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Twin Matters

A Family Newsletter from the Mid-Atlantic Twin Registry

Volume XXV

Dear MATR Community,

Happy Spring from all of us here at the MATR! We are diving head first into some really fascinating new twin studies this season and finishing up with some of our successful ongoing studies – all thanks to the participation of MATR twins! We hope that you will take a few moments to review our newsletter and our website to learn more about how you can take part in our current research. We also invite all MATR twins ages 18 and older to participate in the online MATR Health, Personality, Lifestyle, & Social Attitudes Survey. If you are interested, please visit our website and follow the “MATR Survey” link to let us know you want to take part!

Thanks to everyone for your participation in the MATR and for helping our researchers tremendously by taking part in their research studies. Keep an eye out later this year for our fall newsletter when we will provide some updates from our studies so you can see how MATR twins and their families are making a difference in research!

Warm Regards,

Judy Silberg, PhD
MATR Scientific Director

In This Issue:

- Microbiome Study Winding Down
- Healthy Aging in Twins
- Juvenile Study (ages 9 – 11)
- Multiples Family Days 2013

A stroll down MATR’s “Memory Lane”

Hello, I am Carol Williams - the Participant Coordinator for the Mid-Atlantic Twin Registry (MATR). As the Participant Coordinator, I interact with many of the twins, multiples and their family members that are part of the MATR. Because of that, I thought this newsletter would be a nice opportunity to say hello to “old” friends and introduce myself to new ones as the MATR continues to grow. I’ve been with VCU for 38 years and with the twin registry for 33 of these years and have worn many hats, gotten to meet many of the wonderful members of our MATR community, and seen the Registry evolve and flourish.

In 1980, when I started in the Department of Human Genetics at VCU, the Virginia Twin Registry, the predecessor to the MATR, was in its infancy. As the registry grew throughout the 1980’s, ‘Twin Clinics’ were held in different areas of Virginia which gave registry faculty and staff the opportunity to meet participants and their families and collect scores of valuable information. (I love that I still get approached by MATR participants that remember meeting me at those clinics!)

The 1990’s brought more growth and opportunity for the MATR. The VA Twin Registry, consisting of multiples born in VA, merged with the MCV Twin Study. In 1997, the Virginia and North Carolina Twin Registries merged to form the Mid-Atlantic Twin Registry (MATR). Not long after, South Carolina twins were recruited into the Registry and our growth continued.

Over the years I have had the pleasure of working with some of the top researchers in the world and the satisfaction of knowing that I am part of a support team in research that continues to lead to findings that benefit human health. And while research is our main focus, I’ve so enjoyed those moments and events, such as our Multiples Family Day at Kings Dominion and Carowinds and the Mid-Atlantic Parents of Multiples Conventions, which allows me to interact personally with large numbers of our participants outside of the research setting. It provides us with the opportunity to say “Thank-you!” for all that our MATR participants do.

As you can imagine, lots of things have changed in 33 years; from manually pulling records and entering the data on key punch cards to online registrations; from hours of tracking addresses and phone numbers to emailed updates from participants and social media; with all the changes one thing has always remained the same, MATR participants, without whom the research would not be possible, are still individuals willing to give of themselves and their time to make a difference in the health of generations to come.

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DO YOU HAVE FIBROMYALGIA?

Fibromyalgia is a chronic, painful, musculoskeletal disorder of unknown cause, which affects 5 to 6 million adults in the United States. The pain and fatigue associated with fibromyalgia are often severe enough to limit activities of daily living which adversely affects quality of life. Recently, more researchers are interested in studying twins with fibromyalgia, and we are hoping that all MATR twins with this condition will respond to this ad. We are looking for twins ages 18 and older, who have been diagnosed with fibromyalgia or are in the process of being diagnosed with fibromyalgia. If this describes you, we ask that you call the MATR and leave a message at our toll-free number 1-800-872-8946 or send us an email at matr@vcu.edu. Please include your full name, date of birth, and the best phone number to reach you. The MATR will store this information and as researchers come along that are interested in fibromyalgia, we will contact you with an invitation for their study.

