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HANNO FOURIE TRUST

I have been involved with Hanno's care over the last 4 years as his paediatrician and pulmonologist. Hanno was diagnosed in infancy with Spinal muscular atrophy Type 1. This means that he has profound muscle weakness of all his muscle groups as the messages that has to travel between his brain and spinal cord to his muscles are not being relayed by the anterior horn cell. As such he is unable to breathe or eat on his own. He requires 24/7 ventilation through a tracheostomy (small tube in his neck that is connected to his windpipe) with a ventilator. He feeds through a small tube in his stomach. Hanno is unable to sit or even turn by himself which means that he is 100% dependent on his carers for all his needs. Despite all of this Hanno is completely awake, alert and very bright. His cognition is completely normal. He has developed very good speech over the last 18 months and communicates very well.

In the past children with Hanno's condition did not survive past their second birthday as they succumbed to lung failure and malnutrition. In the last decade the life expectancy of these infants have increased dramatically with the advent of breathing support. Unfortunately the breathing support often meant that these children were hospitalized for the rest of their lives. Of course this had huge detrimental effects on the psychosocial development of the child as well as on the family dynamic.

Through programs and initiatives similar to Breatheasy (www.breatheasyprogramme.org) in Cape Town, these children are now transitioned to homes and fully cared for at home by their parents mostly. Parents are trained and empowered to take over the care of their child despite the fact that their care is very labor and time intensive.

Hanno has been cared for by his parents at home since October 2012. Living and developing at home with the support and care of your family is by far the best for the family and the child. Hanno has thrived at home over the last 3.5 years. He is surrounded by the most dedicated parents and loving sister as well as lots of other family members and friends. Hanno has developed beautifully with their guidance and the input of therapists. He has taught himself to speak well despite being on a ventilator. He loves music and interacting with other children.

His most recent hospital evaluation was performed on the 27th of January this year. It showed that Hanno was in excellent health despite his muscle condition. His ventilation settings were adjusted according to his needs and we performed a bronchoscopy (a flexible camera is passed through the mouth and down the throat into the big windpipe) that showed that his tracheostomy was working well and that there was no ling infections. An ultrasound of his heart confirmed that his heart muscle was working normally. All of these test results are very reassuring that Hanno is currently doing as well as we can hope for.

Unfortunately there is still no cure or treatment for Hanno’s condition but we remain hopeful.

Private health care funders are not supporting parents to cover the cost of monthly supplies or any nursing care support .Hence his parents are forced to raise all the funds themselves.

I urge you to support their endeavors to offer their child all the medical care and support in their own home. By supporting the Hanno Fourie trust you are not only just helping this one family, but by helping them they are also raising awareness of the special needs of children like Hanno and supporting other families who have similar challenges.

Kind regards

Dr Fiona Kritzinger