been dispensed by an association. In addition, Ostomy product suppliers are more than happy to assist stomal therapy nurses and medical practitioners by providing directly to the Ostomate a range of product samples for trial purposes to assist with the selection of a suitable product.

The keys to managing an ileostomy that you put forward are valid and well thought out and I am sure our Associations are striving for a similar result. Thank you for sharing your experiences with us.

• • • • • • • • • • • •

Trial and Trial Again

Submitted by G.O., WA

I frequently read of ostomates who seem dissatisfied with their appliance, or keep wondering if they are using the most suitable one, or say they have tried only one type, or even ask how they obtain others to try.

When I left hospital it was explained to me how I would need to go through the normal trial period of experimenting and searching for my most suitable appliance. Surely everyone is told this, and we all go through that trialling period? Perhaps some STNs neglect to give this guidance. (I can't answer that as I have never felt I needed to consult a STN.)

Before I had selected and settled on my appliance I had trialled about 15 different models over more than six months. I looked at the ads in the publications, studied the examples displayed at my local Association, telephoned suppliers for samples, and varied my monthly orders.

As was to be expected, during my 'trial period' I suffered many leaks. Some leaks resulted from mistakenly trying a flat base (no convexity) on my flush stoma, some before I realised I must attach a clip-on belt with convexity, some through trying a base not flexible enough for my big hernia hump, some simply did not have enough 'stickiness' and they lifted. Finally I settled on my most suitable and effective one.

Probably many of the people getting leaks are still going through their 'trialling period'. Hopefully they don't give up on their trialling part way through, because if they stick with it they are sure to finally find what succeeds for them. ■

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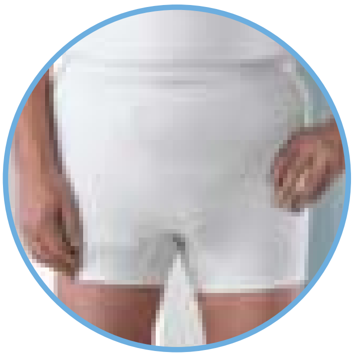

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9th Biennial World Council of Enterostomal Therapists Congress - Adelaide

Submitted by Ruth Horne

Adelaide recently played host to the 9th Biennial World Council of Enterostomal Therapists (WCET) Congress with 900 attending from 47 countries for 5 days from 19th to 23rd April 2012. Stomal Nurses from around the world meet every two years to share ideas and be informed on the latest trends in management and care of stomas and wounds.

As part of the Conference there were some forty-plus exhibitors displaying their wares over the four days of the Conference. Whilst most were suppliers, keen to show nurses the latest developments in their products, some were organisations established to help ostomates etc. The Colostomy Association of South Australia (CASA), on behalf of the International Ostomy Association (IOA), the Australian Council of Stoma Association (ACSA), the Ileostomy Association of SA and CASA, was privileged to set up an exhibit to highlight the role of Stoma Associations throughout the world.

The stand was manned by personnel from CASA with frequent visits from ACSA President, Peter McQueen, and International Ostomy Association Coordination Committee (IOA CC) Chairperson, New Zealander Barry Maughan, who were both very busy networking throughout the Conference. Barry also presented a paper to the Conference.

We also used the opportunity to highlight the work of the Australia Fund (ACSA's charity arm) which, with the aid of funds donated and using returned and/or supplier donated supplies, send products to many third-world countries. Our National Relief Co-ordinator (Bruce Harvey) produced a world map highlighting where returned and supplier-donated product was currently sent by the Australia Fund and the approximate value of that product. It was lovely to see "Mr Bruce" meeting the sponsored nurses with whom he has been in regular email correspondence.

It also gave us the opportunity to showcase our wonderful Gastronauts, the stoma hand-puppets that seem to be "invading" the world to help ease the distress for many young ostomates and their families. The visitors to our stand fell in love with the little guys and some are now a little worse for wear from much handling. The suppliers of the Gastronauts (www.thebowelmovement.co.uk) fantastically donated a set of puppets which were part of the Conference prize draw and saw the five puppets heading off to Thailand.

Our exhibition was very well received and extremely well visited. The representatives manning the stand, particularly on the first night, were rushed off their feet providing information and answering questions on the role of Associations. We had many return visits for further information.

Donations to the Australia Fund can be made through your local Association.

ACSA's stand at the WCET Conference

CASA reps Ali, Bruce and Ruth

ACSA's Peter Mcqueen and IOA's Barry Maughan

CASA President Rosemary Quick with an Indian STN

Indonesian STNs at the WCET Conference

CASA President Ruth presenting puppets to an STN from Thailand

CASA'S Bruce Harvey with Indonesian delegates at the WCET Conference

"Ask Kylie" A.C.S.A. Administration Officer

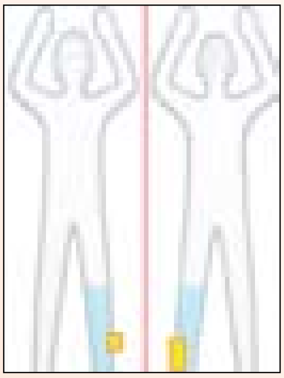
1. *I have returned to work after my stoma surgery and find that, because of the work I do, I need more bags than the monthly amount I am allowed. My association has told me to visit my stomal therapy nurse or GP to get an authority for more supplies but I really don't have the time and, besides, I don't think I should have to. I have been a taxpayer for almost 30 years and feel that I should be able to have as many stoma bags as I need. My association won't give them to me though without an authority. This just doesn't seem fair as I need these bags and my association is supposed to be there to support me as a member.*

The Stoma Appliance Scheme (SAS) is a Federal Government program which provides stoma related products free of charge to people with a stoma. Stoma Associations are non-government, self-help organisations which distribute these supplies to a member in their capacity as support organisations and service providers to the Department of Health and Ageing.

One of the challenges faced by associations is being able to balance their objectives of assisting ostomates' wellbeing with their obligations to the Department of Health and Ageing as documented in the Operational Guidelines for Stoma Associations.

In other words, while I am sure that your association would like to help you by providing the additional goods you need when you need them, they are prevented from doing so if it results in a breach of the Department's operational guidelines. Thankfully though, there are provisions in place within the SAS to supply additional appliances to ostomates when a genuine need exists as determined following a review by a stomal therapy nurse or medical professional.

2. *I have read a lot in the media about the introduction of Body Scanners at all Australian International Airports. I am planning to travel overseas next year with some friends and am very concerned that my colostomy bag will be revealed by the scanner. I have kept my condition private and really don't want it to be revealed by a complete stranger! Can you explain what impact the new scanners will have on ostomates like myself?*



As announced by the Federal Government in February of this year, the roll out of Body Scanners across Australian International airports will commence from July 2012. The new technology will exist alongside existing scanning technology as an additional layer of security and is expected to operate on a random selection basis.

The Federal Government does recognise the privacy concerns that some passengers may have concerning the use of body scanners and has accordingly developed policies and procedures intended to achieve the desired security outcome while at the same time preserving the privacy and dignity of passengers. Measures to be employed include the use of automated threat recognition technology so that the screening officer will not see a raw image of the person being screened but rather, a generic human outline without any identifying features such as gender, size, or shape. The scanner will analyse the data from the scan and will alert if it detects a foreign item such as an ostomy bag under a person's clothing. In this event, the area of concern will be highlighted on the generic body outline and further investigation will be required to resolve the alert. The passenger can request that this resolution process takes place in a private room where the screening officer can be discreetly informed about the item causing the alert. At no time during the scanning process will a passenger be required to expose their ostomy pouch for inspection.

For more information about Body Screening at Australian International Airports, please refer to the Travel Secure website at: www.travelsecure.infrastructure.gov.au

3. *I have recently made a request to my association for some support pants but the request was rejected as I have already received three hernia belts this year. My GP filled in an "Application for Additional Stoma Supplies" for me so that I could also have three pairs of pants but my association still will not issue them to me. I really need these pants so can you please explain why?*

As you have been correctly advised by your association, the maximum entitlement of support garments that a member can obtain through the Stoma Appliance Scheme is three (3) full units of support garments per calendar year. However, the unit weight of the various support garments does differ depending on their type, which means that you may be able to obtain more of one type of garment per year than another type. For example, one Omnigon hernia belt or one pair of Statina Healthcare Corsinel is equal to one full unit of a support garment whereas one pair of Omnigon or Ainscorp support boxers or pants is equivalent to only half (0.5) of a full support garment unit. Members can choose to obtain a combination of garments as long as the total unit weight received during a calendar year does not exceed three (3).

All support garments listed on the Stoma Appliance Scheme are subject to an R2 restriction which means that no authority for an increase in the yearly allocation can be granted. Additional support garments can however be purchased and I suggest that you contact your association to discuss this option.

Please send your "Ask Kylie" questions via email to feedback@australianstoma.com.au
Alternatively, hard copy submissions may be sent to The Editor, *Ostomy* AUSTRALIA, PO Box 195, Frenchs Forest. NSW 1640

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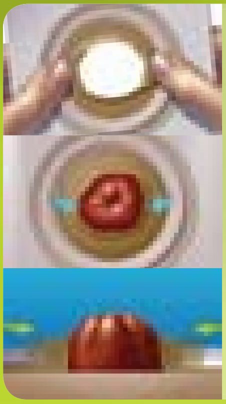

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[1] Scott V, Raasch D, Kennedy G, Heise C. Prospective assessment and classification of stoma related skin disorders. Poster presented at: 41st Annual Wound Ostomy and Continence Nurses Society Conference; June 6-10, 2009; Orlando, Florida.

