

Dealing with Rett Syndrome by Lloyd Robertson

Katie Lynn Baker weighed just 20 pounds when she died. The mother of this 10 year old British Columbia child told authorities that Katie had wanted to die. So she simply stopped feeding her disabled child. Cheryl Baker was never charged for her crime and advocates for the disabled do not appear to have noticed. A movie has just been filmed in Winnipeg that pictures the mother of nine sympathetically. Baker received little sympathy from parents of girls with Rett Syndrome at a conference on the disability held in Winnipeg this past April.

Scientists have identified the gene that mutates leading to the illness. That gene is carried on the X chromosome. Males who receive the mutated gene at conception are spontaneously aborted during pregnancy. Females, who inherit two sets of X chromosomes, have a better chance of surviving.

The RettS child develops normally until she is 6 to 18 months old. At that time purposeful muscle control is lost or fails to develop. Typically the child engages in continual hand ringing motions. Language fails to develop because the muscle control required for speaking is not present. Shakiness is evident in the torso, especially when the child is upset. About half of the girls are able to walk but their walk is unsteady, wide-based and stiff legged. The other half are confined to a wheelchair.

The girls can neither speak nor sign. Most parents report that the girls communicate intention with their eyes. Perhaps this is how Baker learned of her daughter's "desire" to die. But I am sceptical. While I believe that a child may communicate joy, unhappiness or pain in this way, the desire to die is a much more complicated process. It is more likely that Baker was projecting her own feelings on her daughter.

Rett Syndrome is not, by itself, painful. Rett girls often develop constipation and this can be painful. Nutritionists at the conference presented a variety of strategies, both natural and medical, for dealing with constipation in RettS girls.

The girls lose interest in toys at an early age. But they love being with other children and thrive in school settings. One special education teacher from the United States presented on a computer program and technique she has developed that allow these children to communicate and learn more effectively. By restraining the child's non-dominant hand the child can use her stronger hand to punch a computer pad. The specialist divides the computer pad into 2, 4 or 6 squares with each square giving a different response via a computer linked voice resonator. She asks the child questions and the child responds. It appears as tho the child's cognitive abilities may not be affected by the syndrome.

Katie Lynn was going to school at the time of her murder. Her wasting condition was reported to the province's Department of Social Services. We do not know why the social workers involved failed to protect her.

My contribution to this conference had to do with handling the stress that comes from raising a disabled child. We often increase our stress load by illogical thinking. For example, I met parents who seem intent on finding blame for their child's condition. If someone is to blame then the world feels more predictable. But the reality is that sometimes no one is to blame, sometimes genetic mutations just happen. The act of blaming; however, leads to a sense of powerlessness and "unfairness that, in turn, can lead to extreme actions.

Other parents become martyrs. Life has given them an incredible load and they will spend 24 hours a day dealing with that load. This is more than any human being can handle and remain healthy. Parents of disabled children need a balanced life and this includes ways of finding respite care for their daughters.

RettS girls are capable of loving and learning. They show pleasure in a variety of ways. Meaning can be found in developing healthy relationships with these children. They can enrich our lives.

Finally, part of the human spirit is built on hope. A geneticist at the conference reported on Canadian led breakthroughs that, in his estimation, will lead to a cure thru genetic manipulation. When that day comes, I wonder what these girls will tell us?