



**DeBRA** New Zealand

Dystrophic Epidermolysis Bullosa Research Association

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## **A brief report from the DEBRA NZ Family Camp, 25 – 29 April 2008**

The DEBRA NZ Family Camp was held in Christchurch a week ago and already the children are asking when will the next one be? We stayed at the Living Springs Camp and Conference Centre with beautiful views across farmland to Governors Bay and Lyttleton Harbour, near Christchurch. A group of about 50 people including ten families (with 2 from Australia), plus caregivers, 2 DEBRA NZ nurses, a trainee Paediatric Dermatologist and volunteer helpers enjoyed 5 relaxing and fun days together.



Activities were mainly aimed at the school-aged children with EB and their siblings, but provided plenty of entertainment for the adults as well. Everyone loved the farm visit with horse riding, sheep shearing, milking a cow and riding on the trailer behind a farm bike across the paddocks.





There were plenty of things to do at the camp including go-karting, trampolines, mini golf, making and flying kites, and a beautiful evening sitting around a camp fire and toasting marshmallows. The day in Christchurch with punting and paddling on the Avon was very relaxing (although a bit damp for some of the kayakers who took on a bit of water when they tried racing each other); making and dressing teddy bears was a lot of fun while others enjoyed creating bead necklaces.



The focus on DEBRA children and parents getting to know each other and having fun was a great success. There was a camaraderie amongst the children with EB and the siblings that removed the sense of isolation and helped the children with fragile skin to gain self confidence and try some of the activities they had never experienced before.





The DEBRA New Zealand Family Camp, Living Springs, Christchurch, April 2008

The Family Camp provided an opportunity for everyone to learn about how others cope with the daily challenges of living with EB and to share experiences and knowledge with other families and the medical professionals in a relaxed and accepting environment.

In the words of two of the families present:

*“We really enjoyed our time there, actually every minute. We just can't find words to express our thankfulness. May God bless all of you for your great efforts and time you spent to make this brilliant gathering successful and wonderful.”*

*“It was the most enjoyable holiday I think I have ever had with [my son]. Thanks to all of you for giving us the opportunity to be part of that.”*

Thank you to all who helped make it possible, particularly the Paul Newman's Own Foundation, Youthtown and the Sargood Bequest for their support.

And a huge thank you to those who volunteered their time and energy to make the camp such a success, particularly Sharon Cassidy, our Christchurch based EB nurse who put in many voluntary hours to plan and organise the Camp above and beyond her normal role as a part time DEBRA nurse; Holly Gilshnan for her input into the programme to make sure it was fun for the children; Dr Diana Purvis who gave up her weekend to be with us; Jacqui Finnigan our Auckland based DEBRA nurse who left her family to fend for themselves for 5 days; Sharon's and Holly's families and the other DEBRA friends who spent time with us and kindly provided the extra help with the children's activities to allow parents a break and time to talk.

We'll all be looking forward to the next DEBRA New Zealand Family Camp.

Best wishes,

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