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MID-ATLANTIC MATR TWIN REGISTRY VCU

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Twin Matters

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A Family Newsletter from the Mid-Atlantic Twin Registry

MID-ATLANTIC MATR TWIN REGISTRY VCU

Summary of Published Results from the *Genetics & Epigenetics of Healthy Aging in Twins* (GHA) Study

MATR twins that have participated in research studies are often curious about knowing what a study "discovers," so, we are always pleased to share updates on study results! From approximately 2013 to 2015, the MATR helped recruit full pairs of same-sex twins 65 years or older into the *Genetics & Epigenetics of Healthy Aging in Twins* (GHA) study, which aimed to identify why some individuals seem to age "better" than others. Researchers know that, generally, much of the variation seen in aging characteristics is based less on inherited genetic factors and more on environmental factors influencing non-inherited gene changes - called epigenetic changes. The GHA study was particularly interested in the impact these epigenetic changes have on the aging process. Twin participants were crucial to helping the research team understand how some of these epigenetic changes may influence aging.

Epigenetic changes are chemical changes that happen to the DNA that makes up our genes. In simplest terms, these changes often act to turn "on" or "off" certain genes. Though epigenetic changes are part of the normal and necessary chemical interactions in our cells, they can be influenced by a variety of factors, including what we are exposed to throughout our lives, such as pollution, medicines, and other chemicals, as well as by illnesses and even how much sleep we get! For example, someone that is a lifetime smoker will often have epigenetic changes that might make that person look like they have "aged quicker." This is why you may encounter a pair of (genetically) identical twins and the one that was a lifetime smoker sometimes looks older than the one that did not smoke.

For the GHA study, the epigenetic change of interest is called DNA methylation. DNA methylation involves a chemical group, called methyl, bonding to sections of DNA that might "turn on or off" another gene. In this case, the study observed how the methyl groups would prevent a gene, called *PCDHGA3*, from being able to be "turned-on." *PCDHGA3* is part of a group of genes on chromosome 5 that are associated with biological age. Biological age is a bit different from chronological age. You may be a certain age in years (chronological age) but your biological chemical-markers and related health measures may indicate that you are younger- or older-seeming than your actual age in years.

Since biological age is determined by a variety of factors, including scaled answers to health questionnaires, the presence or absence of certain health conditions, and other variables, it can be difficult to treat biological age as a discrete measure. This makes it challenging to use in analysis so researchers will often develop a score, called a frailty index, to represent biological age. A lower frailty index is generally an indicator of "healthier" aging or "younger" biological age. Once the GHA study team established the frailty index for this study, they could then begin to look at this measure and the concentration of methyl groups at various DNA sites to see if there were any predictable relationships between the frailty index and DNA methylation patterns.

Through its analysis, the study found that higher levels of DNA methylation were associated with decreases in the activity of the *PCDHGA3* gene, which in turn seemed to lead to a change (typically higher) in the frailty scores. This suggests a possible relationship between *PCDHGA3* gene-activity, DNA methylation, and biological age. Ultimately, this will help shed light on whether this is one of the potential pathways that influences "healthy" vs. "unhealthy" aging patterns. While this sounds very technical and gene-specific, having these "molecular details" are what is needed to truly understand variation in aging. It is from this type of methodical improved understanding that the GHA researchers seek to find ways to help offset age-related health declines.

The full article, *DNA methylation associated with healthy aging of elderly twins*, by Sangkyu Kim and others, can be found in the August 2018 edition of GeroScience. This article illustrates the complexity of answering seemingly straightforward scientific questions! It also demonstrates the level of care and quality control the researchers took in making sure their results were as reliable as possible. We will link to this article on our website once it becomes publicly available. We thank the MATR twins who took part in this research study for furthering knowledge of the human aging process!

Greetings MATR Participants!

What a whirlwind of a year we've had so far! We recently completed recruitment for the ABCD and T4T studies, both of which had been ongoing since summer of 2016. Over a thousand twins and their families took part in the MATR screening surveys for those studies over the past two years, so we send our gratitude to all of you who participated! As we wind down from those studies, we turn our gaze towards launching several new projects – including revitalizing the MATR General Health Survey for Adults. So, dive-in to learn more about how you can take part in our new twin research projects!

