

HEAR MY VOICE

Persons with Prader-Willi syndrome are often painfully aware of how their syndrome affects their lives. They are aware of their "differences" from peers, family and friends.

This distance between themselves and others, places them in a situation where they feel that no one understands or cares about their feelings, dreams, goals, struggles with food or what it takes for them to make it through a day.

The following is a letter written by a young man with Prader-Willi syndrome shortly before he died.

"We have feelings, dreams and personal thoughts. We have a heart, a soul, mind and spirit and we need you to understand us. Understanding and caring are two of the most important things you can do for us. In High School the students did not understand me either. I loved to learn. I went through so much pain and harassment at school because I wanted to learn so much. The hunger urges at school were difficult to control. It was hard to watch other students eat snacks. I tried to ignore the snacks the best I could but then I became agitated and started constantly trying to sneak food at school and at home. I didn't mean to be a sneak, but I could not help myself. The food desire was in control!

My father was a doctor and my mother was a nurse. If I was left alone I would eat every thing I could. I would think about food all the time, food is everywhere – on TV, at school, at home and in the junk mail. I would even hide food and sneak food that belonged to my brothers and sisters. I had no control. I could feel sharp teeth tearing at my stomach like piranhas -- and still do. I know that I need someone to keep the cupboards locked and I need someone to keep me active to control my weight. I want to have some fun in my life. I have the right to have the same CHOICES in life that you do.

If the government has money to fund crisis situations why can they not prevent situations from becoming a crisis. I need full support NOW before I get into a crisis situation. I want to live and I am sure that you want the same for your child."

John Hudson Symon Ontario, Canada