

Long before our baby was born, we dreamt of his or her life and fantasized various futures.

None of these dreams included a rare genetic disorder called Prader-Willi syndrome (PWS).

The first hint that something is wrong with our precious baby, we experience a multitude of feelings:

- Confusion
- Shock
- Terror
- Fear
- Helplessness

When specialists are brought in, our fear and panic increase exponentially.

From the moment you first encounter a parent, you influence our feelings and attitude.

Where you tell us, **what** you tell us, and **how** you tell us about our child's diagnosis of Prader-Willi syndrome will remain with us the rest of our lives.

When you speak with parents about Prader-Willi syndrome you have the power to instill despair or inspire hope and empowerment.

Please strive to inspire hope.

When giving me the diagnosis:

Speak with me in person.

Don't deliver bad news on the phone.

Please pronounce the syndrome correctly: PRAH-der WILL-ee

Please use person-first language: "Your baby has PWS"; "People with PWS"; "People who have PWS"

I may be in shock when you tell me my baby has a serious medical disorder.

I may not remember details of what you tell me... unless they scare me and then I may never be able to let go of that image.

Schedule a follow-up meeting so that I may ask you questions I didn't think to ask during the first meeting or I don't remember you answering.

Give me *current* printed material from the **Prader-Willi California Foundation's** website www.pwcf.org and the national **Prader-Willi Syndrome Association (USA)'s** website www.pwsausa.org.

Encourage me to call PWCF 310-372-5053 and PWSA 800-926-4797 as soon as I can so that they may provide me with important, accurate information and ongoing support resources. Provide me with their numbers.

Use *current* information and research to answer my questions. PWCF and PWSA (USA) are good resources. If you don't absolutely *know* an answer to a question, don't guess.

Tell me about the genetics of my baby's disorder in words I can understand.

Don't talk at me or over my head.

Don't try to tell me *every* genetic fact about PWS, just the highlights.

Things that are helpful for me to know right away are:

PWS is a genetic disorder but generally not inherited. Tell me I can receive genetic testing if I consider having more children.

PWS is a spectrum disorder; not everyone has all of the symptoms, and symptoms vary from person to person.

This gives me hope.

Tell me that PWS is a part of the human condition and is most often a random genetic event.

Tell me there's nothing I or my spouse did or didn't do to cause our child to have PWS.

Tell me that because my child has an early diagnosis I will be able to address and reduce many of the typical symptoms.

This gives me hope and empowerment.

Tell me my baby is born in a New Generation of PWS where we know much more about symptom management.

Tell me I am fortunate to have an early diagnosis so that I may address my baby's symptoms early.

Inform me of the phase aspect of PWS: difficulty feeding, weaker muscle tone, metabolic problems, difficulty managing behavior, hyperphagia.

Tell me that the more informed I am about symptom management the healthier my child and my whole family will be.

Reassure me that supports are available.

Tell me there are medicines, therapies, and interventions that will help my child grow and develop into a healthy individual.

Tell me specifically about the benefits of growth hormone therapy.

Tell me there are parents who can mentor me, guide me, help me understand the things I need to know.

Tell me that PWS is one small piece of who my baby is, that he has many genes and is much more than just "PWS."

Tell me that there *are* people with PWS who are bright, tall, healthy weight, well behaved, happy, healthy, and productive.

Tell me there is a great deal of research being done in many symptom areas including the hyperphagia symptom.

Discourage me from surfing the net because the very difficult cases are generally highlighted there and don't necessarily reflect *my* baby's future.

Don't tell me, "God only gives us what we can handle" or "God chose me to be this child's parent because He knew I could handle it."

Right now I may be cursing God or questioning my ability to parent my child.

You need to know that as the parent of a child diagnosed at birth or shortly thereafter:

I need to feel like I have supports available

I need to feel hopeful about my child's future

I need to feel empowered so that I have the strength I need to persevere and advocate successfully for my child

I need to know I am not alone on this journey. Ever.