With Thanks,

Judy L. Silberg

Judy Silberg, PhD
MATR Scientific Director

Text-4-Thoughts (T4T) Study Update

The MATR recruitment efforts for this study have now ended, but that does not mean the study is quite done. Participants that completed the MATR step may still be contacted by the study staff for some time to come. Participants that started study enrollment and have not had a chance to finish are encouraged to contact that study (if you have misplaced the study's contact information, feel free to touch base with the MATR at 1-800-URA-TWIN or matr@vcu.edu for the study staff's contact details). We greatly appreciate all the twins and parents of twins who took the time to learn more about this study, and special thanks to those families and twins that took part in the study portion!

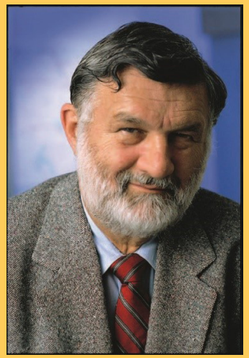
Seeing Double: Take Another Spin with Your Twin at the Southern Women's Show 2019

Next year we will once again partner with the Southern Women's Show (SWS) in Richmond for the 2nd Annual *Take a Spin with Your Twin* contest on Saturday, March 23rd, 2019! This is a contest for **ALL** twins, triplets and higher order multiples; both fraternal and identical are invited to take part! This year we will divide the contest into two age groups, one for juveniles and one for adults.

Twins are invited to take the stage together for the audience to decide on the "twinning" pair. Get creative and show off your twin pride! Winners will take home a prize.

Check our website **go.vcu.edu/matrevents** for more information as the date gets closer. We hope to see you all there!

Introducing Dr. Mack…



Dr Thomas Mack

We are pleased to start a collaboration, looking into breast cancer risk factors, with Dr. Thomas Mack—Professor of Preventive Medicine & Pathology at the University of Southern California. This partnership represents a full circle in Dr. Mack's career. A career, which spans impressive medical training at Columbia University, the Centers for Disease Control, and Harvard; and, includes work on smallpox eradication, certain cancers, and Hodgkin's disease. Much of Dr. Mack's research, including his current work incorporating the MATR, has its footing in a chance meeting from a couple of decades ago. While serving on a National Institutes of Health committee evaluating grants, he happened to be seated next to Dr. Walter Nance. Many of our longtime MATR members will remember Dr. Nance because his work in pediatric twin studies at VCU helped lay the foundation for the Mid-Atlantic Twin Registry. Through their discussions about twin research, Dr. Mack saw the exciting potential for helping to overcome some of the challenges he faced in studying chronic disease. He realized that adult twin subjects could help him sort out the genetic, cultural, and lifestyle factors that all play an influencing role in the development of chronic diseases, like cancer. From that happenstance meeting, Dr. Mack went on to establish twin studies and registries that have helped solidify our understanding of certain chronic diseases. For example, twin participation in his research has helped his team learn that Hodgkin's lymphoma has a strong heritable component and shares features with autoimmune diseases; that childhood exposure to sunlight (thus Vitamin D) seems to help protect against multiple sclerosis; and, that both genes and environment play a role in the development of malignant melanoma. **Now Dr. Mack is seeking continued help from twins on his search for a clearer understanding of just how the factors that influence breast cancer risk (genes, environment, lifestyle choices, etc.) impact the likelihood of breast cancer development**. As you can tell from just a few highlights of his impressive career, Dr. Mack is passionate about improving health outcomes. Both he and the MATR hope that MATR twins that are eligible for the study are equally passionate in supporting these efforts. See the Twin Breast Cancer Study advertisement in this newsletter and visit: **go.vcu.edu/learnmore** to sign up for more information.

Adolescent Behavior Cognitive Development (ABCD) Study Update

The first benchmark in the ABCD study has been reached with approximately 430 twins (215 pairs) completing the ABCD baseline study measures! This is an ambitious, groundbreaking research effort, with multiple university partners across the United States. The ABCD study will use this first set of data provided by participants as a baseline and then hopes to follow those same participants for up to ten years. By doing so, this research will create an impressive depth of data about brain and cognitive development.

Since the ABCD study hopes to follow-up with participants, they will continue to contact families that agreed to hear from the study for some time to come. Families that are enrolled in the study are encouraged to update their contact information. If your contact information changes feel free to visit go.vcu.edu/twinupdate for an online update form.