[2] Hoeflok J, Guy D, Allen S, St-Cry D. A prospective multicenter evaluation of a moldable stoma skin barrier. *Ostomy Wound Manage*. 2009;55(5):62-69.

* U.S. Patent No. 6,840,924 B2

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Sarah's Story

Appreciate the Life You Have

By Sarah Larcombe, SA

In 2010 I was just a 17-year-old girl trying to compete with doing well at Year 12, having relationships with people, enjoying my youth and one other thing - living my life around a toilet. When I look back it seems impossible that I needed to use the toilet twenty times a day for my bowels, and when I did, experiencing severe pain (and losing a lot of blood) while still trying to live a somewhat normal life. It seemed that all the doctors in my town must not have believed me as they didn't refer me to a gastroenterologist.

I now know bleeding in your bowel motions is a medical emergency if it lasts longer than three days, and mine had been going on for five months.

It was in March 2010 when everything changed and I was admitted into hospital due to excruciating pain that left me unable to move, with what they initially thought to be ***Ulcerative Colitis*** but was eventually identified as ***Crohn's Disease***. A week later in my local hospital, with nothing improving and only getting worse, they flew me to Adelaide on the Royal Flying Doctor plane and admitted me into the paediatric ward of the Flinders Medical Centre in Adelaide. A few days later I was getting rushed in to have an emergency operation as my large bowel had started to perforate. Six hours later I woke up with an ***Ileostomy***.

For some reason I never had negative thoughts. I think it was something to do with my surgeon having said that without the ***Ileostomy*** I would be dead. I was told that approximately 8 months later I could have the reversal operation.

After a month of being in hospital (five hours away from home I might add) I went back to school to continue Year 12 and graduate with my friends (even though I was advised not to). That's all I wanted though. It was a challenge carrying heavy textbooks, concentrating, walking up the stairs at school, opening doors, etc as I was so weak and frail after losing 20 kilos (I was not big to begin with) and now having a brand new lifestyle that I had to adapt to.

I had my 18th birthday, and did complete my Year 12 that year (with no special provisions or extensions) as I was determined to do so and got a TER of 84.80 (a much better score than many of the Year 12s) and graduated. I was and still am in my prime, and no way was I going to let having a bag stop me. I went out partying with my friends every night of the weekend, wore the tightest of dresses, got home at 6.00am, went to concerts where I got in the mosh-pit and up on people's shoulders, and no one had any idea of what I had unless I told them.

At the end of 2010, my dream of getting reversed was crushed as my rectum was too diseased and would have to be removed before it turned malignant (within approximately 8 years). I had just started university to be a nurse and thought I would get the operation to remove the rectum after completing my three years of study. However, shortly after I started university I began not to cope with the fact that even after my course finished I still had to get an operation. It was a burden which weighed heavily on me emotionally. Also learning each day about the 'normal human

Continued page 18

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Continued from page 16

Sarah’s Story

body’ was taxing on my emotional well-being. After a phone call with the surgeon, he said he’d operate on me as soon as possible if I withdrew from university.

So from April 2011, I took the remainder of the year off, figured out what I wanted in life (either childcare worker or a fitness related career) and had the operation to remove my rectum and anus. The bag is now permanent (which was hard to accept in the beginning) and I’m usually happy as I have a quality of life I would have never had without it.

Following surgery I ended up in hospital for six weeks with unexpected complications that the doctors had seen only once before, and which required another major operation to correct the complications. That brought unexpected issues such as my scar breaking open which took two months to heal, infections in my wound, blood transfusions, allergic reactions (the list goes on) but I battled on.

I am now out of hospital and have been given good news by my doctors that there is no more surgery on the cards for me (for now anyways) and no active ***Crohn’s Disease***.

In November 2011, I returned home from a short holiday in Sydney where I had the time of my life with my best friend. I am now planning a trip overseas as I want to see certain parts of the world. In March 2012, I started a Certificate Three course in Children’s Services and am really enjoying it. I hope to continue on to the diploma and hopefully be able to go overseas and be a nanny for a year.

Being a 19-year-old, there are many issues that I face as my adult life is only just beginning. Boys is a big one. They seem to be fine with it, it’s just extremely hard to initially open up to them and tell them. Choosing a career which is suitable for me and my future, the constant cost of medication that I’ll be on for the rest of my days (one day my concession card failed and I cried in front of the pharmacist as I didn’t have enough money on me to purchase all the medication I needed), the emotional impact on my self esteem, deciding whether to start a family when I find the right person, are just some of the worries I have but I usually don’t let it get me down.

This whole experience has made me a much more appreciative person, determined to do whatever I want in life, and to have fun, because there might not be a tomorrow or if there is, it could be tragically worse than the present.

I have been tattooed, with the word ‘courage’ on my wrist as it takes a huge amount of courage to overcome something like this, and ‘appreciate the life you have’ on my back as each and every person needs to appreciate what they have as there is always someone worse off. My most recent tattoo is ‘a tragedy can always be a blessing in disguise’ on my ribs; that is a line out of one of my favourite songs by one of my favourite artists.

I live by these three tattoos and they’re just permanent markings that match all my other ‘battle-wounds’ (as I like to call them) that make me the person I am. I plan to get many more as I continue to live out all my dreams with nothing getting in my way.

What I believe has got me through this since all the surgeries and health complications is that I really am a fan and believer of the law of attraction and the power of positive thinking. What I tell people is “in life, nothing good or bad ever happens to you. Something happens to you, and YOU decide whether it’s positive or negative, if you want a constant state of happiness just find the positive in the situation - there always is one - it’s just sometimes hard to find”.

I have recently done a photo-shoot to help some photographers out in my local area (and they want me to continue modelling for them). I now have some really nice pictures and am very proud that after all that I have had to endure, people still want to take photos of me.

I hope this story inspires all of you that read it and for you to be aware this sort of thing doesn’t always happen in adults. It can happen in children and teenagers too and happiness is always your choice. ■

2012 ACSA CONFERENCE PERTH

September 19th - 22nd

We welcome you to Perth

The committee and members of the Western Australian Ostomy Association are pleased and proud to invite Association delegates and guests to attend the 2012 Annual ACSA Conference at The Esplanade Hotel, Marine Terrace, Fremantle.

In choosing this hotel we were mindful of the interest that delegates would have in the history, architecture and culture of this unique place, and the need to have a variety of places to visit within easy reach.
There will be plenty of time to sample much that Fremantle has to offer.

Fremantle is renowned for its well-preserved architectural heritage including convict-built colonial-era buildings. Among these and within easy walking distance to the Hotel are the Round House, the oldest remaining intact building in WA built as a gaol in 1830-31, and Fremantle Prison completed in the 1850s and used as a prison until 1991. In 2010 this site was placed on the World Heritage List. The Fremantle Markets which opened in 1897 are nearby, and just around the corner is the cafe strip and a variety of restaurants. Across a wide green expanse from the hotel is the Fishing Boat Harbour which presents the chance to dine on local seafood.

The Fremantle Railway Station is quite close and travel into Perth city takes about thirty minutes. A free clipper bus service runs in Fremantle City. Walking tours are available catering to a wide range of interests, again all within close proximity to the hotel.

For our Thursday night welcome function we are touring Fremantle by tram with dinner served on board. Given that it will be September and the weather can be cool, visitors are advised to bring a jacket.
We will leave from the Hotel at 6.30 pm and return at 9.30 pm. The commentary on this occasion should give an insight into the colourful history of the area.

Together as One

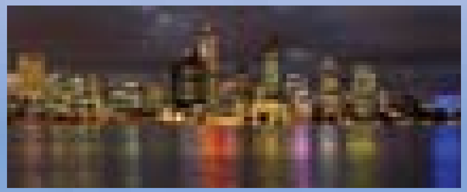
Members of the Western Australian Ostomy Association and their friends are invited to join the Conference on Saturday afternoon to hear the guest speakers and to view company displays. Further details will be given closer to the time.

Friday afternoon and evening will be free time for experiencing the sights of Fremantle. In addition to those mentioned above, the Maritime Museum or the Fremantle Arts Centre could be of interest. Just around the corner from the hotel is trendy High Street known for its art galleries, Aboriginal crafts and home wares and fashion from local designers. Further information will be included in the satchels given to all those attending.

The Saturday Dinner Dance will be held in the Island Room at the Esplanade Hotel. This is in the heritage listed section of the hotel and we are sure our guests will love its charm and sense of history. Music and dancing will follow fine dining.

On Sunday we will board buses to travel to Perth City from where we will cruise from Perth to Fremantle via our beautiful Swan River. Lunch will be served on board.
On returning to Perth those who are flying home will be transported to the Airport. The others will return to the hotel via our northern beaches.

The Organising Committee thanks all the companies for their generous sponsorship of this Conference. With their assistance we are able to present a Conference of a high standard.



Photos courtesy of Fremantle Tram Tours, City of Perth, Captain Cook Cruises, and The Esplanade Hotel, Fremantle.

PROGRAM

Times and other details such as transport arrangements will be confirmed at the conference.

