



## 2008 Australian SMS Camp

## Testimonials from TEAM USA



Above (from left):  
**Mary Beall, Ann Smith and Gail Kopp**

### **Ann C.M. Smith**

M.A., D.Sc.(hon), NHGRI, NIH, Bethesda, MD

“I want to extend my grateful appreciation to the tremendously talented Camp Breakaway staff and volunteers for making the third SMS Camp another truly successful experience! Together we have forged a model partnership among the Australian families of children with Smith-Magenis syndrome (SMS), Team USA researchers from NIH, and the Camp Breakaway community. Camp Breakaway not only provides families and children with SMS with vitally needed support and respite, but it also offers them the opportunity to participate in the SMS Research Clinic conducted by researchers from National Institutes of Health (Team USA). Working in partnership with you, our research has led to several new insights and data about SMS that contribute to the knowledge about SMS across different ages in several critical areas. Without your time, effort, the availability of the beautiful CB facility, this critical research effort would not have been possible.

There are not enough words that express how wonderful they all for all the care, concern and LOVE they shared with all the Australian SMS families! It was a very moving 4-days and I returned on a high (plus a little sleep deprived “fog”) recalling all the great times shared! I am so grateful that Mary Beall and Gail Kopp were able to finally meet the great Camp Breakaway family that I have regaled them about before. I never doubted that they would find CB a very, very, special place... And now all three of us are jealous of what you have been able to make available to SMS families in Australia”.



Above (from left):  
**Jay, Frances and Ann**

### **Mary Beall, Texas**

(Mother of Laura,23, who has SMS, special educator and wife of Randy Beall, President of PRISMS)

“Wow! That’s the first thing that comes to my mind when I think about the SMS camp at Breakaway. It was fantastic. First, the facilities are beautiful, and beautifully maintained also. The food was amazing. Meticulous planning was obvious including the registration process ( including a bulletin board with everyone’s picture; awesome, detailed schedules, meals, sleeping arrangements, volunteer schedules, entertainment, and accommodating the team USA needs”.



Above (from left):  
**Joel and Mary**

"And then the volunteers....what can be said? They are the dearest, most compassionate people. As you know, the children with SMS are charming....but can be SO difficult ! It takes a lot of empathy and patience to spend a day with them,...but your volunteers spent multiple days and nights. As a parent of an SMS child, I know it can completely wear you out...but they were willing anyway. Tantrums did happen, but the volunteers did their best to stay calm and find a way to help the child . It would be so easy to blame the child or the parents, but the volunteers seemed to really understand the biological reasons for the tantrums. They were very curious and willing to learn. Because of the great activities and volunteers, the siblings also had a terrific time...and the kids with SMS got what they want most...one to one attention!"

**Gail Kopp - Wisconsin**

(mother of Elizabeth, 10 who has SMS, nurse)

"Camp Breakaway is an amazing place where parents can eat wonderful food that is otherwise prohibited, sleep uninterrupted nights, laugh at jokes, cry from losses, weep at the happy moments, look at the beautiful gardens and marvel at all the very special children and siblings. How wonderful it is to have each other, those someone's that understand sleepless nights, miscommunication and behaviors. I believe that during this special time that respite was provided; it has opened up a new dimension for professionals, caregivers and the public to be able to understand that sometimes the issues are so difficult to empathize or describe that only seeing and experiencing the situation is believing".



"I hope that my journey to Australia did not end on November 11<sup>th</sup> but will continue in the hopes of trying to replicate the wonderful experience I witnessed at Camp Breakaway in Australia, that it too might happen here in America. I have seen the dedication and Love Jodie Davis, staff and volunteers have put forth and it would be yet another obstacle for an SMS family to take on this daunting task. The concept for such a venture seemed to be an awesome task to attend too and with your guidance I dream that some day in the near future to have such an experience for the parents and their families of SMS, here in the United States".

Above (from left):  
**Gail and Layla**



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