Moving?

Remember to contact the MATR if your name, address, e-mail address or telephone number changes by visiting the Update Your Contact Info section of our website at www.matr.vcu.edu or calling our toll free number 1-800-URA-TWIN.



We Value You.

The Mid-Atlantic Twin Registry (MATR) values its 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.

Spread the Word!!!

Do you know another set of twins (triplets or higher order multiples) or parent of juvenile multiples who might be interested in joining the MATR and participating in twin research? If so, simply click on one of the social media icons on our website and share! From Facebook, to email, to Twitter, it’s a great way to tell other twins about us and keep the MATR community going strong! Smart phone users can scan the barcode to go directly to our website - and spread the word!



Start Your Summer at Multiples Day 2013!

Looking for a great way to kick off your summer? Come to Multiples Family Day 2013 at Kings Dominion on June 15th and at Carowinds on June 29th where you will join other families with twins, triplets and more, for photos, contests and double the fun!

Join the MATR and friends at Kings Dominion, near Richmond, VA on Saturday, June 15, 2013 under the Eiffel Tower from 10 AM – 4 PM. And, if you live a bit further south, come for a day of fun at Carowinds in Charlotte, NC on Saturday, June 29, 2013, where you'll find MATR staff and twins near the front gate on the Plaza Stage from 10 AM – 4 PM.



Visit our website (www.matr.vcu.edu) to purchase discounted park tickets for these two exciting events; ages 3 and up for the unbelievable price of only \$29.99 per person!

Discount tickets will be sold online only; this price will not be available at the park; however, tickets will continue to be available for purchase online the day of the event.

Once again, the MATR is grateful to both Carowinds and Kings Dominion for allowing us this opportunity to say “Thank You” for your participation in the Mid-Atlantic Twin Registry. We look forward to seeing you, your family, and friends at one or both of the parks!



Attention twins involved in the Female Microbiome Study:

Although the Female Microbiome Study will be winding down later this summer there is still time for twins to take part. If you have agreed to participate in this study and have not had an opportunity to schedule your appointment yet, please contact the study to let them know you'd like to do so ASAP. If you no longer have the study's contact information, feel free to contact the MATR by calling us at (1-800-URA-TWIN), visiting our website www.matr.vcu.edu, or by emailing us at matr@vcu.edu. If the MATR has not already contacted you about this study, you may still hear from us as we continue recruiting new participants, but you are also welcome to contact us with any questions you might have. As always, we send a big thank you to all of our twins that have already contributed to this effort to better understand female reproductive health!

New Study opportunity for juvenile twins through the Mid-Atlantic Twin Registry (MATR)...

Are you the parent or legal guardian of same-sex, juvenile twin pairs aged 9 to 11 years old?

Are you and your twins interested in participating in research to help improve our understanding of human behavioral conditions?

If you answered yes, you may be interested in a National Institutes of Health research project being conducted by Virginia Commonwealth University researchers. The Mid-Atlantic Twin Registry (MATR) is partnering with this study to help with participant recruitment. This project aims to increase the scientific community's understanding of how depression and anxiety develop, with the ultimate goal of improved treatment and prevention strategies.

That MATR invites you to learn more about participation. The following provides some basic information about the study.

Participants the study will need include:

- Generally healthy same-sex, juvenile, Caucasian MATR twin pairs (9 to 11 years old)
- One or both parents (or legal guardians) of the twin pair

Study participation involves:

- Parent/Guardian completing a phone call (approximately 20 minutes) with a MATR Research Interviewer. This phone call will include some questions to collect basic study data and ask permission for the study to contact the parent/guardian directly.
- Both members of the twin pair and at least one of the parents/guardians completing an appointment at one of the Study Research Centers (at VCU in Richmond, VA or the National Institutes of Health (NIH) in Bethesda, MD) to complete study tasks and questionnaires.
- Optional online survey to be completed by parents.
- Financial compensation will be provided by the study.

If interested:

Contact the *Mid-Atlantic Twin Registry* (MATR) and let us know that you want to learn more about the **Juvenile Anxiety Study (JAS)**. Please let us know your full name, your twins' full names, their date of birth, and the best phone number to reach you. 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.”