Tuesday, 18th September 2012

Executive Meeting

Wednesday, 19th September 2012

Delegate Registration from 5:30 pm

Thursday, 20th September 2012

Conference day 1 – Annual General Meeting

Official Opening by our special guest

Reports from Committees and Coordinators

Welcome Function touring Fremantle by tram with dinner on board

Friday, 21st September 2012

Conference day 2 - General Meeting

Morning Tea - Buffet Lunch

Afternoon free

Saturday, 22nd September 2012

Conference day 3

Morning - General Meeting

Afternoon – Guest Speakers and Trade Displays

Dinner Dance in the Island Room at the Esplanade Hotel

Sunday, 23rd September 2012

Cruise from Perth to Fremantle via our beautiful Swan River with lunch on board

Colostomy Association South Australia goes INTERNATIONAL World Conference Stomal Nurses visit CASA

Submitted by Ruth Horne

As part of the recent World Stomal Therapy Conference a number of nurses from third-world countries were sponsored to enable them to visit Adelaide for the four day Conference. Many of these nurses have for years dealt with the Colostomy Association of South Australia's (CASA) Secretary and National Relief Coordinator, Bruce Harvey. He and his team have been coordinating the sending of returned or supplier donated products to these STNs' hospitals.

We sent an invitation for all sponsored STNs to visit CASA which was taken up with great enthusiasm. We had two groups attend: one from Iran and a second group of ten from Indonesia, India, Kenya and Fiji.

The second Group were collected from the Convention Centre on Tuesday by mini-bus (driven by our "Mr. Bruce") and transported to CASA. Along with two others and Royal Adelaide Hospital's Head STN, Liz English, they were shown all aspects of the Association. A great luncheon was laid on thanks to our fantastic office staff.

The STNs were given some returned supplies to take home with them and then had a training session conducted by Sharmaine Peterson (STN at St. Andrews) and our own volunteers.

A great day was had by all and it was fantastic for our ***Australia Fund*** team to finally put faces to the names.

Overseas STNs in CASA storeroom

STN Sharmaine, with CASA volunteers Rosemary and Betty, training the overseas STNs

Group shot with CASA Reps in front

(Bronte Harvey, Bruce Harvey, Rosemary Quick and Kris Rosada)

International STNs in front of CASA

Mr Bruce and his side-kick Kris

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Why should you?

Because...

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- Almost 7 out of 10 develop gradually within 1 year of surgery [1]
- Support garments reinforce muscles while they heal, and help prevent hernias [1]

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Diamond Plus Boxers

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Men's Support Pants

Support Briefs for her

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[1] Omnigon data on file 2012.

For more information or a FREE copy of "Your guide to stoma support and hernia prevention and management" Free Call: 1800 819 274

omniwell

“I WISH SOMEBODY WOULD INVENT A MORE DURABLE RING”

Marie, an ostomate since 2004

Think again. Think Brava™

Marie, ostomate since 2004, appreciates the difference her mouldable ring makes but feels that a longer-lasting version would give her greater freedom and peace of mind.

Marie has done everything she can to live a normal life after her stoma operation and accessories have played a big part in her progress. And she’s not alone in that respect - over 70% of ostomates benefit from using accessories.

According to Marie, though, more could be done to make accessories even more effective. Marie explains: “I wish somebody would invent a more durable ring so I could worry less about leakage.”

> “A more durable ring would also give me the confidence to stay out longer as I wouldn’t have to change my base plate so often.”

Marie was worried that her baseplate was coming loose and therefore started to use the tape.

Ostomy issues
- 45% of all ostomates have skin issues
- 62% of this group don’t even realise it
- 77% of skin issues are caused by leakage

“A more elastic tape would give me freedom of movement while giving me the confidence that my base plate is secured.”

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Brava™

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NEW

Reduce leakage

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Elastic tape that fits the individual body

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Care for skin

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on World Ostomy Day , 6 October 2012

World Ostomy Day 2012 will be celebrated on Saturday, 6 October 2012 .

The Australian Council of Stoma Associations Inc invites you to help us raise awareness of ostomy and show your support by wearing a lilac ribbon on World Ostomy Day.

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Terms & Conditions: Competition to win 1 of 5 $50 supermarket vouchers is open to Australian ostomates only. Entries valid from 01 August 2012 through to 30 November 2012. WINNERS drawn at 12.00pm EST on Friday 30 November 2012, and the WINNERS will be notified on that day by telephone & email. The WINNERS shall receive a supermarket voucher to the value of $50. NSW permit no. LTPS/12/05027

*In 2011 over 5 million Pelican pouches were sold world wide. Data on file 2012

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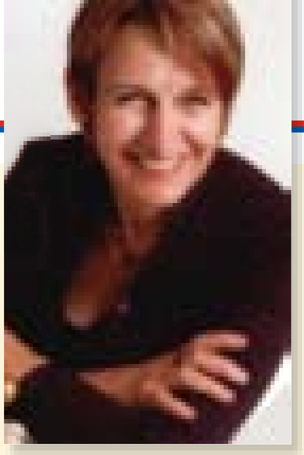
Ask Carmen



OUR STOMAL THERAPY NURSE

Dear Carmen,

I have noticed a small blood blister (about the size of a ladybird) which has appeared about 3cm from the side of my ileostomy. It bleeds now and then as it is under the base plate of my two-piece system.

Is this the start of a fistula or just one of those things that pops up. I am not sure what caused it - maybe the base of my two-piece system was removed too quickly one day. It doesn't seem to be getting larger and does not hurt at all.

Maxine Wade, NSW

Dear Maxine

It could be anything including a burrowing lady-bird? No, that is a joke.

I suspect it is a foreign body of some sort that has worked its way to the surface. Sometimes the sutures used around the stoma are dissolvable but don't always dissolve fully and many months/years later can work their way out. However, without seeing it is hard to advise you properly on what it is or how to treat it.

I suggest that you do see your stomal therapy nurse especially as it bleeds when you disturb it. As it is not painful it is unlikely to be related to a fistula. It also does seem like a good idea to be more gentle in the removal of your base plate, maybe using an adhesive remover wipe would assist with this.

Sincerely, Carmen

Dear Carmen,

I have another suggestion for B.E.T. of Victoria, concerning methods for centring the bag over the stoma. Your solution is a good one but there are some bags which cannot be folded, because of the rigid (convex) flange.

I recall an early magazine article proposing methods for blind ostomates. The instruction (for a one-piece) goes something like this:

(1) Holding the bag in one hand, place index finger of the free hand on the outside of the bag. With this index finger tip you then feel for the outline of the hole in the flange.

(2) By pressing lightly, this index finger tip will push enough of the outer wall of the bag inwards through the hole so that the fingertip is able to touch the stoma (shrouded of course by the outside bag wall.

(3) There is enough sensitivity in the stoma to register the touch of the fingertip, and it's then a simple matter of holding the fingertip in this position (on the stoma) while pressing the adhesive flange home. And Voila! The bag is correctly mounted!

I have no problems with sight, but I confess I always use this method to ensure the aperture always sits dead centre over the stoma. My eyes might occasionally make a mistake (especially in bad light) but my finger never does.

Brian Hunter, QLD

Dear Brian

Thanks for sharing this; I think it is a tried and true method of centring the bag over the stoma.

This is usually OK with a colostomy. The problem with using the finger method you mention is if the stoma is an ileostomy or urostomy as there is usually only a small window of opportunity when the stoma is inactive to actually apply the bag correctly without getting output on the skin adjacent to the stoma.

Actually, even fairly rigid convex bags can be folded as long as you have the strength in your hands.

Thank you for sharing this method with our readers.

Sincerely, Carmen

Dear Carmen,

For the past 34 years I have been a Colostomate due to cancer of the lower bowel, and I feel duty bound to pass on a word of caution to my fellow ostomates who are about to have a routine colonoscopy.

After the examination is over but before you leave the hospital, I suggest that you should visit the toilet and check to see that the replacement bag is secure. Nursing staff in public hospitals are under tight working restraints and mistakes can sometimes happen.

I have experienced two bag incidences, one which turned out to be disastrous.

If you happen to publish this word of caution, I would appreciate it if my name and address be left anonymous, as I only have admiration for nursing staff and the great work that they perform.

R.C. NSW

Dear RC

Thank you for sharing this word of caution. It must have been a distressing situation for you to be in.

Nursing staff in colonoscopy wards/suites are definitely not familiar with all the myriad of appliances (bags) available and can sometimes apply them incorrectly or not do up the bottom or something similar. As you suggest it is a good idea to check any bag you have not applied yourself. After all you are the expert where your stoma and appliance are concerned, not the nurse.

I too have great respect for nurses (being one myself) but their scope of practice is varied and you undoubtedly struck upon one who was not familiar with the principles of applying a leak-proof bag.

Thank you for sharing your experiences.

Sincerely, Carmen

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* Evaluation of the New Hollister High Performance Filter 2008. Feedback from Australian STN's and Ostomates

Turbulence at 36,000 feet

By Brian Hunter, QLD

Travelling ostomates all tell stories about bag changes. Some are humorous. Some are disturbing. Some are best forgotten. Here's one that's a bit different.

It's 2004 and I'm flying with Royal Brunei at night. At 36,000 feet over the South China Sea and heading for Dubai, it is pitch black and freezing outside. The cabin has settled down and I decide to use the toilet for a bag change.

I squeeze into that tiny room and wonder, as always, why we cannot have bigger toilets in aircraft: I mean, the aircraft are getting bigger and wider, so why not the toilets?

But I digress. I can't find anywhere to hang my bag of tricks, so, as usual I do the best I can and hope nothing falls into the pan. They should have more wall hooks. Why do they always forget the hooks?
Next of course I have to drop my trousers and lift my shirt clear of the target area. So far, so good. But not so! I've lost my mini clothes peg. Where is it? Now I'm struggling to stuff the end of my shirt into one of my shirt pockets.

Next I find the solvent remover wipes and begin the flange removal. As I begin this phase, I notice a bit of turbulence. Nothing serious. Pretty mild. I continue with the flange change.

Again the turbulence, and again it's unremarkable, I am making good progress until my shirt falls down. I struggle to stuff it back again into my top pocket.

