

## *Making Waves* Conference

### **Steve Sandilands and Jenny Rollo**

Great location, good food, good company, good speakers

Participation was invited from other disability groups, and it was a pleasure to have three families with children affected by Cri du Chat syndrome join with us for the occasion.

Comments and feedback were extremely positive.

Dr Meredith Wilson, Australia's SAC representative from Westmead Hospital spoke on the genetics involved with CdL and Cri du Chat syndromes, providing excellent explanations on the recent gene discoveries and demystifying many of the issues surrounding genetics for us.

Professor Chris Oliver led off his presentation in great style, humbly trying to refrain from talking about rugby or cricket, but Chris's expertise in both CdLS and Cri du Chat behaviours, and his advice and comparisons of the two disabilities was very enlightening.

Kate Strohm discussed sibling issues with parents and professionals, then held a workshop just for siblings. The excited noises coming from the workshop room were indicative of a lot of fun bonding amongst the sibs! Kate will also be a presenter at the international conference in Canada next year.

Sharon Burke gave an inspiring presentation about the formation of support networks for people with disabilities, using her son's network as the example. The next issue of KIT will provide more detail of family support networks.

Everyone was able to gain some information from all the speakers relevant to their own situations. Thanks to everyone who spoke and presented with such enthusiasm. Your effort and input was appreciated by all.

A conference photo album has been added to the Photos section of our OZNS site. Anyone can add photos to this album, so please do so. Even though the photo files are only accessible by our members, please use only given names.

### **From Rosemary Halling:**

What a lovely weekend on the Gold Coast. Saturday night at the Chinese Restaurant was nice to relax and have a good time - to catch up with some old friends and new ones - like the family with Baby Ella that sat at our table. She was just an angel all night!

The meetings were sometimes a bit of an overload of info but just to take in something relevant to your family and child was very helpful.

Sharon Bourke with 'Issues Families Face' gave us something to think about, including more people's involvement with Sean. Not just us and his respite lady and school etc, but to go that little further with family and friends to be more involved.

Kate Strohms' book on siblings can really bring some home truths that you may not be outwardly aware of - but gave us thoughts of how to do things in future as our son Alex gets older. We do know that he loves Sean dearly but there is some resentment from time to time which, yes, can happen with any other brothers or sisters, but does make you more aware!

What a great effort put in by all the organisers to make the weekend such a wonderful time for all families to take on some info as well as catch up with some old friends and meet new ones!

**A final word from Rose Humphrey:**

Everyone I spoke to commented on the easy camaraderie within the group even though most were strangers prior to meeting at the Gold Coast. Thank you to all who let me nurse their gorgeous children and especially Lyn and Sean who entrusted their children to my older daughters. For a while there I wasn't too sure how many kids I was actually taking home at the end of the weekend.

Thanks to sponsorship from the Aspley Lions Club and Dreamworld, 18 of us spent Sunday at Dreamworld. I didn't venture on anything wilder than the Blues Clues puppies, but my kids had a ball, especially on the rides that are guaranteed to test the strength of your stomach. I did discover my dream job however – I want to be the Pirate who narrates at the Sponge Bob Square Pants show.

Thanks to everyone who travelled to sunny Qld and made this conference a success.



Lynne and Sean with their sons Christian, Corey (CdLS) and Connor

More conference photos



Joshua (CdLS) and Bailey



Christos (CdLS) enjoyed copying everything Olivia did.



Ella's little feet never touched the floor. Everyone wanted a cuddle! Here Phyl has yet another turn.



Some of the Girl Guides who cared for our children, with Rose and Jen, right rear