

AN INTERNATIONAL "PROJECT OF HOPE" SUMMARY

127 persons from all states of Australia and New Zealand were involved and more so, gained much benefit from participating the 5th Family Batten Disease Conference at Seaworld Resort, Gold Coast, QLD over the weekend of the 10/10/10.

60 persons attended the two day conference component. The medicine and science addressed by our Guest Speakers was very encouraging for each family. The Scientists revealed to us their rigorous research and information efforts and was both touching and inspiring to see their dedication and ongoing support towards finding a cure of this dreadful disease. There was some hope in clinical trial treatments, which have just begun this year. Field specialists in areas such as neurology, genetics, music therapy, nutrition and disability education services educated families, carers and other teachers on daily care and support issues. Also knowledge was drawn from the experience of other families; this was invaluable to the complex care of these special children.

Whilst this the conference was taking place, affected children, their siblings, carers including volunteer carers participated in the Kids Program which totalled 67 persons. This group enjoyed time at off-site activities such as Seaworld fun park and Movieworld, then on-site activities with entertainers such as craft & games activities and a drumming attraction. Volunteer carers travelled interstate to offer their time and support, ensuring a fun and safe environment for their allocated children.

Many positive comments from parents and their children were received following this event and these words describe their views:

*"learning experience, well organised, lots of information shared,
making new friends, really fun, support felt"*

Not only is this event valuable to the attendees but to the speakers as they are given the opportunity to network with other speakers and to meet the children and families in a relaxed environment. They too learn more about the world of Batten Disease

It is important for us to thank each of you who helped us to have this opportunity to gather, learn and most of all to share the warmth and compassion that our special children bring out in everyone.

This 2010 BDSRA project become a reality. Please enjoy some of the memorable photos of this event.....

