What if only one parent is a carrier?

If only one parent is a carrier for a condition and the other is not, there is no chance of having a child with that condition. There is a 50% chance of having a child who is a carrier, like the parent. Both you and your spouse have to be carriers for the same genetic condition to have a child with that condition.

Could I be a carrier?

Yes. Approximately 70% of all Hutterites are carriers for at least one of these 14 conditions. You could be a carrier even if no one in your family has any of these conditions.

How is carrier testing done?

Carrier status can be determined by testing DNA collected from your blood or saliva.

Can these conditions be prevented?

Because they are genetic, there is nothing you can do to prevent these conditions. There are also no cures, but some of these conditions have effective medicines and other treatments.

How can I be tested?

Carrier testing is available for many genetic diseases in the Hutterites and we can provide more information on this if you are interested.

Questions? Please contact:

Genetic Conditions in the Hutterite Population

A question and answer guide

Worldwide, many populations are at risk for certain genetic conditions. This brochure provides information on some of the genetic conditions found in the Hutterite population.

Genetic Conditions in the Hutterite Population

What are the conditions?

Listed below are fourteen of the genetic conditions that have been identified in the South Dakota Hutterites. They are listed in order of highest to lowest carrier frequency (shown in parentheses).

- Limb girdle muscular dystrophy 2H (1 in 6): Adult onset, slowly progressive muscle disease causing weakness; many affected individuals have no symptoms.
- Oculocutaneous albinism type 1 (1 in 7): Lack of pigmentation (color) of the hair, skin, and eyes.
- Spinal muscular atrophy type 3 (1 in 8): Childhood onset, progressive muscle weakness eventually leading to loss of ability to walk.
- Limb girdle muscular dystrophy 2I (1 in 9): Adult onset, progressive muscular condition more severe than type 2H; can lead to heart disease.
- Cystic fibrosis (1 in 10): Breathing (lung) and digestive/growth problems. Treatment is available to help lung and growth issues.
- Arrhythmogenic right ventricular cardiomyopathy (ARVC) (1 in 10): Progressive disease of the heart muscle; can lead to abnormal heart rhythms and heart failure. May be treated by medication or by implanting a defibrillator.
- Sitosterolemia (1 in 12): Inability to digest plant fats; can lead to early heart disease and high cholesterol. Treated by specific diet changes and medication.
- Joubert syndrome (1 in 13): Developmental delay, intellectual impairment, and kidney, eye, liver or other medical issues.
- TECR syndrome (1 in 14): Intellectual impairment without birth defects or other medical issues.
- Restrictive dermopathy (1 in 16): Severe skin disorder that usually causes a baby to be stillborn or die during infancy.
- Nonsyndromic deafness (1 in 28): Deafness at birth without other birth defects or medical issues. Treated with hearing aids.
- Dilated cardiomyopathy with ataxia (1 in 35): Childhood heart disease usually resulting in early death; associated with developmental delay, intellectual impairment, and other medical problems.
- Bardet-Biedl syndrome (1 in 36): Blindness and obesity beginning in childhood, specific learning difficulties, and sometimes kidney or other medical problems.
- Usher syndrome type 1F (1 in 40): Deafness at birth and vision problems that develop in childhood. Treated with hearing aids.

What causes these conditions?

All genetic conditions are caused by changes in our genes. Genes are the inherited instructions that guide the growth, development, and function of our bodies. Everyone has two copies of most genes.

Each of these conditions is associated with a different gene. Individuals with these conditions have genetic changes in both copies of the gene associated with that specific condition.

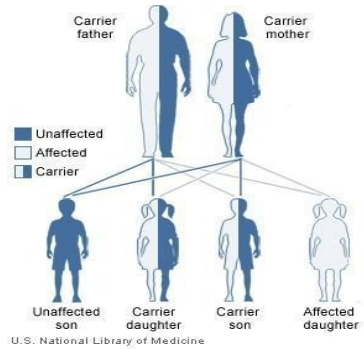
I am healthy; why is this important?

It is possible that you are a carrier for at least one of these conditions. *Carriers* for these conditions have a change in only one copy of their gene. Because their other gene is unchanged, carriers are healthy and typically have no signs of the disease.

Carriers for any of the fourteen conditions are at risk of having children who are affected if their spouse is also a carrier for the same condition.

What if my spouse and I are both carriers?

If both you and your spouse are carriers for the same condition, then each of your children (or future children) has a 1 in 4 (25%) chance of inheriting the gene change from both parents and having the condition.



In this figure, the parents are both carriers, each having one copy of a gene change. The figure shows how there is a 1 in 4 (25%) chance of having a child (either a boy or a girl) with the condition, and a 3 in 4 (75%) chance of having an unaffected child (although they may carry one copy of the gene change like their parents). These chances apply to each pregnancy, regardless of the health of your previous children.