



Virginia Commonwealth University



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The MATR says 'Thank you'

In recent months, we have had the opportunity to provide a token of thanks to some of our twins. Sometimes, this is a thank-you to those that are registered and for others it's to show our appreciation for updating contact information, sharing a story and/or photo, etc. Our tokens of appreciation might include a ticket to an event or a modestly valued VISA or store gift card. Recipients are chosen by periodic random drawings and are notified by mail, email, and phone (see go.vcu.edu/twinupdate to update your contact information). Here are some of the things recent recipients had to say about being in the MATR.

Diane Hart, a MATR participant for more than 20 years, was recently selected to receive a gift card as a token of our appreciation. Ms Hart said 'I am so happy to participate in the MATR studies. The research is so important and it is an honor to be part of it. My sister lives in another country but whenever we see each other it is as if we see each other every day and not once or twice a year. It's a great feeling to be so connected and in tune with each other.'

Clifford Kreiler, a member of MATR since the 1980's, told us he enjoys 'The valuable information about twins that comes in the newsletter that I receive.'

Whitney Carter, another MATR participant since the 1980's, said 'I love the research that comes out of the studies and like to see what makes twins unique and different as separate people.'

Judith Hoyer, a MATR member for 30+ years, said 'The thing I enjoy the most in the twin study is learning the results and medical implications of the research as applied to my twin and me.'

Margaret Hensley joined the MATR in the 1980's and says 'I believe in contributing to science, and the studies conducted through MATR are one of the ways I can be a part of the valuable science.'

A Family Newsletter from the Mid-Atlantic Twin Registry

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Greetings MATR Community,

As we move through fall and into the winter months, the MATR is launching two new studies for our pre-adolescent through young adult twins. This edition of Twin Matters is full of information about current and recent studies that MATR twins are a part of and we invite you to take a moment to read all about how our twins are making a difference in research. As always, we want to send a big, sincere "Thank You" to all of our twins and their families who take part in our studies - you make our research possible!

Warm Regards,

Judy Silberg, PhD
MATR Scientific Director

New Study Opportunity

For families with 9 & 10 year old same-sex twin pairs...

The MATR is pleased to announce that we are inviting twins to take part in a new study, called the Adolescent Brain Cognitive Development (ABCD) Study. This is a ground-breaking project and is part of a consortium of 19 academic institutions. The goal of this study is to provide unprecedented understanding of the adolescent brain and cognitive development. Below are a few words from one of the study's main investigators, VCU's Dr. James Bjork:



Dr. James Bjork

"As a parent of 10-year-old and 12-year old boys, the ABCD project has special meaning to me. What will their adolescence be like? How will their experiences shape their brains, and vice versa? The ABCD project is a very special initiative that holds potential to detect unprecedented connections between brain, behavior, and environment during human adolescence. I feel privileged to be part of such a magnificent team of investigators across the nation, from Hawaii to Florida, to Vermont, who have worked arduously and collegially to come up with a set of tests that offers the most scientific value at the minimum possible burden to children and parents. The team of research staff here at VCU is skilled and eager to work with children and families from Virginia and neighboring states. Particularly special and scientifically valuable is our invitation to families with twins. I am excited too about the cutting-edge technology brought to bear in VCU's Collaborative Advanced Research Imaging (CARI) MRI scanner, with its crystal-clear glimpses of brain structure and function. It is my hope to reach out to every family to express my gratitude for their participation. It is a leap of faith to offer to take part in something so enduring and so grand. It holds potential to change young lives for decades to come."

James M. Bjork, PhD
Associate Professor
Department of Psychiatry

If you're interested in learning more about this study, please see the study advertisement in this newsletter and/or go online to go.vcu.edu/twinstudy.

We Value You

The Mid-Atlantic Twin Registry (MATR) values our participants. If you have feedback regarding your experiences with MATR staff or research staff for any study, please do not hesitate to send us an email to matr@vcu.edu, call 1-800-URA-TWIN (1-800-872-8946) or call our Participant Coordinator, Carol Williams, at 804-828-8116.

One Twin's Story of Loss and Aspiration

We are always saddened by the news of one of our twins passing away, in part because we know that for twins, the struggle with feelings of loss and grief is often compounded by the twin bond. Recently, Jacqueline Hatch shared her emotional experience with us about the loss of her twin and her efforts to create positivity from her bereavement. She asked us to share her story with MATR twins. The full version of her experiences may be found at go.vcu.edu/matrstory. Below are a few excerpts from her compelling and heartfelt story...

We loved being twins! I had my twin brother for 28 years before he died unexpectedly. At the time of his death I had been a social worker for more than seven years. I worked primarily with older adults and thought I knew about grief and loss. I had formal education on how to address grief, and routinely supported others through a variety of losses where I was employed. When my twin died, I quickly realized I had no idea what grief really meant. The level of devastation that engulfed my world remains hard to adequately describe in words. Not only had my twin brother died unexpectedly at such a young age, half of me died too.

As I struggled through the darkness of grief and participated in grief counseling myself, from more than one counselor, I did not gain much traction. I told myself... if I survived the death of my twin and stayed in social work, I would one day try to create a new path for other bereaved twins to travel. I wanted bereaved twins to know for sure they were with a professional who had specialized training to better understand twin relationships and most especially twin bereavement.

In 2014 I launched the Twin Resource Center [an education & counseling service]... in hopes of following through with what I told myself in those early days after my twin's death. Now it was time to create the new pathway for other twins.

How do we choose our twin studies?