And that's when the comedy starts. I am half-way through the flange change when I hear the Captain's voice booming from the little speaker over my head. I cannot believe he is doing this: the turbulence has stopped but he is calling for seat belts. Of course I cannot comply: I must finish my task.

At last I get the flange off and begin to dispose of the bag contents.

I am starting the peristomal clean-up when this little drama escalates. Suddenly there is loud banging on the door. The small Brunei hostie must be terrified of the Captain because she is very excited and very insistent. She is not just knocking: she is banging. I must come out and return to my seat. I must come out at once.

By now I am getting just a bit testy. I yell through the door that I will come out when I am finished. She knocks again. I yell again but she will not desist.
What to do? These delightful Brunei hosties have English adequate to their duties, but I know their vocabulary will probably not extend to ostomy explanations.

I am getting just a bit confused. I am struggling to hasten the cleanup (not a good policy) but she will not cease her demands. I can imagine the whole cabin is listening to her banging on the door.

At last I realise I have no alternative. It must be done.

I suddenly unlock the door, push it back and expose the stoma. I point repeatedly with stabbing finger motions to emphasise my words: "I will not come out until I am finished. Now go away!". With that I slam the door and lock it. I am now just a bit angry. I struggle to work with a cleaner-wipe while she again yells through the door. She must really be frightened of the Captain.

Then suddenly the turbulence really arrives. Suddenly we have real turbulence. This proves a blessing in disguise: the hostie disappears. She's gone, probably forced to sit down and buckle up.

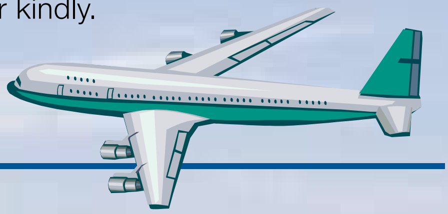
At last I have enough respite to complete the job. I find the new bag and apply it. What a relief to get it on. When you begin to remove a flange you are committed. You cannot go back. You cannot stop half-way, you must go on.

So finally, I gather up all the bits and pieces, then stow them in my bag. I check that I have disposed of all the waste and I do the usual hand washing. Next the dressing and mirror check. Yes, I am finished.

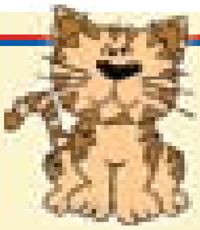
By now the plane is bucking, pitching and yawing but I don't care: I have finished! With great joy I unlock and open the door. But she is gone. She is not there. She must be still buckled in. As I walk back to my seat, I have no way of telling which of the hosties it was.

By the time I get seated (and buckled up) the turbulence has again subsided, my anger has abated and all is quiet. Five minutes later and the Captain cancels the seat belt sign and we all sink back into that quiet, droning hypnosis of the overnight flight.

Somewhere in the Brunei staff list is a hostess who knows what a clean stoma looks like. She is probably still dining out on the story. I hope the Purser and the Captain treated her kindly.



Smile A'While



Cats are Smarter than People

by Harry Ashton

A man hated his wife's cat with a passion. It ruled the household. He decided to get rid of it one day by driving twenty blocks from his home and leaving it in a park.

He returned home and the cat was arrogantly stalking up the driveway just ahead of him.

The next day he decided to drive the creature forty blocks away.

He got home and there was the cat!

He kept taking the cat further and further away and each time it beat him home.

Then he thought "I'll confuse the so-and-so and he won't have a clue where he is".

So this time he drove a few kilometres into a strange suburb, turned left, then right, passed over a bridge, then right again. Just to be sure, he crossed the railway line, turned right at a roundabout, went down a lane, turned left, put the cat out of the car and took off at speed.

Hours later the man called his wife. "Hey, Jen, is the cat there?"

She answered, "Yes, why do you want to know?"

Very quietly, almost tearful and struggling to hold in his complete frustration he said, "Would you please ask him to come to the phone. I'm lost and he's the only one who can tell me how to get home."

Stoma Ditty

By new Ostomate, Walter Soroka

My stoma is my little friend,
we're bonded now for life.
Because we're new acquainted,
he sometimes gives me strife.

Friendship develops cautiously.
to not incur displeasure,
And just like new friends anywhere,
we get each other's measure.

If I eat some "windy" food,
he burps in disapproval.
Blows up the bag with lots of air,
which then needs quick removal.

His table manners can be "suss",
he growls in conversation.
He can be unpredictable,
no matter the occasion.

I'm slowly learning his dislikes,
I don't "pig out" at night.
So then he doesn't wake me up,
we treat each other right.

He likes his shower not hot but warm,
a gentle wash and change.
We take supplies when we go out,
check toilets are in range.

He appeared quite suddenly,
after a major scare.
He is my little lifesaver,
I'm rather glad he's there.

Living with a Drip (Parenteral Nutrition)

by Gillian Anderson

No, the drip that I live with isn't my ileostomy - that's more a 'run', and it isn't my husband - he's wonderful! The drip is actually lifesaving Parenteral Nutrition, and if you haven't heard of it before, it's because there are only about 200 of us in Australia and New Zealand who depend on this form of nutrition, and many of us are also Ostomates.

My story begins in early 2006.The school year had just begun, and I was busy getting my ESL (English as a Second Language) program and timetable up and running. At this time, I was a very healthy 51 year-old, who had built up immunity after 30 years of regular exposure to young children's germs so that I rarely caught a cold, let alone anything more serious! My illness, even now, without a definite diagnosis, began with a headache every day. After two weeks of this, I went to a physiotherapist, thinking it might be due to a back problem. One session of physiotherapy transferred the pain from my head to my neck and shoulder! This pain intensified over the next two weeks, despite regular physiotherapy. After this time I decided to visit my GP, but before my appointment, I vomited and developed diarrhoea. Magically, my neck pain vanished and moved to my abdomen. In too much pain to work, I spent the next three weeks having various tests and trying different drugs to see what the problem was. Blood tests showed there was infection present, but CT scans didn't show anything wrong. At this point my GP sent me to see a gastroenterologist, who luckily saw me within a few days. He also couldn't diagnose the problem, but because of my great pain, admitted me to St George Private Hospital, which was to be my home for the next two months. Here I was introduced to my colorectal surgeon, who planned to do an exploratory operation after the inflammation had settled with the use of strong antibiotics. I don't remember much about this time because I had my morphine pain button, which I can assure you was used frequently! After about 5 days with no change, the resident doctor, feeling my abdomen, realised that my situation had become critical, so on Good Friday morning I was whisked off to theatre and the beginning of my life as an Ostomate.

My surgeon was shocked to discover that almost all of my intestines were necrotic. I had lost all of my large intestine, and most of my small intestine, so I am left with a high output ileostomy. The most likely diagnosis was that it was a form of Vasculitis, where the blood can't get to parts of the body due to a narrowing of the veins, but I had no symptoms of any known form of this disease. Also, the presence of blood clots seemed to point to something else. It doesn't really matter what caused it to happen, I'm just glad that it was my bowel that was affected because it could have been any organ, including my heart or brain or kidneys. I've been lucky that I haven't had any problems associated with my ileostomy, and with the wonderful support of our government in providing all necessary equipment, as well as the marvellous network of volunteers that fill my order each month, and our great Ostomy magazine with so much support and advice and encouragement, I feel that if I have to have a medical problem, this is a good one to have.

As the weeks passed after my operation, unfortunately my small intestine wasn't doing its job of absorbing nutrition from the food that I was eating. My weight had fallen from 62kg to about 45kg, and the output from my ileostomy was often larger than the input of fluids and food. The dietician tried various changes of diet, but nothing worked. They then tried enteral feeds (through a nasal tube) directly into the stomach, but this also didn't work. My remaining 1.2m of intestines were still refusing to adapt, and nearly six years later, they're still sulking. During the latter part of my stay in this hospital, one of the specialists who visited regularly kept saying to another specialist, each visit, that he felt I'd need 'TPN' (Total Parenteral Nutrition - often referred to as simply PN).

It was explained to me that PN was a form of liquid nutrition delivered directly to my heart via a central line in a major vein (the distal third of my superior vena cava, for those with a medical bent). This central line can be a Hickman's, a Port-a-cath or a PICC line. I would still be able to eat for pleasure (although not all people on PN are able to eat), but all required proteins, carbohydrates, fats, vitamins and minerals would be delivered via tube, with the help of a pump, into this vein. The training and monitoring for this could only be done for a long term home TPN patient at the public hospital, so I transferred to St George Public Hospital for the next month.

Although this sounds a relatively simple fix for a major problem, it needs to be monitored very closely, especially in the beginning. PN can affect the liver and cause osteoporosis

Dinner under the stars, Ayres Rock

Continued page 34

Continued from page 32

in the bones. It can set off diabetes because of the sugar content. Kidneys can be affected, and levels of minerals and vitamins need to be regularly checked with blood tests. Potentially life threatening line infections can occur relatively easily, so scrupulous care needs to be taken when setting up each night. In the beginning, my weight dramatically increased by several kilograms a week, because most of my 'weight' was the weight of the 2kg of daily TPN fluid. Over the 5½ years that I've been on TPN, the prescription has changed at times in response to blood test information, and the frequency of feeds has varied. At first I had 5 per week, then it changed to 3, then due to weight loss, back to 6, then, for the past 2 years, it's been every night.

