



GENETIC TESTING

A Fact Sheet

When you are considering genetic testing for yourself or your child there are many things to think about. Some things to consider are similar to other medical tests. Others are specific to genetic testing. Thinking about these issues will help you decide whether you or your child should have a genetic test.

The choice to have genetic testing is a personal one. Here are some issues to consider.

A genetic test CAN:

- determine the presence of an altered gene
- identify an increased risk of developing a particular disease
- influence plans to have children
- help with life planning
- provide reassurance
- be relevant to other family members
- reveal unexpected information about other genetic disorders
- establish a diagnosis in symptomatic individuals
- have uncertain results in some cases

Genetic testing is not always 100% accurate.

Even when a genetic test tells whether or not a person has the gene for a particular disorder, the test might or might NOT tell:

- whether symptoms of the genetic disease will actually appear
- when the symptoms of a disorder will begin
- which symptoms will occur first
- how severe the condition will be
- how the condition will progress over time
- the amount of disability you or your child will have

Speaking with a genetic counselor can help you think through all these issues:

- What treatments are available for the genetic disorder?
- What impact would the test results have on your relationships with spouse, family, children and friends? (For some people, family relationships improve after genetic testing. For others they become more difficult.)
- Will genetic testing cause fears of having “good” or “bad” genes or cause others to think less of me?
- Results of a genetic test can give unexpected information. One possibility is disclosing non-paternity (that your father is not your biological father).
- Who will provide emotional support to you through the process?
- What are ways you might cope with an increased or decreased genetic risk?
- What will your reaction be if your test results are uncertain?
- What are your plans/hopes for having children?
- What are your career interests, and how might the testing affect these choices?
- What is the cost of the test, and who will pay?
- Do you want your insurance company to know the results?
- With whom do you want to share your results?
- Will the results become part of your medical record?
- Would you like to be tested at this time, or would postponing be better?

There are unresolved social and legal controversies about genetic testing that are worth knowing about:

- Should children be tested for a condition that only affects adults?
- Who will have access to the results?
- Do other family members have a right to know your test results?
- Will your results affect your ability to acquire or maintain insurance coverage?
(Note: some states have passed legislation to protect those who seek genetic testing. Ask your genetic provider about the laws in your state.)
- Could an employer refuse to hire you or take away your job because of genetic testing results?

It is important to be aware of resources for emotional support throughout the process of testing and receiving results, as well as for long term emotional support. Your health care provider can help you determine what resources are available in your area.

You can obtain additional information from your genetics clinic. To find the nearest clinic look on the website:

<http://www.genereviews.org>

or call:

Alaska: 907/269-3430

Idaho: 208/334-2235 x258

Oregon: 971/673-0272

Washington: 253/395-6743

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This pamphlet is available from the PacNoRGG website: <http://www.pacnorgg.org/publications.htm>

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