

YOU Inc Newsletter

August 2017

Hi all, I hope you are all looking forward to Spring, not too far away thank goodness, I'm well and truly over this cold weather, bring on the sunshine !!

This is just a short newsletter to bring you up to date with the AGM details. The Annual report and IT report are on our website for you to read and if you would like a copy of our Treasurer's report please ask !

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We had a lovely small gathering of my good self, Helen, Lilian, Anne, Dave, Steph, Ros and Carol at the AGM and although small it's always so nice to catch up. Unfortunately due to my really bad error of typing the wrong address on the newsletter, Jorge came along or tried to, however he couldn't find the Nurses Memorial Centre so my sincere apologies go out to you Jorge.

I'm not sure how I made that mistake after so many years ☺ but I hope you come along next time Jorge.

Discussions at the AGM were as follows:

- Lilian put forward a motion which was presented and passed, for all advertising from other groups to be placed on our website and not on the Facebook page. Contact Helen if you would like something put on our webpage.
- We are hoping to arrange a meeting with the STN's through the AASTN sometime in October to discuss how YOU Inc can assist in the rehabilitation of new ostomates / J pouch patients. We have had a good rapport with many STN's over the years however they change positions and we sometimes lose touch.
- We will be holding a meeting in February with a Gastro who specialises in IBD as our Guest Speaker discussing drugs, surgeries etc and also an STN to discuss skin problems and treatments. Included in this meeting we would like to hold a "panel discussion" titled the three S's, skin, sex and stomas - **This should be a great educational day, we will keep you posted.**
- Elections - Helen, Secretary, Lilian, Treasurer, Anne, committee member, Carol, committee member, and we are so grateful to have Dave, Ros and Steph now on our committee, so a big thank you guys ! The more the merrier ☺
- ACSA (Australian Council Of Stoma Associations) are holding their Annual Conference in Melbourne this year - YOU hope to have a display - details to be advised.
- YOU Inc have applied as we normally do, for a Govt Self Help Grant for 2018-2019

Keep this date free

Xmas break up is on the 2nd December 2017 - place to be advised

YOU Inc Contact details:

Website: www.youinc.org.au

Facebook: <https://www.facebook.com/.../Young-Ostomates-United>

We now have over 200 members on Facebook and are growing steadily so please join up and discuss your experiences or answer questions others may ask

Helen: (03) 9796 6623 (leave a message)

Email: helshae@hotmail.com (Helen)

Our Committee member's bios



Lilian Leonard:
Treasurer of YOU Inc.

Retired Stomal therapy Nurse, founder of YOU in 1989. Nursed at Cabrini for 15years, moved to PANCH in 1984, which became the Northern Hospital in 1997. Moved to East Gippsland in 1998 where I worked as Stomal Therapy, Breast & Continence Nurse. Post Grad Diploma in Human Relationships.

Awarded Advance Australia Award in 1993 for Outstanding Contribution in Community Service.

Helen:
Secretary for YOU Inc for a long time ☺

I joined YOU (Young Ostomates United) after I had had my Ileostomy for 9 years. At the time I had surgery, there were no ostomy support groups around and I hoped I could share my experience and show others life after stoma wasn't as daunting as some may think!

Being a part of YOU Inc for over 26 years has allowed me to have some wonderful experiences . i.e. representing Australia in Canada at a World Conference and again in Copenhagen (along with David Sutton) where they held a Youth Conference, as well as making some lifelong friends along the way.

I have been Secretary for more years than I care to count ☺ and I love being involved in the group and being part of our Facebook page ! I'm married to Tony and we have three children, Ryan 34, Shae 30 and Paige 24 (post surgery) and 3 gorgeous granddaughters.

Mike:
IT Consultant for YOU Inc.

YOU member since 2002. Ulcerative colitis commenced 1993, diagnosed 2000, j-pouch surgery 2002. A member of my family also has UC.

Anne:
Committee member

My story is that I was diagnosed with Crohn's disease in my teens, so life was challenging with this chronic illness. Despite treatment, resting bowel for an extended period and having a temporary Ileostomy I needed to make the huge decision in my very early 20's re having a permanent Ileostomy. It is now 30 years since I had the surgery, I have been part of the Y.O.U group since it was formed and made many special lifelong friends. I am married, have a teenage son and work in mental health.

In short my experience of chronic illness and having an Ileostomy at such a young age meant learning to adjust on a physical and psychological level, and finding my "new normal"- belonging to YOU Group has certainly had a profound impact in so many beneficial and positive ways.

Continued.....

Committee member

I was diagnosed with rectal cancer in 1981 resulting in a permanent colostomy that I have managed by irrigation ever since. I love the fact that social media helps us keep in touch with the Ostomy world. I have a son and grandson and worked full time up until my retirement in 2011. Love to travel and have done so many great trips and look forward to doing many more.

Committee member

I work in Early Learning after working in Medical Administration for many years. I was diagnosed with Ulcerative Colitis at the age of 20, medication worked for a couple of years until it all flared up and I had a total colectomy. I was extremely ill and it was advised to have the operation done in 3 stages. After healing for 12 months and getting well I then had the J Pouch constructed and then the Ileostomy closed. I have had my J Pouch for over 20 years. I have travelled extensively and I haven't had any problems regarding my health !

Ros:

Committee Member

I was diagnosed with Ulcerative Colitis in 1992 which couldn't be maintained with medication and so in 1994 I had a total colectomy with a J Pouch created over 3 surgeries in 6 months. During my research into bag vs. pouch I found the Y.O.U group. The Ostomy association above Bourke Street Mall gave me Anne's phone number. I met Anne, Lillian, Helen and Sue at their table in Bourke Street Mall during Ostomy Awareness week a little while later. I attended all the Y.O.U open days where we had panel discussions, talks from professionals and ostomy fashion shows. We had great fun and fellowship. Over the years I've talked to many people facing J Pouch surgery to give them my experience. In 2014 my diagnosis changed from Ulcerative Colitis to Crohn's Disease. I had a bit of trouble finding medication that my body can accept, which was disappointing given that I'd been medication free for 20 years. My J Pouch is ok as long as I don't need surgery. If I ever do I'll need to go back to an Ileostomy. I've reconnected with everyone after joining the Facebook page and going to the professional days and annual meetings. At the 2017 AGM I was elected as a general committee member. I hope I do Y.O.U all justice.

Committee member

My story is as follows. I was diagnosed with very severe crohns disease in January 1993 (aged 27) following 3 months of constant diarrhea, which doctors had initially put down to gastro. I tried all sorts of medication to control it over the next 2 years, however things only continued to worsen. In January 1995, I was given a temporary Ileostomy in the hope of giving the bowel "a rest". However by January 1996 it was discovered that not only was the large intestine damaged beyond repair, but scans showed the early stages of cancer. In March of 1996, my Ileostomy was made permanent with the removal of all my large bowel. Since then I have lived a fairly healthy and crohns free life with only the odd blockage to contend with (all ostomates can relate to this) I am now 50 years young, and since discovering Y.O.U through social media several years back, my knowledge and understanding of the ostomy world has grown immensely . The encouragement and support they have always shown is amazing :)