

# Amish Research Clinic 2025 Annual Newsletter



UNIVERSITY of MARYLAND  
SCHOOL OF MEDICINE

## Greetings from the Amish Research Clinic!

In this 2025 edition of our annual newsletter we're highlighting our collaboration. You'll read about how we're inviting participation from more Plain communities in different areas of the country. About how our work and that of the Clinic for Special Children together improve the effectiveness of both. And about what we're learning from families with inherited health conditions by helping them inform all their members for better outcomes. We're excited to share quick looks at how the ARC is carrying out its mission to improve healthcare through research (and collaboration!) and to be a health information resource to Plain communities.

## Recently Completed Studies

### BBC-L (Brain Body Connection Longitudinal) Study

We want to thank the community for all who participated or referred family members to the Brain Body Connection study! Part 2 has now ended. After many years of successful data collection, the research results can be used to better understand brain differences and why it's more likely for some people to have brain illnesses than others.

What we learned through clinical testing and detailed questionnaires will help our scientists at the university to learn more about brain and body health, and specifically in the BBC-L data, about blood vessel health in the brain over time. This analysis will take time, as did the two sections of the study. We look forward with anticipation to the insights that will be derived from all this collected information, and to the possibilities of health benefits for the Plain communities and the human community at large.



### 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

# RUP (Umbrella) Study



The Umbrella study has been looking at eight specific gene-changes (variants) affecting health and disease, hoping what we learn leads to development of preventative medicines or treatments for persons with higher risk of certain diseases. The chosen variants were based on research from previous studies, and we have now finished the final two gene changes of the study by contacting previous participants.

The NTM gene is involved in the way our bodies gain weight; we're trying to see whether this variant affects that process. To do this, we talked to people who may have extended family members with this gene change. We asked about their health history, their parents' health history, any supplements and prescription medicines they take; we measured height, weight, blood pressure and pulse measurements. They then came into the clinic for a body density (DXA) scan and fasting bloodwork.

The ASTE1 is a muscle health gene. We asked individuals who may have this variant the same questions as above, and also whether they have pain, tiredness, or shortness of breath while doing daily tasks such as walking, going upstairs, doing chores. They also did four muscle-strength tests, which participants have enjoyed! They came into the clinic for some specific testing and measurement. We are also studying folks of similar age who we don't think have the variant, and will compare their results.

## Amish Aging Study

Because there is a general lack of understanding about how, specifically, human bodies age, we don't know yet the effect of aging on the body's ability to fight or be prone to chronic illness. By comparing blood and skin cells from healthy folks in varied age ranges, this study aims to begin to understand what happens to specific cells in the process of aging. It is now nearly complete. After the information is analyzed, we hope it may be the first step in developing new therapies for treating age-associated diseases.



### Amish Research Clinic Team:

Charlene Wolford, BSN, RN  
Cynthia Rohrer, BSN, RN  
Dawn Fox, RN  
Denise Weiss, BSN, RN  
Diane Montgomery, BSN, RN

Karen Howk, BSMT  
Kamah Woelfel, MS, BS  
Leslie Drummond, BSN, RN  
Maryann Drolet, BSMT, ASCP  
Tracy Broderick

Bob Henry  
David Patterson  
Dennis Brubaker  
Grace Redcay  
Woody Wagner

# Current Studies

## DISC (Direct-Indirect Screening Comparison) Study

The DISC study continues to gain interest from the community. To date, almost 200 Amish community members have enrolled in the study! Its purpose is to learn how families prefer to share important disease-risk information with relatives. The two health conditions we are studying are much more common in the Amish: hereditary high cholesterol (FH) and long QT syndrome (a heart rhythm disorder). Once we identify someone as having one of these conditions, we know that there's a 50% chance for other close blood relatives to be affected too. Those who enroll in the study receive education about their condition, cholesterol checks or EKGs, and are connected to local healthcare providers. We discuss how to share the health information with family members who may also be at risk. For some participants, we send disease-risk information directly to relatives on the participant's behalf. For others, we provide them with information to share with family members on their own. We will then compare the two methods of communication to find out which way is preferred and works the best for most families.