My TPN runs over 9-12 hours at night. This means that every night when I set up, I decide what time I want the pump alarm, which signals that it's finished, to go off and I adjust the time accordingly. For example, on a work day, if I want to get up at 6:30am and set up at 8:30pm the previous night, I would set it to go for 10 hours. 'Setting up' begins with mixing 2 chambers of fluids together in a bag which holds about 2.2 litres. My husband, Ray, usually does this for me, while the bag hangs from a hospital IV pole. For 5 years, once I was set up, I had to walk around the house before bed pushing the pole, or disconnect from the pump and carry the TPN bag with me. However, during last year, I received a new, tiny pump which goes with the TPN bag into a backpack, and when I need to walk around I carry this with me.

The most important thing about setting up is sterility - the biggest threat is infection in the line; so the kitchen bench has to be wiped with surface alcohol, dressing packs, syringe, saline, and pump tubing packs have to be opened carefully without touching the contents. I have to do a sterile hand wash (like doctors before operations) and then be careful not to touch anything else while attaching to my Hickman's line. In my case, this hangs from my chest. Initially, setting up took almost half an hour, but now, with experience and confidence, it only takes about 10 minutes.

Luckily, I haven't had major problems with my TPN, apart from annual infections, but others aren't so lucky, especially babies and young children, who are on TPN as well as having serious health issues. Because TPNers are few and far between, it's difficult, if not impossible, to meet someone in the same boat to discuss issues. However, three years ago, a couple of TPN consumers began a support group called PN-DU (Parenteral Nutrition Down Under) for those in Australia and New Zealand. Anyone who is interested can visit our website, and if there are any Ostomates out there on PN, feel free to e-mail us at contactpndu@gmail.com for further information.

After awakening from surgery that Easter Friday with an ileostomy, I decided that my life would change as little as possible; that this change would be accepted and life got on with. Going on TPN didn't change this decision. One of the best things about the articles in *Ostomy* AUSTRALIA is that almost everyone has a positive outlook and doesn't let their medical problems overwhelm them. One of my friends suggested that I try to get medical retirement, but I wanted to continue teaching; I didn't feel 'sick'. As Ray is retired, I compromised by reducing to working 4 days per week.

Ray and I enjoy caravanning holidays, so we worked out that we could continue this if we put my hospital pole in a water-filled outdoor umbrella-stand beside the caravan bed. In this way, we have not only enjoyed many short breaks in NSW, Victoria and South Australia, but have also travelled 'up the centre' from Port Augusta to Darwin, and back through outback Queensland, taking us and our friends 6 weeks. My TPN, which has to be refrigerated, was delivered weekly along the way, while I had a car full of the necessary peripherals (such as dressing packs) as well as my ileostomy supplies. I had built up these supplies over the months before the trip and had enough to last. However, I was informed that the supplies could be delivered to a town along the way if I'd preferred. Before the trip, I "googled" the towns we were to travel through with the search-word 'hospital', and so had many addresses handy, just in case, but luckily were not necessary. Because a high-output ileostomy is very unpredictable, and there are relatively few toilets throughout the outback, I quite often had to make do with low shrubs or sand dunes. Changing ileostomy bags could be a bit tricky sometimes with the lack of space to spread out in showers at caravan parks, but it was more of a nuisance than a problem.

We also had a wonderful 4 weeks touring around New Zealand last year. I didn't take a base for my pole, just propped it against a wall, but still needed a separate suitcase for all the paraphernalia associated with setting up each night. Nowadays, I don't need a pole, just my backpack and new pump.

From the first, I told everyone I knew that I have an ileostomy, including all of my work colleagues. If I was young and single,

Continued page 36

The Omnigon FOUNDATION

The time to make a FREE phone call is all it takes to CHANGE someone's life!

The Omnigon Foundation is a not for profit initiative founded and sponsored by Omnigon Pty Ltd. Over the past 18 years Omnigon has become a major supplier of ostomy care products in Australia and New Zealand.

At Omnigon we created The Omnigon Foundation on the principle that everyone deserves a chance!

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Bowel cancer research, education, awareness and support

The Fred Hollows Foundation

A world where no one is needlessly blind and indigenous Australians have the same life expectancy as others

The Smith Family Foundation

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To support The Omnigon Foundation all you have to do is VOTE for your most preferred charity from the list above.

You can VOTE by calling us FREE on **1800 065 497**. It's that simple!

For every VOTE The Omnigon Foundation will donate 50 Cents to your preferred charity.

The time to make a FREE phone call is all it takes to CHANGE someone's life!

omnigon
Your healthcare partner

Continued from page 34

I might have a different attitude, but I'm happy to let people be aware of ostomies, and that having one needn't limit what you do, unless it is accompanied by illness. I think the more that people in the community are aware of ostomies, the better the understanding and tolerance.

Different appliances suit different people. I began with a two-piece appliance which mostly worked well, and being a creature of habit, I continued using this for a few years. I had a few accidents, though, when the clip didn't hold and the bag, with its quite liquid contents, fell off, creating a mess to clean each time. So I changed to a one-piece appliance, which is working well for me. I've had an occasional leak around the flange, but a boomerang-shaped flange extender can be put on top to help stick the flange down if it lifts. Barrier wipes are also great to clean the skin when changing the bag and using a dry Chux® cloth wipes the faeces off the stoma quickly and easily.

I know that people cope with difficult situations in different ways, but my strength and resilience is from my faith in Jesus, who promises to be my strength in all situations.

I would encourage everyone with an ostomy to make the most of this wonderful medical answer to bowel problems, and enjoy life in whatever way you are able. ■


Fun on Segways, Homebush

Parenteral Nutrition Support Group

Parenteral Nutrition Down Under (PN-DU) is a self-funded, not-for-profit support group for consumers and carers in Australia and New Zealand on Parenteral Nutrition (PN).

PN is food in a liquid form which is delivered via a catheter in a vein close to the heart, when it is not possible to eat regular food because there is a problem with the digestive system. The nutrients are in a bag of sterile solution which is infused through the intravenous catheter with a pump. All connections and procedures must be aseptic, to minimise infection risk from bacteria entering the bloodstream.

After training to manage their PN themselves (or by their parents/carers), most people can leave hospital to continue their therapy at home. This is known as Home Parenteral Nutrition (HPN). The number of people in this part of the world on HPN is small - approximately 150 children and adults - and the reason consumers end up on this life-support therapy is as a result of 'intestinal failure' which encompasses a wide range of congenital problems and digestive diseases including total Hirschsprung's Disease, Gastroparesis, Short Bowel Syndrome, Crohn's Disease, as well as surgical and radiation effects, amongst others. Many of those on HPN also have small or large bowel stomas.

HPN is a very complex and highly specialised life-support therapy and not knowing anyone else on HPN can be quite isolating and challenging. PN-DU was established in early 2009 by a consumer who is passionate about support, best practice and equality for all HPN consumers. As a group our motto is to "support, research and inform consumers, carers and providers of Parenteral Nutrition for intestinal failure", and we aim to do this through our developing website (which includes a members-only forum as well as lots of information and tips to make life on HPN a little easier), our booklets, and annual meetings for consumers, carers, interested industry representatives and clinicians. We are also involved in various projects and groups to help raise awareness of HPN, and a government-funded brochure for those in hospital starting PN.

PN-DU welcomes new members - not only consumers and carers but also clinicians, industry representatives and others interested. Please contact us on:

Mailing Address:
The Secretary
Parenteral Nutrition Down Under
4/24 Albert Street, Hornsby
NSW 2077

Telephone:
(02) 9987 1978

Email:
contactpndu@gmail.com

Website:
www.parenteral-nutrition-down-under.webs.com


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TINY TOTS CORNER

The Gastronauts are on the move.

The **Australia Fund**, through the Colostomy Association of SA (CASA), has been sending donated product to a little ostomate in Brazil: Anna Mel.

With the introduction of the Gastronaut puppets into Australia the CASA office staff felt that Anna should have a puppet so did a whip around amongst themselves and puppet Lucy flew off to Rio. Anna Mel's mum, Pamela, has been very grateful and approved the publication of Anna Mel's photo. These photos also now appear on the Gastronaut's web page www.thebowelmovement.co.uk

Like to Adopt a Gastronaut Hand-Puppet?

Members and associations can now purchase any of the Gastronauts hand-puppets through ACSA.

Most of the puppets have their own stoma with a miniature drainable ostomy bag attached. Stomal therapy nurses in the UK, USA and more recently Australia, are using the puppets to help child ostomates (and their parents) through scary procedures by demonstrating on the puppet before the child undergoes the procedure.

If you would like to buy a Gastronaut hand-puppet, please contact Kylie McGrory either via email to **feedback@australianstoma.com.au** or phone on **0413 121 565**

Bulletin Board

Open Day at OAM

OAM
Ostomy Association Melbourne

World Ostomy Day

Saturday 6th October 2012
10am-4pm with AGM at 2pm
Please come along and visit our association.
Trade display and light refreshments
ALL WELCOME
Ostomy Association Melbourne
Unit 71 / 170 Forster Road
Mount Waverley 3149

Ileo-Alert - A New Publication

A new publication titled: **Stoma Whisperer:** **AN ADVANCED GUIDE FOR THE AUSTRALIAN OSTOMATE** has just been completed. The cost of the booklet is $6.95 including postage and handling, which is only intended to cover costs and not to generate any profit. A new free website (**www.ileo-alert.com.au**) specifically for people with an ileostomy has also been created.

Contact: Diana Hayes
Clinical Nurse Consultant
Stomal Therapy
4 Vaucluse Avenue
Gladstone Park, Victoria 3043
Email: diana.hayes@stomacare.com.au

New Ostomy Support Groups

SUNRAYSIA / RIVERLAND OSTOMY SUPPORT GROUP

Meets 11.00am to 12 noon.

