

Amish Research Clinic

2023 Annual Newsletter



UNIVERSITY of MARYLAND
SCHOOL OF MEDICINE

Greetings from the Amish Research Clinic

Greetings to all. We are delighted to present the 2023 edition of our annual newsletter. The ARC has had a busy year, starting with a field trip to Pinecraft, Florida in January, for the purpose of expanding our New Wellness Study to other Anabaptist communities. We have also expanded the reach of the New Wellness Study here in Lancaster into the Mennonite community. In addition to these studies, we are continuing activities that fit our core mission, namely to improve healthcare through research and serve as a resource for health information and knowledge to the Amish community. Through participation in research at the ARC, our participants receive information and results relevant to heart health, diabetes, kidney dysfunction, thyroid, anemia and other disorders. In addition, we are continuing to offer the return of results from genetic testing in the small number of cases where this knowledge can be used to reduce risk and improve health. A new study focuses on the most

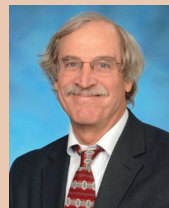
effective and culturally appropriate way to return genetic results. As always, we are very grateful for the continued partnership, trust and altruism of our research participants.

Now nearly 30 years since its beginning, with your help, the

ARC continues to make medical discoveries that have improved health in not only in Lancaster, but around the globe. We wish you and your family a happy and healthful year, and look forward to our continued work together!



Dr. Shuldiner



Dr. Mitchell

New Study Coming

Zinc Supplementation in Prediabetes

Type 2 Diabetes leads to chronic conditions including kidney failure, blindness, neuropathy, and cardiovascular disease. People with prediabetes can suffer similar health risks and often progress to become Type 2 diabetics. This new study will look to see if zinc supplementation will improve how the body handles glucose (sugar) and potentially slow or prevent prediabetic individuals from progressing to Type 2 diabetes. Participants will take either zinc supplements or a placebo for one year and will have an oral glucose tolerance test at the beginning, at six months, and at the end of the study. If you are prediabetic, you might consider participating when this study gets started.



ARC Amish Liaison Team:

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Marian Stoltzfus
Naomi Esh

Susie Fisher
Susie Stoltzfus
Sylvia King
Verna Fisher
Verna Petersheim

Current Studies

PORT Study

This is a newer research study to find out how different people respond to a medication called *semaglutide*, which is an FDA-approved medication used to treat Type 2 diabetes. The purpose of this study is to see whether a person's genes influence how effectively *semaglutide* works to improve how the body processes glucose (sugar). We will also see if gene changes affect whether a person loses weight while taking this medication. We are looking for healthy, non-diabetic volunteers who are overweight to participate in this seven-week study.



Amish Aging Study



There is a lack of understanding about how human cells age and how cell changes contribute to age-related diseases, including skin and immune diseases. In this study, we are comparing skin and blood immune cells from adults in several different age groups to learn more about age-associated diseases. The knowledge gained from this study may increase our understanding of what happens in the process of aging and may be the first step in the development of new therapies aimed at treating age-associated diseases. If you are contacted by our team, we hope you will help us learn more by joining the study.

Amish Research Clinic Team:

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Current Studies, cont'd

Hearing Loss Study



This study started at the beginning of 2021 with a questionnaire mailed to many of your homes. If you returned your questionnaire, we thank you. We are currently visiting individuals who have genetic changes that may affect hearing, and individuals from families that have two or more members with hearing loss. The study visit includes a hearing test and a blood draw. We will use this information to help in the development of new therapies for those dealing with

hearing loss. We are planning to expand this study to include all individuals aged 50 and above, including those with healthy hearing.

SETD1A Study

The purpose of this research is to study a gene change (identified as SETD1A) that may be involved with aspects of mental health and how the brain acquires new knowledge and understanding through thought, experience, and the senses. This information may help in the development of new therapies for those dealing with mental illnesses.

