

# Ostomy

A U S T R A L I A

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## 2015 ACSA CONFERENCE

South Australia  
October 15-18

"DON'T  
WORRY, BE  
HAPPY"



# National Directory of Ostomy 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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**Please take this advice into account when responding to company promotions and competitions.**

Consumers of stoma appliances are entitled to lodge a complaint with the Therapeutic Goods Administration if they have concerns regarding the way in which appliances are advertised. Any such complaints should be directed to TGA Complaints Resolution Panel, PO Box 764, North Sydney NSW 2059.

# President's Message

By the time you receive this Journal, it will be around four months since ACSA purchased the intellectual property for the TOMAS computer program from Ostomy NSW Limited on 16th April 2015. The new national computer system has since been formally named the **Stoma Appliance Management System (SAMS)**. The plan is to have the first version of SAMS installed in an association by the end of August 2015.

During that initial installation we will develop an implementation process which we can repeat at other associations. We will then establish a project plan for implementing the system in all associations that wish to participate. Priority in the implementation schedule will be given to associations that are experiencing operational issues with their current system.

Please pardon my preoccupation with the national computer system, but it will provide a common way for each of the twenty-two associations to manage their distribution of ostomy appliances under the Australian Government's Department of Health Stoma Appliance Scheme (SAS). That responsibility occupies a significant part of the activities of each association and a common management system should help to reduce the effort required to operate the SAS.

All of our associations were established by dedicated individuals with a commitment to support and help their fellow Ostomates. Managing the SAS is an essential part of that commitment but there are other areas where we could also be focusing our collective attention.

As an Ostomate for fifty-five years, I now have my daily stoma management routines down to a refined art that I can manage anywhere in the world. In the first twenty years it took me a lot of time, effort and experimentation to get to that point, with more than a few disasters along the way. During that journey I had the welcomed support of fellow Ostomates who were travelling along the same road and we worked it out together.

In the last twenty or so years, stoma care has become a nursing specialty and Australian Ostomates are now able to more easily access professionally trained Stomal Therapists. These dedicated professionals have the expertise, experience and resources to get all Ostomates, new and old, into effective stoma management routines with the minimum of drama.

Talking recently with my local Stomal Therapists I was astounded to learn that:

- a) Each Stomal Therapist pays \$5,000 out of their own pocket to qualify as an STN;
- b) After this STN training, they can still be directed to other areas of nursing in the public health system; and

- c) Their time to spend with Ostomates outside of the hospital inpatient system is severely limited.

Further conversations revealed that they are very aware that many Ostomates with stoma management issues do not have the timely access to STNs that they need or deserve. Public health systems are stretched to the limit so it is unlikely Ostomates can see a resolution to the shortage of professional STN support from that source.

The question then for our Ostomate community is:

## **How do we ensure that all Ostomates have timely access to Stomal Therapists?**

Perhaps it is time to look for inspiration from those who founded our associations and look to doing it ourselves. Collectively, as associations, we potentially have the resources to establish a Stomal Therapy practice that provides Stomal Therapy Services outside of the respective State Government's health services.

Setting up and financing such a Service would not be easy and would present management and governance challenges. However, other groups and individuals have done this for other special needs groups. All it takes is a committed group to establish a model that can be replicated and expanded. I am sure that we would find enthusiastic support from the Stomal Therapists, provided that the thorny issue of professional indemnity is adequately addressed.

On a more immediate note, the 2015 Federal Budget noted that the Stoma Appliance Scheme would initiate a pilot of tendering for the supply of products under the Stoma Appliance Scheme. At the time of writing this article, there is no indication of the appliance groups which may be involved in the trial or to its extent.

This move by the federal government to manage the cost of the Scheme should come as no surprise. The current annual cost of the Scheme to the government is in excess of \$80 million and approaching \$100 million. This equates to over \$2,000 per Ostomate each and every year.

We all need to ensure that we only use what is necessary for the effective management of our stomas. Excessive and unnecessary utilisation of a very generous government Scheme could see severe restriction placed on our access to these essential appliances.

**Please ensure that you only claim the minimum that you need.**

**Geoff Rhodes** PRESIDENT



# Letters to the Editor



## Dear Editor

I read with great interest the Just a Spoonful of Sugar article in the April 2015 issue [Your Say, In Your Own Write]. I too believe D-Mannose is an absolute life saver and has more than helped me with UTIs. I have had my ileal loop for twenty-eight years, and for the last three years have had continual infections where I was down to courses of antibiotics with only four days between each UTI.

My GP was very concerned as I not only had to continually take the usual antibiotics but sometimes the tests showed that only the "Big Guns" would help. With the situation worsening, appointments were made for me to see my urologist and also a professor of infectious diseases to perhaps help with long-term antibiotics.

I turned to the internet to hopefully get some help and read with interest about D-Mannose. I sent for some and started on them before my appointments. A few weeks later both specialists agreed they could not hurt me, so why not!

I had one UTI attack before they really settled down. Since this time (over the last four months) I have not experienced one attack. Life is back to normal and I am not forever waiting for the next UTI.

Cheers to anyone who feels like trying them.

**J. Walters, SA**

## Dear Editor

Over the last few issues, it appears many Ostomates are not able to access sufficient supplies to meet their needs. I have to admit that I was quite surprised to read this as I thought those with a colostomy would need more bags than those with an ileostomy.

I have an ileostomy and currently use a two-piece drainable system. Through my Association I am able to order a maximum of sixty bags per month along with twenty base-plates. This is more than enough for my monthly needs; one bag a day, or maybe two for the odd blow-out or if I am going out for the evening. This also means that I usually only order every other month, saving me postage and ensuring that I do not have excess unused product at home.

Maybe it is due to the product they are using? I have never asked for additional supplies and the delivery form included with each order from my Association clearly indicates the maximum allowed and cost. I am very aware of not over-ordering, knowing how much these precious supplies might cost me.

**Maxine Wade, NSW**

## Dear Editor

It takes courage to go on flights with a colostomy, what with the fear of leakages, uncomprehending air-stewards and startled security officers when they decide to "pat you down".

Information (multilingual) was in the past available from the Association but the font size used was too small for aircrew to read easily. Hollister also had the right idea with their small "certificate" but again, the font size is just too tiny.

Could someone please tackle this and produce an easily readable brochure for those of us who are fortunate enough to travel, especially overseas?

**Katherine Kingsbury, VIC**

## Help!

**Ostomy AUSTRALIA needs your stories, experiences, helpful hints, etc**

Please send your submission in MS-Word or PDF document format via email to:

**Journal@AustralianStoma.com.au**

Hard copy submissions may be posted to:

**The Editor, Ostomy AUSTRALIA  
PO Box 195 Frenchs Forest NSW 1640**

Please ensure that your contribution does not specifically name any doctors or nurses, unless they have agreed in writing to his/her name being published, 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.

Remember, 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.



**Electronic copies of this journal and several earlier issues are available to Ostomates and others via the ACSA website and internet search engines.**



## Correction

An incorrect email address was printed in the Your Say, In Your Own Write section of the April 2015 edition [Page 10: "My Drip Tray"].

Please note that the correct email for **Alex Kara** is **AlexKara@aussiebb.com.au**

We apologise for any inconvenience.

Ostomy AUSTRALIA does not endorse the contents of readers' letters nor do we vouch for the accuracy of any claims made in those letters. Readers should not rely on any such claims in the absence of medical advice and should consult with their treating doctors prior to embarking on any course of treatment.

## Ostomy: It is Really Between the Ears

Submitted by: **Trev Byrne**

Perhaps they installed my stoma in the wrong spot? No, I have stage four bowel cancer and am managing a temporary ileostomy. But in terms of dealing with the ileostomy and coping, it is all between the ears.



We all deal with things differently. It seems that there are two main ways that people end up with their ostomy. The first is the *surprise ostomy*. This is where we either get a diagnosis and before we have time to think about it we are in the operating theatre, or that we go into the operating theatre for a procedure and surprisingly wake up with an ostomy. In both these cases, one does not have any real time to think or process the idea of having an ostomy.

The second way is more a planned process; the *plan ostomy*. From point of diagnosis we have other treatments for some time prior to going in and getting the ostomy. In this case there is the opportunity to process what is going to happen, to talk to professionals and others about it.

### The Surprise Ostomy

*There is no time to deal with the thought of the surprise ostomy. Before you know it, your plumbing is rearranged and you are forced to, well, just do it. Hugely confronting. Mentally this is a real challenge. Life has changed overnight.*

*The flipside is that you have not had time to make a decision, it's a potentially lifesaving procedure that you have not had to dwell over for a period. It's the "throw the kids in the pool to teach them how to swim" idea. Brutal, but it forces one to adapt and move on.*

### The Plan Ostomy

*There is sufficient time to get used to the idea of the ostomy. After diagnosis there are plenty of doctors and others that can advise on the technical and functional information.*

*The downside is that no matter how much the professionals tell you about it, it is all still an unknown. What is it going to look and feel like? How will I manage my day to day life around it, with it?*

*The positive side is that you have time to think it through and process the idea. To logically plan, to talk to others, including other Ostomates, to get familiar with what you are in for. If done right this can provide a good level of comfort so that when it comes down to the actual procedure, you are in a frame of mind to just get on with it.*

In both cases you end up with the mental pressure of dealing with all that the ostomy brings. The physical restrictions and procedures, and the mental pressure that in many ways is the hardest to deal with. How do I deal with a bubbling ostomy during a business meeting or at a family gathering, swimming, being intimate? All are questions that need to be processed so that YOU can decide how YOU will deal with them, and we will all deal with it a little differently.

### Top 5 Tips to Dealing Mentally with your new Ostomy

1. **Get the right information:** Use your medical professionals, write down all the questions you have before going into any appointment, and follow them up with phone calls for any outstanding questions. Don't leave your mind to fill in the blanks, get them filled in properly. Your imagination will conjure up some interesting scenarios so don't let it. Also be careful with Dr Google, there is lots of misinformation out there.
2. **Talk it over with other Ostomates:** Seek out people that have had the procedure, and ask them open questions about how they deal with it. No matter how much information you get from the professionals and books, sitting down over a coffee to just chat about it makes it just that little bit more real, and hopefully, a little bit more comfortable.
3. **Focus on the positives:** Be real about it. Understand the restrictions and issues but put your mind to work in focussing on what you CAN do, and how you WILL do it.
4. **Treat it as a daily procedure:** No more, no less, just like brushing your teeth. No one enjoys it, but it is just something that you have to do. No need to overthink it, so get on with it. Don't procrastinate, just do it.
5. **Make light of it at every opportunity:** That snap, crackle and pop in the business meeting. That gurgle, gurgle in church. Put your hand up, or blame it on the dog or the creaky floor.

So good luck with your new ostomy. Try and work it through mentally and move on with life. Do what you CAN do.

## No Monsters Inside Me

Submitted by: **P. Wolstenholme, QLD**

A television show named "Monsters Inside Me" on Animal Planet usually tells of body parasites. Recently, a man featured on this show was having bowel problems that could not be identified. Exploratory surgery found a surgical sponge from a previous procedure in his abdomen. It had worked through his colon and caused peritonitis. This led to a permanent ileostomy which he openly showed to the viewing public.

I think the only other time that I have seen anything about stomas on television was many years ago. A nurse was showing ostomy appliances and saying that she knew how it felt because she had worn an appliance filled with water and stuck to her

# Is this what we want to leave for our grandchildren?

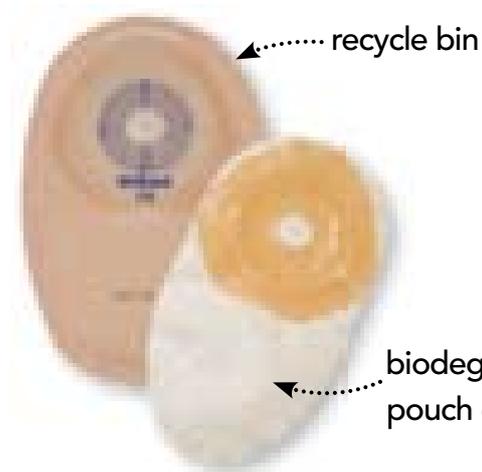


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abdomen for a few days! Hardly an Ostomate's experience!

I feel that if more details regarding stomas and ostomy appliances were shown, there might be less misunderstanding which is sometimes felt by the general public. Most know that there is something called a colostomy, but few know of an ileostomy or urostomy. It could be helpful for new Ostomates as well.

I do not advertise that I have had an ileostomy for thirty-seven years and no one has guessed. If it does enter a conversation then I have no qualms talking about it and most are interested. I have had only one bad reaction from a neighbour, the mother of a child for whom I cared a couple of hours each weekday. She was talking about when she was working in a hospital as a cleaner and how she hated working on "that" ward, as it was disgusting. After hearing my story, she found another to care for her child and did not speak to me again. It was her loss.