The more participants that stay in the study and continue with the follow up requests; the more likely those research efforts are to produce unprecedented understanding of the human brain. And, though we hope each family can remain in the study for its duration, we understand that is not going to be possible for all the participants, so the MATR will contact families, as needed, to help 'fill-in' when this happens.

We are so appreciative of all our participants' generosity of time in learning about this study -- an extra big thank you to those who are participating in the study!

Upcoming & Potential Research Topics

For the past few years, our collaborators have focused their research on human behaviors and mental health. Recently, researchers have been in contact with us to see if it would be feasible to generate enough twin participants for research on physical health conditions. We are excited to get started on two new studies – one that wants to better understand **psoriasis** and **psoriatic arthritis** and another that will investigate **breast cancer risk (see below for more)**. Lastly, there may be a potential opportunity for twins that are impacted by hyperparathyroidism*.

If you are interested in learning more about these any of these studies, please let us know and make sure we have your current contact information by completing the online form found here: ***go.vcu.edu/learnmore***.

*Hyperparathyroidism – a condition due to overactive parathyroid gland(s). The four parathyroid glands sit behind the thyroid and hyperthyroidism is a different health condition.

NEW STUDY OPPORTUNITIES FOR ADULT TWIN PAIRS…

Role of the Microbiome in Monozygotic Twins with Psoriasis & Psoriatic Arthritis

(a.k.a., Psoriasis & Psoriatic Arthritis Twin Study – PATS)

The Psoriatic Arthritis Center and the New York University Division of Rheumatology are providing funding to investigate potential causes of psoriasis and psoriatic arthritis. They are partnering with the MATR to invite twins to participate.

Participants the study will need include:

- FULL PAIRS of Same-sex twins
- Adult twin pairs (18 and up)
- Identical (or unknown/unsure zygosity)

Study participation involves:

- Completing the MATR invitation to "sign-up."
- Providing your consent and possibly medical authorization to access medical records related to psoriasis/ psoriatic arthritis to the study.
- Providing answers to questionnaires as well as stool, blood/DNA, and skin swab samples to the study – participants will be provided the opportunity to complete the study at New York University (travel costs provided by study) or at home.
- Compensation ($) is provided

If Interested in either study:
Contact the *Mid-Atlantic Twin Registry* (MATR) and let us know that you want to learn more about the ***Psoriasis Twin Study*** or ***Twin Breast Cancer (TBC) Study***. Please provide your full name and date of birth. You can reach us at:

- 1-800-URA-TWIN (1-800-872-8946) toll-free,
- matr@vcu.edu,
- Complete the online MATR Form at: **go.vcu.edu/learnmore**

Twin Breast Cancer Study

The National Institutes of Health (NIH) has provided funding to Dr. Thomas Mack of the University of California to study breast cancer risk factors in twins. Dr. Mack is partnering with the MATR to invite twins to participate.

Participants the study will need include:

- Female identical or fraternal twins with
- A history of breast cancer in *one* or *both* twins
- Ages 18+
- Full pairs are ideal but NOT required for participation

After completing the MATR invitation to "sign-up" to learn more:

Study participation involves:

- Providing the study with your consent and possibly medical authorization to access medical records related to breast cancer.
- Providing answers to questionnaires as well as a saliva sample for obtaining DNA.

We Appreciate You!

Recently, we've had the opportunity to say thank you to some of our twins and their families for being registered members, updating their contact information, or sharing a story or photo with us! These tokens of appreciation could be a ticket to an event or a gift card for a modest dollar amount. Recipients are chosen by random periodic drawings, so please keep those updates, stories, and photos coming our way – you might be the next recipient of one of these tokens! Read what some of our lucky members had to say about being in the MATR:

Audrey M. whose family has been registered for 20 years, said "*As a twin, I've always felt uniquely different from society. The studies MATR performs are interesting and vital to mankind. Through these studies, much is to be learned. I am grateful such an organization exists.*"

Monica P. and her family have been members for almost 10 years and she said she enjoys "*Being able to help science and scientists find clues and solutions to different studies" and "helping others learn too.*"

Sara J. and her twins have been members since 2012 and Sara enjoys "*learning more about current research*" and "*being involved in [the] overall community*"

Allison S. and her family have been registered since 1998, said she and her twin, "*…have done surveys over the phone, which were enjoyable to participate in! Many friendly people!*"