

RETTNZ CONFERENCE 2014

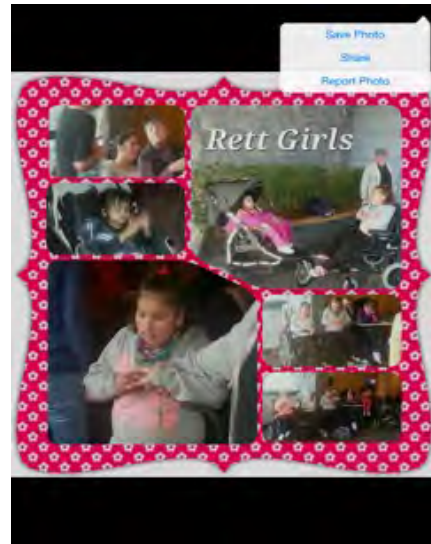
GETTING TOGETHER

We all looked forward to seeing each other and sharing our experiences.

This year we had four outstanding speakers who inspired and challenged us.

The Education seminar and Workshop enabled us to discuss age related challenges.

SUSAN NORWELL came back to Auckland to inspire us with her videos and stories of the girls with Rett Syndrome learning to read by eye gaze movements. Susan said that Rett is a motor problem not a cognitive problem. Parents were thrilled by their daughters' responses to the individual lessons they had with Susan. So many teachers and therapists joined the conference and like us found her work exciting. Susan is going to send PDF's for us to copy to use with the girls when they do not have a tobii or an ipad.



Joanne and Tony's collage of the girls



Susan with some of her fan club

A CLINICAL NETWORK FOR RETTNZ



Rosie Marks (centre) with Rett Chair Dugald MacBrayne and his wife Christine with Rob and Megan Pakes

Dr Rosie Marks spoke to us about the possibility of her leading a Rett Clinical network. This is an exciting outcome for Rett NZ and we look forward to hearing what Rosie would like us to do to assist her. Workshops were held to ask parents about what their priorities would be. There was an overwhelming vote that all age groups should be included in consultations as the girls often do not feel comfortable in an adult ward. Dugald will liaise with Rosie and keep us in touch. Rosie is attending the Rett Scientific conference in Washington at the end of June, 2104.

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We welcomed three new families.

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It was a great honour to listen to **Distinguished Professor Margaret Brimble** speak about her discovery of NNZ2566. Margaret is with Phil Creswell, President-elect of Rett Australia who attended our conference.



Prof Margaret Brimble was awarded the three most prestigious NZ Scientific awards two years ago. We have followed the social media on the trials of the drug she created. Some Rett women over the age of 18 years are taking part in a Clinical trial in Houston. We were fascinated by Margaret's story of the long journey it takes with complex research to discover these compounds. Although the chemistry was complex, Margaret explained her work in a way we could understand and follow her dream which we hope will make a difference to the lives of so many people. We do understand there are months of trials and approvals to be sought, however, our heartfelt thanks to Margaret for giving us the gift of hope. An interesting article is on http://nzic.org.nz/CiNZ/articles/CiNZ%20Jul%202011_brimble.pdf

RETT AMBASSADOR MR HAEMISH CRAWFORD



Rett parents were delighted to welcome our Rett Ambassador Mr Haemish Crawford. Ever since his first visit to us at the Rotorua Conference he has fought for more girls to have the scoliosis surgery at the right age to ensure the best results from the surgery.

Haemish asked us to bend our backs both ways and try to look up at him. Not only did we feel giddy, we also could not see him very well, so we began to understand how difficult it is for the girls to be comfortable and to breathe properly.

Haemish gave us all the pros and cons of surgery and said although it was such a big decision the benefits were very great to the girls.

Our thanks to Haemish for his kindness and that of his wonderful nurse Tina Rawlings at the Starship Clinic.