### How I Solved my Shaving Problem

Submitted by: **Graeme Mitchell**, QLD

I noted with interest John Samphier's comments, especially point three, which he made in his article [Living comfortably with my stoma] in the December 2014 issue of the *Ostomy AUSTRALIA* journal.

Like John, I am a very hairy male who had to shave around his stoma site daily upon changing my ostomy appliance. I will also mention that I am very lazy and have had facial hair since age eighteen. I am now fifty-eight and have never shaved it off. The only shaving I do is a little on my neck and under my eyes for special occasions. My wife and children have never seen me without facial hair (she would probably leave me if she was to see what is underneath).

After having a permanent ileostomy due to Crohn's Disease in November 2007, this shaving every day was a pain in my life (you can figure what I would like to say!) that I did not need.

At that stage I was working in Mackay but lived in Caloundra on the Sunshine Coast. However I had a great GP in Mackay, who also happened to have a skin care clinic attached to his practice.

In the end my shaving problem was solved by having laser hair removal (IPL: intense pulsed light) around the area of the stoma which is covered by the flange of the appliance. This was not embarrassing to me as the ladies who worked in his clinic were nurses and all had seen stomas before. My appointment times were always made when the stoma was generally least active.

Nowadays I am back living in Caloundra and last year I had to have my stoma re-sited for various reasons (mainly hernias). After ringing a number of skin care businesses, I happened across one that again had doctors and nurses in the clinic who carried out this work. The funniest part of this was that the nurse who treated me in Mackay had moved down to the Sunshine Coast and was now at this new clinic. So we recommenced our nurse to patient relationship and needless

to say, another shaving problem was solved!

As I write this I am again getting IPL done at the same skin care clinic (this time before surgery to again re-site my stoma). The STN at the hospital who sited me for my new stoma was quite surprised when she came across an area of skin as bare as a baby's bottom to put her "X" on the spot. The original stoma site is still bare after eight years.

Basically I'm just letting other males out there know that there is a way around having to shave every day (and it is not painful, nor does it hurt the wallet). I truly believe it is cost effective when considering the chore of having to shave every time I change my appliance.

.....

### X Marks the Spot

Submitted by: **Colin Thornton**, VIC

My journey began in 2010 when at the age of fifty-four, I was diagnosed with growths inside my bladder. I had an operation to have them scraped out and this was followed up by horribly invasive chemical treatments weekly to prevent re-growth. All was good at my first three monthly check up, but unfortunately at the second check up the news wasn't quite as positive as the growth had returned and it was discovered that I also had a spot on my right kidney.

It was decided that the best course of treatment would be to have both my bladder and right kidney removed along with my prostate. Prior to the operation I had an appointment with a Stomal Therapy Nurse who marked the whereabouts of the future stoma with a very large cross on my abdomen. I was also supplied with some information about what to expect regarding living with a stoma. It was evident to me that the stoma would be exactly where the waistline of all my clothing sits and that my existing underwear would be too low to cover up the appliance.

The internet is a marvellous creation for supplying answers to the unknown and I located an ostomy clothing service in the UK that supplied underwear and I purchased three pairs to wear after the operation. At that time I was unaware of the wonderful benefits that the Ostomy Association of Melbourne (OAM) could provide.

The operation took eight and a half hours and all went well until the following day when I suffered a stroke while still at the hospital. A word of advice, if you are going to have a stroke have one in a hospital in front of four specialists and a gaggle of nurses. I was rushed off to have tests and was transferred to another hospital that could better manage my conditions. My care at all times and at all hospitals was brilliant and I cannot praise the staff highly enough. I do not believe that I have any residual effects from the stroke, however my golf game has certainly deteriorated albeit that I was not that good to start with.

After a few weeks of rest and recreation at home I was due to return to work and that was the start of my next dilemma as I now had no suitable trousers to wear. This time the internet was of no help as I was looking for that 70's fashion statement of high waisted pants with a twelve inch zip (hopefully this fashion will return soon). I started scouring all the local retailers without luck until one suggested that I try larger trousers with a belt. I purchased a pair three sizes larger than normal and hitched



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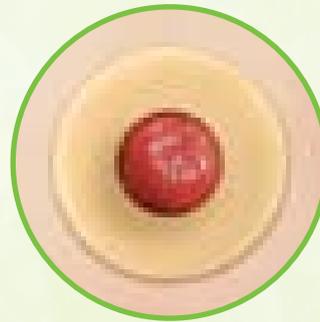
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them up with a belt and I now buy all my pants that size.

I have since tried the ostomy underwear provided on the Scheme via OAM but have found these to be too restrictive and they also compress the appliance's tap hard up against my skin, which I find uncomfortable. However, through the internet I have found companies (mainly overseas) that specialise in ostomy wear and have tried using pouches and other types of underwear.

The most successful that I have found incorporates an inner pouch to contain your bag and also keeps it away from your skin. I have found [www.living-with-a-stoma.co.uk](http://www.living-with-a-stoma.co.uk) to be the best site as it also provides many links to other sites. I now buy normal briefs, three sizes larger than normal and take them to a dress maker in Beaumaris who sews an inner pouch into them which works out at about half the price of buying them from overseas.

I have now retired and have been living with a stoma for five years and have found that my recovery is all but complete thanks to the love and support that I received from family and friends. I can do basically everything that I could do before.

Whilst there is a lot of information that can be provided to you before and after your operation, it is the small things that are neglected and to those who have to live with them daily, it is often the small things that matter most.

I have been reluctant to put pen to paper previously but a friend of mine unfortunately has suffered the same fate and has repeatedly stressed his thanks to me for providing assistance on the small everyday things that we have to learn to cope with.

.....  
**How Lucky We Are!**

Submitted by: **Beth Johnson, VIC**

How do you thank the people who fix that pestering stoma leak or incorrect fitting? Or just listen to you vent about the stoma hiccups you are experiencing? Stomal Therapy Nurses understand the challenges you might face with your stoma and are armed with invaluable knowledge and treatment options to help you live a happy stoma life.

They patiently educate you before and after each surgery, hold your hand through as many nervous bag applications as you need, will exhaust all options to help you no matter how taxing, and are only a phone call away.

I cannot thank my three Stoma Therapy Nurses enough for their unwavering professionalism, care and genuine personalities that supported me through all my stoma challenges. They encompass a level of knowledge that has developed over years of experience, patience and education.

Trial and error of multiple bags, appliances and invaluable tricks gave me the confidence to continue on with my day despite any setbacks or negative experiences.

I hope this article reminds all stoma patients of how lucky we are to have these professionals available.

It takes a special type of person to become a Stomal Therapy Nurse and I'm thankful that I found three of the best in the business.

.....

**Through the Eyes of a Crohn's / Ileostomy Patient**

Submitted by: **Murry DrUITT, NSW**

Way back in 1970 after suffering abdominal pain for some time, I had a laparotomy performed, Crohn's disease diagnosed and the first of eight resections done. Two months later, severe pain had me back in the operating theatre where more of my small bowel was removed.

Over the next twenty years I led a fairly normal life, with cortisone quietening everything down but still with the occasional upset.

At the twenty-first year mark, I had another flair up which required more surgery and more resections of the small bowel and colon, repairs to the bladder and the removal of my caecum.

Moving forward to eighteen years ago and another flair up had me in hospital for a fourth time. After many colonoscopies to balloon the join where the caecum once lived, a strictoplasmy was performed to make the join stay open instead of collapsing to two small openings.

Now onto 2013 where after many weeks in hospital, my small bowel had shut down and I was transferred to a larger hospital that could handle the emergency operation. After six hours of trying to rid the path of adhesions, my small bowel was found to have "shrivelled" to approximately 100mm. The next two hours were spent clearing the blockage and trying to retain the best of a very diseased bowel.

After a fortnight I was allowed to travel home to the south west Riverina area, but two weeks later I was readmitted with suspected peritonitis. A very fast ambulance trip of two and a half hours saw me entering theatre again at 1.00am. Sometime the next day I awoke in ICU where I learnt that I had had a jejunoileostomy and with only about eighty centimetres of colon left, I was now very close to having "short gut" syndrome.

Over the next eighteen months there were many trials with ostomy pouches, rings, bases, etc to find what was best for me. Due to having a very high output, the leaks were constant and my skin red raw and bleeding. Sometimes up to twelve changes a day of clothes and pouches was necessary.

This problem has had me at loggerheads with my Association over the need for more supplies. My surgeon's letter didn't make any difference but a certificate (*Application for Additional Stoma Supplies: PB050*) from his surgical nurse, who happens to be a Stomal Therapy Nurse, eventually worked. However, these certificates are valid for up to a maximum of only six months (*commencing from the date the Application was completed by the medical professional*).

On 31 January 2015, I was operated on in Melbourne with the hope of re-joining it, and if not, repositioning of the stoma, but unfortunately the colon was too badly damaged from the Crohn's. Another problem I had from the effects of the Crohn's was that a fistula popped up in the suture wound, causing it to open to 80mm in size with the small bowel used to make the stoma protruding through it. More fistulas also appeared around the stoma and anus, which would leak constantly.

Today is day thirteen post operation, with the nasogastric

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tube, central line and indwelling catheter now out. All the fluids bags have just been removed, including four blood transfusion packs but I'm lucky to still have the PICC line available for retrieval of bloods.

So I hope I can live with the knowledge that a stoma may be my constant companion for the rest of my life. Hopefully next week I can fly back to my country town to recuperate and be with my family.

## Ileostomies and Slow Release Medicines

Submitted by: **J.W., QLD**

Having had a total colectomy and permanent ileostomy seven years ago, I would like to warn Ostomates about the dangers of medication side effects, especially diuretic therapy or medicine for treatment of hypertension. These medicines can greatly affect electrolytes and may reduce potassium, magnesium and sodium levels. It is my experience that each time I visit a doctor or specialist I have to constantly remind them that I have an electrolyte absorption



problem. Most have never had a patient without a colon and perhaps forty centimetres of the ileum missing. Some have prescribed slow release medicine in spite of being warned that this may not be absorbed.

When I had the ileostomy surgery my daughter (a pharmacist) asked me to enquire regarding slow release drug therapy. I received four different answers from three specialists in different fields and my GP.

I have become very cautious having found out the hard way that there is indeed a problem with some coatings on some medications, which permit the medication to pass through me in their entirety, let alone the medication not working.

With medication reducing my electrolytes, I have been forced to take soluble potassium (script only), soluble magnesium powder (massive dose daily) and a sports drink containing sodium, potassium and magnesium daily just to stay in front of the leg muscle cramps, muscle pain and general muscle weakness in my legs. Nevertheless, all three of these electrolytes are frequently below normal or borderline in my blood tests.

I urge Ileostomates to request frequent blood tests to ensure that their potassium, sodium and magnesium are in normal levels if being treated for hypertension. Apart from very unpleasant side effects, potassium irregularities can be very dangerous. ●

## Congratulations Judy Wells

Submitted by: **Paula Lawrence**

### School Students with a Mitrofanoff the Big Winner from Inaugural Scholarship



Mitrofanoff Support Australia are pleased to announce that the winner of the inaugural **Hollister Mitrofanoff Support Australia Scholarship** is **Ms Judy Wells**, a Stomal Therapist and Continence Consultant at the Royal Children's Hospital in Melbourne. The \$2,000 scholarship sponsored by Hollister will enable Judy to develop the first ever Australian education package for Australian schools to support students with a Mitrofanoff stoma for continence.

CEO of Mitrofanoff Support Australia, Janelle Solomon, said "the education pack developed from this Scholarship will make an important difference in the lives of the children who have had this procedure and are back at school."

"It will be the first time that an

education pack of this nature will be available in Australia to support children to settle back into school with the appropriate levels of support and understanding."

The Scholarship will facilitate the development of a PDF booklet, video/podcast, competency checklist and a Certificate of Competency for use initially in Victorian schools.

Hollister MSA Scholarship winner, Judy Wells said "I have worked in Stomal Therapy at the Melbourne Royal Children's Hospital for the last thirty years and during that time there have been more than sixty Mitrofanoff stomas fashioned for children."

"Having made many school visits related to Mitrofanoff catheterisation, I know there is a great degree of confusion in schools regarding school

requirements, funding for assistance, who can do the catheters and where it can be done."

"This education pack will demystify the Mitrofanoff and enable these kids to get on with enjoying learning and school rather than worrying about catheters."

The education pack will support school staff, explain the long term care and implications of non-adherence to medical guidelines and assist the school with questions and potential problems.

The education package will be made available through Mitrofanoff Support Australia's website **www.mitrofanoffaustralia.org.au** for **e-learning**.

Applications for the 2016 Scholarship will open early in 2016. ●

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# 2015 ACSA Conference



## You're Invited to the 2015 ACSA Conference in Glenelg South Australia

This year's National Conference Program, with its theme of "Don't worry, be Happy", will commence on the afternoon of Thursday 15th October and conclude on Sunday 18th October.

The beautiful beachfront Conference venue is the **Stamford Grand Adelaide** situated at **Glenelg**.