23rd August	Informal Meeting on at Sunraysia Cancer Centre, 145 10th St. Mildura
11th October	Formal Meeting at Mildura Base Hospital Conference Centre
22nd November	Workshop Speaker Nutritionist Margaret Allan at Sunraysia Cancer Centre
Contact:	Norma Murphy 0409 252 545

WIDE BAY OSTOMY SUPPORT GROUP

Meets from 1.00pm to 3.00pm on the third Thursday each month at Wide Bay Ostomates, 88a Crofton Street, Bundaberg West. For information please contact Heather James: 0406 472 486 or leave a message on (07) 4152 4715

TWO NEW SIZES

Dermacol® helps stop leaks on all types of stoma*

Not everyone has the perfect stoma. But everyone can get help to eliminate leaks and sore skin with Dermacol.® This unique stoma collar comes in 8 different colour-coded sizes. So whatever your size, shape or stoma type, Dermacol® will help form a leakproof barrier and stop output from coming into contact with your skin.

- **Easy to apply**
- **Soft and flexible collar**
- **Strong, yet gentle, adhesive**
- **8 colour-coded sizes**

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SALTS
HEALTHCARE

Have Mojo, Can Go (to Borneo)

Barbara, the Bag Lady, Western Australia

First I found my mojo. And then I found Murray. This is Murray (pronounced Moo-ree). He is the scallywag of the Semenggoh Wildlife Rehabilitation Centre in Kuching, Malaysia. Look at him - isn't he beautiful?

And how did I find him? Well, not too long after our cruise return I had a seventieth birthday looming. How, my husband asked, did I want to arrange the day? It should be special - as a further means of celebrating my recovery - and something I could have fond memories of for a long time to come. What did I want?

"Well," I decided, "I want to go to Borneo to see the orang-utans." And that was that.

Our early research showed us two possible locations in Borneo - neither of which are able to be reached by the recently experienced, reassuring and supportive, home-like environment of a cruise-ship. This time, travel to foreign parts would involve *real travel* - by air (gulp), buses, taxis and local transport. But now that I'd found my mojo there was no reason to be frightened. I'd be fine, providing I did my planning, got myself well-organised and prepared.

So out with the map, or rather, onto the internet we went for our map of Borneo - a tropical island that sits right on the equator in South-East Asia to the east of the Malaysian Peninsula, Kuala Lumpur and Singapore.

The first location we looked at was Kota Kinabalu, the capital of Sabah, East Malaysia (see the yellow bit up there on the map). Malaysian Airlines had just launched a direct flight from Perth and the cheap fare being offered was a definite lure. So we "Googled" and found we could visit the Sepilok Orang-Utan Rehabilitation Centre about 23kms out of town. But when reading the reviews of those who'd been there we were prompted to keep looking.

Our next look-up was Kuching (capital of Sarawak, Malaysia - see the white bit on the map) and the out of town, Semenggoh Wildlife Rehabilitation Centre. What a lovely spread of reviews there were, including those that gave a comparison between the two locations we were considering:

"This place is much better than Sepilok Orang-Utan in Sabah. Would recommend this place to people who wants to see Orang-Utan in the wild."

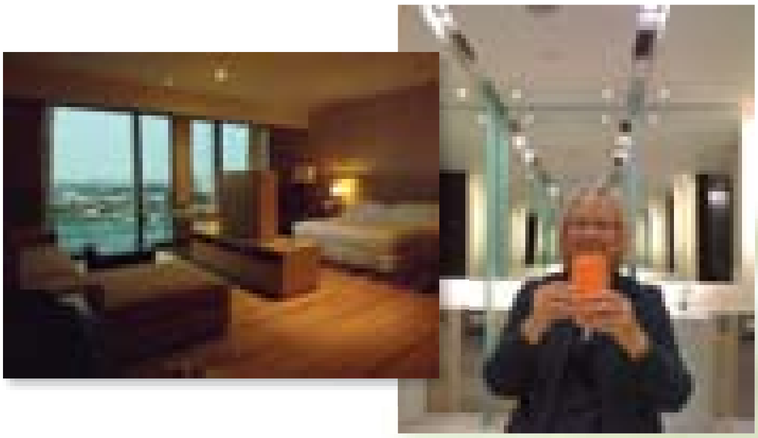
"By far the best day I had in Kuching! I ended up staying the whole day. The rangers and staff were friendly and a wealth of knowledge. In total I saw around 14 Orang-utans during the whole day. It was defiantly one of the highlights of my life."

And so on. We were sold. As well, there was a good offer of accommodation going at the Four Points by Sheraton Kuching - a notch or two up on the standard we usually provided ourselves but right now, at a most attractive and "too-good-to-refuse" discount offer.

Next step, arrange for advance stoma supplies and the "do-not-leave-home-without-absolutely-must-have" travel insurance. As usual, the wonderful volunteers at the WA Ostomy Association were a delight to deal with. With nothing ever being too much trouble at all for them, my supplies arrived in plenty of time for me to do the pre-cutting and packing into my over-the-shoulder, carry on-board, travel bag. Yes, as other contributors have flagged, **always carry your supplies with you**. My GP also provided me with a brief letter, to show if ever necessary, identifying my stoma condition and the need to carry ostomy supplies.

As for the travel insurance, not only a form-filler's nightmare but a costly item to boot. But looking at things sensibly, the outlay of a few hundred dollars for this is far less than the cost of an overseas hospital stay or airlift out or whatever if something might happen to go astray.

But these are the boring bits. I've got my mojo and I'm heading for Borneo. We travel by Qantas to Singapore and then, a couple of days later by Malaysian Airlines to Kuching.



Plenty of space in the Qantas Lounge ladies toilets at Singapore.

Flights are a breeze and the Four Points by Sheraton Kuching is amazing! A courtesy hotel car collects us and we end up on the top floor of one of the most spacious and palatial suites in which we've ever stayed. A huge apartment with everything that opens and shuts (automatically of course). A king-sized bed and an enormous TV that swivels around to the large lounge - all overlooking the local village shops below. A walk-in dressing room through to a spa bath, separate shower and toilet, and towels large and thick enough to soak up the wetness from the bodies of half a dozen sumo wrestlers. Yes! I do a little dance and sing a lot at which my husband falls back in his chair and rolls his eyes.

Hotel staff are attentive and wonderfully helpful. We arrange for a taxi to take us to the Semenggoh Centre. Next morning, our wonderful

Continued page 42

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Call for a free sample now on: 1800 819 274

Terms & Conditions: Competition to win a $300 petrol voucher is open to Australian ostomates only. Entrants need to be over 18 years of age. Entries valid from 01 August 2012 through to 30 November 2012. WINNER drawn at 12.00pm EST on Friday 30 November 2012, and the WINNER will be notified on that day by telephone & email. The WINNER shall receive a $300 Petrol voucher. NSW permit no. LTPS/12/05044

For more information or a FREE sample of these products call Omnigon Customer Service: Freecall 1800 819 274

Continued from page 40

driver, Charlie, is already waiting next to his taxi and away we go for the day. It's about a 40-minute trip with lots to take in on the way. My eyes hang out for the several pottery sheds we pass with large, earthy urns lined up and ready for the taking. Exactly right for my garden and verandahs, but impossible to fit in my suitcase so my yearning becomes an "Oh dear" and on we go.

And here we are right at the ticket office. We pay a small fee, drive into the car-park, then negotiate a tricky and rather steep slope down to a modest shed (with cleanly hosed-out toilets) and gathering place right in the middle of the jungle. We wander around reading the information boards that give stern warnings about not approaching the orang-utans. Some gruesome pictures of damaged limbs lend weight to the message that these animals are wild. My own thoughts are that having come from harsh captivity conditions, it's no wonder that for some, humans are not to be trusted or dealt with very kindly.

"But look up there," one of the keepers points out. "Here come a couple of early arrivals for breakfast." Eyes peeled, I'm looking, looking, looking but nothing to be seen. Ah-ha, over there, I now see the top branches rattling and I follow the progressive path of shaking and rattling until at last I can make out my very first orang-utan arrival. And then another, and another until the keeper moves in to deliver the bananas, coconuts and other breakfast delights onto the feeding platform. A bit of a scurry, but no fights and the food is pretty much gone.

The keepers identify each of the orangs for the gathered group of around 20 or 30 of us. "This is Nora. She is the mother of four, including Edwin and Murray (Moo-ree)." Speak of the devil himself, here he comes. Eight years old and described as "Murray, the Rascal", the keeper warns us he is known to throw things when moody and urinate on unsuspecting visitors standing below - so watch out! Then there is the energetic and agile nine-year-old "Manap, the Notorious", son of Mina who with his accomplice Murray, are recognised as the resident mischief-makers.

A quick "snatch and grab" manoeuvre from the feeding platform.

"Nora the Homemaker" watches over her offspring.

..and enjoys her coconut lunch.

And there is Nora and nameless others that arrive, hang around, feed and leave - about ten or so over a couple of hours. We watch Nora grab a coconut, take it to a comfortable fork in a nearby tree and hit it against the trunk until it cracks and the juice starts to run out - a refreshing drink and then, with a further hard hit, it breaks into several pieces that are jealously held onto.

It was a really wonderful experience to watch them in their own environment and without the restraint of cages and bars. With the knowledge they are under such threat it's a sobering event to watch these beautiful creatures almost within reach. I think back to our travel experience on board the Sun Princess earlier in the year and how I recorded it:

DAY 8. TUESDAY 10 MAY 2011

"Oh how I love the smell of burning forests in the morning"

Oh what a pall of smelling smoke hangs over the ship as we sail from Singapore thru to Port Kelang. There are some passengers who tell about waking in the early hours thinking the ship was on fire. Subsequently, it seems to be those experiencing this fright to be located on the port side and on upper levels - being both on the side facing Sumatra and in the first line of "air conditioning".

