

RETTNZ ANNUAL REPORT 31 March,2018

The year between conference is always much quieter. The second half of it consists of writing budgets and organising speakers for the conference. By having the Conference at the Ibis Ellerslie, every two years we have an excellent relationship with the hotel who treat our families very well.

We are very grateful to families who have helped fundraise for the Conference. The IHC Foundation have supported bringing Susan Norwell to NZ to help to educate Doctors, Teachers and Parents.

Family and friends of Nikky van Rooyen and the Hooligans Car club gave generously in memory of Nikky to help with the conference.

Prof and Mrs John Weaver, Mrs Lyn O'Connor and the ANZ helped support families attending the conference. The ANZ Bank kindly helped with our funding.

Melah's family and friends fundraised to provide funds for the Conference. Bruce Grant our diligent webmaster is designing a new format so we can add people but keep a record of those who have been kind to us in the past. We thank Bruce for his generous sponsorship and help with the website.

In October 2017 we had news that the FDA had confirmed Phase 3 plan for the trial of Trofinetide.

The Facebook group page allows families to keep in touch and to help each other as problems emerge. There is usually one other family who has had the same Rett problems that others are dealing with.

Wendy Brenkley had been busy organising material for the CARING AND SHARING part of the conference. We are grateful as there are so many avenues to find funding in each geographic area it is often hard to negotiate when one is tired and has so many day to day problems to solve.

Dugald had been busy organising Susan's schedule. We are grateful to Christine and Dugald for taking care of her from collecting her at the airport to making her feel part of the family at their home.

Doug Laing has been our Treasurer since our Trust was formed. We want to say thank you to him for the great work he did looking after our accounts and writing letters and receipts to those who gave RettNZ donations. We wish him all the best with the reconstruction surgery he is having this winter.

Mark has liaised with the Medical Practitioners who will speak to us at the Conference. Dr Rosemary Marks is also giving clinics on the Sunday afternoon.

Gillian has been liaising with families about their accommodation needs to attend the conference.

There have been six new girls diagnosed since Dr Rosemary Marks and Susan Norwell talked on the Telepaedatric Conference Call after the May Conference.