The venue allows easy access to local cafes, restaurants and the Jetty Road shopping precinct. A tram outside the door of the hotel can take you into the heart of Adelaide, Central Market, Convention Centre and the Entertainment Centre.

The Conference program begins on Thursday at 3.30pm with a Supplier Trade Show, which is open to delegates, Ostomates, STNs and medical practitioners. Welcome drinks and finger food will follow, from 5.30pm until 7.00pm. On Thursday night you can unpack and unwind, catch up with old

friends or make some new ones in the numerous local restaurants and cafes.

The Conference continues on Friday at 8.00am with registrations. ACSA's Annual General Meeting follows at 8.30am and will be officially opened at 9.30am by the multitalented **Mr Luke Escombe**; a Crohns and Colitis Ambassador, comedian and musician. Luke will share his experience as an Ostomate.

For the first time the Supplier Trade Show will continue into Friday and is open to all delegates, Ostomates and industry professionals.

At 2.00pm the Gold Sponsors, Coloplast and Convatec, will give short presentations during the Appliance Officer's session following which the Annual General Meeting will resume. At 4.00pm we welcome **Dr Jimmy Etuati**, Colorectal Surgeon, who will present on the advances in Colorectal Surgery.

Friday night the delegates will then have the opportunity to tour the magnificent Adelaide Oval precinct.

Saturday 8.30am sees the beginning of the General Meeting. At 9.30am **Janelle Solomon** (Mitrofanoff Australia) will give a presentation and at 1.30pm, **Kimberley Douglas** (Corporate Orphans) will speak on the difficulties for child Ostomates in Vietnam.

The Conference Dinner will be held on Saturday evening with a cabaret "Chronic Symphonic" performed by comedian/musician and Ostomate Luke Escombe.

On Sunday, we will wind down with lunch in historic Hahndorf situated in the lovely Adelaide Hills, followed by a tour of Hans Heysen's Cottage - "The Cedars".

All members of any Ostomy Association are invited.

For full details and costs please email: [Conference2015@colostomysa.org.au](mailto:Conference2015@colostomysa.org.au)

## Preliminary Program

Full details and relevant times will be confirmed at the Conference.

### Wednesday 14 October 2015

#### ACSA Executive meetings

### Thursday 15 October 2015

- 3.30pm Supplier Trade Show
- 5.30pm Registration and Welcome Function

### Friday 16 October 2015

9.00am - 3.00pm Supplier Trade Show

#### Annual General Meeting

- 8.00am Registrations
- 8.30am Annual General Meeting  
Official opening - Luke Escombe  
Committee meetings and reports
- 4.00pm Presentation by Dr Jimmy Etuati (Colorectal Surgeon)
- 5.00pm Adelaide Oval Tour for delegates

### Saturday 17 October 2015

#### General Meeting

- 9.30am Presentation by Janelle Solomon (Mitrofanoff Australia)
- 1.30pm Presentation by Kimberley Douglas (Vietnamese Child Ostomates)
- Evening Conference Dinner

### Sunday 18 October 2015

Delegate Day Trip - Tour to Hahndorf for lunch followed by a tour of "The Cedars" (famous painter Hans Heysen's Cottage)



Sea Lions:  
by Neale Winter



Sunset, Glenelg Jetty:  
by Greg Snell



Adelaide:  
by Adam Bruzzone



Bethany Wines, Barossa:  
by Nick Rains



The pain was going to start soon. I knew it was coming. You could almost feel it in the air around me, like the sharp metallic smell of ozone in the air after a big storm. The road was soon going to take a sharp turn left and go skywards towards Mount Hotham. The sounds of metal and carbon creaking would increase under the strain from the power of the cyclists' legs around me. The first twinges would arrive a minute or two after that turn as the muscles in my legs would quickly transform from their current relaxed, loose and flexible state to something resembling lumps of aged and gnarled oak; dense and thick with hard twisted fibrous knots. My lungs would then start to sting and burn as they attempted to overcome the oxygen deficit that would begin to occur throughout my body. The thumping of my heart would start to echo and bang inside my head as it rose towards its maximum pitch and a red mist would cloud my eyes and my vision would narrow to just what was in front of me. This is what racing a bicycle up mountains does to you and I was in the midst of the third stage of the **Tour of Bright** race in early December 2014.

The self-inflicted torture was just about to start. However, this pain was different from that I'd experienced three and a half years earlier as I now had control over it. I could stop it at any time I liked, unlike before when I had no say over when it started and stopped and was captive to its merciless grip.

Turn back the clock to late February 2010 when I was on a bike ride in the hills east of Melbourne with a group of friends. I had been a fairly fit and active individual all my life and competed at a high level in short course triathlons up until my early forties. As I hit my fifties, with work, family and study commitments reducing the amount of time for training, I was now just focusing on bike riding and racing the occasional weekend criterium or road race.

On that ride, which wasn't particularly hard or fast, my heart-rate monitor started to misbehave, or so I believed at first. Signalling that I had a heart-rate of 220 beats a minute whilst cruising along while not putting any effort into pedalling was a bit weird, and so was the strange thumping, crashing feeling in my chest. After testing my pulse using the age-old finger-to-the-wrist technique I found that my heart-rate was irregular and all over the place in terms of rhythm and pressure. I presented to an inner city hospital emergency department and

upon telling them of my symptoms, found myself in a surreal situation as alarms went off, people ran at me from different doorways, forced me into a wheelchair and sped me through into the emergency room as doctors and nurses attached multiple pieces of equipment and took my vital signs.

The upshot was that I spent a day in the cardiac unit and watched the USA play Canada in the Olympic Ice Hockey Final when I should have been at work. After being pumped full of beta-blockers and diagnosed with Paroxysmal Atrial Fibrillation, I was released a day or so later. **Atrial Fibrillation** (AF) is a cardiac arrhythmia where more than one

electrical impulse is generated in the heart; instead of the top two chambers contracting and relaxing normally, they just twitch or shiver leading to the bottom two chambers contracting in an irregular and fast manner. The dangers of AF mainly relate to increased risk of stroke and heart attack and in my case it also meant that I quickly ran out of energy as blood wasn't being pumped freely round my body when I put it under pressure.

Over the next few months the AF attacks continued and my mood and general feeling of well-being were severely compromised by taking differing medicines and doses to try and treat the symptoms. Eventually I arranged for a referral to an electrophysiologist.

The difference between an electrophysiologist and a cardiologist, both of whom specialise with the heart, is that a cardiologist is like a plumber; they are adept with the heart's pipes and

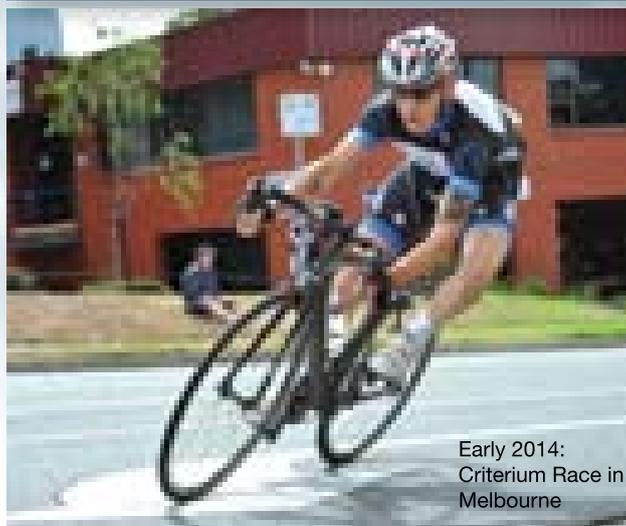
valves, while the electrophysiologist is like an electrician; skilled in the wiring and signals that stimulate the heart. As my problems were electrical rather than plumbing, consulting an "electrician" proved to be the right path.

During late May 2010. I started to notice blood in my stools and was booked in for a colonoscopy after my GP ruled out haemorrhoids. I was quite naively not expecting anything unusual but I did want an answer to the bleeding, which seemed to be getting worse. A visit to the gastroenterologist to discuss the findings was pleasant enough to start with but soon changed as he said the words "**Ulcerative Colitis**" (UC). My first thoughts were "OK, *what do I need to take or do to cure this thing?*", but as the conversation continued I realised it might be something bigger than first anticipated. The initial diagnosis was moderately severe proctitis and a treatment of Predsol enemas was prescribed.

*Continued page 18*

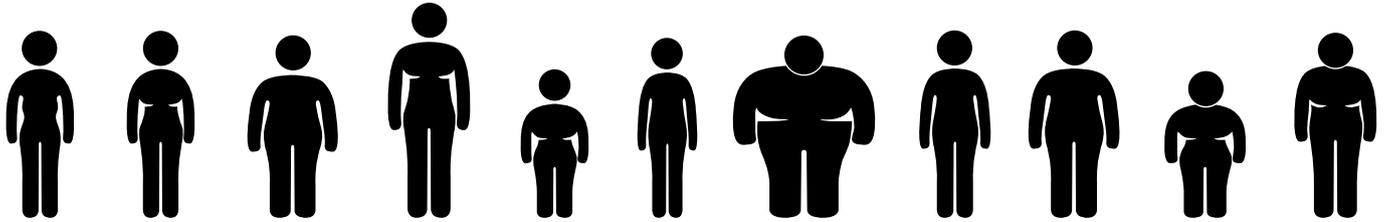
# Conquering Mountains

Submitted by: **Noel Jacobs, VIC**



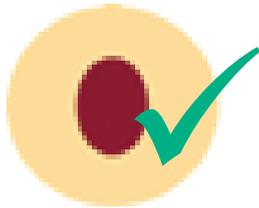
Early 2014:  
Criterium Race in  
Melbourne

# People come in different shapes and sizes and so do stomas!



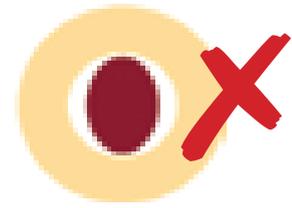
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\* Effect of a long life ostomy seal on faecal enzyme activity by Grace McGroggen, TG Eakin & Dr Lorraine Martin, Queens University Belfast

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Fast forward to early July 2010 and I was in Belgium, having won a competition to spend a week following the Tour De France around the famous climbs of the area as the race passed through. The group was led by Phil Anderson, the first Australian to ever wear the fabled “Maillot Jaune” or leader’s Yellow Jersey of the race and I was riding a bike behind him up a particularly long and steepish climb in the Ardennes region. Phil wasn’t riding at race pace anymore but it was still hard for me to stay close behind him and not give into the mental signals coursing through my mind, telling me to slow down a bit and not suffer so much. That “don’t give up” spirit had been with me all my life so I wouldn’t allow the hurt to better me now and I crested the top of the climb right behind him.

However, it wasn’t all good as I stood at the top looking out across a beautiful heavily wooded vista as the rest of the group struggled up the hill one by one. The pain in my abdomen and bowel were telling me that things weren’t as they should be. The medication didn’t seem to be making things any better; in fact I felt decidedly fuzzy and unwell. Along with the occasional AF attack that could last up to an hour, I was also constantly feeling the need to empty my bowel and felt physically drained most of the time.

Back in Australia, my gastroenterologist prescribed Salofalk enemas to replace Predsol in an attempt to control the inflammation. I also altered my diet to try and eliminate most dairy, alcohol and caffeine, which I had read could exacerbate the symptoms.

Over the next month or so the feeling of wanting to empty my bowels reduced slightly but I now had to contend with an ever increasing incidence of mouth ulcers. At times I had up to fifteen to twenty of them on my tongue, around the inside of my mouth and at the entrance to my throat. Swallowing and eating became a major problem with constant pain that

no over-the-counter remedy seemed to alleviate. Visits to my GP and a specialist ruled out bacteria and other causes. I was eventually referred to an oral medical specialist in late October, who instantly said he believed they were a manifestation of the UC and prescribed Dexamethasone as a mouthwash but advised me to consult my gastroenterologist to try and find a medication that treated both the mouth ulcers and UC.

Unfortunately, just prior to the appointment I was knocked off my bike while on my way to work, landing heavily on my lower back. I knew this wasn’t just another bruise and a bit of skin off my knees as my legs were numb and I was in immense pain. I spent an hour lying on the ground where I fell, waiting for an ambulance and being attended to by some very patient and helpful passers-by. An ambulance ride to one of Melbourne’s major hospitals and nearly twelve hours later, I was discharged from the emergency department with painkillers after being told it was only a soft tissue injury and I should take it easy. After a very uncomfortable and pain wracked night the hospital called and asked me to urgently attend the emergency department as their diagnosis had changed following a review of my x-rays. I had 30% compression fractures to two of the vertebrae in my lower back with small cracks in one of the vertebrae’s small wing-like protrusions. A week off work, constant pain and a chest brace that I had to wear for at least three months put paid to any thoughts of exercise. This coupled with the effects of the UC medication severely dented my mental state.

