

RETTNZ ANNUAL REPORT

For the year ended 31 March 2017

RettNZ is an informal association of parents of girls with Rett Syndrome and their families, supporters, teachers, therapists and medical advisers. We endeavour to support each other and learn from each other. The RettNZ Charitable Trust acts as a fundraiser to support our activities.

Conference 2016

The past year was an exciting one for RettNZ. The biennial Conference was a great success in Auckland in May 2016. Parents found much comfort in talking to others who are going through similar emotional challenges as well as having the very supportive medical advice through clinics or question time with two outstanding paediatricians.

Susan Norwell, our outstanding communications expert and advisor, came back again from the US to inspire us with help for the girls in reading and writing including training in the use of Tobi machines. Susan was very pleased with the progress many of the girls had made. The individual sessions were a great help as they were videoed, so they can be shared with Doctors, teachers, therapists and families.

Rett NZ was very grateful to the IHC Foundation for their generous grant to help with Susan's expenses, so that she could also give a special seminar to professionals such as teachers and speech therapists. We know a lot of parents would have loved to attend too ! It was wonderful to be able to include the speech therapists and teachers at a special session while many of the therapists also attended some of the plenary conference sessions where Susan was speaking.

One of our Ambassadors, Mr Haemish Crawford, orthopaedic surgeon, offered Rett families a wonderful opportunity for the future. He pointed out the difficulty in a small country of running an ongoing national clinical network but explained that this could be done on an occasional basis when we can gather together the families from across New Zealand and he would undertake to assemble a range of specialists to provide diagnosis and assessment of the variety of challenges encountered by Rett women and girls, from medical problems to treatment options to education issues to support arrangements.

Another highlight of the week, organised by Dr Rosemary Marks, was to have Susan speak at a nationwide teleconference session for paediatricians across New Zealand.

It is interesting to note that six new families contacted us to say they had a daughter with a diagnosis of Rett Syndrome. Although it is a diagnosis that one does not wish to have, to research it does take away a lot of the guilt when one's child is not meeting normal milestones. It also helps to give the right programme for the girls to understand and to be understood.

The Deane Endowment Trust gave a generous grant to help fund the parent's accommodation at the Novatel for the period of the conference and the one-on-one sessions.

Sad Departures

It is sad to report that three of our Rett Angels left us during the year.

Briar Rawhiti had the happiest time the week before and died peacefully on 27 April 2016. It was lovely that Marlene could join her friends at the Conference where we could talk about the sadness of leaving but knowing they were resting from their brave fight.

Then soon after Conference Gill Poulter wrote to say that Jessica who had just started her eye gazing after Gill being inspired by the conference had been having a lot of seizures and had given everyone a surprise by leaving us. We get so used to "bad days" we think the girls will always pull through but sadly on some occasions, they do not. Gill writes how hard it is when you have been so busy and devoted to have this gap in your life which was previously filled with unconditional love.

Then Robert van Rooyen wrote to say that Nikky had just finished watching her favourite video and went into a final sleep. Very many kind friends of Nikky gave generous donations to RettNZ which will be used to help fund our next conference. There was a lovely obituary in the Waikato Times which will be on our RettNZ website.

Welcoming New Families

A number of new families have contacted us. We think these contacts were stimulated in part by the paediatric teleconference talk given by Dr Marks and Susan Norwell when Susan was visiting NZ in May 2016. Sometimes Doctors say a session such as this makes them think about girls they have seen and not known which category they fit in to. We hope that more publicity for medical people and speech therapists will be generated by Susan's next visit to New Zealand for the "Caring and Sharing" RETT New Zealand Conference in May 2018.

The new families are mainly from the North Island and include their daughters:

Kendall King, Rotorua

Gemma Youngman, Taranaki

Josie Torr, Napier

Lotus Ngaturere Peckston, Lower Hutt

Olivia Latu, Whangarei

We have heard of a Philipino family in Auckland. Their speech therapist has been in contact however, the family are reserved about contacting us.

We are indebted to Susan Norwell for her pilgrimages to New Zealand to show us the potential of the girls with Rett Syndrome. For years everyone has commented on their bright eyes following conversations and social events.

Susan said the girls who have been In classrooms are better at spelling as they have seen the words on the blackboards and can point to them straight away. Our eyes have been opened to the full potential of the girls and their joy in showing they know how to make decisions.

Clinical Trials in USA

In March 2017 Neuren Pharmaceuticals announced that the Phase 2 Trial of Trofinetide demonstrated significant clinical benefit in paediatric Rett Syndrome. We are optimistic that the NZ designed drug will go through to Stage 3.

The formal Financial Report for the RettNZ Trust is being prepared. We are grateful to KPMG for their accounts and audit over so many years. My accountant has kindly offered to take over this role and help convert our annual accounts into the format required by the Charities Register.

The Trust wishes to maintain its term deposit intact if possible. Although it is a distant dream we would like to be able to participate in any suitable clinical trial if this were to be available in New Zealand. We would need funding for this if it comes to pass.

Our next Conference will be in May 2018.

Dugald MacBrayne
Chairman

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