

RETTNZ ANNUAL REPORT 31.3.19

The highlight of the Year was the Rett conference SHARING AND CARING held in Auckland from 4 -6 May, 2018. Rosemary Marks and Mark had arranged a fantastic group of Medical Speakers. The Geneticist, Dr Nerine Gregersen on the random nature of Rett mutations and explained the low chance of reoccurrence of Rett was a great comfort to many parents.

After the talk Jennifer Leong said she had met a Tauranga parent with a son who had CDKL5 which her daughter has. Dugald took Susan down to meet the new Tauranga family later in the week. They were pleased to know about the eye pointing technology.

The session given by Dr Saman Moeed on Gynaecological needs showed the great problems the families have with a wide range of problems including endometriosis. Dr Rosemary Marks and Dr Sue Davis gave very helpful answers to the many questions we have from parents especially about dealing with epilepsy.

Susan Norwell inspired her pupils, their family and their teachers with her explanation of modelling techniques in learning to use eye gaze technology. It is exciting to see the look on the girls faces when they know that we know how much understanding they have. We had a good number of speech therapists who came to a special session.

Wendy Brenkley organised a wonderful afternoon of excellent advisors. Laurie Hilgreen who co-founded MY CARE gave an interesting commentary on the needs of carers. Rebecca Walton from Care Matters gave practical ideas to other families. One of our Mother's Marianne was able to give her personal experience of Care Matters. Marsha Marshall gave a lively address with ideas of how to access help. Technology is going to be able to help to find suitable employees.

Sincere thanks to Lisa and her amazing caregivers who looked after the girls and arranged paintings for lovely Mother's Day cards which brought tears to the eyes of the recipients.

ATTITUDE films filmed an excellent programme called My Perfect Family Rett Girls and it was viewed by a lot of families and friends.

Three RETT NZ Certificates of APPRECIATION have been awarded to special people who have helped Rett Syndrome this year.

Dr Rosemary Marks who has cared for the Auckland Girls with Rett and has been so generous in helping with our Conference Planning For her dedication to Rett Families.

Distinguished Prof Margaret Brimble for her brilliant scientific discoveries and her work for Rett Syndrome.

Mr Haemish Crawford was visited by Mark and Jean Campbell to present his certificate for his surgical skills and the brilliant confidence he gives to families undertaking the scoliosis surgery. Haemish has advocated for more operations to be performed at the right time so maximum benefit can be obtained for straighter spines.

Susan Norwell, who has travelled to NZ to educate our children, our families, our Doctors and Specialists and our teachers to show how her pupils do know and can comprehend and respond to language in spite of the apraxia which makes it so difficult to use these skills.

RettNZ was delighted that our Margaret Brimble received two significant honours this year, one being the first NZ Woman to be invited to become a member of the Royal Society in London and secondly to become a Dame Companion of the New Zealand Order of Merit. Margaret was recognised for her outstanding contribution to the development of Medicinal Drugs.

Margaret's drug Trofinetide is going into Stage 3 of Clinical trials in USA this summer.

The Trustees are busy planning the next conference to be held in Auckland on May 15-17, 2020