Meanwhile my use of the Dexamethasone mouthwash had an almost instant effect on the mouth ulcers and reduced their incidence enormously. I was just glad to be rid of the constant pain in my mouth. I also noticed that I was putting on weight and struggling to sleep but just put this down to lack of exercise, the back injury pain and still eating as much as normal. In early November 2010 my gastroenterologist agreed that



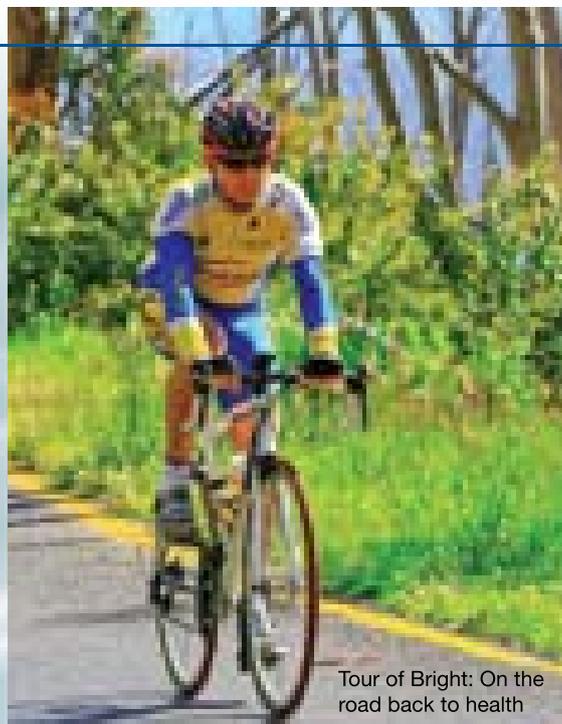
Tour of Bright 2014: Mount Hotham Stage in cold and wet.

the mouth ulcers may be connected to the UC and prescribed a tapering dose of Prednisolone after which I should resume the Salofalk enemas and in the meantime to stop taking Dexamethasone. After one week I had a mouth full of ulcers again and was nearing the edge of my mental limits, just wanting to curl up in a corner and for it all to go away. A call to my gastroenterologist and commencement of Dexamethasone soon meant that whilst I had that spaced out feeling, I no longer had to contend with the pain of mouth sores. This was tempered by my having to rinse my mouth roughly every four hours or else I would quickly feel new ulcers emerging.

By early January 2011, I was still tapering down the Prednisolone but continued to suffer the UC effects, mouth ulcers and cumulative side-effects of the various medications. I could hardly sleep for more than two to three hours a night and my mind raced constantly. I had trouble concentrating and was subject to wild mood swings ranging from aggressive euphoria to deep despair and depression along with significant cramps in my hands, feet and abdomen at any time day or night. The need to empty my bowels increased with up to fifteen-plus visits a day to the toilet coupled with significant blood and mucus loss. I had also taken on the typical moon-face and my weight was skyrocketing with an increase of almost a kilogram a week over the last couple of months.

The other really strange thing was that I started growing hair and had to shave for the first time in over thirty years. Since my mid-twenties I had suffered from an auto-immune disease called Alopecia Universalis, which presents as loss of hair over the entire body due to the immune system mistakenly attacking hair follicles. The medication combination had suppressed my immune system just enough to allow the hair follicles to regain their ability to function properly again.

The first few weeks of January 2011 were a bit of a daze for me as my health spiralled ever deeper downwards. Abdominal cramps were a regular part of my day and night. I couldn't stray far from a toilet as I had very little control over my bowel when the cramps occurred. The first two days after completely stopping Prednisolone was quite strange as I felt as if I was walking around in a hallucinatory state, stuffed full of cottonwool and unable to hear, think or see straight. Recommencing the Salofalk enemas also caused pain so severe that at times I was crying out aloud in agony. But I continued using them as I still naively believed they were doing me some good. My gums appeared to have receded significantly during the last couple of months and I was starting to erupt with many small pimples and spots all over my body. My kidney area and joints all ached as if I was coming down with the flu.



Tour of Bright: On the road back to health

I talked to my gastroenterologist about my rapid mental and physical decline and made an urgent appointment to have a flexible sigmoid exam on 3rd February 2011. The results were not encouraging as the UC had spread and was now categorised as severe.

Throughout this my AF had gradually been getting worse with significant periods of attacks and ongoing issues with ectopic beats. I had managed to deal with these but on the morning of 5th February I had an attack in the shower which literally felled me and wouldn't stop. I should mention that from the time of my initial UC diagnosis through to that day, my wife and children

had without complaint put up with an ever demanding, extraordinarily difficult and sick person. They never knew who they were going to face on any day but it certainly wasn't the same person they had known up until six or so months earlier. This day was especially traumatic for the children as my wife was at work, I could hardly stand and was obviously in deep distress. I phoned a nurse friend and asked if she could come to my house to help. After one look she called for an ambulance. The initial issue for the ambulance crew was my AF as I was suffering a long and intense attack and was visibly unwell. I can only praise those paramedics but to see the look of fear and uncertainty on my children's faces as I was taken away on a stretcher and with our family friend in charge of them will haunt me for a long time.

My visit to the emergency department passed in a daze as the doctors and nurses administered drugs to alleviate the AF symptoms. However it soon became apparent to them that my UC was the main issue as my heart had now returned to what is called normal sinus rhythm. Tests revealed my CRP or inflammation level markers were dangerously high and indicative of a significant issue. I was admitted to hospital and emerged nearly three weeks later a lighter and slightly healthier person.

My first days in hospital were terrifying. My bowel had become so inflamed that they thought there was a good possibility it would rupture and the surgical staff seemed very anxious to remove it. "Toxic megacolon" along with "stoma" and "ileostomy" were words I had not encountered before or knew the meaning of but which were now being used in my presence. Luckily I was put under the care of a gastroenterologist whose main concern was to try and avoid surgery wherever possible and I was quickly put onto intravenous Cyclosporine, a very aggressive immunosuppressant. It was quite confronting when the nurses donned full rubber gloves, plastic aprons and large protective face masks when preparing the bottles and connecting them to cannulas in my arms because of

*Continued page 22*

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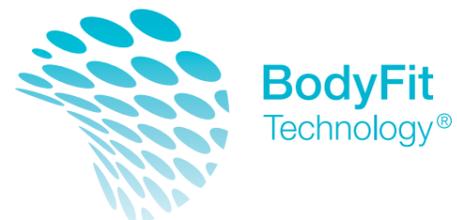
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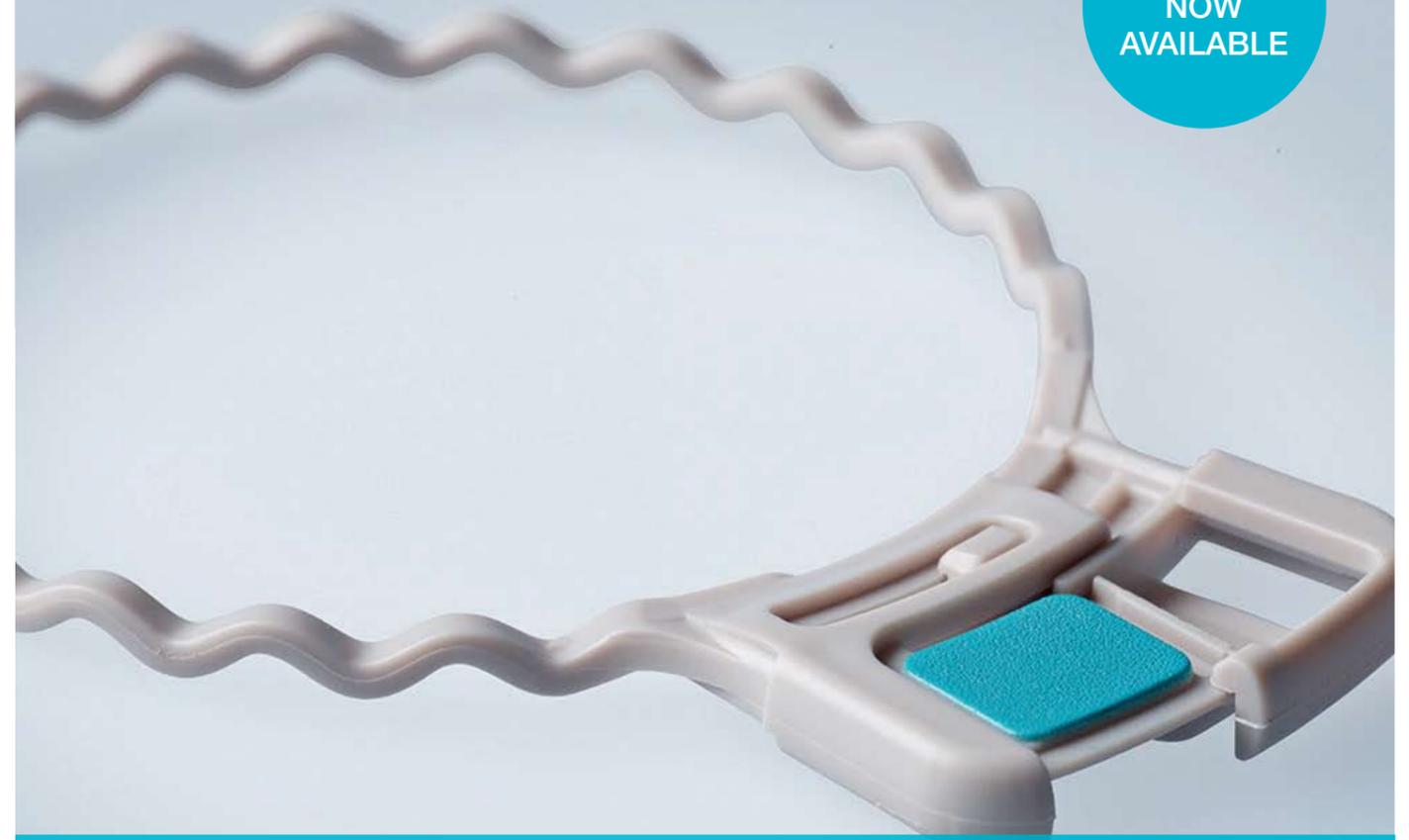
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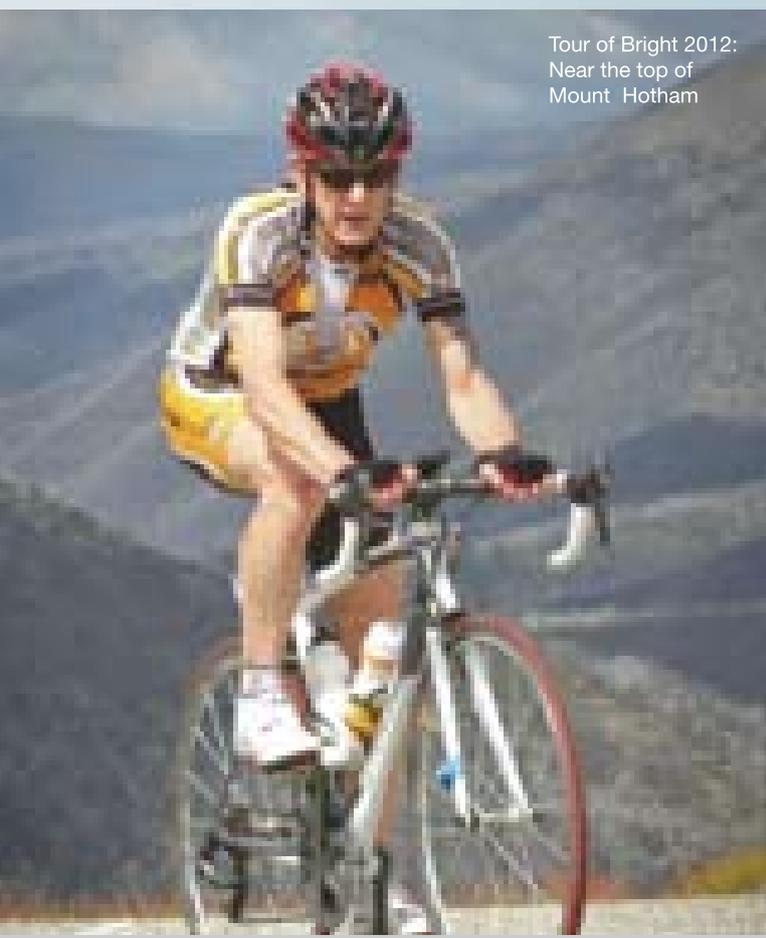
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the drug's toxicity. Whilst progress wasn't immediate and the threat of surgery still hung over me, within a week my body started to react to the medication and my CRP level started to slowly drop and with it, the potential for surgery diminished. It also became apparent from tests that I may have been allergic to Salofalk, which may have caused the increasing flu-like aches and pains, large boils and gradual deterioration in my overall health.

My recovery was slow but steady and over the next two weeks I gradually felt physically and mentally better as the uncontrollable pain and distress at having no control over my bowels subsided.