Through the DISC study, we've been able to identify many individuals with dangerously high cholesterol levels or abnormal heart rhythms, giving them the opportunity to take action and prevent related heart attacks, strokes, or even sudden death. We discuss both lifestyle changes and medication options that can greatly lower risks. The community has been very receptive to having check-ups with local healthcare providers and starting life-saving treatment. Sharing risk information with your children can be a gift, giving them the chance to make informed personal decisions about how best to stay healthy. Early identification of the conditions can also greatly decrease the financial burden of heart surgery. As the study progresses, we are very encouraged by the community's growing interest and thankful for their participation!



### University of Maryland Team:

Alan Shuldiner, MD

Amber Beitelshoes, Pharm D, MPH

Braxton Mitchell, PhD, MPH

Hilary Whitlatch, MD

Joshua Lewis, PhD

Kate Autry, MS, BS

Kristen Wood MS, CGC

Lisa Geraghty

Melanie Daue, MS

Samantha Lightner, BS

Seth Ament, PhD

Simeon Taylor, MD

Toni Pollin, PhD

## Did you know that the Amish Research Clinic and the Clinic for Special Children sometimes collaborate?

We both work toward improving health within the Plain communities. ARC performs research studies trying to learn more about the nature of disease caused by gene changes or about the ways some medicines are more effective in individuals with certain genetic characteristics. CSC works to treat or prevent genetic illnesses through their research and clinical practice. Sometimes our work compliments each other.



Photo: Dawn Fox RN

For example, Dr. Amber Beitelshes, Professor at the University of Maryland School of Medicine, is currently conducting a study comparing two methods of sharing important disease-risk information in families with hereditary illnesses (our DISC study, previous page). It's helpful to learn preferred or more effective ways of sharing this kind of information within families, as awareness can reduce risk of harm from conditions like Long QT syndrome and hereditary high cholesterol. "The main purpose of this study is to help us better understand the most effective way to notify and screen family members of an affected individual," Dr. Beitelshes explains. CSC provides the clinical testing on each sample collected in participant homes as part of the study to confirm the gene change in the affected individuals, and to identify whether their family members inherited it.

The work of both clinics will continue to identify gene-change-caused disease as well as ways to treat or prevent it. These ways can only be useful if individuals are aware of their particular risk.



In turn, findings from our studies at the ARC have informed updates to the CSC carrier test, called the Plain Insight Panel™ or PIP, a genetic test to determine carrier status for a wide variety of inherited conditions (currently over 1,300) found in the Plain communities of PA, OH, DE, IN,

and WI. For example, both the of gene changes being studied in the DISC study were discovered through ARC studies and are now part of the PIP panel. We can even draw samples, sometimes, for the PIP while we're in homes for our study visits. This test is most informative when done as a couple before or during pregnancy, but can be done diagnostically also.

The ARC and the CSC are proud collaborators on Plain Community Health!

# Current Studies, cont'd

## Genetic Diversity in Plain Populations

This huge study aims to identify gene changes in people of Anabaptist ancestry around the country, and to understand how these gene changes affect health. Our findings may help to improve healthcare for future generations.

We're so grateful for the response we've received this past year from settlements outside Lancaster County, both Amish and Mennonite! We continue to expand our efforts and reach geographically.

We're searching for ways to reach out to young adults not yet listed in the 2022 Mapbook. And we welcome anyone who is 18 years or older, of Anabaptist ancestry, and who has not previously participated in the study to participate. The benefit is bloodwork results at no cost that give a good overview of your health. At the same time, these results are helping us reach the goals of our research.



We are looking for more connections to settlement areas outside of Lancaster County, particularly in PA and NY. If you know folks who might want to help bring the study to their area, we'd be happy to hear from them.

If you would like more information or would be interested in participating in this study, please contact Leslie Drummond at 717-917-7304.