We are enrolling families in this study who have this genetic change and we are specifically interested in enrolling siblings (brothers and sisters) who have and do not have the genetic change. This simple study is completed in your home. If you are contacted by our team, we hope you will agree to join our study.



Umbrella Study



We've combined the genetic results received through our collaboration with the Regeneron Genetics Center under the "umbrella" of this study. Several genetic changes (called variants) that appear to affect an individual's health or risk for disease have been identified from the

results of more than 7000 Amish participants who took part in 15 different studies over the past 25 years. Some of these variants seem to improve health and lower disease risk. To increase our understanding of these changes, we are currently studying eight specific variants, hoping that what we learn may help create new medications or treatments for people at risk of certain diseases.

Return of Genetic Results

A few of the genetic variants that we have found in Amish participants are already known to have significant impacts on human health or an individual's risk for particular diseases. Out of care and respect for our previous participants, we want to provide them with an opportunity to learn about these variants and to have the research results confirmed in a clinical lab. Providing this information could help with early diagnosis of a health problem, early treatment to decrease their disease risk, or potentially lowering the cost of searching for the cause of health issues that they may be experiencing.

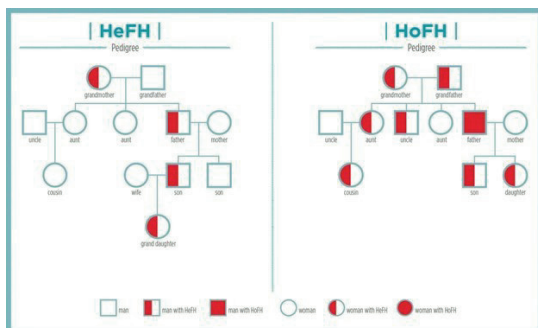
One example is *KCNQ1*, a gene change that causes Long QT Syndrome (LQTS) which affects the electrical activity of the heart and the heart rhythm. This can lead to increased risk of fainting and sudden death (including stillbirth and crib death). This gene variant is present in 1 of 45 Amish persons. LQTS is treatable with a safe, low-cost medication. Presently, we provide the clinical genetic testing to our participants at no cost to them using donated funds. If the gene change is confirmed, we help them connect with a primary care provider for follow-up.

Cascade Screening Study (DISC)

When a genetic change that is known to cause health problems is found in an individual (proband), it is important to let other family members who may be at risk for the genetic change know about this risk and provide genetic screening (cascade screening).

This new study will try to

determine the most effective way to perform cascade screening by comparing two methods of delivering this information. One method will be by the proband (affected family member) and the other will be by a genetic counselor.



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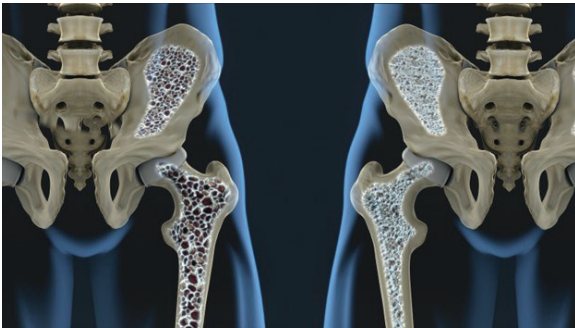
Current Studies, cont'd

Brain Body Connection Study (Part 2)

Thanks to the support of the community, the original Brain Body Connection Study was successful. This new study expands our scientific ideas to not only look at brain health but also blood vessel health. The purpose of this research is to better understand brain changes that occur over time, and which may be related to the development of brain illnesses. Causes like environmental factors, stress, and genetics will all be studied. This research study will again use the MRI method that takes pictures of the brain. We will ask a series of questions about health topics and mental health and perform some tests that look at brain function. The study will also involve tests to measure blood vessel health.



The Amish Research Clinic (ARC) and the Maryland Psychiatric Research Center (MPRC) are bringing back previous participants who completed the MRI for the new, expanded study of the brain. This study will continue for two more years.

