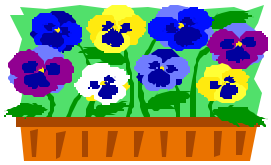
Amish Research Clinic
at the Clinic for Special Children
535 Bunker Hill Road, Strasburg, PA 17579
717-687-8371



Greetings! Our yearly Christmas Newsletter was so successful that we decided to send this Summer Newsletter. It is hard to believe that we are celebrating our 10th year 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, breast density, celiac disease, and longevity. The purpose of this research is to identify genes for these diseases and traits. Genes are the parts of our cells that allow traits to be passed from parents to children. We continue to work busily at the Clinic and to recruit volunteers into these and other studies. If you, your family, friends or neighbors are interested in possibly volunteering, please feel free to spread the word and have them contact us.

My staff and I would like 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 disorders. We look forward to serving the Amish community for years to come and wish you and your family health and happiness during this summer season.

The Amish Research Clinic Staff

Alan Shuldiner, M.D.
Elizabeth Streeten, M.D.
Dan McBride, Ph.D.
Braxton Mitchell, Jr., Ph.D.
Richard Horenstein, M.D.
Soren Snitker, M.D., Ph.D.
John Sorkin M.D.
Wendy Post, M.D.
Nanette Steinle, M.D.
Rosalie Naglieri, M.D.
Scott Hines, M.D.
Mary Morrissey, R.N.
Janet Reedy, R.N.
Theresa Roomet, R.N.
Mary McLane, R.N.
Marian Metzler, R.N.
Yvonne Rohrer, R.N.
Donna Trubiano, R.N.
Sue Shaub, R.N.
Nancy Weitzel, L.P.N.
Shawn Hendrickson
Patrick Donnelly, R.D.C.S.
Anita Martinez, R.D.C.S.
Maryann Drolet, M.T.
Rhea Cosentino, M.T.
Sarah Raush

Amish Family Hypertension Study

Hypertension or high blood pressure is a common disorder that predisposes people to heart and kidney disease and stroke. As a result of our research in the Amish, we have located a region on chromosome 2 that harbors a blood pressure gene. Dr. Nanette Steinle at the University of Maryland has recently received a grant to use state-of-the-art laboratory methods to identify the blood pressure gene on chromosome 2. 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 participate.

Amish Family Celiac Study

Celiac disease is a disease of the small intestine caused by an allergic reaction to gluten, a substance 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, weakness, abdominal pain, vomiting, bloating, loss of appetite, anemia (low blood count) and osteoporosis (weak bones). Often, symptoms can be mild and the disease may not be diagnosed. 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. An intestinal biopsy (a minor procedure to removal a tiny piece of the small intestine) to confirm the diagnosis is being offered to individuals with a positive blood test. If you have any of the symptoms listed above and want to be tested for celiac disease, please contact us in writing or by telephone at 717-687-8371 at The Amish Research Clinic.

The HAPI Heart Study

If you have already participated in our osteoporosis or coronary artery calcification study, or have a family member who participated in this 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 continue for the next year. To date, over 500 Amish volunteers have participated in this study. So far we have found that people respond very differently to the same stressor (immersion of the hand into ice water) and diets (high and low salt, and high fat). This is likely due to the effects of inherited factors that differ between people. In the laboratory, we are working to pinpoint these genetic factors so that we can understand better these differences, which may one day lead to new ways to prevent or treat heart disease. We continue to recruit volunteers into this study, so if you or a family member are interested in this study, please call the Amish Research Clinic at 717-687-8371 or

Amish Family Calcification Study

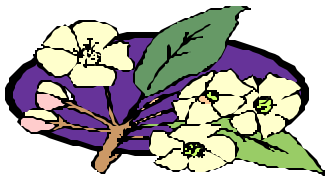
Approximately 700 participants have been enrolled into the Amish Family Calcification Study so far. In this study, we are measuring the amount of calcium present in the blood vessels of the heart using a special x-ray, called EBCT. EBCT can detect heart disease in its early stages and can be used to identify people at risk for heart disease so that measures can be taken to prevent heart attacks. Already we have learned that that the amount of calcification people have tends to run in families. In addition, people with calcification in their blood vessels tend to have higher blood pressures and levels of cholesterol than people without calcification. We will soon be starting a major effort to try to identify which genes influence a person's susceptibility to getting calcification.

