



Twin Matters

A Family Newsletter from the Mid-Atlantic Twin Registry

“Why don’t you go change your shirt?”

My brother Keith and I have been fooling people for 63 years now. When we were young, our parents dressed us alike. Over the years, we did not intentionally dress alike, but many times we would show up at the same place with matching pants and shirts. Of course we would say to each other, “why don’t you go change your shirt?” It has happened so many times, that most people think we probably planned it that way.



Both of us have had experiences with perplexed strangers. I even had a teenage boy jump on my back in Walmart thinking I was Keith. Of course he and his parents were embarrassed when they finally figured out I was not the one they knew. We both received pacemakers within a few months. There have been a few other sicknesses or injuries we both have had. Regardless of what some think, one of us does not feel the physical pain the other may be experiencing.

It has been a joyful life being a twin. I wouldn’t change it for anything.

Story shared by William P. Note- minor edits were made to the original story

Greetings!

We have several new studies underway, so be sure to keep reading to find out more about how twins can help promote research looking into breast cancer risk as well as the relationship between the microbiome and psoriatic conditions. And, as always, we are so very appreciative of our twins who are participating and doing their part to advance our knowledge of human health and behavior.

Thank you all for being part of the MATR community!

Judy Silberg, PhD
MATR Scientific Director

Twin Matters

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Surprise...it’s twins!

I’d always wanted a little boy of my own. I tried for several years with no luck; then I tried fertility drugs for a couple of years with no luck. My doctor told me that I’d never have another child (I have a daughter who is 10 years older than my twin boys).

I moved on with my life, finally coming to peace with the fact I’d never have a son of my own. A few years after coming to terms with this fact, I began having morning sickness. I took a home pregnancy test never expecting it would read positive. I couldn’t figure it out; I must be reading the test wrong, I was certain there was no way it really read positive.

My first appointment at the OBGYN, I was certain they would tell me that I wasn’t really pregnant... instead they showed me Baby A and Baby B on the sonogram!!!! I started laughing I was sure she was playing a trick on me, she assured me that it was no joke, I was pregnant with identical twins! From that moment on, life has never been the same.

The boys came two months early and spent a month in the NICU. They are each other’s best friends and have been a double blessing to our lives. I feel so lucky to have been chosen to receive the gift of twins.

Story shared by Jennier S. Note - minor edits were made to the original story.



We love hearing from our twins!

Share your story or photo with us at: go.vcu.edu/photostory - submitting a photo or story enters you into a drawing for a gift card and you might be featured in our future newsletters!

Twins marry twins



Photo Courtesy TLC

A Recent Quaternary Marriage

With the closeness of many sets of twins, it seems natural that sometimes twins would end up marrying other twins but surprisingly, it's not that common at all! The official term for marriages between sets of identical twins is "quaternary marriages."

As chance would have it, a quaternary marriage just happened last fall! Identical twins Jeremy and Josh Salyers met identical twins Briana and Brittany Deane at the 2017 Twins Days Festival in Twinsburg, Ohio. In February 2018 the Salyers twins proposed to the Deane twins at Virginia's Twin Lakes State Park. Six months later the couples held a joint wedding at the 2018 Twins Days Festival, one year after having met there. Talk about a twin-centric wedding ceremony! News articles as well as a video from TLC about their marriage can be found here: go.vcu.edu/twinnews.

Children of Quaternary Unions

When a pair of identical twins has children with another set of identical twins, their offspring are considered to be related as first cousins. However, because identical twins have identical DNA, the children of these quaternary couples are actually as genetically alike as full siblings. This is an oddity of genetics that only occurs in this type of union. Much more common is when identical twins have children with unrelated individuals. The children from these couples are also considered related as first cousins, but are actually as genetically alike as half-siblings.

Adolescent Behavior Cognitive Development (ABCD) Study update

As those that follow our newsletters know, the MATR recruitment for this study has predominantly ended. We remain excited to see the results of this groundbreaking research effort in the years to come. The ABCD study staff will continue to contact the families that completed their study baseline appointments for follow up requests. Families that are enrolled in the study are encouraged to keep us up to date with any new contact information at go.vcu.edu/twinupdate.

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.

Both the MATR and ABCD study staffs continue to feel a great deal of gratitude to all the families that have taken time to learn more about this study and we send a big thank you to those that were able to participate!

For those who are participating in the ABCD study, we'd love to hear a twin family's perspective about what it's been like for you to take part.

Please email us at matr@vcu.edu if you would like to share your experience with us!

Have you ever heard of semi-identical twins?

There is a very rare form of twins that are more genetically alike than fraternal twins (who share an average of 50% of the same genes), but are less alike than identical twins (who share nearly 100% of the same genes); they are also not polar body twins. This rare form of twins is called semi-identical or sesquizygotic. Doctors in Australia recently identified a pair of semi-identical twins and we thought our MATR twins might be interested to learn more. A link to the full article can be found here: go.vcu.edu/twinnews.

Keep us Updated!

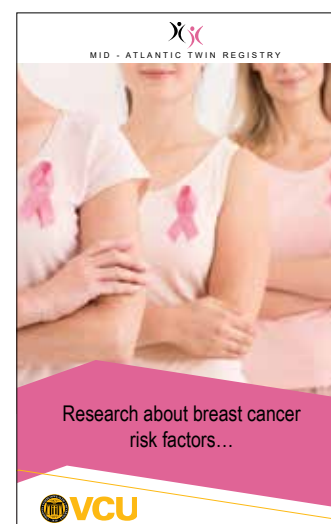
Please let us know if your name, address, email, or phone number changes by going to: go.vcu.edu/twinupdate, sending us an email at: matr@vcu.edu or calling our toll free number 1-800-URA-TWIN (800-872-8946).

Current and potential research topics...

The MATR has recently started recruitment for two new studies focusing on health conditions. For each of these studies, twin participants are crucial for shedding light on how such conditions develop.

We have sent out informational brochures for both of these studies, so you might have received one of the brochures in the mail already (the images here show what the brochure covers looks like).

The Psoriasis & Psoriatic Arthritis Twin Study (PATS) hopes to better understand how portions of the human microbiome influence psoriasis and psoriatic arthritis development.



While the Twin Breast Cancer (TBC) Study, will investigate breast cancer risk and attempt to identify the relationship between the genetic and environmental influences (including those from childhood) that impact risk for breast cancer development.

More information for these studies can be found in the "New Study Opportunities" segment on this page. If you are interested in learning more about these

studies, please let us know and help make sure we have your current contact information by completing the online form found here: go.vcu.edu/learnmore.

Lastly, there may be a potential opportunity for twins that are impacted by **hyperparathyroidism**.* The form found at go.vcu.edu/learnmore can be used to volunteer interest in learning more if the research group decides to move forward with this study.

* *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

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.

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