

IMAGINE...

What it would be like if you were born with Prader-Willi syndrome

By Teresa Kellerman of Tuscon, Arizona

Imagine that your desire to get food is so strong that you would do ANYTHING to get it, even crawl out of your bedroom window in the middle of the night to walk to the store several miles away.

Imagine that you are hungry all the time, and that you are on a diet, all the time, and that you can only eat about half as much as everybody else, not to lose weight, but just so you don't gain weight. Imagine that if you do gain weight, you will have to go on an even stricter diet, getting about as many calories in one day as there are in just one cheeseburger and fries. Boy, would you like to have a cheeseburger and fries! But that's not in your diet. You are told that your diet is very important, because if you gain weight you could get really sick and die, because your heart can't handle the burden of obesity.

Imagine that everybody in your group is going on a hike, and you want to go, but you know you will get tired easily, because your muscle tone is not really good, but you don't want to be left behind, so you go along, and it's really hard for you to keep up with everybody. And when you stop for lunch, the person next to you has a big sandwich with mayonnaise and cheese and roast beef and five cookies and potato chips, and the person sitting on the other side of you has three granola bars and trail mix with nuts and a candy bar. And you have two skinny slices of diet bread with mustard and a thin slice of ham, and a rice cake, and a teeny apple. You think that candy bar looks really good, and you watch that candy bar, because maybe it will get set down, and maybe you can get your hands on it, and maybe it would taste so good, and you can't think about anything else but that candy bar.

Imagine that you find a \$20 bill laying on the ground, and you pick it up and put it in your pocket and don't tell anybody, because maybe you can buy some candy bars with it some time when no one is looking. But you get found out and you are accused of stealing, and nobody believes that you just found it.

Imagine that when you see a little scab on your arm, you just have to scratch it, you can't help it, you just have to! And when it bleeds, you get in trouble. And you try really hard to leave it alone, but you can't! And sometimes it takes over a year for sores to heal.

Imagine that when you want something to eat you have to ASK, and then you usually get told NO or you get carrot sticks, and you can't eat what you want because there is a lock on the refrigerator and on the pantry, too. But you know if there were no locks, you would get more food, and gain weight and get sick. So you really don't mind if the food is locked up. At least you don't have to worry about getting food like you used to before there were locks, and you would wait until the middle of the night to get up and go get food without anyone knowing. You feel safe with the food locked up.

Imagine that there's something you like to do and you're really good at it, like working jigsaw puzzles. And you have one that is a THOUSAND pieces, and you've been working on it for days, and you want to put it together all by yourself, because it's YOUR puzzle and you know where all the

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pieces go, and then someone else puts pieces in for you, and you take it all apart to start over, and you get yelled at, and you are told you are STUBBORN, but it's YOUR puzzle, and you just want to work it yourself.

Imagine that you are going to the movies, and everybody else is getting popcorn and candy, but you can only have a diet pop, but you have to sit there and smell everybody else's popcorn and chocolate, and watch them eat, and hear them munch. You really wish you could have a giant tub of popcorn like that guy over there! And you see a piece of popcorn that someone dropped and you pick it up and someone tries to grab it from you but you are faster than they are and you eat it, and they get mad at you, but it was worth it because that one little piece tasted so good. Better than the air-popped stuff.

Imagine that you have a hard time expressing your feelings and you get mad easily, but only when things aren't fair. Only when someone breaks a promise. Only when you're not getting what you think you need or deserve. Imagine that when you can't say what you want to say you scream and hit. You wonder why you get in trouble for hollering when everybody else is hollering too! Or sometimes you just sit and REFUSE, and nobody can make you move. You know you feel better when you take your medicine, but you don't want to take your medicine. You don't know why, you just don't want to take it. When you refuse to take your medicine, you get in trouble. But when someone in charge forgets to give you your medicine and you lose control, then you are the one who gets in trouble.

Imagine that you have family and friends who understand you. Imagine that your teacher, your case manager, your care provider, your doctor, all understand PWS. They know you are different, but they know you are special, too. Imagine how lucky you would be!

Note: Teresa Kellerman is the mother of Karie, who has PWS.

Prader-Willi syndrome (PWS) is a birth defect first identified in 1956 by Swiss doctors A Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition which affects appetite, growth, metabolism, cognitive functioning, and behavior. The Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers. PWSA(USA) is supported solely by memberships and tax-deductible contributions.