

# The other mothers knew

Doctors told Denise Bray that her 18-month-old daughter was vomiting because she had a virus. But it was the mothers of other children with Williams syndrome who told her what was really going on.

Denise says it was the family's first time at a New Zealand Williams Syndrome Association family camp. "My daughter was 18 months. She was just on solids and she was vomiting all the time, and about three mothers said: 'She'll have celiac disease – get her tested'."

So Denise did get her tested and the doctors confirmed it. "They said she had severe allergies and she was probably allergic to several things, but she definitely had celiac disease."

No one understands what it's like to raise a child with an intellectual disability better than other families struggling with the same issues. Intellectual disabilities, such as Williams syndrome, aren't always well understood at the local medical centre and it's often other parents who can throw the lifebelt at the right time.

"Because it's quite a rare condition, the doctors in New Zealand often don't know much in terms of day-to-day support. You get it from other parents," Denise says. "Sometimes other parents can give you that invaluable advice as to what they have done."

The IHC Foundation makes it a priority to fund organisations that support families. Top of its list of five priorities for funding are projects that build family networks and support access to information.



Finn Wickham, Reagan Todd, and Lania Vaireka hang out at the playhouse at the New Zealand Williams

The Foundation has contributed funds towards the New Zealand Williams Syndrome Association's biennial conferences since 2012. The conferences alternate between the South Island and North Island to make it as easy as possible for families to attend. As many as 30 families come to the camps to participate in educational and support forums and to hear visiting experts provide updates on the latest research, treatment and support strategies. The Association has between 80 and 90 members.

"Conferences for parents and caregivers and people with disabilities can make a huge impact through the sharing of information, resources, strategies and experiences," says IHC Foundation Chair Paul Baines.

The New Zealand Williams Syndrome Association's most recent conference, in Rotorua last

year, featured Dr Melanie Porter, a senior clinical neuropsychologist at the Centre for Atypical Neurodevelopment at Macquarie University in Sydney. She is a specialist in Williams syndrome, Down syndrome and autism – and her research now includes New Zealanders as well.

The Association invited American developmental psychologist and author Dr Karen Levine to its conference in 2015. She camped on site and spoke to families about how to coach children out of the phobias and anxieties they often experience – how to deal with the noise of thunder or even the lawnmower.

Rett New Zealand is another parents' group that has benefited from IHC Foundation funding. Since 2012 the Foundation has contributed funds towards the Rett New Zealand Trust's biennial conferences, which

# what was really going on



Syndrome Association's camp in Rotorua last year.

regularly feature American Rett education specialist Susan Norwell along with local medical specialists. Rett syndrome is a neurodevelopmental disorder that almost exclusively affects girls and has a profound effect on their ability to communicate. Susan Norwell has introduced New Zealand families to eye-gaze technology that allows them to communicate with their eyes.

Rett New Zealand conferences offer individual consultations between families and local and international experts, lectures on genetics, discussion groups and practical sessions on caring for someone with Rett syndrome.

At this year's conference in Auckland in May, Susan Norwell will talk to parents and teachers about learning to read and write through eye-pointing and will hold individual lessons with girls and their families.

Rett New Zealand Trust Chair Dugald MacBrayne says some girls with Rett syndrome can speak, but most cannot. "The ultimate cruelty is that some speak and then lose the ability to do so. Susan Norwell is a specialist in communicating with non-verbal children." He says the eye-gaze technology has opened new horizons for the girls and their families.

Auckland paediatrician Dr Rosie Marks, who works at Starship Hospital's Developmental Paediatrics Service, will also be available for individual appointments during the conference.

Dugald says about 40 families attend the conference. Some bring their daughters, but not all the girls can travel. "It's a huge networking opportunity for parents. It also allows people from Southland, Northland, all over the country, to meet people with the same problems and who think the same way."

Dugald says it's costly for parents to travel to Auckland, but the Rett New Zealand conference itself is free, thanks to support from the IHC Foundation, the Deane Endowment Trust and other sponsors.

A third parent-led organisation receiving support from the IHC Foundation is Fragile X New Zealand. Since 2015 it has received three grants from the Foundation to run its 'No Longer Fragile' workshops in schools. The workshops – usually held five or six times a year nationwide – are run in schools where there are children affected by Fragile X syndrome. The workshops are delivered free and their aim is to build inclusive communities.

Fragile X Executive Director Andrea Lee says that despite Fragile X being the leading inherited cause of intellectual disability internationally, and easily diagnosed by a blood test, the genetic condition is not well known in New Zealand.

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Christine and Dugald MacBrayne make a point of taking their daughter Mandy everywhere with them. Mandy, 36, has Rett syndrome and Dugald says the condition is by its nature isolating because of the inability to communicate.

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Andrea says her 13-year-old son was diagnosed at the age of three. "It was life-changing for us because we suddenly had access to information that explained many things we had struggled to understand about Andre. And it made a big difference to know a little of how he might be experiencing the world, about his sensory sensitivities and high anxiety."

She says the condition has been widely studied and a lot is known about the neurobiology of the condition. "We understand what is happening in the brain and the impact that has on learning." This information is shared through one-hour workshops in pre-schools, primary schools and high schools.

"Instead of everyone having to research every time a child with Fragile X comes along, we go out to them and we individualise the information to the child, working together with the whanau and school community."

A request for a workshop usually comes from the family, and after preliminary discussions with the family an approach is made to the school. The aim is to build a partnership between the family and the school. "Hopefully, it supports and deepens the relationship the family already has with the school."

Andrea says it's about letting people see the world through the eyes of someone with Fragile X and saying, "These are the things that will help the child or young person to be successful in your community".

"One of our aims is to show people they are not dealing with children who are choosing to behave badly." Andrea says if a child is highly anxious they are unable to process what is being said. However, if the child can be supported to self-regulate then they can learn.

"What we are trying to say to people is when a child or an adult is in that state, that is compromising how they function. We are keen to send a positive message that people with Fragile X are really capable people, given the right support



Fragile X Executive Director Andrea Lee reading with her son Andre.

and opportunities to learn and develop skills."

There is a high demand for the 'No Longer Fragile' workshops, but they are limited by cost and by the availability of those who are trained to deliver them. Andrea says there are already four lined up for 2018 with people who were on waiting lists last year.

Her son, Andre, now in Year 7 at an inclusive mainstream school, has made big progress. "We have been able to share with the school how he learns – what we call the Fragile X learning style. For example, we know that he learns visually and simultaneously, not sequentially. It has changed the way he has been taught to read." She says students like Andre learn better if they can see the whole picture, rather than the learning being broken down into parts. "We know that visual applications work very well for helping students to learn to spell, for example, and he is very motivated by the use of technology."

IHC Foundation Chair Paul Baines says more parents are looking for support directly from parent-led groups that are focused on a particular syndrome or condition, where there is a strong community of interest and shared understanding of the challenges they face. IHC has always supported, and will continue to support, groups that can create effective support networks.

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