

Twin Matters

A Family Newsletter from the Mid-Atlantic Twin Registry

Greetings MATR Families

As we move towards the holiday season, we send our sincere gratitude to each of you for being a part of our MATR community! Twin studies have led to scientific discoveries that are only possible with the participation of twin families such as yours. In this volume of *Twin Matters* you will find info about current and past studies as well as our newly launched, just for fun, *Twinning Experience Survey*. Also, in a few months you can expect an invitation to complete our MATR Health & Behavior Survey for Adult Twins, so be sure to update us with your email address in the meantime. Thanks again for your continued interest and support of twin research!

Judy L. Silberg

Judy Silberg, PhD
MATR Scientific Director



Twinning Experience Survey - Just for Fun!

Are you curious about the experiences of other twin families?

We are too...and so are other MATR twin families...

One of the comments we often receive about why twins and their families have registered with us is that they want to hear about other twins' experiences. Things like...Were you and your twin dressed alike as children...or dressed so that people could tell you apart? Did you ever swap places and pretend to be one another? Could you tell when your twin was upset or hurt when you weren't together? For parents of twins – what is your favorite part about raising twins? What is most challenging? . . . Let us know all about being twins and parenting twins by completing our new “just for fun” *Twinning Experience Survey*. This survey is for our adult twins as well as parents of twins and answers are anonymous. We will compile the responses and present them in future newsletters and on our Facebook page so you can see just how much fun being a twin can be!

Visit go.vcu.edu/twinfunsurvey to complete the survey.

ABCD Study Update

It's hard to believe that the *Adolescent Behavior Cognitive Development* (ABCD) study is already in its third year of follow up! The VCU ABCD staff started the latest follow up requests in October of this year. We are very appreciative of all the MATR families that have contributed to the initial accomplishments of this groundbreaking effort and are doubly impressed by those completing the follow-up requests. And, if you're an ABCD family wondering if the data is producing useful information, we think you will be pleased to learn there are interim findings that are only possible because of your efforts! We encourage you to visit abcdstudy.org/news to learn more.

Since the ABCD study is a collective effort between multiple institutions, an unprecedented depth and quality of data has been produced and is being shared with the scientific community. This has enabled multiple investigators and research groups to begin working with this data to quickly establish early findings. The preliminary analyses have explored the relationships between brain development and activity, and everything from exercise, sleep, & social media use, to participation in team sports, screen time, & environmental exposures. Screen time seems to be garnering quite a bit of research interest, particularly because cell phones, tablets, and similar technologies are increasingly available to young children. This has caused concern in parents and educators about the possible impacts on the brain. It is important to keep in mind that these early findings are merely laying the groundwork for improving our understanding of if, and how, brain and cognitive development might be influenced and it is much too soon for causal relationships to be identified. This means that these interim findings are suggesting associations between an activity (say social media use), the brain and thus behaviors and/or mental states. Still we think you will find these early findings interesting and they demonstrate how continued participation will help provide insights needed to strengthen our understanding of how these factors are influencing brain and cognitive development.

Twin Breast Cancer (TBC) Study Update

In January of this year, the MATR sent TBC study brochure invitations to over 16,000 twins in order to find adult female twins who have been diagnosed with breast cancer. We are now in the final phase of recruitment for this study. If you received a study invitation (through the mail or email) and want to sign-up to hear from the study staff, then please complete the mailed or online form and we will let the study staff know that you are interested in learning more.



A big thank you to all of the twins that provided information or contacted us about this study. Our twins also shared stories with us about their experience with breast cancer; either their own diagnosis or someone in their family, so we realize that participating in this study may have been emotionally challenging for some. We truly appreciate hearing your stories and wanted to acknowledge this difficulty. For those that have lost a twin, we hope the *Twin Loss & Grief* article in this newsletter provides helpful resources.



Multiples of America Convention

In July 2019 MATR staff had the pleasure of attending the 59th Annual Multiples of America National Convention in Alexandria, Virginia. We were so happy to have the opportunity to meet representatives of twin clubs from around the country.