I woke around 4.30 am to the mill pond calm that has been our fortune all of the way, opened the sliding door on the balcony to find myself taking in the lung-wrenching stench of what I remember as being the smell of burnt potatoes. Even in the pitch black of night a pall of smoke could be seen.

Yes, this is the indisputable evidence of the devastating, burning-off of the native forests in Indonesia. And with the animals that are also disappearing along with it, it really stinks in more ways than one!

These orang-utans once lived all the way from Southern China to the foothills of the Himalayas and south to the island of Java, Indonesia, but now are only to be found in the dwindling forests of Sumatra and Borneo. Even so, without shame, and under a banner of economic prosperity, even these remaining forests are progressively being stolen by the palm-oil industry.

So, it's been an experience of mixed emotion (joy, wonderment and excitement) at seeing these beautiful creatures scooting across the branches, and sadness at knowing they are just a remnant group of an estimated total population of 2,500 orang-utans in Malaysian Sarawak. Expectations are that few, if any, will survive from the diminishing Sumatran jungles of Indonesia.

But I have seen them - the survivors. And they have re-charged my mojo. If they can survive against all human odds, so can I. ■

What to pack

1. *Don't forget your mojo!*
2. *Scissors (only in your checked-in baggage)*
3. *Letter re stoma, medication & supplies from your GP*
4. *Copy of travel insurance policy*
5. *Stoma supplies in your carry-on-board hand-luggage*
6. *"Security blanket" containing one set of change supplies for any emergency event (including wipes, tissues, hand-sanitiser, etc)*

Like you, all the people pictured in Dansac advertisements are living with a stoma everyday.

It's important to Dansac to show real people, doing real activities, living real lives. Introducing Mariam, a 28 year old with a permanent colostomy who wears her discrete Dansac NovaLife pouch in the spa.

NovaLife is discrete, comfortable and secure and like Mariam you can enjoy your everyday activities confident that you are wearing the most discrete pouch available.

Please call Customer Service on **1800 119 231** to request a sample of the **NEW** NovaLife Closed **flat** pouches or the **NEW convex** pouches in 1 or 2 piece, so you can experience comfort and discretion for yourself.

NEW!

NOVALIFE

dansac

In The Kitchen

with Diana Hayes

Recipe photography by William T. Page

The theme for this issue is Australasia. I have chosen three of my favourites from Chinese restaurants: Short soup, Fried Rice and Banana Fritters.

Short Soup

(also called Wonton Soup)

- *1 cup of vegetable broth*
- *4 wonton wrappers (available in some supermarkets and Asian grocery stores)*
- *2 tablespoons of cooked meat or prawns*
- *2 tablespoons of grated vegetables (e.g. carrots, zucchini)*
- *½ teaspoon of cornflour*
- *1 teaspoon of water*
- *½ tablespoon of soya sauce*
- *Shredded lettuce*
- *Extra water*

Combine the meat or prawns and grated vegetables. Make a smooth paste with the cornflour and water, then add it to the meat mixture and combine well. Add the soya sauce.

Lay out the 4 wonton wrappers on a board and brush lightly with water. Add 2 teaspoons of the mixture to the middle of each wonton wrapper. Fold the wonton wrapper into a triangle shape and seal the edges well. Take the two ends, moisten with water and join them together to make the wonton shape.

Heat the vegetable broth in a small saucepan. Gently place the 4 wontons into the hot vegetable broth and cook until the wonton wrapper is cooked and almost transparent.

Place the shredded lettuce into a small bowl and add the wontons and broth.

Fried Rice

- *2 eggs*
- *Olive oil*
- *1 cup of chopped cooked vegetables (e.g. carrot, zucchini, green beans, peas)*
- *½ cup of chopped tender bamboo shoots*
- *½ cup of cooked and chopped prawns*
- *2 cups of cooked basmati rice*
- *Soya sauce*

Beat the eggs and cook in a pan using the olive oil. Once the omelette is cooked, chop it up into bite-sized pieces.

Add the vegetables, bamboo shoots, chopped eggs and prawns to the hot pan and cook until heated. Add the rice and combine well. Add enough soya sauce to flavour and colour the rice.

Serve as a complete meal or to accompany another Chinese dish.

Banana Fritters

- *1 ripe banana - peeled*
- *1 egg - beaten*
- *½ cup of plain flour – sieved*
- *½ teaspoon of baking powder*
- *½ cup of skimmed (no or low-fat) milk*
- *Olive oil*

Using an egg-whisk combine the flour, baking powder, beaten egg and milk in a small bowl. Continue whisking until you have a smooth consistency.

Cut the banana in half and slice each one in half again lengthways. Using a fork, coat each banana piece with batter, then allow the excess batter to fall off.

Cook in a shallow frying pan in the heated olive oil, turning to cook each side thoroughly. Drain onto a plate lined with paper hand-towels.

Serve warm with ice-cream.

CAUTION: Ostomates who also have Crohn's Disease should note that some recipes may contain wheat and/or dairy products which may be detrimental to your health.

National Directory of Ostomy Support Groups

NEW SOUTH WALES

BROKEN HILL
Meet: Every 3rd month or as required
Venue: Broken Hill Hospital Conference Room
Contact: Tarndra 08 8080 1333

CENTRAL COAST
Meet: 2.00pm to 4.00pm mid-month
15th Feb - 16th May - 15th Aug - 21st Nov
Meet at a different venue each month.
For further information, phone the Stomal Therapy Service on 02 4320 3323

COFFS HARBOUR
Meets 2:00pm to 3:30 pm
Club Coffs, West High Street, Coffs Harbour.
9th Feb - 12th Apr - 14th Jun - 9th Aug - 11th Oct - 13th Dec
Ostomates & friends welcome.
Contact Mandy Hawkins STN on 02 6656 7804

EUROBODALLA REGION
Meet first Sunday in Feb, April, June, Aug, Oct, Dec. 11am
Venue: Laughter Room, Moruya Hospital.
Phone: Betty 02 4476 2746

FAR NORTH COAST
Meet at Lismore Workers Club
225 - 231 Keen St Lismore.
11.30am - 2.00pm
1st Saturday March, July, December
Contact: Marie: 02 6686 7248

FAR SOUTH COAST
Bega & Surrounding Areas
Meets second Sunday of Feb - Apr - Jun - Aug - Oct - Dec at 11.00am at a different venue each time.
Flyers are sent to ostomates 10 days beforehand.
Inquiries:
Eileen. Phone: 02 6492 2530
Geraldine. Phone: 02 6492 2366

GRAFTON
Meet: first Thursday of each month from 9.00am to 11.30am
Venue: Community Health Centre, 175 Queen Street, Grafton.
Contact: Anne: 02 6640 2298

GRIFFITH & DISTRICT
Griffith and the surrounding areas (100km radius including Leeton, Coleambally, Yenda, Hillston, Hanwood, Coleambally)
Enquiries: Barry 02 69635267 or 0429 635 267
email: ann.bar@bigpond.com
Karan: 0434 785 309

HASTINGS MACLEAY
Meet: The Old Hospital in Room 4 at 10am to 12noon on Wed. 15th Feb - 18th Apr - 20th Jun - 15th Aug - 17th Oct - 19th Dec
Inquiries: Keith (President) (02) 6583 3970 or Barbara (Secretary) (02) 65824206

ILLAWARRA
Meet: 10.00am to 12 noon on Wed. 15th Feb - 4th Apr - 13th Jun - 15th Aug -17th Oct - 12th Dec (Christmas lunch)
Venue: Education Room, Figtree Private Hospital, Suttor Place, Figtree 2525
Contact: Helen Richards STN Monday only: 02 4225 5046

MANNING/GREAT LAKES
Meet: 10.00 am to 12 noon on first Wednesday in Feb - Apr - Jun - Aug - Oct - Dec
Venue: Skills for Life Building, 5-9 Elizabeth Avenue, Taree NSW (wheelchair accessible)
Website: www.mglostomy.co.cc
Contact: Karla MacTaggart on 02 6592 9469

NEWCASTLE DISTRICT
Meet at 1.30pm on Saturday 25th Feb - 30th May - 25th Aug (AGM) - 24th Nov
Venue: Hamilton Wesley Fellowship Hall, 150 Beaumont St. Hamilton.
Enquiries: Geoff 02 4981 1799 or Maree 02 4971 4351

ORANGE & DISTRICT
Meet: Mar - June - Sept - Dec
From 12 noon.
Venue: 15 Olver St, Orange. NSW
Contacts: Louise: 02 6330 5676 and Joanne: 02 6362 6184

PENRITH
Meet: at 2.00pm on 27th Jul - 14th Sep -23rd Nov
Tresillian Lecture Room, Tresillian, Penrith (end of Barber Ave next to Nepean Private Hospital off Northern Rd). Parking Barber Ave or within Hospital grounds.
Enquiries: Naomi Houston (Stomal Therapist) 02 4734 3118

SHOALHAVEN
Meet at 2:00pm on Monday 27th Feb - 14th May - 13th Aug - 19th Nov
Venue: Nowra Community Health Centre, 5 -7 Lawrence Ave, Nowra.
Contact: Margaret or Tracey on 02 4424 6300

ST.GEORGE/SOUTH EAST SYDNEY
Meet: 11.00am first Wed. each month Feb through to Dec
Community Centre, Premier Street. Kogarah
Contacts: June: 02 9311 0201
Allan: 02 9556 3268

