



**Amish Research Clinic**

**2021 Annual  
Newsletter**



## Greetings from the Amish Research Clinic

Greetings to all. We hope you enjoy this abridged version of our annual newsletter. More than ever, we wish you and your family health and happiness during these extraordinary times. The COVID pandemic certainly challenged all of us. We are so glad that the ARC is now back in full operation after a one year pause. During that time it was particularly important for us to return to our core mission, namely to improve healthcare through research and serve as a resource for health information and knowledge to the Amish community. We hope you and the community found some of the activities of our staff helpful in navigating the complicated health and social issues that COVID brought all of us.

Thankfully, we see better days ahead and more than ever are most grateful for the continued amazing 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. Shuldiner



Dr. Mitchell

## Current Studies

### Poison Ivy Study

We have expanded our study to test whether genetic differences between people may affect how they react to exposure to urushiol, the oily substance found on the leaves of poison ivy plants. Many people develop a rash and itching while others do not. We are testing our hypothesis that changes in a gene called CD1A affect an individual's reaction to urushiol. We mailed a survey early this year asking about poison ivy experience to several thousand members of the Amish community. We



are also enrolling participants for a blood draw and skin biopsies to help us learn more about allergic response and levels of CD1A in those with different genetic make-ups. Research results may lead to a new therapy to prevent reactions to poison ivy by subduing this allergic response.

### Amish Research Clinic Team:

Susan Shaub, BSN, RN  
Maryann Drolet, BSMT, ASCP  
Dawn Fox, RN  
Diane Montgomery, BSN, RN

M. Ranea Riehl, BSN, RN  
Denise Weiss, BSN, RN-BC  
Karen Howk, BSMT  
Patrick Donnelly, RDCS

Tracy Broderick  
Grace Redcay  
Elizabeth Zehr  
Woody Wagner

## Umbrella Study

Through our collaboration with the Regeneron Genetics Center, we have received genetic results for approximately 7000 Amish participants from 14 different studies. Multiple genetic changes (variants) have been identified which appear to affect an individual's health or risk for disease. We have combined these genetic results under the "umbrella" of one study to better understand these changes.



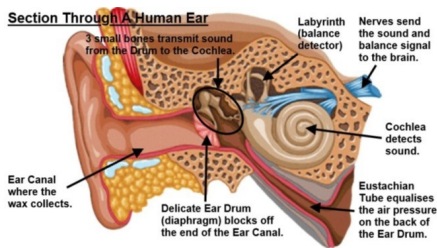
We are currently working with six specific variants that seem to improve health and lower risk of disease. We hope that what we learn may help create new medications which mimic the health effects of these variants for people at risk of disease.

## 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. Presently we provide these services to individuals at no cost to them using donated funds. We hope we can continue doing so in the future.

One such variation in the KCNQ1 gene causes Long QT Syndrome, affecting the electrical activity of the heart and possibly affecting heart rhythm. Long QT syndrome increases the risk of fainting and of sudden death and causes at least 10% of crib deaths. The KCNQ1 gene variant is present in one (1) of 45 Amish persons. About half of these individuals will never have symptoms and their risk of sudden death is low. Unfortunately, we cannot predict who will and who will not have symptoms. LQTS is treatable with a safe, low-cost medication that is 70-90% effective.

## Hearing Loss Study



This is a new study started at the beginning of 2021 with a questionnaire mailed to many of your homes. Thank you to those who have already returned your questionnaire. Even if you do not have hearing loss, we would still like you to complete and return the questionnaire. We're now visiting individuals who have genetic changes that may affect hearing and individuals

from families that have two or more members with age-related 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.

