

Leukodystrophy Camp at Bear Cottage



Ben Galbraith with his Mum, Faye, at the Leukodystrophy Camp. (Inset: Ben enjoys a tempting feast at the Camp's Bollywood night dinner)

Bear Cottage was built to provide specialist care and support for children with life limiting illnesses and their families – and, whilst that is achieved, families caring for their child 24 hours a day can still feel extremely isolated and alone. With that in mind, Bear Cottage recently looked at ways that families with children who have similar conditions can come together to share stories and experiences.

One way that was identified was to partner with organisations and support groups whose members are eligible to access Bear Cottage and host a camp for those families. And so, in association with the Australian Leukodystrophy Support Group (ALDS), the first Leukodystrophy camp was initiated.

Leukodystrophy is an inherited, progressive, degenerative disease of the nervous system and is estimated to affect one in every 20,000 people

worldwide. It occurs mostly in children and is usually diagnosed when a child starts to show signs of hearing or vision loss and a change in body tone, movement, gait, balance, speech, eating abilities, behaviour and memory or thought processes.

Five families were welcomed to Bear Cottage for the three-day camp, two of whom had never visited the Cottage before. They were encouraged to share ideas and coping strategies, and, most importantly, to 'recharge' their batteries.

As soon as the families had settled into their rooms, trained massage therapists arrived to assist with the relaxation process and each parent was treated to a tailored massage. Of course, the atmosphere was distinctly different in the playroom, where the Clown Doctors kept the kids amused.

A number of activities were

planned to enable the families to spend quality time together, free from the daily pressures of caring for a sick child. A professional photographer joined the group for an afternoon to take family photographs and portraits – such a simple activity, yet one that would provide everlasting memories. In addition, a family craft session was conducted, with everyone being encouraged to get involved in the production of a photo mobile.

A definite highlight of the camp had to be the Bollywood-themed dinner. Bear Cottage was transformed into an Indian Palace as families donned their saris and turbans while Tim, the chef, prepared a feast fit for any king.

"The Leukodystrophy camp allowed us a unique opportunity to meet and spend quality time with other families with kids with the same group of diseases – all in a relaxed environment. It was a fantastic experience for everyone," said Earl Shonberger, NSW Representative of ALDS.

This is just one of the many services and initiatives provided by Bear Cottage for families whose child has a life limiting illness. The facilities and services at Bear Cottage cost more than \$2 million each year, funded entirely by the community and our committed donors. If you would like to find out more about Bear Cottage, please call (02) 9976 8300 or visit www.bearcottage.chw.edu.au 🐾

