



Kristen Deane, only child

Roderick Deane of Telecom talks about family life and the bravery of his beloved daughter.

By Mary Holm

Dr Roderick Deane has just one more thing to attend to before he can sit down and talk. Tonight, as Telecom boss, he is to speak at a ceremony sealing the long-sought local service inter-connection deal with Clear Communications. He wants to make a few changes to his speech. Then he can talk about his daughter.

Kristen Deane died six months ago. For almost all of her 27 years, she lived with a rare illness that made her more and more handicapped. Yet, by all accounts, she was an enormously positive influence on everyone who knew her –

and especially on her parents, Gillian and Roderick.

Talking publicly about Kristen for the first time since her death, Deane says, "I would hate people to think I'm trying to parade my family life in public, or promote my interests in a way that is self-indulgent." On the other hand, "I'm always prepared to talk about anything that might help parents of youngsters with disabilities. My big theme in working with the IHC has always been inclusion." (Deane recently retired from 20 years with the IHC, the last six as president. He was "greatly chuffed" to be made an IHC life member recently.)

Kristen was born in March 1968. "She appeared to be normal for the first year or two, although she didn't walk until 18

Roderick and Gillian Deane with daughter Kristen: "We were thick as thieves."

months or two years – quite late," says Deane. "She was blonde, fair-skinned, blue-eyed, attractive, vibrant. She was very orderly, would take things out of cupboards and put them back in a tidy way.

"We were living in Sydney, and she was about two, when we noticed that she dropped an ice cream once or twice. It was so uncharacteristic of her. Then she would wake up crying in the night. And she had trouble with walking – she was slightly ungainly – and trouble going up steps."

The family returned to New Zealand. "From age two to five we took her to numerous specialists, most of whom were mystified ... They wondered about autism, hearing problems, balance problems. She appeared to be so bright, and smiled a lot. She captured the mood in a room. She spoke only the occasional word. Then, all of a sudden, she would come out with a full, comprehensive sentence, perfectly formed and in the right context – but only occasionally."

The Deanes couldn't get Kristen into the New Zealand education system. "There used to be a myth – free education for everyone. But her problems were so complex, nobody (including schools for

Kristen Deane: "She appeared to be so bright, and smiled a lot. She captured the mood in a room."

the intellectually handi-capped) was prepared to take her. I had terrible battles." He went to the top at the Education and Health Departments and the IHC. "There were all manner of excuses ... It was a combination of resources, costs and, I think, ultimately fear."

Later, when Deane was involved with the IHC, "I set off on one of my great campaigns [to get schooling for the children]. I obviously had high nuisance value." At one point, Sir Robert Muldoon threatened to withdraw funding from the IHC. Legislation entitling all handicapped students to schooling was finally passed in the late 1980s.

Meanwhile, when Kristen was about six, Deane went to work for the International Monetary Fund in Washington DC. Things were different there. Within two weeks of arriving, Kristen was accepted into three state-funded and three private schools. She went to one for a while. "The kids were wonderful. When the school bus came, all these hands would reach out for her and look after her." However, "she became too fragile and tottery on her feet" and had to pull out.

On the medical side, the American system was "formidable in its comprehensiveness and devotion to the tasks", says Deane. At one point, two dozen paediatric neurologists spent a whole afternoon with Kristen. They didn't know exactly what was wrong, but said that she had a degenerative neurological disorder. They told the Deanes there was a high chance that any future children would have the disorder or be a carrier. The couple had no more children.

It was not until Kristen was 15 or 16 that her illness was diagnosed. The Deanes received a letter from one of the US neurological paediatricians, who had heard a lecture about the recently discovered Rett Syndrome, and who felt sure that Kristen suffered from the syndrome, which affects only girls.

"We were having guests for lunch that day. We were so excited to know what it was, the guests turned up on the front door step and we didn't have any lunch ready ... It was incredibly reassuring to know what the problem was. In the early



stages in New Zealand, a number of medical people thought it could be our own behaviour."

Gillian set out on a hunt for other families. She felt they would share the relief of knowing. Symptoms of the incurable disorder – outlined in a brochure that features a young Kristen and is entitled "Lost Girls" – include unexplained hand wringing, body rocking and seizures. Victims often also have an engaging quality.

There are now about three dozen New Zealand girls diagnosed with Rett Syndrome. Almost all are cared for at home.

Kristen stopped talking when she was about five or six, and walking at about 13. Later she lost the ability to feed herself. It would take an hour to give her a meal, which had to be specially prepared. "She couldn't do anything for herself at the end."

Her seizures were intensive at times. In early 1981, she had more than a hundred a day. "The doctors thought that was the end. They had taken me down the hallway several times, and suggested we get ready for the worst, but then she would come round." At times she couldn't take her drugs, so they had to be given around the clock by eye-dropper. Sometimes she didn't eat for a month. "She was always extremely slender."

