



Amish Research Clinic at The Clinic for Special Children

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It is hard to believe that we are celebrating our 9th Christmas season since the opening of the Amish Research Clinic in 1995. During that time, we have seen over 3,000 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. We continue to recruit volunteers into these and other studies, so if you, your family, friends or neighbors are interested in possibly volunteering, please feel free to spread the word and to have them contact us.

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. Through our research, we have helped numerous people to improve their health and thus the quality and quantity of their lives. In addition, 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. 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.

The Amish Research Clinic Staff

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News from Our Studies The Sitosterol Study

Sitosterolemia is a rare disease in which levels of plant cholesterol in the blood are very high. High plant sterol levels can lead to early heart disease and death, sometimes in childhood. Individuals with sitosterolemia have changes in both (two) copies of a gene that controls how plant cholesterol is transported into and out of the body. The Amish Family Sitosterol Study was started in 2003 to help us compare levels of plant sterols among individuals who have one or zero copies of the changed sterol transporter gene. Scientists have not previously studied this question in otherwise healthy adults. To date, over 220 Amish volunteers have provided blood samples to help us search for answers. We hope that knowledge learned from this study will 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 study and wish you much happiness during the holiday season.

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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, 22 Amish men and women aged 90 years or older have participated, as well as 101 of their children, and 75 of the children's spouses. In the course of the study, a number of individuals have been found to have medical problems that can lead to disease such as high blood pressure or high cholesterol levels, and a number of individuals have been identified who do not have any medical problems. We hope that the letters we sent you about your health status have helped you remain well. Above all, we would like to thank everyone who has participated in the study.

The HAPI Heart Study

If you have already participated in our osteoporosis or coronary artery calcification study, you are eligible for a study that examines how genes interact with lifestyle factors, such as stress and diet, to cause heart disease. Volunteers in this study receive free testing for anemia (low blood count), heart, kidney, thyroid, and liver disease, as well as other special tests. The study started in 2003 and will be conducted over the next 2 years. To date, over 300 Amish volunteers have participated in this study. If you are interested in this study, please call the Amish Research Clinic at 717-687-8371 or write to us.

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 located a region on chromosome 2 that harbors hypertension gene. With your help, as a participant of the Amish Genetics of Hypertension Study, we are well on our way to identifying the gene. Understanding hypertension genes will help to treat and prevent heart and kidney disease and strokes in millions of people. We thank you for your participation in this important study. Please feel free to tell others who may have hypertension about our study and have them contact us if they wish to be tested.

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 500 Amish subjects have participated so far. Analysis of the information collected so far indicates that people with calcification in their blood vessels tend to have higher blood pressures and levels of cholesterol than people without calcification. 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.

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. Recruitment continues, so please feel free to contact us or have others contact us if they think they may have diabetes and want to be tested.

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 several other research groups around the world to find the diabetes gene on chromosome 1. 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.

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. So far, we have learned that Amish women have slightly less osteoporosis and less broken hips, compared to non-Amish women. The rates in men are the same in Amish and non-Amish. We also found in women that having large numbers of children is not bad for the bones.

Amish Family Osteoporosis Study

Amish Family Celiac Study

Celiac disease is a disease of the small intestine caused by eating foods containing gluten, a protein found in foods made from wheat, barley, rye, oats, and pelt. Children and adults with celiac disease can have symptoms that include diarrhea or constipation, weight loss, fatigue, abdominal pain, vomiting, bloating, loss of appetite, anemia (low blood count) and osteoporosis (bone loss). Diagnosis and treatment with a diet free of gluten results in a dramatic improvement in symptoms. Recently, we began a new study to identify people (and families) with celiac disease to search for genes that predispose to this disease. We test for celiac disease with a questionnaire and a simple blood test. Some of those who have a positive blood test will be offered an intestinal biopsy (a minor procedure to removal a tiny piece of the small intestine) to confirm the diagnosis. If you have any of the symptoms listed above and want to be screened for celiac disease, please contact us in writing or by telephone at 717-687-8371 at The Amish Research Clinic.