Tour of Bright 2012:  
Near the top of  
Mount Hotham

After discharge from hospital in late February 2011 the UC seemed to be under control and I was returning to something resembling normal life again. By mid-March 2011, I was able to ride my bike to and from work although the faster social riding and racing I had undertaken in the past was still absent from my routine and I was now taking Cyclosporine in tablet form. I was back at work in a part-time capacity, my bi-weekly gastro ward visits were reducing to weekly and my CRP levels, whilst not ideal, were nearing a normal level. The pain and turmoil along with the disturbed person I had become during my Jekyll and Hyde phase from October through to January had become a distant bad dream and things seemed to be heading towards a brighter future. The only downside was that I couldn't stay on Cyclosporine for a significant time and would have to change to Imuran, the last drug in the arsenal against UC. The changeover from one drug to the next was done gradually over six weeks by

way of reducing the Cyclosporine dose and increasing the Imuran at a relative rate, during which time my CRP levels remained fairly stable.

However, as we approached mid-June my CRP levels started rising, the severe UC symptoms returned and I started to lose weight and general strength. I had discussed the possibility of the medications not working with my gastroenterologist and whilst I'd heard what surgery would entail it was always put to the back of my mind as something I wouldn't have to go through.

There was always something to believe in, no matter how far-fetched it might be, that would take me back to the person I was a year or so ago. The medication would work, my mental strength would get me through and the UC would disappear if I changed my diet. I just didn't want to think of the consequences of having my bowel removed and living with a bag. The fear of surgery and the unknown effects on my future life was very strong, irrespective of the pain I was again enduring on a daily basis.

I'd now been living with the disease for around a year and my health was again deteriorating. Now with no further pharmaceutical options, I decided in consultation with my wife and gastroenterologist to have surgery. After assessing the option of retaining my anus and rectum for a future J-Pouch procedure and taking into account the possibility of pouchitis, especially with my propensity to auto-immune issues, I decided to have them removed along with my large intestine and to create a permanent stoma.

The operation was scheduled for early on the morning of 6th July and I was becoming weaker and weaker as the days ticked down. The morning of the surgery was especially hard as I knew there was no other option, but still didn't want it to happen. My wife and I were both in floods of tears as I was wheeled into the operating theatre.

Later that day I awoke back on the ward, significantly lighter after having several kilos of my gastrointestinal system removed, feeling rather groggy and with another large vertical scar in my abdomen. Even though I still hurt from the surgery and didn't really have a firm understanding of what my new body could now do or how it would work, I actually felt like the dull fuzziness I had continually experienced over the last year had been lifted and I was normal again. The nursing staff even had me up and walking a few steps around the ward the next morning and afternoon. Even though this bag thing was unusual the uncontrollable bowel pain and general feeling of sickness had lifted. This was too good to be true, which proved to be prophetic words!

After two days and even though I had eaten, my stoma had produced little to no output and I was starting to feel lethargic and drained. The doctors called it ileus, or a shutdown of the intestinal tract, which sometimes happens after surgery but normally resolves itself within a few days. Unfortunately mine went on for nearly eighteen days. Lying in bed was also creating significant pain in my lower back as my spine had not fully recovered from my accident. As the days wore on

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my weight declined and a nasogastric tube was inserted to try and drain the gastric fluid from my stomach. This, as anyone who has had one inserted while fully conscious will know, is not an easy or painless experience. After a week I was returned to surgery to check that everything was okay. Nothing untoward was found and it was just a matter of waiting for some catalyst to set my system working again. Ten days after the initial surgery I was fitted with a PICC line so that I could be fed TPN or liquid food as I could only swallow fluids and my strength and weight were both diminishing fast. My body stabilised with this nourishment but there was still no sign of my gastrointestinal tract working.

After the sixteenth day in hospital the nasogastric tube was removed and the next day, while three of my cycling friends were visiting, my stomach decided to quite suddenly expel everything all over me and the bed. This was quite a shock to everyone but luckily it was the kick start that my body needed to get everything working.

After twenty-one days in hospital it was time to go home. At around 1.77 meters tall, my lightest weight ever had been 72 kilograms when I was in serious training for competitive events. Yet I was now down to 58.6 kilograms, had thighs I could wrap my hands around and overlap the fingers, could hardly walk more than fifty meters without resting and physically shook with cold most of the time as I had no body fat anywhere. The one positive was that I didn't have one AF attack during my entire time in hospital.

Three months later and I had put on ten kilograms, had tried numerous types of ostomy pouch and associated products, had many blow-outs and leak disasters, and on more than one occasion cursed this new thing emerging from my abdomen as I found out how to live with an ileostomy and all of its vagaries. I gave up trying to keep my stoma quiet at inopportune times and accepted that I'd been given a new lease of life, albeit one that wasn't quite like the old one.

I realised that my fears prior to surgery were exaggerated as I grew accustomed to a new way of dealing with going to the toilet. Whilst the pouch is there always, there were even times when I ceased to think about it.

Obviously changes had to be made to routines and even now, over three years later, I relish the occasional full night's sleep I get when I don't have to get up to empty the pouch at some unearthly hour of the morning. I also have issues with pouch adhesion especially when time-trialling as the position on the bike means my body is bent across my abdomen, but these are small prices to pay when I remember how ill and mentally dysfunctional I had become and the path I was heading down.

By December 2011, I was back at work full time and whilst I wasn't well enough to compete that year in the Tour of Bright, I travelled with friends who were racing and rode slowly over the routes which on the last stage ends at the top of Mount Hotham.

In February 2012, I at last had a pulmonary vein isolation procedure (ablation) on my heart which successfully cured my AF. Whilst I occasionally get an ectopic beat I now no longer experience prolonged arrhythmias and the associated energy depletion.

By December 2012, I had competed in several cycle races, was fitter I think than I had ever been in my life, and in the 2012 Tour of Bright finished in seventh place in every stage and seventh overall in my age group. When I reflect that this race attracts some of the best cyclists from Australia's south-eastern seaboard I can't believe what I had achieved. Whilst I can't deny that I put myself through lots of self-inflicted pain during training and actual racing to be at that level, what kept me going was thinking of where I'd come from and that if I didn't do my absolute best I would be letting down all the people who had been part of my care and recovery. In 2013, I dropped two places and finished ninth overall but was very happy as the level of competition has taken another jump up with more talented riders now eligible in my age grade.

Throughout all the desperate times and the many highs and lows, the people who were there for me deserve my thanks. My wife and young children who suffered along the way with me; the many groups of fellow cyclists and friends who visited me in hospital and organised a fundraiser, kept in contact and generally helped out when things were tough; the nurses, medical staff and the ever patient Stomal Therapy Nurses who put up with my million questions and helped me adapt to this amended body. Without help from many different people I doubt I would be where I am today.

I am quite open about my ileostomy and often jokingly get called "The Gutless Wonder" by my regular cycling friends who know my history. When people ask me about the effects and limitations, and how I cope with them (I'm lucky in that there aren't that many for me), I try to simply explain that we all have limitations but I accept them and focus on what I can do, rather than what I can't.

As I write this I'm nearing the end of twelve weeks training for the 2014 Tour of Bright and would love to retain my spot in the top ten of my age grade but know that when that road turns left and goes up towards Mount Hotham it will hurt, but it will be a good hurt.

*Postscript: I achieved my highest place in this year's race coming in fifth overall after the three races, which was beyond my wildest dreams.* ●



Christmas 2010:  
With my wife during my fat face stage

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### Dear Carmen

I have an ileostomy and have been fairly trouble-free for the past three years but late last year I suddenly began having massive leaks, mostly during the night and in spite of not changing the products I use. The leaks were from under the pouch and in different directions. Sometimes on removal it looked like a "poo-pancake"! After frequent showering and replacing my clothing and bedding (often around 3.00am), I began sleeping with a small towel on my abdomen and wearing elastic support briefs.

My GP thought it could be a faulty product batch but I had used pouches from different deliveries so thought this unlikely. I have since twice visited Stomal Therapy Nurses and followed all the instructions given but the leaks continued, often four or more per week. I have tried several pouch types and use Stomahesive®, Eakin Slims (to seal) and different brands of extensions to which I found I had a bad allergic reaction.

I'm again using the original product with a seal and a little Stomahesive®, strangely now with success. I've tried a couple of other pouches but had a leak each time. Other than fearing more leaks my main problem is the skin has become quite raw and painful and blood often trickles when I remove the pouch. I have been using Calmoseptine ointment to treat this.

I have two questions which I hope you will be able to help me with.

1. Is there a better product(s) to heal the skin under the pouch?
2. Why my sudden problems when I hadn't changed anything? I wonder if my skin condition has changed and the adhesive no longer works. I shower without the pouch each morning and most times I am problem free throughout the day, but leaks almost always occur during the night.

I look forward to your comments and advice.

**Regards, V.J.**

### Dear V.J.

It is concerning that with no obvious changes you have suddenly experienced leakages. You may have imperceptibly lost or gained weight, your stoma may have "tethered in" more and altered the stoma spout/opening position, or as you suggest, after years of using appliances your skin condition may have changed.

You don't tell me if you use flat or convex pouches, but I suspect a flat one as you change it daily. It is difficult for me to give advice without seeing your body contours, peristomal skin or stoma shape and size. Sight unseen and regardless of whether your stoma is spouting or not, I would suggest you try a shallow convex two-piece appliance pre-cut to the size of your stoma, such as Coloplast's Alterna Flex which has belt lugs on it. Request both belt and bags when phoning for samples.

For preparing your skin I would suggest no more Calmoseptine, which is a zinc based ointment and difficult to rub in and remove. Although providing a barrier it can also stop the appliance from sticking. I suggest getting some Cavilon No Sting Barrier Spray through your ostomy association. Spray this on after gently cleaning and drying the skin around your

stoma using a soft lint free cloth or paper towel (no face washers). It doesn't matter if it gets on the stoma. Let it dry then spray again to provide a good barrier. Stick on your baseplate with the belt lugs going left/right, attach the bag and then the belt, firmly but not too tight. The baseplate should last a couple of days allowing time for your skin to heal. Most two-piece baseplates are designed to last three to five days.

Use of a stool thickener in the pouch at night may also be beneficial as it bulks up the output and hopefully make it harder to leak under the baseplate. Eakin make one called "Perform" also available through your stoma association.

Please keep returning to your STNs until the solution is found.

**Sincerely, Carmen**

### Dear Carmen

I read with interest the article about "Kidney Stones" sent in by Neil Watson [*Ostomy AUSTRALIA* April 2015: "Ask Carmen"].

I have been an Ileostomate for thirty-six years and have found that hydration is so important. I also use alkaline minerals in my filtered water every day and usually drink one-and-a-half to two litres per day.

It is just as important that we have a much more alkaline diet and this fact is not as well known. I was given a Food Combination Chart many years ago and even with an ileostomy it is very viable to choose foods from the Chart that are easily accessible, suit our personal likes and needs, and which can be easily prepared.

**Regards, Julia McBratney**

### Dear Julia

Our gut physiology is complicated and fascinating. On a very simple level, the "body juices" added to the food and drink that we consume alters the pH of "chyme" to facilitate nutrient absorption.

Intestinal juices are alkaline so when people say their ileostomy output is "like acid" and burns their skin they are incorrect as it is alkaline but will still burn their skin. For example, saliva is alkaline and we produce about 800mls each day which we swallow. In the stomach we do produce acidic gastric juices which again chemically alters our food to facilitate breakdown and digestion of protein. The natural pH of skin is acid.

The chemical breakdown and absorption of nutrients is highly complex and sophisticated. Physiologists are constantly learning new things about how our amazing bodies work.

**Sincerely, Carmen**



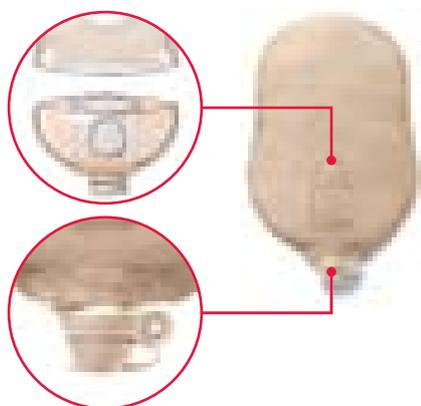
### NEED MORE HELP?

Please send any questions or concerns you might have to Carmen, our journal's Stomal Therapy Nurse.

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Submitted by: **Ruth Horne, SA**

In March we at Ostomy SA lost Betty Johnston, a much loved and well respected volunteer of seventeen years. Betty fulfilled a number of roles whilst volunteering for us including Appliance Officer; Newsletter Editor; Committee Member and more recently our Australia Fund Packer. She will be sorely missed. Betty was a great advocate for not letting a stoma get in the way of fulfilling life to the fullest.

In 2006 she took an escorted trip to Russia, cruising from St Petersburg to Moscow. She wrote of her experience/adventure and we at Ostomy SA thought there were a number of lessons that we could all learn from this article written following her return.



