

Breakaway Invited to the USA

"Breakaway have been invited to speak and present at the Smith Magenis Syndrome (SMS) Research Roundtable and the International SMS conference in Reston, Virginia on 16-20th September, 2009" stated Jodie Davis, Breakaway's Funding and Sponsorship Coordinator. Mrs Davis added "the invitation came from world leading researcher into SMS, Professor Ann Smith".

Smith Magenis Syndrome is a clinically recognizable chromosome micro-deletion syndrome. It is caused by a missing piece (deletion) of part of number 17 chromosome. There are only 40 known children in Australia with SMS and approximately 600 worldwide.

A specific pattern of physical developmental and behaviour characteristics have been found in individuals with SMS. These children are much loved by their families and are affectionate and loving when not plagued by outbursts. Common features include developmental delay, severe sleep disturbance, self-injurious behaviours – head banging, hand biting, picking at skin, pulling off finger and toe nails, inserting objects into ears, noses and other body orifices, prolonged tantrums and explosive outbursts, destructive and aggressive behaviour, speech and language delays, characteristic, yet subtle facial appearances, infant feeding problems & low muscle tone.

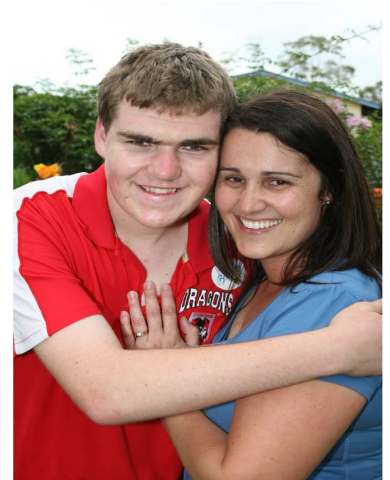
Mrs Davis added "What began 7 years ago as the plight and voice of a Central Coast Father of six, desperately seeking support and respite for his three year old daughter with Smith Magenis Syndrome (SMS), has now become a bi-annual respite camp at Breakaway with proposed plans to replicate Breakaway's SMS program in the USA."

Breakaway's Model of respite has and continues to enthuse, excite and motivate national health professionals and specifically Professor Ann Smith from The National Institute of Health in the USA. Professor Smith has been a significant part of Breakaway's three SMS respite camps (2003, 2006, 2008) holding research clinics along with her 'Team USA', and using the results to add to the world's knowledge about SMS.

These unique SMS respite camps encompass the whole family incorporating 3 specifically devised programs (parents, siblings and SMS children) that run simultaneously. Our Australian SMS camps are delivered and organised by a team of amazing, educated, professional and dedicated volunteers caring for an average of 16 families per camp.

Breakaway is a not-for-profit organisation, committed to enhancing the lives of children and adults with disabilities. The community and more than 280 dedicated volunteers ensure our commitment to supporting people with disabilities and enhancing their lives and those of their families.

SMS camp coordinators, Gae Miller, Jodie Davis and Michelle Price OAM, will leave for the USA on 14th September for the conference. Jodie stated "It is a great honour to be asked to participate at this conference regarding our unique SMS respite camps and is a wonderful credit to our dedicated volunteers. This trip is not possible without the generous support of the **East Gosford Lioness Club, HV McKay Trust, Allcare Nursing Services and Office of Rare Diseases Research at the National Institutes of Health (USA)**. While in the USA we will also be exploring the possibility of holding a collaborative SMS Respite Camp in the USA in 2011."



Jay who has SMS, with Jodie Davis



From left: Professor Ann Smith with Gae Miller



Michelle Price with SMS child Abby

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