



*"We've been waiting sixteen years for an answer," said Mark Kauffman, an Amish farmer with four profoundly handicapped children.*

The Old World Amish, an Anabaptist Christian domination in the United States and Canada, are known for their plain dress, avoidance of modern technology, and separation from the mainstream society.

A traditional agricultural religious group, the Old World Amish maintains isolation from the rest of the community. Financially well-off, they are homogeneous on education, occupation by gender, age at marriage, religion/ethnicity, and health care.

Although the Amish strongly discourage marriage between close cousins, the Lancaster Amish genealogy is described as mutational – inbreeding from multiple, remote connections rather than close consanguinity (first-cousin marriages).

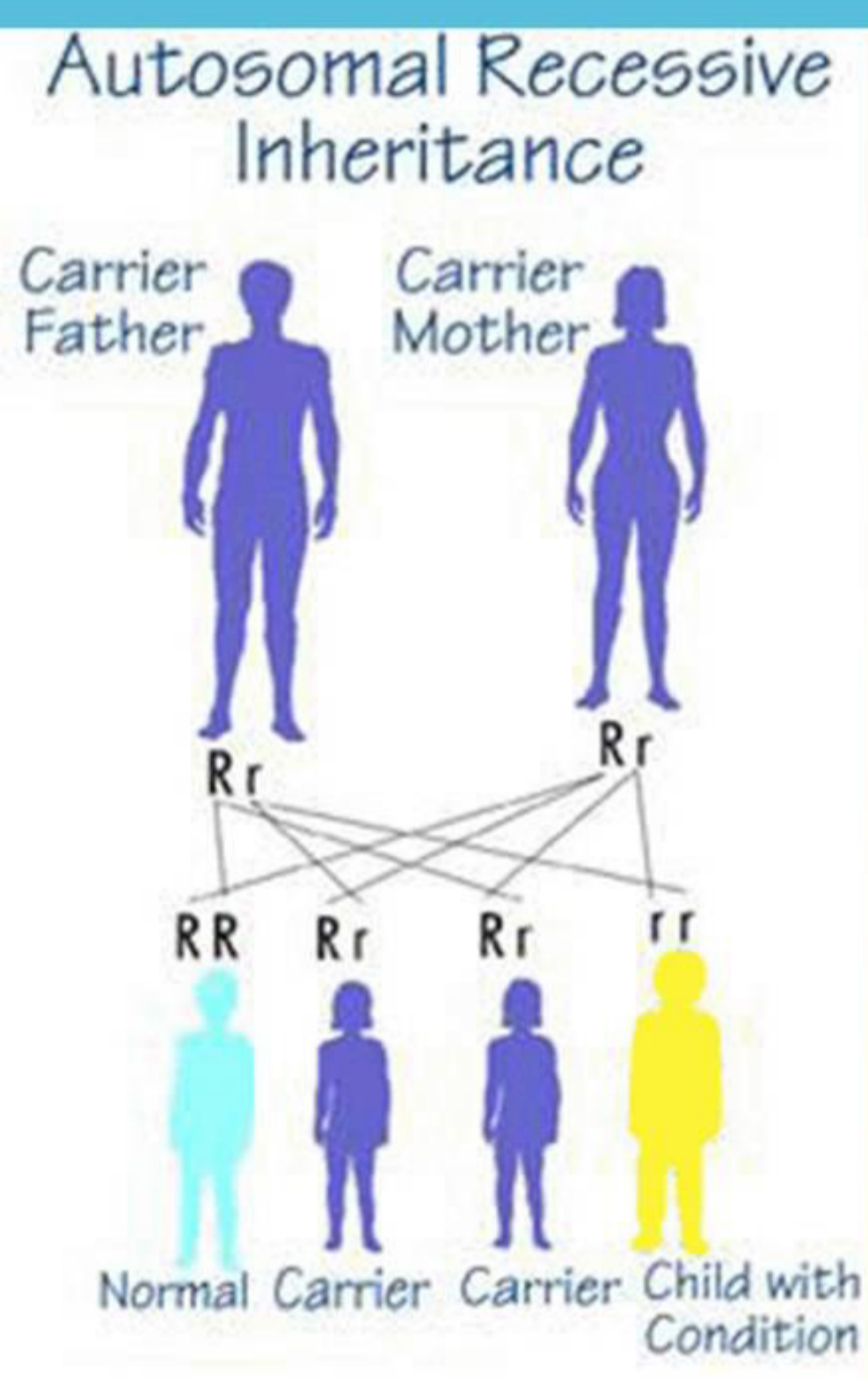
Amish settlements have been identified with certain genetically transmitted defects which connect with infant mortality.

*Romans 12:2: And be ye not conformed to this world, but be ye transformed by the renewing of your mind that ye may prove what is good, and acceptable, and perfect, will of God.*



Primarily a biological factor, inbreeding increases the likelihood of death in the neonatal and post neonatal periods of early childhood. Inbreeding is the mating of people who share a common ancestor. Most genetic disorders are the product of genes that are recessive.

Recessive genetic diseases are the typically increased by inbreeding. Close relatives may have the same mutation and are genetic carriers for the recessive disease. When children are born they are more likely to have the full symptomatic version of the recessive disease.



The Human Genome Project has enabled us to locate genetic mutations and has improved our knowledge of genetic diseases that are widespread among certain people such as the Old World Amish.

The Human Genome Project was completed in April 2003. This international research effort to sequence and map all of the genes gives us the ability to read nature's complete genetic blueprint for our



Success can be gained by geneticists and other scientists targeting communities such as the Amish for biomedical research. The discoveries made can have important implications for prevention and treatment. Public concern for protections for the communities in biomedical research is driven by fear of discrimination.

In 1989, Morton and his wife, Caroline, moved to Strasburg, Pennsylvania to open the Clinic for Special Children. This community hospital provides affordable care, counseling, and genetic testing for disorders unique to the Amish and Mennonite populations.

Crigler-Najjar syndrome, maple syrup urine disease, glutari aciduria, pigeon breast disease, and pretzel syndrome are some of the rare disorders seen in Morton's Clinic for Special Children built on what was once an Amish farmer's field. Special formulas and dietary regimens are tailored for these children that would have never survived in the past.

## When Old-Order Amish Meet New Order Science: Genetic Maladies and the Amish Dilemma

By Kelley L. Downey

Recommendation by Dr. Tom Segady, Sociology Department