



THERE'S NO REASON TO FACE IT ALONE

Questions you may have for your health care provider

We bring you this brochure as parents and individuals who have genetic conditions touching our lives. We prepared it with you in mind as you visit a health care provider.

Take a moment to look at the questions in this brochure. Carefully consider their importance and remember that not all apply to your situation. Many of us found that during our visits we were too overwhelmed to remember to ask all the pertinent questions. You may feel more prepared if you have a list of questions. There is a space for you to write down the answers.

Checklist of Key Questions Notes

What is the diagnosis? _____

Is there a cure for this condition? _____

How does an individual get this condition? _____

What tests are available to see if a person has or carries this condition? _____

Is there a prenatal test for this condition? _____

What diagnostic procedures are recommended and what are their risks? _____

How accurate is the diagnosis? _____

Where can I obtain a second opinion? _____

What are the characteristics of this condition? _____

What is the treatment for this condition? _____

What specialists will I need to see? _____

How do you care for a person with this condition? _____

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 or her children? _____

Will my other children or siblings be affected? _____

How will this diagnosis affect my health insurance? _____

What are the medical costs likely to be? _____

When might it be appropriate to see you again? _____

Is there financial assistance for those who have this condition? _____

Where can I get additional information about this condition? _____

What organizations or support groups are available (local, state, national)? _____

What number of cases have you handled with this disorder? _____

Is research being done on this condition? _____

Your other questions

For additional information
may we suggest:



Pacific Northwest
Regional Genetics Group

<http://www.pacnorgg.org/publications.htm>

This brochure has been
produced by the
PacNoRGG Consumer
committee, and was



adapted from a brochure developed by the Pacific
Southwest Regional Genetics Network Consumer
committee (PSRGN). Supported by Project MCJ-
421002-13 from the Maternal and Child Health
Bureau Health Resources and Services
Administration, Department of Health and
Human Services. Reviewed 2007