

If your child has or might have a genetic disorder, you may be feeling upset, shocked, or just numb. Perhaps your consultant has already explained some of the features of the disorder to you, but perhaps you found it difficult to take in. The questions in this leaflet have been designed to assist you in getting as much information as possible from the meeting with your specialist. He/she can often provide this information, although limitations do exist and finding answers is not always possible.

If your specialist cannot answer any of your questions, ensure you are referred to someone who may know the answer.

HELPFUL HINTS

- ✓ Write down the questions you want to ask and what you want to achieve from the meeting before you go.
- ✓ You could take a tape recorder and ask if you could record the meeting
- ✓ Take a pen and paper with you to write down the answers
- ✓ Take a trusted friend, they will remember more and write down the answers for you
- ✓ Don't be afraid to ask what you really want to know

This leaflet has been jointly produced by:

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Please feel free to contact any of the above organisations direct for more information or further copies of this leaflet.

Does your child have a genetic disorder?



What do you need to know and from whom?

Here is a list of some of the questions, which may help you gain the understanding that you need.

The following may point you in the right direction when forming questions of your own.

- What is the diagnosis and what does it mean?
- How accurate is the diagnosis?
- What are the characteristics of this condition?
- What is the treatment for this condition?
- Will my child require medication?
- What other specialists will I need to see?
- Is there a cure for this condition?
- What are the long-term prospects for my child?
- What kind of help will my child need?
- What can I do to help my child?
- Was it something we did wrong?
- How is this condition passed from one generation to the next?
- Can a person not have this condition and still pass it on to his/her children?
- Will my other children or my siblings be affected?
- What tests are available to see if a person has or carries this condition?
- Are there any prenatal tests that can be done if I get pregnant again?
- How many people have the condition?
- What can I expect my child to achieve?
- What services is my child likely to need?
- Are there ways my child can be involved in the decisions concerning their life?
- Are there any benefits I can claim for my child?
- Is there a support group for this condition?
- Can my child or I contact other people who are also affected by this condition?