### To Russia and Back

September 2006: We checked our luggage through to St Petersburg and caught the plane to Sydney. We were delayed in Sydney for four hours as the plane's air-conditioning was not working and we had to wait for a replacement plane.

We arrived in Bangkok and left the plane so it could be cleaned and refuelled. More delays but we finally arrived in Heathrow too late to make the connection and there were no more planes out that day. The temperature at Heathrow was hot and humid, and again the air-conditioning was not working. Just long queues and tight security!

Staying overnight in a hotel at Heathrow, we eventually arrived at St Petersburg twenty-four hours late. Again we proceeded through security then on to pick up our luggage, where three of us were then told we had no luggage. It had been lost in transit but we were told it could arrive tomorrow and were asked to complete the necessary forms, etc. Eventually we were told we were so late we would have to go straight to that night's entertainment, the Russian Ballet performing "Giselle".

With no dinner and only our dirty clothes on after two days of travel, we went to the ballet which was a lovely performance,

but we received a few glances and raised eyebrows at our appearances, especially when our ship sent us some "food in doggy bags" as a snack at interval!

Eventually we arrived at the ship for our cruise. Thankfully, we were told that those without luggage could have their clothes laundered each night at no charge and it would be ready and fresh for us each morning. Some of the group loaned us their "spare clothes". I used a borrowed dressing gown as a nightdress for the duration of the trip, one spare jumper and we shared a cardigan. We tried a store in St Petersburg for new clothes but all were thick winter outfits which were not really suitable and we hoped our suitcases would arrive soon. Thank goodness I had my ostomy appliances in my hand luggage.

Russia is a beautiful country, very green, extensive rivers, canals, locks and lakes, and grand old buildings were dotted along the banks of the river. We cruised through Lake Ladoga and on to Lake Onega, then Kizhi Island where we explored the museum of wooden architecture and two remaining wooden churches constructed entirely without nails. Then on to Goritsy and Yaroslav for a cruise along the Volga River to Kostroma for even more monasteries and churches. It is interesting to note that the churches there don't have seats. Everyone

stands and the services are two hours long!

We went for breakfast to the home of a local family and enjoyed porridge, crepes and coffee or tea. They were very friendly people who lived in a very small wooden log house, with one daughter at university and the other at the local school. We conversed with a combination of Russian, English and gestures and it was a lovely morning. But still no luggage!

We arrived in Moscow for our last two days and saw many more churches and monasteries. A trip to Moscow's Red Square by night was one of the highlights. This Square is huge, can accommodate one million people and has many fascinating buildings.

Two of our three suitcases were eventually located at different airports in Russia and I picked mine up at a foreign airport the day before we returned home. It had been to Germany, Finland and finally Russia (with my camera in the case so no photos of our trip).

As an Ostomate I had no issues as thankfully I had carried all my supplies in my hand luggage!

*PS. There is a moral to this story: Always carry all your supplies with you in your hand-luggage and you can do anything you wish with a stoma.* ●

## Vale, Julie Little

13 April 1936 - 4 March 2015

Submitted by: **Lilian Leonard, Founder of PANCH Ostomy Support Group**

It is with sadness that we heard of the passing of our beloved Julie Little, an inaugural member of the Preston and Northcote Community Hospital Ostomy Support Group (PANCH), Treasurer for ten-plus years and a Committee Member until five years ago when she moved to live in Sydney to be close to family.

Julie was the smiling face around our Group, always willing to help and she continued to be involved when PANCH relocated to The Northern Hospital. She was a friendly face around Preston, willing to visit new Ostomates and anyone who needed that extra support. Julie was a resilient and courageous person proudly managing her ileostomy for thirty-four years, battling breast cancer and an auto

immune disease. However the diagnosis of Non-Hodgkin's Lymphoma associated with the chemotherapy became a battle she could not win.

Julie left behind her loving daughters Judy, Pam and Sue, nine grandchildren and four great-grandchildren. She will be sadly missed not only by her family but by all who knew her. The last time I spoke to her and having expressed my dismay at her diagnosis, typical Julie said "But Lilian, what a wonderful life I have had."

Vale special friend. ●



# AASTN President's Report

Submitted by **Kirsti Dixon** - AASTN National President (Australian Association of Stomal Therapy Nurses)



Just where has the year gone? I can't believe that it is June already; before we know it the bi-annual AASTN Conference to be held in Melbourne will be here.

The National Executive Committee have been meeting monthly. Some of us recently met face to face at an Education Subcommittee meeting in Melbourne, which was a great time to network and catch up with the other members who we don't get to see often due to our locations.

Helen Nodrum and her team are doing an amazing job on our Conference and it is all coming together. We are encouraging new and old hands to present at the Conference and there are various themes that allow for a broad scope of information to be presented. It is certainly going to be very exciting. Stomal Therapy Nurses have always been forward thinkers and our keynote speakers will enhance this. I feel that we will certainly see some innovations in Stomal Therapy Nursing that will take us through the next ten years.



Stomal Therapy Week is fast approaching and with this in mind the AASTN wishes to thank Liberty Medical and Omnigon for all their assistance and input, helping

the Education and Professional Development Subcommittee in promoting this exciting Week. Liberty Medical has helped with the design of new posters and brochures that bring the AASTN into the forefront to promote our services. Julia Kitchsha, Omnigon and the National Executive have also been working together to produce great T-shirts for the event (pictured), so keep an eye out for them.

Many AASTN members have now completed their Continuing Professional Development portfolios for the year. This is a tool that identifies learning goals and outcomes for the past twelve months. It is a personal reflection on how well (or not so well) the person has done for the year. Congratulations to all those who have successfully completed theirs.

The AASTN website is also a great tool for all members and the public to

access the wealth of information available. If you would like to advertise your upcoming event please be sure to contact Louise Linke and she will add it to the page. We are also encouraging STNs to have their work contact information on our website so that those who access it have the most up-to-date information.

Till springtime, have a great winter. We will be dancing to the snow gods for a good ski season. ●

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[www.corsinel.com.au](http://www.corsinel.com.au)

Regular Briefs also available on the SAS or for purchase online at [www.statina.com.au](http://www.statina.com.au)

## South Gippsland: More than just a support group

Submitted by: **Thea Dent**

South Gippsland Ostomy Support Group

We are more than just a support group and have our social catch-up on the **first Tuesday of each month**, meeting at 2.00pm in different coffee shops around our area.

Mostly what we talk about is not printable and consequently we do have a lot of fun and laughs. We also talk

about our conditions and support each other with our individual needs. Mostly it is just pure fun.

If you live in the South Gippsland area, please join our fun club. Family are also more than welcome.

Please contact **Thea** on **(03) 5655 2628** for more information. ●



## Young Ostomates United Inc. Update

Submitted by: **Lilian Leonard, Committee YOU Inc**

Now twenty-five years on, YOU Inc. is still a viable self-help group based in Victoria but offering help and support for the young Ostomate, not only in Australia but overseas as well.

Times have changed and the way to fulfil the guidelines of this group is mainly through social media, which for YOU Inc. is the YOU webpage, Twitter and Facebook. Our Facebook page is steadily growing and up to early March

there were seventy-two members, with forty-five new members. As this is a 'closed' page, it is a great opportunity for people to privately ask questions, discuss the issues concerning their children, family and themselves with fast response and support.

A new addition to the YOU webpage is Carmel's story about her disabled son, Wim, and a set of Dietary Fact Sheets from Melanie McGrice, a dietitian from

Nutrition Plus. These Fact Sheets are titled Crohns Disease, Ulcerative Colitis, J Pouch, Slow Transit and Diverticular Disease. Readers can access these on **www.youinc.org.au**

In November, YOU Inc. will be hosting a seminar which will be open to all Ostomates, their families and friends. Further details can be obtained by emailing Secretary Helen Ebzery on **helshae@hotmail.com** ●

## Bulletin Board

### CHANGE OF MEETING VENUE

#### Wagga and District Ostomates Support Group

New Venue: The Men's Shed, 11 Ashmont Ave, Wagga Wagga  
Meeting Day: first Wednesday of each month  
Meeting Time: from 10.00am to 11.00am  
Enquires: **David** on (02) 6971 3346 or 0428 116 084  
**Baz** on (02) 6922 4132

#### Coffs Harbour Ostomates Support Group

New Venue: Sawtell RSL Club, First Avenue, Sawtell  
Meeting Day: second Thursday of the month every two months starting February  
Meeting Time: 2.00pm to 3.30pm  
Enquires: **Mandy Hawkins STN** on (02) 6656 7804

#### Sunshine Coast Ostomates Support Group

New Venue: 40 Buderim Pines Drive, Buderim  
Meeting Day: third Monday of every month  
Meeting Time: 10.00am  
Enquires: **Winifred Preston** on (07) 5476 6313 or **presto1849@hotmail.com**  
**Evon Fuller** on (07) 5447 7158 or **eful@bigpond.com**  
**Laurie Grimwade** on (07) 54459008 or **sid.and.laurie@gmail.com**

### NEW OSTOMY SUPPORT GROUPS

#### Western Australia Ostomy Association

**Weekend Support Group.** for anyone working and unable to make the weekday meetings. Meets on the third Saturday of every month from 11.00am to 1.00pm.

**General Support Group.** Meets on the fourth Tuesday of every month from 2.00pm to 4.00pm.

**Meeting for New Members.** Meets on the second Tuesday of every month from 2.00pm to 4.00pm.

Venue: **19 Guildford Road Mount Lawley**

#### Warrnambool and District

Meets at 7.00pm on the second Tuesday of the month in February, April, June, August, October and December.

Venue: **History Works** (behind Mozart Hall) **Gilles Street** (over Merri Street) **Warrnambool**

Contacts: **Heather** on (03) 5561 1159 or **Terry** on (03) 5562 5093

# Change your life with Simplicity®

Simplicity® stoma support wear is made from a lightweight breathable fabric which contains no cotton. Soft and comfortable, the two-way stretch fabric allows you to move around freely, while ribbing on the front provides a flush finish, making your pouch virtually invisible. And now, our ladies' briefs and unisex boxers are available in a discreet, neutral colour – perfect under any clothes.



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Deeper, higher waistband covers the pouch for extra comfort

Soft and comfortable against the skin

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Virtually invisible under most clothing

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**ASSOCIATION MEMBERS ARE ENTITLED TO**

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*Ostomy AUSTRALIA does not endorse the contents of readers' letters nor do we vouch for the accuracy of any claims made in those letters. Readers should not rely on any such claims in the absence of medical advice and should consult with their treating doctors prior to embarking on any course of treatment.*



In the April 2015 edition of *Ostomy AUSTRALIA* [Your Say, In Your Own Write], Marie Kelly from NSW described how wearing a second pair of cotton hi-cut briefs helped her to overcome problems with skin irritation on her lower abdomen during summer, resulting in instant relief. Marie also asked if anyone had a simple solution to keeping a bag dry when showering.

A number of readers have responded to Marie's query, describing the various strategies that they have employed to better manage skin relief on those hot and sticky, high humidity days, as well as how they keep their ostomy bag dry when showering.

### Bob from the Northern Territory writes:

On reading Marie's submission I realised that we shared similar problems. I became an Ostomate in June 2014 after having my bladder removed due to cancer. As I learnt how to drive this new piece of my anatomy I found that I had issues such as those experienced by Marie.

My operation was performed in the wonderful seaside town of Gosford in NSW but that is another story for another day. I returned to Darwin and as the area of the operation settled and I prepared for chemotherapy, I had issues with the ostomy bag getting wet when I showered and having to try to dry it before I dressed as well as it rubbing on the skin below the stoma. We were also heading into the wet season when the humidity climbs into the high 90% range.

I also had issues with the support-belts, or corsets as I call them, which were supplied to support the ostomy appliance. They were too tight and tended to squash the bag. If I didn't empty it in time it popped the seal and well, you all know the rest of that story. They were not flexible and were very uncomfortable to wear so I went "free willy" so to speak. They were not high humidity friendly either.

My wife, God bless her little cotton socks, Googled the world and came up with the two websites:

1. [www.ostomybagholder.com/ostomy-support-belts/?sort=bestselling](http://www.ostomybagholder.com/ostomy-support-belts/?sort=bestselling)

2. [www.stealthbelt.co.uk](http://www.stealthbelt.co.uk)

Stealth Belts make to order and the site tells you how to measure yourself. They are made for both vertical and horizontal bags and for a colostomy as well. They take about twenty-one days plus freight time. Although this is a UK website all Stealth Belts are made in the USA.

The first company manufactures loads of stuff for ostomy wearers but for me the best are their shower pouches. My days of a wet soggy bag and all the issues that go along with that ceased as soon as I tried it out. I actually bought five of these. They also make a belt/pouch but I wasn't as keen on these as they use a hook-and-eye connection plus a flap to cover the bottom of the bag. The material was a bit of a problem during the wet season up here as well.

