

RETT NZ TRUST

ANNUAL REPORT 31 March 2017

We are pleased to welcome Wendy Brenkley as a Trustee of the RettNZ Trust. Wendy has extensive professional experience as well being a Mother and an advocate so we are delighted she has agreed to join us.

The highlight of the year was the Biennial Conference in Auckland in May 2016. The Trustees were grateful to Dr Rosemary Marks for agreeing to give individual consultations to families who wanted their daughter to be seen by her. Many parents miss the friendly comfort of a Paediatrician once their daughter is over eighteen years of age. It was interesting that a number of parents said they were satisfied with their family arrangements for medical help in their home town. The parents who did have consultations said they learnt a lot from Rosemary and it was a valuable time for them.

It was great to welcome back Susan Norwell from the United States and we can see the advantage of the regular contact Susan has had with the families and with the speech therapists. Rosemary and Susan have developed a close relationship. For Rett families it was great that Susan was able to be on a Paediatric Telephone Network conference with Rosemary to tell paediatricians about the strides being made with reading and writing for those with expressive aphasia.

Rosemary also used her links with speech therapists to hold a one-day seminar in Auckland which was very helpful to those who attended. The Trustees are most grateful to the IHC Foundation for their contribution towards these special events and for Susan to be able to spend time with each of the families who had requested appointments with her. It is wonderful how the girls have developed and how quickly they react to being back with her.

Families loved hearing Distinguished Prof Margaret Brimble with an update on her work and they had many questions for her. We were very pleased that the second Clinical Trial using her compound trofinetide was proceeding well that a third one was being planned. The Rett Syndrome programme has been given Fast Track designation by the FDA in the US and has Orphan Drug designation in both the US and European Union.

Haemish Crawford heard we were meeting and called in at lunch time to ask how the conference was progressing. He offered to help us organise a more comprehensive analysis of the girls with Retts by a variety of specialists so we are thinking of how it would be best to involve the special use of time of these specialists. The Q & A question and answer sessions are valuable because all parents and other conference participants can benefit from them.

KPMG have said they are no longer able to do our audit. We have been grateful to them for their help over so many years. Gillian has written to them to thank them for their kindness for doing the audit for so many years.

There have been five new families we know about through FaceBook, however, apart from Lotus's Mother Tammy and Lily's Mother Jessica we have no numbers to contact them. So FaceBook is a help in some ways but makes it difficult in other ways.

This is the most new families we have had for some years. I wonder if the Telepaediatric conference in May alerted Paediatricians to the Rett symptoms.

March 2017 Kendall King Rotorua

February 2017 Gemma Youngman Taranaki

November 2016 Josie Torr Napier

November 2016 Marcelline from the Philippines through her speech therapist

August 2016 Lotus Ngaturere Peckston.

Angel Status

We learnt about the passing of:

Rebecca Marks aged 43 years at New Year

Jessica Poulter July 2016

Nikky van Rooyen August 2015

Generous donations were made by family and friends of the von Rooyen Family.

Nikki's brother Jonathan is organising a fundraiser with his car club at Easter in Cambridge so Nikky lives on in the hearts and minds of those who loved her.

Financials

Doug Laing kindly prepared the accounts for the year to 31 March 2017 so they are now on the Charities Register website.

We are grateful to the IHC Foundation, the Deane Endowment Trust and the Friends of Nikki von Rooyen for their generous donations to the RettNZ Charitable Trust.

The Report to the IHC Foundation on the success of the Rett Conference is attached to this report.

Trustees of the Rett NZ Trust:

Dugald MacBrayne (Chairman)

Wendy Brenkley

Mark Campbell

Doug Laing (Treasurer)

Gillian Deane