



Print the full form and bring to your child's doctor's appointment.

Doctor's name/specialty _____

Date _____

Discussing peroxisomal biogenesis disorder- Zellweger spectrum disorder (ZSD) with your doctor

PBD-ZSD affects many parts of the body, so you will be visiting different specialists to get your child the best care possible. Use this form to organize your conversations with these doctors by highlighting the questions you plan to discuss based on your child's condition and the type of doctor you are seeing. Take notes and check off the questions as you go!

Background and expectations

- How might my child's symptoms change over time?
- What are the approved treatments for people with PBD-ZSD?
- How often should my child come in to see you?
- How rare is PBD-ZSD?
- Do you see any other patients with PBD-ZSD in your practice?

List other questions you may have for your doctor in the lines below.



Monitoring and managing PBD-ZSD

Recommendations for monitoring and managing PBD-ZSD were published in 2016 in the medical journal *Molecular Genetics and Metabolism*, and entitled *Peroxisome biogenesis disorders in the Zellweger spectrum: an overview of current diagnosis, clinical manifestations, and treatment guidelines*. Ask your doctor if he/she is familiar with the article and how these recommendations might apply to your child's condition.

Ask the following questions for each body system/function visualized below.

- When was the last time my child had his/her _____ checked?
- What were the results?
- Are there any changes in my child's _____ we should address?
- What should we do next? When should my child get his/her next evaluation for _____?



Nutrition and growth



Hearing



Vision



Neurology



Liver function



Kidney



Hormone imbalance (adrenal)



Bone abnormalities



Teeth



Control of movement

Monitoring and managing PBD-ZSD (cont'd)

- Which of the recommended tests has my child received (this year, and in previous years)?
- Are there any recommendations we haven't tried yet?
- I know routine liver function tests are recommended for people with PBD-ZSD; how would I go about getting my child's liver tested?
- What should I be monitoring at home day-to-day?
- Which specialists can you refer me to for monitoring other organ systems that may be affected by PBD-ZSD?
- What other resources can you refer me to?

List other questions you may have for your doctor in the lines below.



Don't miss a thing!

Caring for a child with PBD-ZSD involves tracking many different conditions of your child's health and seeing a team of different healthcare specialists. Use this guide and the published management recommendations to help organize your conversations with your child's doctors and clearly identify the next steps in getting your child the best care possible.

Make sure you check off these items before leaving your appointment.

- Schedule your next follow-up appointment.
- Get referrals to other specialists who should evaluate your child.
- Let your doctor know about the latest recommendations for monitoring and managing PBD-ZSD, available at www.understandingpbd-zsd.com.