In this expansion of the old Wellness Study, we have collaborators at the Community Health Clinic in northern Indiana and at the DDC Clinic in Middlefield, Ohio, who are also gathering data. At this point, our study contains data from 4,103 individuals.

## PORT Study

The PORT study is a 'targeted' study, meaning that we want to include people with a specific gene change, asking them to test a medicine most often used to treat diabetes, called *semaglutide*. So these are individuals who've taken part in previous studies through our clinic and have given permission for us to re-contact them. Our goal is to have 325 healthy, non-diabetic, overweight adults test the medicine over seven weeks, with two clinic visits during that time. We hope to see how each one's genes influence how well *semaglutide* controls blood sugar levels, and influence the side effect of weight loss. We hope you'll consider participating if you receive a brochure in the mail or a visit from one of our nurses.



# Zinc Supplementation Study

## HEMOGLOBIN A1c



We're one year into our Zinc study and are making progress in enrolling 200 pre-diabetic participants (meaning that blood sugar (glucose) levels are higher than normal but not yet at the level of diabetes). Over time if not controlled, this can progress to full-blown type 2 diabetes, which affects approximately 90 million

Americans and leads to significant negative health consequences.

One may not know s/he has prediabetes without a blood test called an A1c. Currently there are no FDA-approved medications for treatment. We're inviting participants who've been identified as having prediabetes by being in previous studies. If qualified, they'll be asked to take a low-dose Zinc tablet or a placebo (a pill without the medicine but that looks the same) for one year. We'll evaluate the health of the individual initially at a baseline visit, then at six months, and again at 12 months.

The study's goal is to design new therapies, with little to no side-effects, that slow or prevent the progression of prediabetes, ultimately helping to reduce chronic complications associated with type 2 diabetes. This could potentially lower related healthcare costs as well.

## Donation Message

### Support the Amish Research Clinic

Since 1995, the Amish Research Clinic has served the Plain Community through vital medical research. Thanks to your generosity, we've made meaningful progress - and with your continued support, we *can do even more*.

### How Your Donations for ARC Help:

- **Clinic Operations:** Covering lab supplies, equipment, and essential technology.
- **Transport Van:** Replacing an aging van ensures safe travel for participants and home visits.
- **Genetic Services:** Supporting diagnosis and counseling for inherited conditions.

Your freewill donations sustain our mission to improve health care and share knowledge within the Plain Community. This year, we've set a goal of \$10,000—a **reachable target with your help**. Every gift makes a lasting impact on our community. **It is time to give.**

**To Donate:** Make checks payable to **UMBF/Amish Clinic** and kindly mail your annual donation to:

### University of Maryland School of Medicine

Office of Development  
31 S. Greene St., 3rd Floor  
Baltimore, MD 21201  
Attn: Traci Morgan

**Or donate online:** [www.medschool.umaryland.edu/AmishClinicGift](http://www.medschool.umaryland.edu/AmishClinicGift)

Questions? Call Robert Brown at 410-706-0106

UMBF, Inc. is a tax-exempt corporation, exempt from federal income tax under Section 501 c 3 of the Internal Revenue Code, and recognized by UMB's governing board as an affiliated foundation of UMB. At UMB's request, UMBF, Inc. may accept gifts and grants intended to be transferred to, and to support the work of, UMB when the receipt of the funds by UMB is not feasible. A portion of any contribution to the University of Maryland School of Medicine may be used to enhance advancement efforts.



University of Maryland  
School of Medicine  
**Amish Research Clinic**  
**921 Village Road**  
**Lancaster, PA 17602**  
**Phone: 717 392-4948**

### Coming Soon ~

#### **Sitagliptin Study**

This is a new study to find out how different people respond to a medication called *sitagliptin*, which is FDA-approved and used to treat diabetes. We are looking for healthy, non-diabetic volunteers with a particular gene-change and who are overweight to participate in this seven-week study that involves two clinic visits four to six weeks apart.

If we contact you and you fit the criteria, we hope you'll consider participating and helping us to continue producing important medical research that can improve or even save lives in the future.

### **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 Plain Community.

