

The Hile Family

“A New Life”

“It’s worse than having a newborn baby for 16 years,” Wendy Hile explains.

Wendy’s sixteen-year old daughter Jenny has Wolf-Hirschhorn syndrome, a rare condition that causes problems including dwarfism, developmental delay, an inability to eat orally, heart problems, seizures and a sleep disorder.



“She’s still in diapers. She has the cognitive ability of a two year old. She’s dependant on a caregiver for ever aspect of her life. She can walk a bit, but she mostly uses a wheelchair. She eats through a tube. She’s also has a lot of anger, and is emotionally very challenging. It was like coming home to an abusive person everyday. And because of her sleep disorder, neither she nor her caregivers get much sleep,” says Wendy, on the phone from Victoria, B.C. “Don’t get me wrong—I love my Jenny, she’s such a joy. But she’s also incredibly exhausting to care for.”

Wendy, a positive, friendly, efficient sounding woman, is a single parent who also has another, older daughter. Jenny was living part time with Wendy, part time with her dad, and part time with her grandmother, while Wendy and Jenny’s father both worked full time. That set up wasn’t working for anybody.

“The stress of going back and forth was too much for her; Jenny just looked terrible,” says her mother. “So I said I would do it all, and I did take everything over. But there was no way I could keep it up. At one point I thought I would have to put her into foster care, which I didn’t want to do. But I didn’t see any other option.”

Then Wendy got a grant from Giving in Action’s Family Independence Fund to create a separate suite for a live-in caregiver. The difference, she says, has been nearly miraculous.

“Jenny now has a full-time nanny, Jessie, who lives with her downstairs. It has to be that way, because if Jenny sees me, she won’t go to anyone else,” Wendy notes. “It’s working really well. Jenny is flourishing; she loves her nanny. Jessie is there for her when Jenny comes home from school; Jessie prepares her all this completely organic food, so Jenny doesn’t have to eat all canned food anymore... Jessie is also a physiotherapist, so she can do Jenny’s exercises with her. Jenny has someone that can focus completely on her.”

“It’s been incredible for me too,” says Wendy. “Finally, I can get proper amounts of sleep. I can go for a swim after work, I don’t have to rush home. It’s been such a relief. It’s even made a big difference for my older daughter, Alyshait gave her the freedom to go on with her life instead of being there for me.”

“It’s like it’s given all of us a whole new life.”