



Make the most of the conversation with your child's doctor if you suspect Bardet-Biedl syndrome

Your child's constant, hard-to-control hunger and weight gain from an early age could be signs of a rare condition

Bardet-Biedl (pronounced BAR-day BEED-el) syndrome, or BBS, is a rare genetic disease that has a wide range of symptoms. Some symptoms may include vision impairment, kidney problems, or learning disabilities.

There are also two key symptoms of BBS related to weight: obesity and constant, hard-to-control hunger.

Obesity due to BBS has a unique cause, which means that standard weight management methods may not work. That is why it's important to discuss symptoms with your child's doctor. They may help lead to a specific diagnosis, which is a positive first step to managing it.



Unlike general obesity, obesity due to BBS requires different management and treatment.

Use your voice

It's important to have an open and honest conversation with your child's doctor to receive a diagnosis sooner rather than later. The more you share about your child's medical history and daily life, the more their care team can help.



Talk to your child's doctor about whether genetic testing for BBS may be right for your child. Genetic testing may aid in diagnosis.



Tips to support a productive conversation



Prepare for your child's appointment by collecting their full medical history and documenting their symptoms.

Use the checklist below to summarize their symptoms

- ☐ Continuous weight gain that led to obesity at an early age
- ☐ Weight gain that doesn't respond to a calorie-restricted diet and regular exercise plan
- ☐ Constant, hard-to-control hunger
- ☐ Food-seeking behaviors such as hiding food, stealing food, or waking up at night to find food

Other seemingly unrelated symptoms, including:

- ☐ Vision loss or impairment
- ☐ Kidney problems
- ☐ Born with extra toes or fingers
- ☐ Developmental issues or learning disabilities
- ☐ Hormonal problems/delayed puberty

If you have your child's growth charts, you should bring them in to review with their doctor. Consider keeping a food diary for at least a week before your child's next appointment. This can help their doctor understand their eating patterns.



Ask questions to guide the conversation. Some suggestions are included on the next page.



Repeat the doctor's answers in your own words to make sure you are understanding them correctly.



Don't be afraid to be open with your child's doctor. You are your child's best advocate. The more information you share with their doctor, the better they will be able to help your child.



Act early: A BBS diagnosis is a positive first step to managing it.

Remember: Obesity due to BBS requires tailored management.



Questions to ask at your child's next appointment

Starting the conversation

- 1 Based on my child's symptoms and medical history, do you think they could have BBS?
- 2 Could it be another rare condition that causes obesity?

How to confirm BBS

- 1 Should we consider genetic testing for BBS?
- 2 When and where should my child be evaluated?
- 3 Would we need to go to a specialist?

If your child is diagnosed with BBS

- 1 What might we expect after a BBS diagnosis?
- 2 How should I expect to change how I manage my child's weight and hunger?
- 3 Are there treatments that can help with obesity due to BBS?
- 4 Are there other doctors that should be added to our care team to help manage obesity due to BBS?

To learn more about rare conditions that cause obesity, visit DifferentObesityBBS.com or scan the QR code to the right.