The Sitosterol Study

Sitosterolemia is a rare disease in which levels of plant cholesterols (sterols) 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 otherwise effectively controls plant sterol levels in the body. The Amish Family Sitosterol Study was started in 2003 to help us compare levels of plant sterols in 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 285 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.

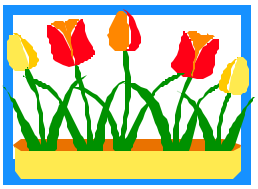
Amish Family Osteoporosis Study

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 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 1,300 Amish volunteers. Over 800 genetic markers have been measured from blood of each volunteer and the search for osteoporosis genes is now underway. 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, 28 Amish men and women aged 90 years or older have participated, 20 of their siblings as well as 146 of their children and 100 of the children's spouses. In addition to looking for traits that are associated with a healthy and long life, we have identified a number of individuals with medical problems such as high blood pressure and high cholesterol levels. Sharing the results of the study with your family doctor is important since these disorders are easily treatable. Thus, we are proud that this study has contributed to improved health of many of our volunteers. Above all, we would like to thank everyone who has participated in the study.



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 Study began 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 better understand and 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 for 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 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.

Amish Childhood Obesity Study

Overweight and obesity has become an increasing health concern over the past several years. Excess body weight is associated with problems such as diabetes, heart disease, some cancers and arthritis. Our earlier studies found that although the frequency of overweight and obesity in the Amish are similar to the general U.S. white population, the frequency of adult (type 2) diabetes is about one-half that of the general U.S. white population. This has led us to wonder about obesity rates in Amish children. We suspect that childhood obesity is much less common in the Amish than in the general U.S. white population. The Childhood Obesity Study is designed to gather exact information about activity (by wearing an activity monitor), eating habits (by a questionnaire) and health parameters (blood pressure, weight, waist measurement, height) concerning Amish children, aged 8-14. In addition to gathering information from the children, we would also like to gather the same information from the parents, since family interaction plays a large role in choices the children make. Gathering this information will not only help us understand how good eating habits and activity can prevent obesity in children but also serve as information to you about your children's growth and development. All children ages 8-14 are eligible and will receive a book for their participation and all adults will receive $10.00. Please call Theresa Roomet at 717-687-8371 at The Amish Research Clinic if you are interested. We would like to thank all of you who have participated thus far.

NEW RESEARCH FINDINGS

Do people with more children live longer?

We looked at the genealogical information available in the Amish Church Directory to determine whether the number of children you have is related to how long you live. Our analysis included over 2,000 Amish individuals born between 1749 and 1912 and who survived at least until age 50. For both men and women, there was a clear relationship between having more children and living longer. On average, each five children born was associated with living an additional 1 to 1 ½ years longer. However, in women, but not men, with more than 14 children, additional children did not appear to be related to living longer.

Searching for Diabetes Genes

Adult onset or type 2 diabetes is caused by the interaction of several genes with an unhealthy lifestyle. Studies in Finnish people and in Ashkenazi Jews suggested that a specific gene called HNF4A might be involved in the development of diabetes. Our recently published study in the Amish confirmed the role of this gene in the development of diabetes. These findings are important because consistency among different studies suggests that the discovery is true and relevant across multiple populations.

Does having a lot of children weaken mom's bones?

In a recently published study, we examined the relationship between the number of children a mother has and her bone density. Remarkably, we found that the number of children a mother has does not affect bone density. This finding should be reassuring to mothers with many children and shows that even with the great demands of multiple pregnancies and subsequent breast feeding, mom's bones are not compromised.

Are diabetes and osteoporosis (weak bones) more common in the Amish?

No! In fact, our studies show the opposite. For adult (type 2) diabetes, the frequency in the Amish is only about one-half that of the general U.S. white population. Similarly, we found that the frequency of hip fractures that occur in the Amish is significantly lower than in the general U.S. white population. Protection from diabetes and hip fractures may be because the Amish are more physically active, which is known to have beneficial effects on these two diseases.