During one of the General Session meetings, our MATR Participant Coordinator, Carol Williams, had the opportunity to give a presentation for the Board of Directors and 200+ convention attendees, which included an overview of the MATR and a short video about participating in twin research studies (go.vcu.edu/matrvideo). Thanks to the twin families at the convention, we registered over 20 pairs of twins and collected email addresses from 37 clubs from across the US.

We are always grateful when we can share the importance of twin-based health research and get the word out to the twin community! We would like to extend a special “Thank you” to Terri Gillis, Meeting Planner, for her guidance and kindness.

Psoriasis and Psoriatic Arthritis Raffle Drawing...Coming Soon

Participants that returned a completed *Psoriasis & Psoriatic Arthritis Twins Study* (PATS) form might be wondering if the drawing for the study has occurred yet. We are still receiving completions, so we are waiting a little bit longer to hold the drawing to ensure everyone that completes the form is entered.

For twins that received a study invitation and sign-up form for this study and haven't returned it yet, there's still time. And, if you and your twin are interested and think you might qualify (adult twin pairs where at least one twin in a pair has psoriasis and/or psoriatic arthritis) please visit: go.vcu.edu/learnmore to let us know that you are interested in learning more about future opportunities.



Keep us Posted!

Please let us know if your name, address, email, or phone number changes by...

- visiting: go.vcu.edu/twinupdate
- emailing us at: matr@vcu.edu or
- calling our toll free number: 1-800-URA-TWIN

Show and Tell

We love hearing from our twins! Go online and share a story about your adventures or submit photos to show us what you've been up to. Visit go.vcu.edu/photostory to upload photos and stories to a secure, confidential server.

Sharing a story or photo is another way you can be entered in to our drawing for a gift card or other token of thanks and your story or photo might be featured in a future newsletter or on our website!



Watch This Space...

In early 2020, MATR twins ages 18+ will be invited to complete an online survey that covers a range of topics about health, attitudes, and behavior. The goal of the survey is to collect data for researchers to learn more about a variety of topics as well as basic health information so the MATR will know which studies our twins might be interested in learning more about.

In order to receive an invitation to this survey, please visit: go.vcu.edu/twinupdate to make sure we have your current email address and please select "MATR Health & Behavior Survey (MATR Survey) for 18+ twins" under studies you might be interested in.

Providing your email address will also enter you to win one of several \$10 Target gift cards



Twin Loss & Grief

We know that just as twins are unique throughout their lives, for many, the passing of their twin can lead to a distinctive sense of loss and grief that only fellow twins would fully understand. Because of this, we wanted to take a moment to thank all of our members for being part of this community of twins and multiples (some have been members for decades!) and to provide some resources that might be helpful to those twins that have lost a twin.

Twinless Twins Support Group International, LLC
twinlesstwins.org

"...a safe and compassionate community for twinless twins to experience healing and understanding. TTSGI also provides support for twins and other multiples who have lost their twin due to death at any age."

Twin Resource Center
twinresourcecenter.org

This North Carolina-based center was started by a twin after she experienced the loss of her twin brother. The center provides outreach and "...counseling services to twins and their loved ones by giving them the unique perspective of a trained, professional counselor who happens to be a twin herself." We featured a twin story shared by the twin that started this center in the fall 2016 newsletter. Visit go.vcu.edu/twinmatters to view this article.

The Lone Twin Network
lonetwinnetwork.org.uk

"... a voluntary support group run by and for lone twins, over the age of 18, whose loss has occurred at or around birth, in childhood or during adulthood."

We hope these resources will be helpful to those that need additional support, but please feel free to contact the MATR to share your stories with us and to ask if we know of other support that might be useful. And, to twins who have undergone the loss of their co-twin, please know you have our deepest sympathies and condolences.

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 call our Participant Coordinator, Carol Williams, directly at 804-828-8116.