

Preparing for a genetic appointment

Questions to ask: What test can be done to genetically confirm the diagnosis? If the tests come back negative is there a more sensitive test that can be run? How long does it take for the test to be completed? Regarding protocol (AFP and ultrasound) are you going to handle the order and results or do we need to arrange with pediatrician or oncology? (If genetics handles results) When can we expect to hear from you with test results?

If we want to have more children what are our risks of having another child with BWS?
Will my BWS child be at a higher risk to carry the gene or have a BWS child of their own?
What is the long term plan of care? How often will you want to follow us?
Are there any resources you have or other families in the area we can connect with?
Additional notes: