



Questions To Ask Your Child's Doctor After A Rare Disease Diagnosis

My child was diagnosed with a rare disease. What should I ask my child's doctor?

1. What treatments, including medication and therapy, are available for my child?
2. What is the evidence that the treatment will be successful for my child?
3. How will I know if the treatment is working or not?
4. How should we decide how often we need to see you?
5. What other specialists would be helpful for my child to see? Be prepared to bring up any concerns you have. Talk to the physicians, nurses, therapists, care managers on your child's team, about how to address and prioritize your concerns.
6. What is the best way to support communication between the different specialists my child sees?
7. What can I expect as my child gets older?