

"Who Cares For The Carers?" Report

... by Lilian Leonard

The audience might not have been large but the empathy and compassion was evident for the wonderful carers that graced the panel, which was ably chaired by Anne Epifanio.

Wilma, a foster mother of a baby who was born drug & alcohol addicted, that was in 1981, Jessica was diagnosed with N.I.D.S. (Neuronal Intestinal Dysplasia) & had a colostomy formed in 1996. Jess now a beautiful 20 yr old still lives with her foster parents.

Julie-Ann the mother of Robert, who was born with his bladder outside his body, resulting in a urinary stoma. That was nearly 30 yrs ago & now we see Rob as this lovely young man, coping with life & having a supportive partner.

Jenni who lives near Wagga, mother of two girls and young Jack who was diagnosed with Ulcerative Colitis when he was 3, resulting in an ileostomy. Now nearly 7 Jack still has many problems, living in a rural area makes it difficult for Jenni to access help.

Melinda who had twin boys in 2008, at birth Alexander had an imperforate anus, so had a temporary colostomy for 12 months & still has problems.

Vicki whose first child, Jake was born with only one-leg & bowel problems resulting in a permanent colostomy. Now 18 Jake is representing Australia in the Para Commonwealth Games in Delhi.

These brave carers spoke of their feelings of guilt, helplessness, fear of the unknown & gradually acceptance of their child's problems & their own coping skills. Other parents in the audience reiterated these feelings & emphasised how important it is to remember the siblings & partners, who often feel neglected.

Following the panel **Jenni** gave a very comprehensive report on what help & aides are available to children after stomal surgery, this Jenni has made available to those interested.

Following lunch **Jane** gave a brief outline of the Gutsy Group & their latest research on Inflammatory Bowel Disease. Jane an ostomate herself as a result of Crohn's Disease then spoke of her personal challenges with her 10yr old son having a stoma for Ulcerative Colitis

At the conclusion of the meeting everyone asked for a similar meeting at least annually. Judy Wells, Stomal Therapy Nurse from the Royal Children's Hospital offered to assist YOU Inc. Permission has been sought by the panel members to publish their stories on the YOU Inc Web site.

"Who Cares For The Carers?" was a Y.O.U. Inc Meeting held in conjunction with the ACSA Annual Conference on Saturday 2nd October 2010 at Rydges Hotel in Melbourne.