Amish Research Clinic
at The Clinic for Special Children

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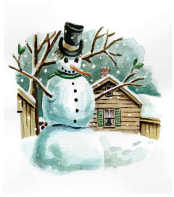

It is hard to believe that we are celebrating our 8th Christmas season since the opening of the Amish Research Clinic in 1995. During that time, we have seen over 3,200 Amish volunteers walk through our Clinic doors to participate in research studies on diabetes, osteoporosis (weak bones), high blood pressure, cholesterol abnormalities, heart disease, and longevity. My staff and I would like to take this special time to thank you and your family for your valuable time and dedication to our research. Your participation will one day lead to the genetic discoveries that will pave the way to new preventions, treatments, and even cures for these common diseases so that people can live longer and healthier lives. Over the years, we have helped numerous people with these diseases to improve both the quality and quantity of their lives. We look forward to serving the Amish community for years to come and wish you and your family a merry Christmas and happy and healthy new year.

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News from Our Studies

The HAPI Heart Study

If you have already participated in our osteoporosis or coronary artery calcification study, you are eligible for a new study to investigate how genes interact with lifestyle factors, such as stress and diet, to cause heart disease. These studies will provide to our volunteers free testing for heart, kidney, thyroid, and liver disease, anemia, as well as other special tests. The study will be conducted over the next 3 years. To date, over 50 Amish volunteers have participated in this new study. If you are interested in this study, please call the Amish Research Clinic at 717-687-8371 or write to us.

The Sitosterol Study

Sitosterolemia is a rare disease in which levels of plant cholesterols (fats) in the blood are very high. This can lead to early heart disease and death, sometimes in childhood. Individuals with sitosterolemia have two copies of a particular form of a gene that controls how the body transports plant fats in and out of the blood. The Amish Family Sitosterol Study was started this year to help us compare levels of plant fats among individuals who have one or zero copies of the form of the sitosterol transporter gene that causes sitosterolemia. Scientists have not previously studied this question in otherwise healthy adults. To date, over 40 Amish volunteers have provided blood samples to help us begin to search for answers. We hope that new knowledge learned from this study will help provide new insight into the relationship between fasting blood plant cholesterol levels and heart disease. We thank those who have volunteered to participate in this new study and wish you much happiness during the holiday season.

Amish Family Diabetes Study

Diabetes is a disease in which the level of sugar in the blood is elevated. This can lead to eye, kidney, nerve, and blood vessel problems. The Diabetes Research Clinic was established in February 1995 to identify genes that predispose to diabetes. To date, we have seen over 1400 Amish volunteers, and have helped over 190 diabetic subjects to take control of their diabetes.

In the laboratory we have identified regions on chromosomes 1, 14, 15, and 18 that are likely to contain diabetes genes. We are working with six other research groups around the world to find the diabetes gene on chromosome 1. Indeed, the Amish Family Diabetes Study may hold the key to identification of this gene, which may also be relevant in Native Americans, Chinese, and whites.

It is our hope that these new discoveries will lead to better medications for patients with diabetes and also allow us to identify individuals at risk for the disease so that it can be delayed or prevented.

We thank each and every one of you for your participation.

Amish Family Longevity Study

The goal of this study is to identify genes that allow for a long productive life and to understand what these genes do. To date, 17 Amish men and women aged 90 years or older have participated, as well as 83 of their children and childrens' spouses. Already we have learned that people who live to an older age tend to have parents and other close relatives who have also lived to an old age. In the coming years we hope to gain a better understanding of why some people age more successfully than others. We would like to thank our participants for helping us in this unique study.

Amish Family Hypertension Study

Hypertension or high blood pressure is a common disorder that predisposes people to heart and kidney disease. As a result of our research in the Amish, we have identified a region on chromosome 2 that harbors a gene related to hypertension. This region contains only a handful of genes (from more than 30,000 in total). With your help, as a participant of the Amish Genetics of Hypertension Study, we are well on our way to identifying which of these genes increases susceptibility to hypertension. Identification of hypertension genes will help to treat and prevent hypertension, heart disease and strokes in millions of people. We thank you for your participation in this important study, and wish you and your family health and happiness during this holiday season.

The Amish Family Osteoporosis Study

The Osteoporosis Research Clinic was established in March 1997 to identify genes that predispose to osteoporosis (weak bones). Osteoporosis is responsible for hip fractures in older people and can cause loss of height and chronic back pain in others and other complications. Identification of osteoporosis genes will lead to better medications for patients with osteoporosis and also allow us to identify individuals at risk for the disease so that it can be delayed or prevented. With your help, we are well on our way toward meeting our goals. Since the Osteoporosis Research Clinic opened, we have seen over 1,000 Amish volunteers. Over 800 genetic markers have been measured from blood of each volunteer and the search for osteoporosis gene is now underway. We thank each and every one of you for your participation.

Amish Family Osteogenesis Imperfecta Study

During the course of our osteoporosis study, we identified several individuals with a rare bone disorder called Osteogenesis Imperfecta (OI). OI is a genetic disorder that results in brittle bones and many bone fractures that can be painful and debilitating. We can easily identify affected individuals from a blood sample. Early diagnosis and treatment can help people with OI to prevent fractures. We are pleased that of our research on OI offers direct benefits to Amish families with OI and to the Amish community.

The Amish Family Calcification Study

The Amish Family Calcification Study was designed to test whether heart disease runs in families and whether people with osteoporosis are also at high risk for heart disease. We are measuring the amount of calcium present in the blood vessels of the heart using a special x-ray, called EBCT. EBCT can detect heart disease in its early stages and can be used to identify people at risk for heart disease so that measures can be taken to prevent heart attacks. Over 350 Amish subjects have participated so far. Analysis of the information collected so far indicates that many people with high calcification in their blood vessels also have high blood pressure. We have also learned that the amount of calcification people have does tend to run in families. Over the next 3 years we will continue to offer this test to members of the Amish Family Osteoporosis Study as well as other members of the Amish community.