Over the years, many of you have asked us how the MATR decides what studies we will help to conduct. Any new MATR project always starts with a researcher who is looking to study twins in order to answer a specific health or behavior-related question. They know that twin studies provide a unique insight used to increase understanding of the genetic and environmental factors which play a role in human health and behaviors. The researcher sends the MATR a summary of their proposed twin study as well as how many twins they need to take part and what study participation entails. We then evaluate the study to ensure that it is scientifically valid, that we have enough twins available to invite to take part, and that it is not too much burden on our twins to complete the study. We also decide whether the research actually requires twins or if the researcher could conduct the study with singletons instead. Finally, we verify the researcher's credentials to make sure they are qualified to conduct the research that they are proposing. If the researcher and the study pass all of the above tests (as well as some other factors), then we decide if their study is up to par with the high quality of research that MATR helps to conduct. We extensively screen all of our research studies to ensure that MATR twins are only invited to participate in studies that will be worth their time and will hopefully lead to valuable scientific results!



If you have not already, please take a minute to like our page to stay up to date on studies, twins in the news and events for twins! Check us out at www.facebook.com/twinsmatr or by searching "The Mid-Atlantic Twin Registry of VCU."

New Study Text 4 Thoughts (T4T)

The Text-4-Thoughts (T4T) study is being conducted by Dr. Cristina Bares, a professor with the School of Social Work at the University of Michigan. Similar to the JAS and AYATS research, she is focusing on twins ages 16-21 because adolescence and young adulthood are time periods of rapid physical and emotional development coupled with the pressures of key life changes. Dr. Bares will focus on an important research question; how mood is related to behavior choices in older teens and young adults. This age range is one in which individuals often develop certain behavior patterns (positive and negative) and health outcomes that can go on to affect a person well into adulthood.

If you are a parent of teenage twins, you are likely familiar with the sometimes rapid change in your teens' moods. And young adult twins have the additional stressors related to experiencing key transitional events, like going to college, starting careers, and/or moving out on their own. Dr. Bares is hoping to track changes in moods and behavior choices throughout the day over the course of a little over a week. Using this data, she hopes to identify patterns of moods that may be influencing choices such as who a teen or young adult chooses to spend time with or what activities they might be doing.

We hope that data from this study will further the understanding of factors that are driving decisions made by teens and young adults and could ultimately help to improve how teens make choices that may influence their life. If you'd like to learn more about this please see the study advertisement to the right or visit go.vcu.edu/twinstudy.



New Study Opportunities!

FOR JUVENILE TWINS...

Adolescent Brain Cognitive Development (ABCD) Study

National Institutes of Health (NIH) has funded groundbreaking research being carried out by a consortium of 19 academic agencies. Virginia Commonwealth University's (VCU) Department of Psychiatry, is only ONE of four twin sites recruiting for this study that hopes to provide unique insight into the brain and cognitive development starting in childhood.

Participants the study will need include:

- FULL PAIRS of Same-sex twins
- 9 or 10 years old
- Fraternal or identical

Study participation involves:

- Completing a 20 min (approx.) phone call with the MATR to hear more about the study.
- Coming to VCU to complete the study
- Compensation is provided

If Interested:

Contact the *Mid-Atlantic Twin Registry* (MATR) and let us know that you want to learn more about the **ABCD Study**. Please let us know the full names and DOB of the twin pair. Parents, please provide your full name as well. You can reach us at:

- 1-800-URA-TWIN (1-800-872-8946) toll-free
- matr@vcu.edu
- www.matr.vcu.edu; click "Contact MATR"



Adolescent & Young Adult Twin Study (AYATS) Update

Since the beginning of 2014, the MATR has collaborated with the AYATS study on their twin recruitment efforts. We have enjoyed finding MATR twins who are willing to participate in this research and we just finished actively contacting twins about this study at the end of October. The study will continue to contact the twins who have let us know they are interested in participating in order to schedule them for their first study site visit. Starting this past May, the study staff have been reaching out to participants that completed the first study appointment to invite them to complete follow up activities. For the next year or so, the study will continue to invite twin families to complete these follow up tasks. For some, the second phase of the study will involve an invitation to return to VCU to repeat some of the study tasks, while for others the tasks can be completed online from home. We really appreciate everyone's participation thus far and hope twins that completed the first appointment will have the opportunity to take part in the second phase of the study as well. We will continue to keep you posted in the newsletter and on our website and are excited to see the findings from this study!

FOR ADOLESCENT AND YOUNG ADULT TWINS...

Text 4 Thoughts (T4T) Study

University of Michigan's Dr. Cristina Bares is working on an innovative study investigating the impact that daily changes in mood have on driving certain behavior choices. This study is funded by the National Institutes of Health.

Participants the study will need include:

- FULL PAIRS of Female-Female MATR twins, 16 through 21 years old
- Can be identical or fraternal

Study participation involves:

- Completing a phone call with the MATR to hear more about the study.
- Providing assent (juvenile twin pairs) and/or consent (adult twin pairs and parent(s) of juvenile twin pairs) to participate.
- Completing online surveys:
 - Definitely completing one baseline data & eligibility survey that takes about 20 min.
 - If eligible, completing multiple short surveys (approx. three min each) online for a little over a week.
- Receiving text messages, which contain the links to the study surveys. Participants can use their own phones or be loaned one by the study.
- Participants receive compensation for their time.

If Interested:

Contact the *Mid-Atlantic Twin Registry* (MATR) and let us know that you want to learn more about the **Text 4 Thoughts Study**. Please let us know the full names and DOB of the twin pair. Parents of juvenile twins, please provide your full name as well. You can reach us at:

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