### A R C Amish Liaison Team:

Naomi Esh  
Barbie Stoltzfus  
Hanna King  
Susie Fisher

Verna Petersheim  
Sylvia King  
Barb Stoltzfus  
Anna Esh

Esther Smucker  
Marian Stoltzfus  
Katie King

## Current Studies, cont'd

### GAL-B4GALT1 & Serpine Call-back Study



This study's purpose is to better understand the function of a variant of the B4GALT1 gene that is strongly associated with low levels of LDL (bad) cholesterol among Old Order Amish by comparing Amish individuals with and without the gene variant. Results of the study may lead to discovery of new medications to combat high cholesterol, a major risk factor for heart disease – the leading cause of death worldwide. We mailed questionnaires to previous ARC participants. If you have received one but have not yet returned it, you can still help us by answering the questions and sending it back to us! Participants identified with specific variants of this gene are invited to visit the clinic for an array of testing. If you are on this list, you will be contacted by a nurse to ask if you would like to join the study. Thank you to all those who have already returned their surveys or taken part in the clinic portion of the study!

### CES1 Study

When a person has a heart attack, there are several drugs that can be used to help prevent future attacks by thinning the blood. They each do this in slightly different ways. Many patients receive a drug called clopidogrel (Plavix) because it generally works well and is less expensive than others. However, there are individuals for whom clopidogrel does not work well due to numerous factors, one of which is genetics. It would be helpful for doctors treating heart attack patients to know when clopidogrel would be helpful and when a different drug, like ticagrelor, would be a better choice.

We are studying whether variants in the CES1 gene cause differences in the way persons respond to clopidogrel, and we also want to learn whether that same participant would respond to ticagrelor. Our goal is to predict which medication works best to prevent heart attacks or other complications in certain people based on their genetics.



### University of Maryland Team:

Alan Shuldiner, MD  
Amber Beitelshees, Pharm. D., MPH  
Braxton Mitchell, PhD, MPH  
Christy Chang, PhD  
Coleen Damcott, PhD  
Elizabeth Streeten, MD  
Elliot Hong, MD

Jeff O'Connell, DPhil.  
Joshua Lewis, PhD  
Kathy Palmer, BSN, RN  
Kristi Silver, MD  
May Montasser, PhD  
Nanette Steinle, MD  
Pamela Lambert

Robert Reed, MD  
Samantha Lightner  
Simeon Taylor, MD  
Teodor Postolache, MD  
Toni Pollin, PhD

## 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/Amishgift](https://medschool.umaryland.edu/Amishgift)

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.*



## Osteoporosis Study

60 genes have been found that are important for bone health! Thanks to our many Amish participants and in collaboration with many other groups around the world, our Osteoporosis Study, beginning in March 1997, is one of our longest running studies. To study a gene change may increase bone strength, we are presently enrolling participants. If you are contacted by our team, we hope you will help us learn more by joining the study. We still 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].

## Genetics of Response to Canagliflozin (GRC) Study

Canagliflozin is an approved medication used to treat Type 2 diabetes. We know that medications do not work the same way for everybody, sometimes because of genetic differences. This 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 they influence 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!

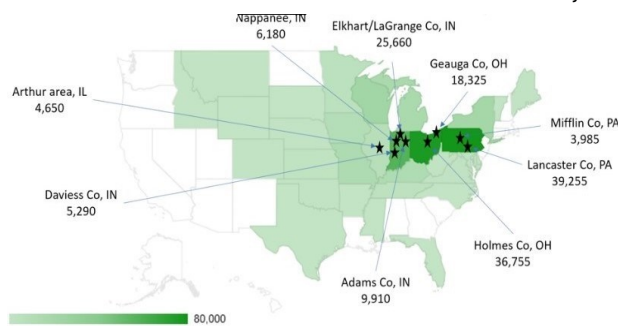


## Current Studies, cont'd

### 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 is now complete. 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 now expanding the Wellness Study to include other Anabaptist communities in Lancaster, 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. We will also offer this study to the Lancaster Co. Old Order Mennonite communities.



### 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 hoping to bring back previous participants who completed the MRI for the new, expanded study of the brain. We also plan to recruit about 50 new participants in the first year of the study, who would repeat the study four years later.





*University of Maryland*  
School of Medicine  
**Amish Research Clinic**  
**921 Village Road**  
**Lancaster, Pa 17602**

**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.

Cover photograph  
by Dawn Fox, RN  
at Smucker's  
Gourd Farm  
Kinzers PA

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/myncbi/  
collections/  
47782571](https://www.ncbi.nlm.nih.gov/myncbi/collections/47782571)