

Amish Research Clinic

2022 Annual Newsletter



UNIVERSITY of MARYLAND
SCHOOL OF MEDICINE

Greetings from the Amish Research Clinic

Greetings to all. We hope you enjoy the 2022 edition of our annual newsletter. This past year has been another challenging one in many ways, and we hope that you and your family have prospered and have enjoyed health and happiness. We are glad that the ARC is now back in full operation after a few pauses due to the COVID pandemic. We have started some new studies this year which fit our core mission, namely to improve healthcare through research and serve as a resource for health information and knowledge to the Amish community. For example, some of our new activities now include returning results from genetic testing in a small number of cases where this knowledge can be used to reduce



Dr. Shuldiner

risk and improve health. As before, 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 Lancaster and around the globe. We look forward to our continued work together!



Dr. Mitchell

New Studies

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 new study, we will compare 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.

ARC Amish Liaison Team:

Anna Esh
Barb Stoltzfus
Barbie Stoltzfus
Emma Beiler
Esther Smucker
Hanna King

Kate Kauffman
Katie King
Lavina Ebersol
Malinda Zook
Marian Stoltzfus
Naomi Esh

Susie Fisher
Sylvia King
Verna Fisher
Verna Petersheim

SETD1A Study

The purpose of this new 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 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 help us learn more by joining the study.

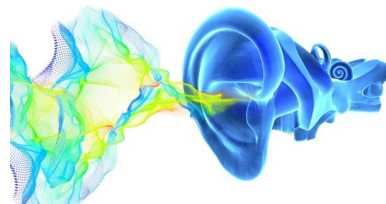


P O R T Study

This is a new 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 the study is to see if 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.

Hearing Loss Study

This newer study started at the beginning of 2021 with a questionnaire mailed to many of your homes. If you returned your questionnaire, we thank you. Even if you do not have hearing loss, we would still like you to complete and return our questionnaire. We plan to mail them again this summer to folks from whom we received no response. 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.



Current Studies

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.



Donation Message

The Amish Research Clinic is a nonprofit organization that first opened in the community in 1995. 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 donation to:

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

Alternatively, you can donate online at: medschool.umaryland.edu/amishclinic

We want to thank those of you who have provided us support in the past. With your help, we have been able to purchase two new transport vans, provide free genetic confirmation and counselling of the *KCNQ1* variant to participants, and cover other expenses associated with our clinic. If you have any questions, please call Pamela Lambert at 410.706.0419 or 717.512.6013.

Gifts to support the University of Maryland School of Medicine are administered by the University of Maryland Baltimore Foundation, Inc. A portion of any contribution to the University of Maryland School of Medicine may be used to enhance advancement efforts.



Umbrella Study

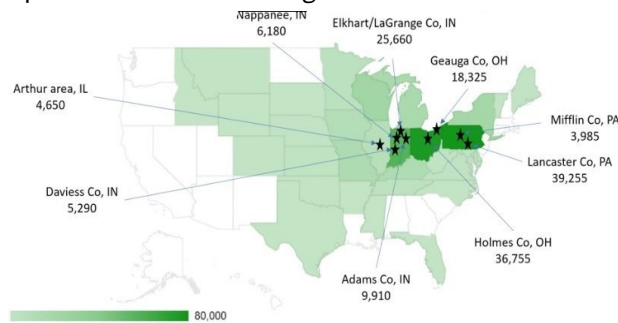
We've combined the genetic results received through our collaboration with the Regeneron Genetics Center under the “umbrella” of this study. Several genetic changes (called variants) that appear to affect an individual’s health or risk for disease have been identified from the

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 seven specific variants, hoping that what we learn may help create new medications or treatments for people at risk of certain diseases.

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 of 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 are about to expand 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 will include 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 plan to visit the remaining Church districts in Lancaster County that did not have an opportunity to participate in the original Wellness Study, invite those who were too young when we visited their church district, and also offer this study to the Lancaster Co. Old Order Mennonite communities.



Amish Research Clinic Team:

Ada Stoltzfus, BSN, RN	Diane Montgomery, BSN, RN	Patrick Donnelly, RDCS
Bob Henry	Elizabeth Zehr	Susan Shaub, BSN, RN
Charlene Wolford, BSN, RN	Grace Redcay	Tracy Broderick
Cynthia Rohrer, BSN, RN	Karen Howk, BSMT	Woody Wagner
Dawn Fox, RN	M. Ranea Riehl, BSN, RN	
Denise Weiss, BSN, RN	Maryann Drolet, BSMT, ASCP	

Current Studies, cont'd

Poison Ivy Study

We continue to study whether genetic differences in a gene called CD1A may affect how people react to exposure to urushiol, the oily substance found on the leaves of poison ivy plants. We do this by enrolling persons with different genetic make-ups for a blood



draw and skin biopsies to help us learn more about allergic response and levels of CD1A. This research may lead to a new therapy to prevent reactions to poison ivy by suppressing this allergic response.



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 are getting ready to install a new DXA machine. Once that is complete, we plan to focus 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].

University of Maryland Team:

Alan Shuldiner, MD	Elliot Hong, MD	Melanie Daue, MS
Amber Beitelshees, Pharm D, MPH	Hilary Whitlatch, MD	Pamela Lambert
Barbara Kupec-Brown	Joshua Lewis, PhD	Samantha Lightner
Braxton Mitchell, PhD, MPH	Kate Autry	Seth Ament, PhD
Coleen Damcott, PhD	Kathy Palmer, BSN, RN	Simeon Taylor, MD
Elizabeth Streeten, MD	May Montasser, PhD	Toni Pollin, PhD

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.

Over the next four to five years, the Amish Research Clinic (ARC) and the Maryland Psychiatric Research Center (MPRC) are hoping to bring back previous participants who completed the MRI for the new, expanded study of the brain. We are also recruiting new participants who will repeat the study in four years.

G R C Study

We know that medications do not work the same way for everybody. This sometimes occurs because of genetic differences. *Canagliflozin* is an approved medication used to treat Type 2 diabetes. Our ongoing study measures the effect of *canagliflozin* on healthy, non-diabetic people to see whether an individual's genes influence how effective it is – how well it removes sugar from the blood – and whether the gene change influences the experience of side effects. Our findings may help doctors to choose the best medicine or best dosage for patients with Type 2 diabetes. If you would be interested in participating, please call the Amish Research Clinic!





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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 316 publications. These can be viewed on this website:

[https://
www.ncbi.nlm.nih
.gov/sites/myncbi/
braxton.mitchell.1/
collections
/47782571/public/](https://www.ncbi.nlm.nih.gov/sites/myncbi/braxton.mitchell.1/collections/47782571/public/)

Save the date!
ARC
Health
Conference
on October 6!

Cover photograph
on Harvest Drive
in Ronks, PA
by Tracy Broderick