“Nothing is unachievable if you set your mind to it”

Longtime MATR participants, Justin and Jason Capps, were born five and a half weeks premature on Feb. 23, 1996 and spent their first week of life in the Neonatal Intensive Care Unit (NICU). According to their parents, Dianna and Jesse Capps, “They were your average everyday twins. They had their differences, even when they were babies, but you could always tell their bond was unique. They still have their differences to this day, but even though they're twins we've raised them to be themselves.”

“Since they were toddlers we can remember them carrying around small musical instruments and always wondered if they would develop a love for music but we encouraged them to do what they liked.”

At age five, Jason got his first guitar and a few months later he started guitar lessons. His teacher always said he learned quickly and had an ear for music. He took lessons for a couple of years and then continued teaching himself. He also taught himself how to play keyboard and his current instrument is bass guitar.

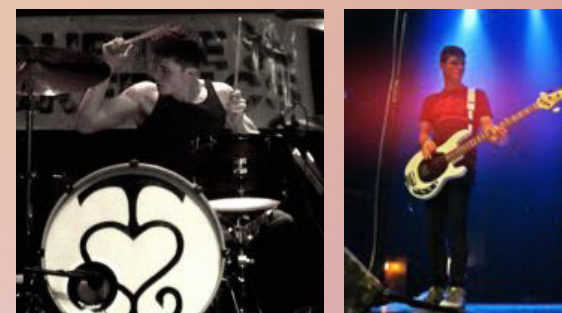
When Justin was a toddler he would carry around a plastic drum with sticks attached to the side. At age eleven, he got his first drum set and started lessons. He only took lessons for about eight months and during that time his teacher noticed he had a gift of music like his brother. Justin then began to teach himself and would play for hours at a time.

Jason and Justin began to practice together and not long after that began to play with the youth band at church. A few years later they were approached about starting a band outside the church and this is when their gifts really began to shine due to the different styles of music they would learn. Their band, The Subtle Skeptics, has since added two new members and really begun to move forward. They have headlined at a few local venues in Virginia as well as playing at festivals with other bands. In September 2012 they competed in a ‘Battle of the Bands’ competition in Richmond, VA against 11 other bands... and they won! They used their winnings to release their first single, Conscious Conditions, which has become a hit and the band has since released a second song (unmixed) called Avron. “In their minds nothing is unachievable if you set your mind to it. They are the greatest blessing my wife and I could have ever received. Even though they are unique because they are twins they are also unique as individuals.”



To learn more about The Subtle Skeptics check them out on facebook and ReverbNation.

As their way of saying ‘Thank You’ to the MATR, and paying it forward, The Subtle Skeptics look forward to playing with some of their friends at Kings Dominion on Multiples Day June 15, 2013 starting at 10 AM, be sure to stop by the band stand on International Street and check them out!



The Genetics and Epigenetics of Healthy Aging in Twins

You may be wondering what is meant by “healthy aging” in the title of this article. Though we all age in similar, predictable ways — we all get wrinkles and most of us get gray hairs— it's also apparent that some of us just appear to age “better” than others, or seem to demonstrate “healthy aging.” Unraveling the complexities of aging and shedding light on why certain people age better would also provide insight in to why some people seem to experience harsher or more rapid onset of age-related conditions, such as Alzheimer's disease, dementia, arthritis, endocrine problems, etc.; conditions clearly of more concern than wrinkles or gray hair. We know that certain environmental factors like sun or radiation exposure, as well as choices in diet and health habits, influence the development of age-related conditions. However, not all people that made generally healthy lifestyle choices necessarily experience “healthy aging.” There must be some other piece of the puzzle. To help solve this mystery, the MATR is now partnering with researchers at Tulane University, in New Orleans, Louisiana, who hope to better understand the aging process. By looking at environmental and genetic factors of same-sex, identical and fraternal twin pairs 65 years or older these researchers hope to identify which factors or combination of factors might improve outcomes for age-related health conditions. Stay tuned for future MATR Newsletters for updates on this new study.