



# Twin Matters

A Family Newsletter from the Mid-Atlantic Twin Registry

Volume XXIV

### Dear MATR Community,

Throughout the MATR's history we have had the pleasure of collaborating with researchers investigating a variety of topics whose findings help improve the scientific community's understanding of health conditions and human behaviors. By introducing the researcher and their topic to twins and multiples that are part of our MATR community, the MATR has enabled twin research to help further our understanding of cardiovascular disease, obesity, epilepsy, sleep disorders, substance use, eating disorders, depression and many other conditions and human behaviors. Each newsletter, we attempt to highlight interesting findings from previous studies as well as studies which are currently being conducted with the MATR. We hope you enjoy the highlights we've provided in this Fall's newsletter. Also, since we know our participants enjoy hearing about study findings, over the coming months we hope to add more features, such as links to scientific journal articles, to our website that will allow you to pursue specific findings in greater scientific detail than what can be provided in our newsletters.

The MATR staff and the researchers involved in twin studies using the MATR greatly appreciate the willingness of twins, other multiples, and their family members to be such active contributors to scientific advancement. We continue to partner with scientists on the cutting edge of discoveries about the human microbiome's influence on female health as well as rheumatoid arthritis and outcomes dealing with health care and political attitudes related to skin tone. We also anticipate starting up new partnerships with researchers interested in the development of anxiety and depression in adolescent twins, healthy aging in elderly twins, and fibromyalgia. We encourage you all to stay tuned to our website and future newsletters to hear more about these potential opportunities to help drive the engines of scientific discovery!

Warm Regards,

Judy Silberg, PhD  
MATR Scientific Director

### In This Issue:

- New Study for Juvenile Twins
- Two Multiples Family Days in 2013
- The Human Microbiome and Female Health
- Rheumatoid Arthritis Study

### 2013 Multiples Family Days - SAVE THE DATES!

Again in 2013 the MATR will double the fun with two Multiples Family Days! Together with Kings Dominion and Carowinds theme parks, the MATR is happy to offer discounted park tickets, twin contests, giveaways, and photo opportunities.

Meet the MATR and fellow twin families at Kings Dominion, near Richmond, VA on Saturday, June 15, 2013 under the Eiffel Tower from approximately 10 AM – 4 PM; prizes for winners of the twin contests announced at 3:30 PM. For our families who 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 other twins near the front gate from approximately 10 AM – 4 PM; prizes for winners of the twin contests announced at 3:30 PM.

Watch our website ([www.matr.vcu.edu](http://www.matr.vcu.edu)) and look for our postcard or email closer to the event dates for more information on how to purchase discounted park tickets, as well as finalized daily schedules for these two exciting events.

We look forward to seeing you and your family at one or both of these great events!



### Do you know multiples who would like to register with us?

If so, please ask them to visit the *Register with MATR* section of our website at [www.matr.vcu.edu](http://www.matr.vcu.edu), or call us at 1-800-URA-TWIN (800-872-8946). We would love for them to join the thousands of multiples who are willing to consider participating in health-related research.

### Adult Twins - Who Can Refuse For You?

When the MATR sends an adult twin (18+) an invitation to take part in a study, the decision of whether or not to participate is always theirs to make. Just as we need your consent to include you in a study, we need to hear from you that you are not interested in order to remove you from the study. When someone else refuses for you we can't be sure that we are honoring your wishes - that's why we always prefer to hear it straight from you. The MATR research interviewers will never pressure you regarding a study, so please don't hesitate to pick up the phone and let us know when you wish to decline an invitation for a study. If after reviewing the information in the invitation letter you decide you are not interested in the study you can call us at 1-800-872-8946 and leave a message letting us know that you would like to decline. When calling, make sure to leave your name and date of birth, and please include the name of the study and the barcode number printed on the letter.

VIRGINIA COMMONWEALTH UNIVERSITY



# VCU

Make it real.

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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](mailto: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.

### 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 [matr@vcu.edu](mailto:matr@vcu.edu), call 1-800-872-8946 or call our Participant Coordinator, Carol Williams, at 804-828-8116.