The second site manufactures a belt/pouch to order made of a stretchy material with a Velcro connection. I found it changed my life and I wear one every day. Now that I am back at work it has been a blessing and allows me to move more freely and carry out ninety-percent of my previous duties.

The only issue is now that the Australian dollar has dropped, the last belt/pouch I ordered cost close to AUD \$200 with freight. I thought that I would be restricted to owning only two and made inquiries about getting some made locally but that didn't pan out.

Marie and others may be interested in checking out these sites if they have not already done so.

I also noticed Raymund Credlin [Letters to the Editor] mentioned airport-friendly braces and as I am a FIFO worker I could see issues arising when I went through airport security every week. I found a USA manufacturer called the **Hold Up Suspender Company** which produce undergarment suspenders that do not irritate the skin. They make an array of different types of suspenders and it is worth visiting their website: [www.suspenders.com](http://www.suspenders.com)

I hope this information helps others who are experiencing similar issues.

### S.J.B. from Queensland writes:

Living in Queensland during months of high humidity, I also suffer discomfort from perspiration to the lower abdomen under my urine bag. However, I have made pouches from very soft lightweight interlock material, using a urostomy bag as a pattern and leaving the bottom open to slip over the bag. I make a small circle on one side bound with T-Shirt ribbing to fit over the stoma circle. This gives my skin relief from the bag on those hot and sticky days.

Another simple tip to keep your bag dry when showering is to place a plastic zip-top bag (sandwich size) over the top of your ostomy bag and secured to your stomach with micropore tape.

### M.C. from NSW writes:

I solved my heat and humidity problems by purchasing cloth covers for my ostomy bags.

Firstly I tried using a baby's bib; those little round ones used in the early days before they invented bibs that now cover most of the baby. Worn so that the round part goes beneath the ostomy bag, it was good but not perfect.

However, I don't give up easily! I then found a delightful lady on the internet with a business called **Between You and Me** who makes the most perfect covers for ostomy bags. I think she has a sample of every bag used in Australia to use as a pattern.

When you visit her website you will need to know the exact brand and product number of your ostomy appliance. She also has sample pictures of the various materials. Some of mine have little flowers on them and a cheeky one is black with lace across it. These are called "Under Undies".

### J.H. from Queensland writes:

My simple solution to keeping my ostomy bag dry when showering is to use two small bulldog or fold-over clips and a plastic bag or shower cap.

Firstly, fold the ostomy bag up and away from your abdomen (rather than tucking it underneath) and clip it near the filter with the first clip. The lower part of your ostomy bag will now cover the filter.

Next, put a small thin plastic bag (or even an elasticised shower cap) over the ostomy appliance and use your second bulldog clip to secure the plastic bag to the top of your ostomy bag.

I experimented with trimming the plastic bag to fit over the appliance wafer, but it wasn't worth the bother. Sometimes water will collect in the bottom of the plastic bag or shower cap, but since you have folded the stoma bag up it stays mostly dry.

I have also made an ostomy appliance cover out of a small travel towel, which is super absorbent but lightweight. Even if the ostomy bag does get damp it will quickly dry while you are dressing and you can slip the towel cover off in a minute or two.

I have also used Marie's trick of wearing two pairs of briefs to protect my skin, one low-cut under the bag and the other high-cut over the bag, but due to the heat I am not that keen on wearing two pairs of knickers. So I made my own with a double layer only in the front: the short layer fits under the pouch and the tall layer over the ostomy bag. Ready-made underwear of this style can also be purchased online from manufacturers in Scotland and the United Kingdom.

Hope this helps!

# Smile ☺ A'While



## A Poem for Meika, our Hirschsprung's Hero

Submitted by: Julie Tighe

After being blessed with two healthy boys,  
Our third was a girl, our hearts filled with joy.  
Mummy's instinct kept saying "there's something not right",  
Was reassured many times, "she's fine, she's alright".

I was made to feel paranoid when I voiced my concern,  
But I was right all along, as I would later learn.  
We were discharged from hospital, sent home to our farm,  
Where you struggled to drink, while I tried to stay calm.

You would vomit a lot and cry out in pain,  
I felt lumps in your body, to doctors I would explain.  
I could feel the wind inside you, didn't know it was stuck,  
They said it was normal and wished us good luck.

Little did I know, your bowel didn't work,  
Looking back now, I feel like such a jerk.  
We asked them to test for Hirschsprung's, a disease in our family,  
They told me it is too distant and couldn't possibly be.

Later you became lethargic and couldn't stay awake,  
You were dehydrated and my body began to shake.  
You have a bowel disease my girl, which is very, very rare,  
As you were being poisoned, you had a weird blank stare.

Finally a doctor listened and started treatment straight away,  
He phoned for a helicopter and you were flown out that day.  
I dread to think what could have happened to you,  
If we waited any longer, you wouldn't have pulled through.

After weeks of waiting for your big operation,  
The day finally came, no more constipation!  
They removed all your colon and some small intestine,  
Surgeons made you a stoma, then I knew it was test time!

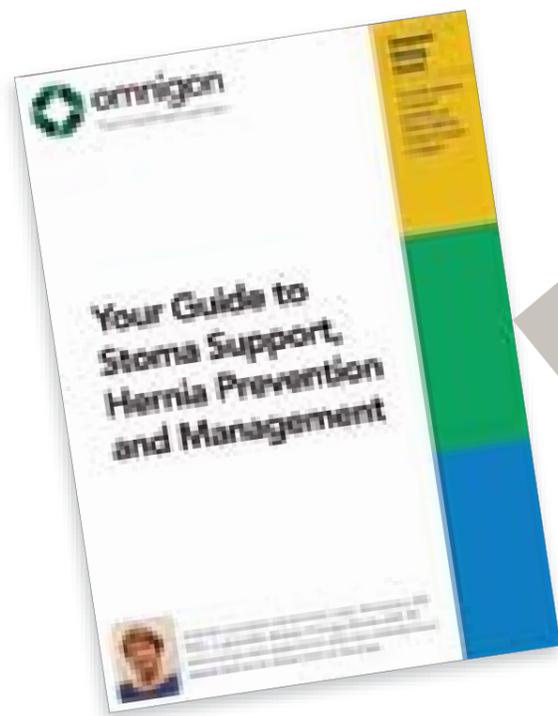
A week post-op, we were free to go home,  
With no nurses to help us I felt all alone.  
It has been a few months now, we get by week to week,  
With blow outs and changes, no one said it might leak!

We are getting used to "the bag" and your ileostomy,  
And soon will prepare for your next surgery.  
We look forward to the future and what it will hold,  
There will be some hurdles, we'll get through so I'm told.

We will fight this disease until the end, here we go.  
We love you Miss Meika, our little Hirschsprung's Hero!

# Did you know? 3 out of 10 people with a stoma will develop a hernia<sup>1</sup>

Ensure you have the right security with one of Omnigon's scientifically<sup>2</sup> tested support pants and belts.



Reduce your risk of developing a hernia by following practical advice, together with regular use of a comfortable, well fitted support garment.

<sup>1</sup>: Data on file Omnigon 2012 <sup>2</sup>: A review of 16,470 on the American United Ostomy Association Register revealed 30% incidence over all types of stomas. (Gray et al, 2005)



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#### Diamond Plus Waistband

- Seamless circular knit which moves with the body
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Support Rating  
**3**  
MODERATE



#### Support Briefs for Her

- Comfort of pants with the benefit of a belt
- Discreet yet very supportive



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- Excellent support for all activities
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#### KoolKnit

- Aerated fabric-perfect for active people
- Moulds to the body to provide firm support

Support Rating  
**5**  
FIRM

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[www.omnigon.com.au](http://www.omnigon.com.au)



# Nutrition for Ostomates

Submitted by: **Margaret Allan**, VIC



*Margaret Allan is a qualified Nutritionist. She advises Ostomates and the general public on diet and health-related matters.*

*Margaret is based in Melbourne and is available for clinical or Skype consultations by*

*appointment. She can be contacted via email on: [margaret@foodfirst.com.au](mailto:margaret@foodfirst.com.au)*

## ***In this article Margaret discusses fermented foods and how they can be of benefit to Ostomates.***

There are many nutritional and digestive benefits for Ostomates in consuming fermented foods and/or beverages on a daily basis. It has been postulated that the lack of fermented foods in our modern day diets may be a contributor to the influx of digestive disorders related to lack of beneficial bacteria in the gastrointestinal tract. The lack of these beneficial bacteria may leave us vulnerable to infection from pathogenic organisms, and make it harder for us to derive some essential nutrients from the foods we eat.

Ostomates in particular are often nutritionally depleted due to the illness and/or surgical and medical procedures which preceded them becoming an Ostomate, and so any interventions that assist nutritional status are beneficial. Even small changes can reap big rewards!

Fermented foods have played a major role in many traditional cuisines but are not considered an essential component of our modern day diet. Prior to industrialisation the Europeans frequently consumed milk in a fermented state as yoghurt, cheese, curds and whey, etcetera, but it wasn't until the 1930's that physicians began to notice the healing properties of these foods.

Without pasteurisation or refrigeration, milk naturally sours and separates spontaneously. This is due to the process of lacto-fermentation during which lactic acid producing bacteria begin digesting or breaking down both the milk sugar (lactose) and milk protein (casein).

When these beneficial bacteria have produced enough lactic acid to inactivate all the putrefying bacteria, the milk is effectively preserved from spoilage for several days or weeks. In the case of cheese, which undergoes further fermentation of a different type, preservation is sustained for years. Yoghurt is the fermented milk product that we are most familiar with in our modern society.

I ♥  
Yogurt



Kefir is another form of fermented milk that originated in the Caucasus Mountains on the border of Russia. Prior to the 1930's, the Nobel Prize winning bacteriologist Élie Metchnikoff identified that Bulgarians who ingested large quantities of fermented milk enjoyed a longer lifespan than most, and with little to no known disease.

Kefir is prepared by culturing fresh milk with kefir 'grains', which bear no resemblance to cereal grains but instead are bacteria and yeast existing in a symbiotic relationship. They have small, soft, gelatinous bodies that resemble tiny, cooked cauliflower florets. Fresh milk is added to the kefir grains and left at room temperature for approximately twenty-four hours for the milk to ferment. Once fermentation is complete, the cultured milk product is strained to retrieve the kefir grains for re-use and the process is repeated. Milk kefir can also be made using a powdered starter culture.

Fermentation of milk results in numerous beneficial changes to the beverage, such as:

- Breaking down the protein in milk (casein), which is one of the most difficult proteins to digest. This makes it easier for the digestive system to handle, and is why fermented foods are more easily digested by people who have digestive disorders.
- Reducing the amount of lactose in the cultured milk by as much as 50% and restoring many of the important digestive enzymes that are destroyed during pasteurisation of milk, such as lactase, which helps to digest the lactose that remains in the milk. Therefore many people who are sensitive to milk or have lactose intolerance are able to more comfortably assimilate the fermented form.
- Increasing nutrient quantities such as the levels of B vitamins and vitamin C.
- Releasing nutrients from the food, making them more bio-available for the body to digest and absorb.

Fermented dairy products have the added benefit of introducing beneficial bacteria into the digestive tract, which can help to keep pathogenic bacteria at bay and guard against infectious illness. As such, kefir is referred to as a probiotic beverage. Yoghurt contains

two or three strains of beneficial bacteria, but kefir has been found to contain as many as twenty-seven different strains. Therefore, **kefir is a much more potent probiotic beverage and so, when introducing fermented milk, it is important to start with yoghurt before transitioning to kefir.**

Kefir can also be made from water 'grains' immersed in sugar water, juice or coconut water that produces an effervescent, slightly alcoholic beverage that tastes like dry lemonade. The grains used to make water kefir are small, translucent, gelatinous structures comprised of an assortment of bacteria that give them a crystal-like appearance. The process of fermentation produces a variety of beneficial acids, enzymes, B vitamins and beneficial bacteria whilst also reducing the sugar content.

Fermented vegetables are also popular in traditional cuisines and are similarly produced via a lacto-fermentation process that inhibits putrefying bacteria and increases beneficial organisms and nutrients. A bacteria, mould or fungus is often added to the vegetables as a starter culture to begin the fermentation process, but is not always necessary. The benefits are similar to those of fermented milk products in that enzyme levels and digestibility are increased, along with antibiotic and anti-carcinogenic substances.

