

My Questions

National Information Centre for Metabolic Diseases



Questions you may find helpful to ask

*For more information, support or
advice please contact the Family
Services team.*

Freephone: 0800 652 3181
Email: fam.svcs@climb.org.uk



**This information is available in larger print
and on tape or CD**

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Original

Supporting families, changing lives

Climb Building, 176 Nantwich Road, Crewe, Cheshire, CW2 6BG, UK

Freephone: 0800 652 3181

Climb is the only charity in the United Kingdom that provides support on all Metabolic Diseases with links worldwide

Email: info.svcs@climb.org.uk
Family Services: 0845 241 2172

Website: www.climb.org.uk
Development Services: 0845 241 2173
Facsimile: 0845 241 2174

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Patron: Her Grace The Duchess of Westminster. President: Phil Collins L.V.O.
Executive Director: Mr Steve Hannigan MIOD ACMI

Questions

You may find helpful to ask

Climb has compiled this list of questions to help you to make the most of your appointment with your specialist. You can take this list with you as a gentle reminder of the questions you may wish to ask and to point you in the right direction for making some questions of your own.

Tests

- What kind of tests will be taken?
- What are the tests for?
- When will I get the results?
- Who will give me the results?
- Will my child have to have further tests in the future?

Diagnosis

- What is the diagnosis and what does it mean?
- How accurate is the diagnosis?
- What tests are available to see if a person carries this condition?
- Are there any prenatal tests that can be done if I get pregnant again?
- What are the chances of having another child with this condition?

Inheritance

- How is the condition passed from one generation to the next?
- Can a person pass this condition on to his/her children even if they do not have the condition?
- Will my children or siblings be affected?
- Does this mean my children may be carriers?

Symptoms

- What are the symptoms of this condition?
- What can I expect my child to achieve in the short term and long term?
- What is the prognosis?
- Do you have any written information?

Treatment

- Is there a treatment for this condition?
- If there is a treatment, what is it?
- Will my child require medication?
- Will this be a life-long treatment?
- What other specialists will my child need to see?
- What kind of help will my child need?
- How will I know if the treatment is working?
- Are there any side-effects?
- Is there anything my child should avoid?
- What do I do if things do not improve or get worse?
- Who is my next appointment with and when is it?
- What can I do to help my child?
- What services is my child likely to need?

Support from Climb

Contact Climb to find out more about benefits that you can claim. Climb will help you to fill in any forms such as DLA forms. Climb can help you to find other families with the same condition and put you in touch. Climb offers a free helpline for information, advice and support for families and professionals.

A few hints and tips

Ask for copies of letters written about you.

Take a list of all of your child's current medications.

Put the dates of all of your tests in your diary.

Take notes throughout the appointment.

Take a family member or a friend with you. One of you may wish to make notes while the other listens.

Keep a diary of your child's progress including a list of symptoms.

Check that you have asked everything you need to.

Always...

Make sure you understand what your doctor has said. Do not be afraid to ask questions and clarify what you have been told.