

Introducing Your Baby

The following are tips from registered members of The Sturge-Weber Foundation.

This always depends. If it's someone who will be around my child a lot (like his preschool or Sunday School teachers, friends, etc.) I explain right away. If it's someone we will only see very occasionally (if ever again) I wait until they ask about it. I do make a point to explain if they show interest. I don't want my child to feel like his PWS is something to be ashamed of but I also want him to understand that it doesn't define who he is.

As well as I can remember casual acquaintances usually just stared at my little baby girl. Family members, friends, and church folks got an explanation of the little I knew about SWS at the time. Since finding the SWF in 1989, I am very open about SWS and try to educate everyone.

I find for the most part people are kind when they ask but others can be very insensitive. Once a woman at the grocery store told me that Child Protective Services should take my baby away from me because of the terrible sun burn on her face. I tried to explain to her but she just keep yelling at me so I told her to call, and I would wait right there for them

I get upset when people stare and don't ask. I have to get over that before my son gets old enough to notice. If people ask I tell them otherwise I usually don't bring it up.

Always smile and be friendly. I never hold back if someone is attentive, staring or asking. If just staring, I offer a friendly hi! I always tell them the medical name for the condition, then ask "Would you like to know about it?" "What would you like to know". Your answer can be based on their medical knowledge (I ask how technical I can get), but always put it in "Layman's terms"

- Birth defect
- rare
- blood vessel disorder in the head
- every child is different
- seizures, glaucoma, possible strokes, learning disabilities maybe

Most important is to be friendly, open and honest, and try to make sure that your child is a part of the conversation as well...If a question is asked that I know he can respond to, I throw it to him...I'll even, in a polite way, ask my son if he feels comfortable talking about it. That's great as a child gets older. I think it builds some self-worth. Imagine how I would feel if my parents were talking about me and I was there, and wasn't asked to participate? As the child gets older, I think it's important. Open and honest, and it's ok to share feelings...

I always found it was important how I answered people because my daughter was listening as she was growing up. I always smiled and said she was born like this. To children I made it simple, but always tried to be friendly. Eventually as my daughter grew a little older, she would

answer for herself with confidence. She saw that it was easy to smile and let people know it was alright to ask the questions.

I've had a few bad remarks. I've been at the grocery store and the clerk says "he's got paint all over his face". Like I'd bring my child shopping with paint all over his face. The worst though was at Subway the lady making our sandwiches said "Boy, I hope the other guy doesn't look worse than he does!" This was when my son was 1. If someone asks I explain but in situations like these I am so taken back that I just move on. I'm just glad he's not old enough to know what they are saying. It's funny because people I've gotten to know say that his face looks so much lighter than when they first met him and I think the lasers have lightened it some but mainly I think that once you get to know him, it becomes part of who he is and so it doesn't stick out to you like it did at first.

I also had a couple ignorant remarks one of which was when my daughter was 6 months old and she was in the hospital in the PICU because of a wave of long seizures early on. A cleaning woman looked into her crib and asked what happened to her face and when I replied that it was a port wine stain she asked if I drank (wine) while I was pregnant. I said no and she just looked at me like "Sure". Now I don't explain unless people ask and when they do I only go as far as to say it's a birthmark.

Although my daughter gets an occasional stare or, more rarely, a hurtful, ignorant comment, people are generally well-mannered about her PWS. Most people greet her with smiles and coos like any other baby and are rewarded with smiles and blown kisses from my sweet angel. I've always expected the worst when dealing with the public at large and have been truly surprised at how tolerant, caring and informed so many people are. The bad apples are apt to stick in our minds, but try to remember those who look beyond the physical differences and delight in the shining personalities of our children.

The only time I ever addressed his SWS immediately was when he started school, and then I walked into school SWS ready with all my literature and ready to answer what questions I could. For the most part when he was a baby before he had seizures no one but our close family and friends knew he had SWS.

I just judge by true interest.