For as long as possible, the Deanes took Kristen out and about. She loved the outdoors. "It was so windy last night. I thought that the only person I knew who loved the wind was Kristen. I remember we were on the Cook Strait ferry one day when she was little. We were the only passengers on deck. I was holding her hand. She was laughing and enjoying herself so enormously. She was a wonderful traveller.

"We all went round the world several times. It was pretty nutty, really. The last

time, when she was 12, she was walking like a newborn foal, so half the time she was in a buggy. I think people thought we were rather strange. But the Italians were amazing. The fact that she couldn't speak didn't matter. They picked her up and held her hand."

Deane also recalls an elegant middle-aged woman in the US kneeling on the footpath to speak to Kristen. But public reactions varied. "It was interesting how resilient we became. In the early days, in some New Zealand restaurants, some people would comment about her wringing her hands, or making strange noises trying to articulate something."

At home, Kristen spent most of her time in the Deanes' lounge. When she was young, the Deanes might move her into a bedroom if they had important business visitors. "But we felt slightly uneasy about it. And we did it less as the years went by. Everyone had to accept that was the way it was."

Although Kristen's communication skills deteriorated, "she recognised people, and knew how to let us know when she wanted something". She had her favourite music and TV programmes, including soap operas and rugby. "She smiled a lot, and cried rarely. She had great resilience to pain." How much pain was she in? "We never quite knew."

"Kristen had a warm and loving feeling about her. Tom Scott had a house up near

Paekakariki, with lots of animals. We would visit him from our beach-house. He would pick her up and carry her around the farm for an hour, showing her all the animals. People like that she fell in love with. Often she was disconcertingly attentive and made direct eye contact. That's typical of people with Rett Syndrome."

Among Kristen's friends were the people who cared for her, in some cases for 15 years. They were paid for their work, "but it went miles beyond that. They would do

anything for her. Then there were youngsters around Kelburn, who would come after school, then work for us in their university years. It was like a big extended family, in a way."



Despite all the home help, Gillian spent a great deal of time with Kristen, says Deane. "And she couldn't go shopping without having somebody else in the house. It needed a degree of organisation ... She had a wonderful ability to have a dinner party and right before it she'd be feeding Kristen, who was on a go-slow because she was enjoying the dinner so much. It never fazed Gillian, at least not on the surface. She was so equable about it."

Deane, too, spent lots of time with his daughter. "I gave up sport at the weekend. But it wasn't self-denial, just a practicality. We'd go for long walks instead."

When Kristen was younger, Deane often did the night shift with her. "Her time clock was shot. Sometimes she was awake all night and slept during the day." At one stage, for a month, Deane was awake with his daughter most of the night. "I'm quite resilient. But I had some physical symptoms for a month or two afterwards, from the extreme stress and weariness."

For all the hard times, Deane says, "I wouldn't have had it any other way. That sounds odd. But there was such enormous pleasure from having her as part of the family. We did so many fun things together. We were thick as thieves. That was the way it was."

"Gillian and I are lucky that we had the dispositions to be able to accept that."

"Having a good job and a good income is helpful. But the first requirement is being able to handle it in terms of emotion. We just loved her and she was part of us, so be it. I don't think Kristen ever received a cross word in her life."

One thing Kristen taught her father was "how important today is, and to get on and enjoy it. And how unimpor-



tant ambition is. That sounds ironical. I've had the good fortune to have senior jobs [before Telecom, at Electricity Corp, the State Services Commission and the Reserve Bank]. But I

haven't applied for them. The jobs have typically been offered to me by people I've known."

Deane is gradually getting used to Kristen's not being there when he comes home. "Her room at the beach house, I hardly ever go and sit in it. And the lounge at home, we don't use it very much. It still feels strange. I suppose that's part of the grieving."

"The first three months were really hard for me. It gets you in strange ways. Gillian - she's got all this freedom now, but in a sense it's not freedom she wanted. It's still difficult, but she's getting used to being able to just walk out and meet a friend."

Deane says that he values his marriage above all else. Towards the end of Kristen's life, her parents felt confident enough to leave her in others' care while they took two-to-three-week breaks. "We had to live our own lives. But, if anything, Kristen brought Gillian and me closer together. We were a real team."

It was Kristen's birthday a few weeks ago. "Dozens and dozens of people turned up. They'd been coming to her birthday for so many years, and they rang and said could they call by. Gillian got a big ham, and we had 40 or 50 people at lunch."

When Kristen was five years old, the Deanes were told she would live only five years more at the most. "Several times subsequently we were told there wasn't far to go. She lived till 27!"

Deane is interrupted. There is someone here to see him. The biggest company in the country needs Kristen's Dad's attention again. ■