

YOU Inc. Education Seminar February 2018 The 3 S's – Skin, Stomas & Sex

Incorporating an Update on IBD by Dr Emily Wright, Gastroenterologist.

& a Panel chaired by Anne Epifanio

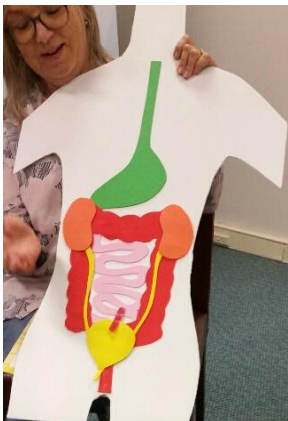
It was wonderful to welcome quite a few new members to this seminar including families from Western Victoria and Brisbane. Plus two stomal therapy nurses from the Goulburn Valley, Genevieve Cahir from the Northern Hospital plus Judy Wells from the Royal Children's. Sincere thanks to the 6 Trade Displays who prior to the Panel each presented one of their latest appliances. YOU really appreciates the support from the companies & vital for all Ostomates to view the newest or alternate appliances.

Unfortunately 3 members of the panel were unable to attend Andrew was sick (wretched Crohns) and Janelle with daughter Lilah did not attend but fortunately Ann, mother of 10 yr old Declan, substituted.

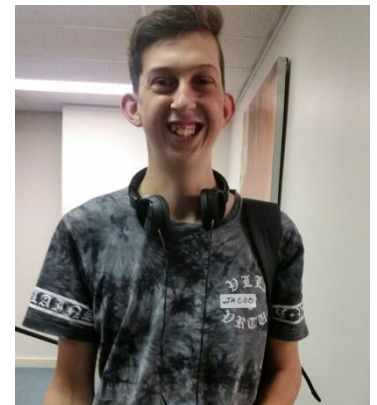
Panel Members

Judy Wells: Stoma Nurse RCH, **Amber:** Colostomy since she was a toddler, **Ros:** J Pouch and **Ann** mother of a child with a Mitranoff Stoma.

With her usual finesse **Anne** chaired this panel encouraging questions and interaction from the audience.



Judy Wells had a chart re Mitranoff stomas and both **Declan & Jacob** from Brisbane demonstrated their stomas.



A Mitranoff stoma is where the appendix is inserted into the bladder as a stoma, used particularly with young people with congenital abnormalities including spina bifida.

Declan had his formed when he was 4years old it has been a long journey for his parents but Declan now self catheterises his stoma approx every 4 hours even at school. Ann has been using a new catheter each time but Judy talked about the Cliny Catheters that can be used for 2 weeks, just sterilize in a Milton Solution.

The Panel also provided an opportunity for mothers/families to talk about their experience of supporting a young child and the range of emotions felt. Some of the parents reflected on their journey & how this can be isolating, being a carer/parent can be tough. There was discussion around education and support from schools & teachers. Judy Wells talked about her role supporting this by visiting schools & giving talks to children. Amber recalled her experience of this at school and how much she benefitted from this visit

Amber who is now a confident, attractive young lady cannot remember when she did not have a stoma. She is getting married in June, her fiancée is supportive of her colostomy. Unfortunately skin problems with numerous bleeding granulomas is Ambers main concern, she received many helpful tips from the audience. Amber also talked about her teenage years and that while she was used to living with a stoma she became aware of body image issues and the need to be more open by talking to her peers about her experiences.

Ros has had her J Pouch since the late 90's, sadly Ros was diagnosed with Crohns a few years ago, but treatment with one of the new IBD drugs has enabled Ros to keep her J Pouch intact. It was reassuring to hear that sexually having a J Pouch has not been a problem with leakage. Peri stomal and anal skin problems seem to be an ongoing problem, tips on preserving the anal area with various creams e.g. lanolin, Vaseline. A general feeling is that too many lotions and potions can be a hindrance on peri stomal skin.

Dietary tips were also discussed with the audience.

The panel discussion was a great way for members to relax discussing their stoma concerns & issues in a relaxed atmosphere.

THANK YOU to Anne & the panel members.

Summarized by Lilian Leonard/ Anna Epifanio