*Some examples of common fermented vegetables include:*

**Sauerkraut** *Produced principally from fermented cabbage via the lacto-fermentation process.*

**Kimchi** *A traditional Korean fermented food made from a variety of cabbages and chilli.*

**Kombucha** *A sugary tea that is fermented to make a fizzy, slightly sour but sweet, mostly non-alcoholic beverage that is low in calories and sugar. It is reported to boost the immune system and detoxify the body.*

**Tempeh** *A traditional fermented food made from soaked and cooked soybeans inoculated with a mould. After fermentation, the soybeans are bound together into a compact cake. The mould helps to synthesise enzymes that improve the nutritional quality of the food.*

**Miso** *A fermented soybean paste made by steaming soybeans and a grain, then adding a fermentation starter and allowing it to sit in cedar vats for eighteen months to two years. Complex proteins, oils and carbohydrates are broken down during the fermentation process into more easily digested nutrients. Miso is a dietary staple in many Japanese cultures.*



Sauerkraut



Kimchi

## Natto

*Another traditional Japanese food made from fermenting soybeans with a bacterium. It is often eaten as a breakfast food, but is considered an acquired taste due to its pungent smell, strong taste and slimy texture!*

**Please note that fermented vegetables are not meant to be eaten in large quantities but instead consumed as condiments with a meal. In fact, introducing any form of fermented food or beverage should be done very slowly to allow the digestive system to adjust, and is best achieved under the supervision of a person experienced in the process.**

This is because the fermented product introduces beneficial bacteria that may initially 'fight' with any pathogenic bacteria present and lead to slight stomach cramps, diarrhoea, nausea or vomiting.

These symptoms usually subside after a short period of time. Ingestion of vegetables that have not fermented for at least seven days can also result in bloating and poor digestion in those with sensitive digestive systems. So it is important to assess each case individually as to the degree of imbalance between so called 'good' and 'bad' bacteria and initiate the process appropriately.

Small quantities of fermented foods or beverages can be made at home in your own kitchen with relative ease, but **they require frequent monitoring as the fermentation progresses.** I have some kefir grains that I give to my patients and students, and I do so with the advice that they are like pets in that they need to be monitored and checked every day!

As you can see, there are many benefits for Ostomates in consuming fermented foods and/or beverages on a daily basis. In addition to the extra nutrients that can be derived from these products, they also serve to assist digestion of nutrients that are harder for some people to break down and absorb. The acids that are produced in the fermentation of vegetables and milk can also be of particular benefit to older individuals, as they may aid a digestive system that is becoming more and more feeble.

As stated previously, fermented milk in the form of yoghurt or kefir can be suitable for those with lactose intolerance, as the lactose content is lower and the lactase content higher.

However, please note that it is the acids that are produced during the lacto-fermentation process that create this result, so any yoghurt in particular consumed by those with lactose intolerance needs to be very acidic. And, as also stated previously, **it is very important to slowly introduce fermented foods or beverages into the diet.** If you do, I look forward to hearing your feedback!

Wishing you good health and happy days, **Margaret.** ●

# National Directory of Ostomy Support Groups

## NEW SOUTH WALES

### ALBURY/WODONGA BORDER DISTRICT

Meets: 10.00am on the second Tuesday of each month Feb to Dec.  
Venue: Hilltop Accommodation Centre,  
600 Keene Street, East Albury NSW  
Contact: Alex Watson 0428 578 385

### BATHURST

Meet on the first Tuesday of March, June, September & December at Daffodil Cottage  
Contact: Louise Linke  
(02) 6330 5676

### BROKEN HILL

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

### CENTRAL COAST

Meet: 1.30pm to 3.30pm on the third Wednesday in Feb, May, Aug and Nov at a different venue each meeting. For further information, phone the Stomal Therapy Service on  
(02) 4320 3323

### COFFS HARBOUR

Meets 2:00pm to 3:30pm  
2015: 12 Feb - 9 Apr - 11 Jun - 13 Aug - 8 Oct - 10 Dec  
Venue: Sawtell RSL Club, First Avenue, Sawtell.  
Ostomates & friends welcome.  
Contact Mandy Hawkins STN on  
(02) 6656 7804

### EUROBODALLA REGION

Meets first Sunday of Feb - Apr - Jun - Aug - Oct - Dec at 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 & DISTRICT

Meets first Thursday of each month from 9.00am to 11.30am  
Contact: Anne: (02) 6641 8200

### 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 the third

Wednesday in Feb - Apr - Jun - Aug - Oct - Dec.

Inquiries: Jennifer (02) 6586 0270

### ILLAWARRA

Meet: 10.00am to 12 noon on Wednesdays 18 Feb - 19 Aug - 22 Apr - 21 Oct - 10 Jun - 16 Dec in the Education Room, Figtree Private Hospital,  
1 Suttor Place, Figtree 2525.  
For further information, contact Helen Richards STN on  
(02) 4225 5046 (Monday only)

### 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 Ave. Taree NSW (wheelchair accessible)  
Website: www.mglostomy.co.cc  
Contact: Karla MacTaggart on  
(02) 6592 9469

### NEWCASTLE DISTRICT

Meet at 1.30pm on last Saturday in Feb - May - Aug (AGM) - Nov.  
Venue: Hamilton Wesley Fellowship Hall,  
150 Beaumont St. Hamilton.  
Enquiries: Geoff 02 4981 1799 or Eleanor (02) 4997 5141 or Maree (02) 4971 4351

### ORANGE & DISTRICT

Meet: Mar - June - Sept - Dec  
From 12 noon.  
Venue: 15 Oliver St, Orange. NSW  
Contacts: Louise: (02) 6330 5676 and Joanne: (02) 6362 6184

### SHOALHAVEN

Meet: 2.00pm on 2 Feb - 11 May -17 Aug - 16 Nov  
Venue: Nowra Community Health Centre, 5 -7 Lawrence Ave, Nowra.  
Contact: Margaret or Tracey on  
(02) 4424 6300

### SYDNEY - LIVERPOOL / CAMPBELLTOWN AREA

Meets Thursdays from 1.00pm to 3.00pm in the Heritage Auditorium at Camden Hospital (Menangle Road, Camden).  
2015 meeting dates to be advised.  
For further information, please contact: Diane or Lu (STNs) on  
(02) 8738 4308

### SYDNEY - PENRITH AREA

Meets: 27 Feb - 24 Apr - 26 Jun - 8 Sep - 6 Nov commencing 2.00pm.  
Venue: Learning and Development Centre at Nepean Hospital, located behind the multistorey car park in Somerset Street. Entrance via the rear side door.  
Enquiries: Naomi Houston (Stomal Therapist) (02) 4734 1245

### SYDNEY - SOUTH-WEST AREA

Meet: Saturdays 3pm-5pm on 2 May - 22 Aug in the Macarthur Room and 6:00pm on 21 Nov in the club's Bistro Restaurant for our Christmas Dinner.  
Venue: 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: San Cancer Support Centre  
(02) 9487 9061

### SYDNEY - ST. GEORGE / SOUTH EAST AREA

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

### TWEED

Meets: third Tuesday of March, June, September and December from 12 to 2pm.  
Venue: South Tweed Sports Club.  
Contact: Jane Bright on 0409 671 162

### WAGGA & DISTRICT

Meets: first Wednesday of each month from 10:00am to 11:00am.  
Venue: The Men's Shed, 11 Ashmont Ave, Wagga Wagga  
Enquiries: David (02) 6971 3346 or 0428 116 084  
Baz (02) 6922 4132

## VICTORIA

### BAIRNSDALE & DISTRICT

Available for people to talk to and for home visits in the local area.  
Contacts: Janine: 0418 854 562  
Derelle: 0448 458 997  
Email: bdosg@hotmail.com

### BENALLA / WANGARATTA

Meets 2.00pm on the third Monday of each second month.  
Venues: Wangaratta Masonic Centre, 99 Appin St. Wangaratta in Apr - Aug - Dec and Benalla Masonic Centre, Cnr Benalla St. & Walker St, Benalla in Feb - Jun - Oct.  
Contact: Rex Nankervis  
(03) 5762 2080  
Email: rexmar@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 Rd, 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

### MOUNT WAVERLEY

Our support/social group meets bi-monthly on the fourth Wednesday; alternately at Mount Waverley Youth Centre or at a local restaurant for a luncheon.  
Contact: Ron Butler on 0403 163 327 or crocrite@gmail.com

## 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

## SOUTH GIPPSLAND

Socials held on the first Tuesday of each month at 2:00 pm. Please contact Thea on (03) 5655 2628 for more information.

## SUNRAYSIA / RIVERLAND

Venue: Sunraysia Cancer Centre  
Enquiries: Norma Murphy  
0409 252 545

## WARRNAMBOOL & DISTRICT

Meets at 7pm on the second Tuesday of the month in Feb - Apr - Jun - Aug - Oct - Dec.  
Venue: History Works (behind Mozart Hall) Gilles St (over Merri St) Warrnambool  
Contacts: Heather on (03) 5561 1159 or Terry on (03) 5562 5093

## WESTERN AUSTRALIA

### ALBANY

Meets in the Albany District Hospital Conference Room at 9.30 -11.00am on the 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

### PERTH (WAOA)

Venue: 19 Guildford Road, Mt Lawley  
Weekends: third Saturday of every month 11-1 pm.  
General: fourth Tuesday of every month 2-4pm.  
New Members: second Tuesday of every month 2-4pm.

## QUEENSLAND

### BEENLEIGH

Meets 10am - 12noon on last Monday of the month from Feb to Nov at Beenleigh Community Health Centre,  
10 -18 Mt. Warren Blvd. 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

## MACKAY

Meets at 2.00 pm on the fourth Friday of every odd-numbered month (Jan - Mar - May - Jul - Sep - Nov).  
Venue: Gordon White Library on Phillip Street, Mt Pleasant.  
Contact: Graham Stabler for further information on 0428 776 258 or email  
grahamstabler@bigpond.com

## 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 three months at various venues.  
Private and Confidential, C/- PO Box 703, Labrador, QLD 4215  
Phone: 0429 126 163  
Email: gcsong@live.com.au  
Facebook: www.facebook.com/goldcoastostomysupport

## 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) 5495 1335

## ROCKHAMPTON

Meet: 1.30pm third Saturday, Feb - May - Aug - Nov.  
Venue: Community Health Centre, Bolsover St. Rockhampton  
Contact: Frank & Marge Noy  
Phone: (07) 4921 0728

## 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 40 Buderim Pines Drive, Buderim on the third Monday of every month commencing at 10am.  
Enquiries:  
Winifred Preston (07) 5476 6313 or presto1849@hotmail.com  
Evon Fuller (07) 5447 7158 or eful@bigpond.com  
Laurie Grimwade (07) 54459008 or sid.and.laurie@gmail.com

## 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

"SEMI COLONS" – a support group for men and women impacted by

Colorectal cancer. Meets in Hobart on the third Thursday of every month, from 3.00 pm to 4.15 pm.  
Enquiries: Cynthia Taafe, Senior Officer Support Services, Cancer Council Tasmania on (03) 6212 5715

## NORTH & NORTH-WEST

**North:** Meets 10.00 am on the first Monday of Mar - Jun - Sep - Dec at the Cancer Support Centre, 69 Howick Street, Launceston.  
**North-West:** Meets 10.00 am on the second Monday of Mar - Jun - Sep - Dec at the Ulverstone Senior Citizens Club, 16 Edwards Street.  
Contact: Adrian Kok (03) 6326 4664

## SOUTH AUSTRALIA

### CENTRAL

Meet: Third Tuesday of Jan, March, May, July, Sept, Nov.  
When: 2pm.  
Where: Ileostomy Assoc Centre, 73 Roebuck St, Mile End.  
Information: Val: (08) 8381 1646

### FLEURIEU

2015 meeting dates to be advised.  
Meet: 10.00am until 12 noon at the Flinders Rural School, Bay Road, Victor Harbor.  
Please contact Sue McKay STN for further information on 0412 692 418

### 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

## NORTHERN TERRITORY

### DARWIN

Meet: 5.00-6.00pm on the first Tuesday of every month.  
Where: Cancer Council NT, 2/25 Vanderlin Drive, Wanguri NT 0810  
Contact: Marg Lavery: (08) 8944 1800

### YOUTH GROUP

Doris Steyer,  
Telephone: (02) 4296 5354

### YOUNG OSTOMATES UNITED (YOU)

Tel: Helen (03) 9796 6623  
Web: www.youinc.org.au  
Email: helshae@hotmail.com  
Facebook:  
Young Ostomates United

### BOWEL GROUP FOR KIDS INC

Tel: (02) 4659 6067 or 0431 857 188  
Email: enquiries@bgk.org.au  
Web: www.bgk.org.au

### PARENTERAL NUTRITION DOWN UNDER

Secretary on (02) 9987 1978  
Email: contactpndu@gmail.com  
Web: www.parenteral-nutrition-down-under.webs.com

## Stoma Appliance Scheme Product Suppliers



### AinsCorp

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



### Dansac

PO Box 575, Port Melbourne, Victoria 3207  
Phone: 1800 331 766  
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

PO Box 171, Moonee Ponds, Victoria 3039  
Freecall: 1800 819 274  
Email: info@omnigon.com.au  
Website: www.omnigon.com.au



### 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

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With its unique soft and flexible construction, the convex shape of the barrier gives a gentle push around the stoma to create an enhanced seal for greater security and comfort.

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NEW NovaLife Soft Convex with EasiView™  
viewing option



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