SYDNEY SOUTH-WEST AREA
Meet: Saturdays 3pm - 5pm on 3rd Mar - 18th Aug - 19th May and 6pm-7pm on 17th Nov (followed by Christmas Dinner)
The Macarthur Room, Revesby Workers Club, 2b Brett St. Revesby (closest parking at front of Club)
Contact: Ann-Maree McDonald STN Phone: 02 9722 7196

SYDNEY NORTHERN AREA
Meet: first Wed. 10.00am - 11.30am monthly in the Jacaranda Lodge, Sydney Adventist Hospital, 185 Fox Valley Rd. Wahroonga.
Contact: Nerolie: 02 9487 9061

WAGGA & DISTRICT
Meetings on first Monday of the month from 10am to 12 noon.
Venue: Horizon Club, Yathong St, Wagga Wagga (located rear of Yathong Lodge, Wagga Wagga Base Hospital)
Enquiries: David (02) 6971 3346 or Baz (02) 6922 4132

VICTORIA

BAIRNSDALE & DISTRICT
Meet: Second Tuesday of March, June, Sept, Dec.
Venue: Bairnsdale Neighbourhood House, 27 Dalmahoy St, Bairnsdale, VIC
Contacts: Janine: 03 5156 0933
Derelle: 0448 458 997
Email: bdosg@hotmail.com

BENALLA / WANGARATTA
Meetings held Mondays at 2.00pm: 20 Feb - 18 Jun - 15 Oct at Delatite Community Health Service, 45 Coster St, Benalla
16 Apr - 20 Aug - 17 Dec at Wangaratta Masonic Centre, 101 Appin St, Wangaratta
Contact: Rex Nankervis (03) 5762 2080
Email: rexmarn@bigpond.com

OSTWEST
Meetings held third Monday of the month in February, May, August and November. 7-9 pm at Melton Health, 195 - 209 Barries Road, Melton VIC 3337
Contacts: Jenny Brown (03) 9746 9121
Tricia Young (03) 9743 5868 or 0416 128 069
Cheryl Prendergast (STN): 9747 7600 (Tuesday and Fridays, every second Wednesday).

MILDURA
Meet: Every third month
Venue: Mildura Base Hospital Conference Room
Contact: Tarndra 03 5022 3333 or Norma 0409 252 545

NORTHERN
A Melbourne based Support Group with a welcome to all with a stoma.
Venue: Darebin RSL Function Room, Preston.
Contacts: Peter: 03) 9460 1125 and Krys: 03) 9431 2779
STN Email enquiry: genevieve.cahir@nh.org.au

SUNRAYSIA / RIVERLAND
Meet 11.00am to 12 noon.
Informal Meeting on 23rd Aug at Sunraysia Cancer Centre, 145 10th St. Mildura
Formal Meeting on 11th Oct at Mildura
Base Hospital Conference Centre
Workshop Speaker Nutritionist Margaret Allan on 22nd Nov at Sunraysia Cancer Centre
Contact: Norma Murphy 0409 252 545

WESTERN AUSTRALIA

ALBANY
Meet at Albany District Hospital Conference Room
At 9.30 -11.00am. third Friday every three months
For details: Terry: 08 98474701

BUNBURY
Meets:1.00pm second Monday of every second month. Feb - April - June - Aug - Oct - Dec
Venue: Cancer Council Meeting Room, Plaza Street, Bunbury.
Contacts: Kevin Jones: 08 97959229
Fiona: 08 97216797

GERALDTON
Meets: 2.30pm last Saturday every second month
Venue: Bluff Point CWA Rooms
Contact: Dawn Hall: 08 9921 8533

MANDURAH/ROCKINGHAM
Meet third Friday of each second month from Jan.
Meetings are held at different locations each time normally over a barbecue lunch.
Visitors welcome.
Contact: Bethwyn: 0439 927 491

QUEENSLAND

BEENLEIGH
Meets 10am - 12noon on last Monday of month - Feb to Nov at Beenleigh
Community Health Centre,
10 -18 Mt. Warren Bvd. Mount Warren Park QLD.
Contact: Pat Miers 07 3827 9811

LOGAN
Meets 10am - 12noon on third Monday of each month at Logan Central Community Health Centre
Corner Wembly & Ewing Roads
Contact: Pat Miers 07 3827 9811

BRISBANE
Operated in the Greater Brisbane Area by QLD Colostomy Assn and QLD Stoma Association
Phone: 07 3359 6500
Website:
qldstoma.asn.au/bosvs.htm
Operating hours: 7 days, 8am to 8pm

GOLD COAST
Supporting Ostomates Needs Group
Meet every 2 months at various venues
Private and Confidential
C/- PO Box 703
Labrador, QLD 4215
Phone: 0429 126 163
Email: gcsong@live.com.au

MACKAY
Meets at Community Health Rooms, Nelson Street, Mackay
At 2pm on the second Friday every second month
Feb - April - June - Aug - Oct - Dec
Contact: Fay: Phone 07 4942 5135
Gerry: Phone 07 4956 3409

REDCLIFFE
Meets first Tuesday each month at 10.00am in the Shillam Room, Redcliffe Cultural Centre - off car park Irene Street, Redcliffe.
Enquiries: Dorothy Douglas
07 5486 4743

ROCKHAMPTON
Meet: 1.30pm third Sat, Feb - May - Aug - Nov.
Venue: Community Health Centre, Bolsover St. Rockhampton
Contact: Frank & Marge Noy
Phone: 07 4928 5248

SOUTH BURNETT
Meet second Tue. each month at 10am
Venue: Nanango Community Health Centre, Brisbane St. Nanango. QLD
Contact: Anne Davoren
Phone: 07 4171 6750

SUNSHINE COAST
Meets at Headland Bowls Club, Syd Lingard Drive, Buderim
third Monday each month at 10am
Enquiries: Winifred Preston:
(07) 5476 6313
presto70@bigpond.net.au
Don Lindsay: (07) 5477 0864
lindsaymar@optusnet.com.au

WIDE BAY
Meets from 1.00pm to 3.00pm on the third Thursday each month at Wide Bay Ostomates, 88a Crofton Street, Bundaberg West.
For information please contact Heather James: 0406 472 486 or leave a message on
(07) 4152 4715

TASMANIA

Meet for lunch 12.30pm on the third Monday in March, June, Sept and Dec. For venue, please contact Anthony Widdowson (Launceston) on (03) 6344 9579 or mobile 0418 595 730 email: acwiddowson@bigpond.com

SOUTH AUSTRALIA

CENTRAL
Meet: third Tuesday of Jan, March, May, July, Sept, Nov. When: 7.45pm.
Where: Ileostomy Assoc Centre, 73 Roebuck St, Mile End.
Information: Val: (08) 8381 1646

SOUTHERN
Meet: first Wednesday of Feb, April, June, Aug, Oct, Dec.
When: 2pm.
Where: Elizabeth House,
112 Elizabeth Rd, Christie Downs.
Information: Val: (08) 8381 1646

YOUNG OSTOMATES UNITED
Helen - (03) 9796 6623,
Website:
www.vicnet.net au/~youinc
Email: helshae@hotmail.com

YOUTH GROUP
Doris Steyer,
Telephone: (02) 4296 5354

Stoma Appliance Scheme Product Suppliers

AinsCorp
PO Box 572, Niddrie, Victoria 3042
Toll Free Number: 1300 784 737
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Website: www.ainscorp.com.au

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PO Box 575, Port Melbourne, Victoria 3207
Phone: +61 3 9673 4144
Email: customerservice@dansac.com.au
Website: www.dansac.com.au

Coloplast
PO Box 240 Mt Waverley Vic 3149
Freecall: 1800 653 317
Email: au.care@coloplast.com
Website: www.coloplast.com.au

ConvaTec
PO Box 63, Mulgrave, Victoria 3170
Freecall: 1800 335 276
Email: connection.au@convatec.com
Website: www.convatec.com.au

Future Environmental Services
PO Box 155, Caulfield South, Victoria 3162
Phone: +61 3 9569 2329
Email: health@futenv.com.au
Website: www.futenv.com.au

Hollister
PO Box 599, Port Melbourne, Victoria 3207
Freecall: 1800 335 911
Email: customerservice@hollister.com.au
Website: www.hollister.com/anz/

Nice Pak Products
Free call: 1800 506 750
Email: healthcare@nicepak.com.au
Web: www.nicepak.com.au

Omnigon Pty Ltd
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3M Australia
Locked Bag 19, North Ryde NSW 1670
Phone: 136 136
Website: www.3m.com.au

Statina Healthcare Australia
3/30 Leighton Place, Hornsby, NSW 2077
Toll Free Number: 1300 365 404
Email: sales@statina.com.au
Website: www.statina.com.au

WHAT YOU DO ON THIS PAGE WILL CHANGE SOMEONE'S LIFE!

The Omnigon
FOUNDATION

VOTE for your preferred charity from the list below.

For every VOTE The Omnigon Foundation will donate 50 cents to your preferred charity.

2 simple steps to change someone's life:

Step 1) Select your preferred charity from the following list

Bowel Cancer Australia
Bowel cancer research, education, awareness and support

The Fred Hollows Foundation
A world where no one is needlessly blind and indigenous Australian have the same life expectancy as others

The Smith Family Foundation
Breaking the cycle of disadvantage by supporting childrens' education

Step 2) Call **FREE** on **1800 065 497** to lodge your VOTE

Support The Omnigon Foundation! It will only cost you the time of a FREE phone call.

As a thank you for your support you will receive a gift.

See page 35 to learn more about The Omnigon Foundation

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