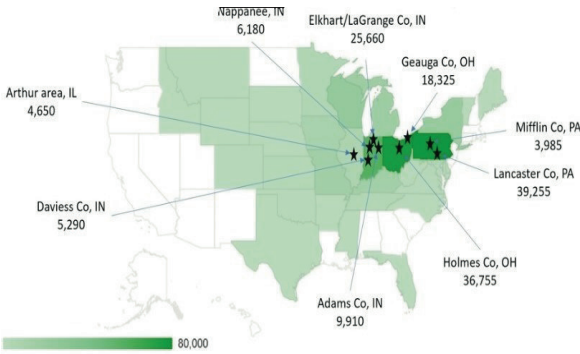


Osteoporosis Study

60 genes have been found that are important for bone health!

Thanks to our many Amish participants, our Osteoporosis Study, which began in March 1997, is one of our longest running studies. We have installed a new DXA machine. We are currently focusing on genes that affect body composition and bone strength. If you are contacted by our team, we hope you will help us learn more by joining the study. We continue to offer free DXA bone density scans as a two-year follow-up to previous participants diagnosed with osteoporosis [a condition where bone strength weakens, and bones are more susceptible to fracture].

New Wellness Study - Genetic Diversity in Plain Populations



The Amish Wellness Study that was conducted over the past ten years among the Lancaster County Amish was completed a couple years ago. Almost 7000 Amish adults received a basic wellness screening. The genetic research from that study is the basis for most of our current studies.

We expanded the Wellness Study to include other Anabaptist communities in Lancaster (PA), Ohio,

Indiana, and Sarasota, Florida. This study is funded by our partnership with the Regeneron Genetics Center LLC and includes screening for cholesterol, diabetes, thyroid health, and heart health. Blood will also be collected and stored at the University of Maryland for research on genetic and non-genetic factors in health and disease. We are enrolling people who have never participated in the Wellness Study or our other genetic studies. We are visiting Church districts in Lancaster County that did not have an opportunity to participate in the original Wellness Study. We are also inviting those who were too young to participate when we visited their church district, as well as offering this study to the Lancaster Co. Old Order Mennonite communities.

This past January and February, our study team spent six weeks at Pinecraft in Sarasota, Florida offering this study to vacationers from plain communities in the eastern U.S. (and Canada). We will return to Pinecraft from January – March 2024. If you live in the Lancaster area, we want to do your study here, but if you have friends from other locations, let them know that we would love to have them participate in the study while they are in Sarasota.

Donation Message

The Amish Research Clinic is a nonprofit organization that first opened for the community in 1995. We want to thank those of you who have provided us with charitable support in the past. With your help, we have been able to provide free genetic confirmation and counselling of the KCNQ1 and other genetic variants to participants, provide educational opportunities for our Amish liaisons, purchase new vehicles for participant transportation, and cover other expenses associated with our community clinic.

Freewill donations to help with operating expenses are appreciated. Checks can be made payable to the University of Maryland Baltimore Foundation/Amish Clinic (or UMBF/Amish Clinic), which administers gifts for the University of Maryland Amish Research Clinic. Kindly send your annual donation to:

University of Maryland School of Medicine
Office of Development
31 South Greene Street, Third Floor
Baltimore, MD 21201
Attn: Traci Morgan

Alternatively, you may donate online at: www.medschool.umaryland.edu/AmishClinicGift

If you have any questions, please call Pamela Lambert at 410.706.0419 or 717.512.6013.



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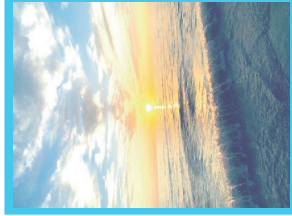
Phone #: (717) 392-4948

Our Mission

The Amish Research Clinic contributes to improvements in healthcare through research. We serve as a resource for health information and knowledge to the Amish Community.

Studies from the Amish Research Program have been described in over 350 publications. These can be viewed on this website:

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Cover photographs
on the beach in
Sarastoa, FL
by Denise Weiss