Recent findings from studies involving MATR twins

In order to make sure our twins know how their participation in the MATR is making a difference, we want to provide you with a summary of recent publications from studies utilizing MATR twins. MATR twins have participated in research studies for over 35 years, so there is quite a large amount of data available for researchers to analyze. As you can imagine, researchers can utilize the data collected from each study by looking at the information in many different ways; furthermore, scientific methods also improve over the years so researchers have opportunities to look at the same data with enhanced analytical techniques. This provides them with years worth of analyses to conduct and means that publications can continue to come from studies that took place many years ago – the data is just that rich! So keep in mind that numerous analyses and publications typically come from each study, we have just selected a few of the more recently published findings to share in this newsletter.

Disclaimer: Findings from these studies can be applied generally to the population. Readers should not apply this information to an individual, or use this information for self-diagnosis. As with all scientific endeavors, replication of the results may be needed in order to validate these findings.

**Study:** Screening MATR twins for a study of sleep deprivation  
**Study PI and Institution:** Dr. Samuel Kuna, University of Pennsylvania (UPenn)  
**Twin’s contribution to the study:** Identical and fraternal twin pairs traveled to UPenn to undergo 38 hours of sleep deprivation. Every two hours during this period of sleep deprivation, they took a 10-minute Psychomotor Vigilance Test (PVT) which measures the individual’s capacity for sustained attention and behavioral alertness.  
**Topic of this analysis:** sleep homeostasis (the urge to fall asleep)  
**Findings:** This analysis found that a person’s ability to focus on a task when s/he is under conditions of sleep deprivation has is a very high rate of heritability (80%).  
**Journal Article:** Kuna, et al. (2012), Heritability of performance deficit accumulation during acute sleep deprivation in twins. Sleep, 9:1223-33.

**Study Title:** Virginia Twin Study of Adolescent Behavioral Development (VTSABD) and the Young Adult Follow Up (YAFU)  
**Study PI and Institution:** VTSABD - Dr. Lindon Eaves, Virginia Commonwealth University/Dr. Judy Silberg; YAFU  
**Topic of this analysis:** anxiety and panic  
**Findings:** The same genes influence childhood separation anxiety and panic disorder in young adulthood.  
**Journal Article:** Roberson-Nay, R., et al. (2012), Childhood separation anxiety disorder and adult onset panic attacks share a common genetic diathesis. Depression and Anxiety, 29: 320–327.

**Study Title:** Understanding Maternal and Fetal Genotype on Risk for Preterm Birth: A Mid-Atlantic Twin Registry Study (MATR)  
**Study PIs and Institution:** Dr. Timothy York, Dr. Jerome Strauss Virginia Commonwealth University  
**Topic of this analysis:** Preterm birth  
**Findings:** Using a children-of-twins design, the researchers determined that genes from both the mother and the child contributed to preterm birth.  
**Journal Article:** York, T., et al. (2009). Estimating fetal and maternal genetic contributions to premature birth from multiparous pregnancy histories of twins using MCMC and maximum-likelihood approaches. Twin Research and Human Genetics, 4:333-42.

**Study Title:** DAD Dissemination Interview  
**Study PI and Institution:** Dr. Kenneth Kendler, Virginia Commonwealth University  
**Topic of this analysis:** Depression  
**Findings:** This analysis looked at twin pairs that were dissimilar for depression, meaning one twin had depression and the other did not. One of the strongest differences was whether or not they had difficulties in a romantic relationship- the twin with the depression had more difficulty in their relationships than the twin who did not have depression. The power of this study design is that you can identify environmental factors while controlling for the effect of the genes. However, the authors underscore the complexity of the relationship between genes and environment in depression.  
**Journal Article:** Kendler, KS and Halberstadt, L. (2012), The road not taken: life experiences in monozygotic twin pairs discordant for major depression. Molecular Psychiatry, doi: 10.1038/mp.2012.55.

**Study Title:** Virginia Adult Twin Study of Psychiatric and Substance Use Disorders (VATSPSUD)  
**Study PI and Institution:** Dr. Kenneth Kendler, Virginia Commonwealth University  
**Topic of this analysis:** Nicotine and depression  
**Findings:** There is a genetic association between depression and nicotine dependence. This work suggests that nicotine dependence has a causal role in susceptibility to depression.  
**Journal Article:** Alexis C. Edwards, Kenneth S. Kendler, A twin study of depression and nicotine dependence: Shared liability or causal relationship?, Journal of Affective Disorders, Available online 15 August 2012, ISSN 0165-0327, 10.1016/j.jad.2012.03.048.

**Study Title:** Children of Twins Study (COT)  
**Study PI and Institution:** Dr. Judy Silberg  
**Topic of this analysis:** Maternal and child depression  
**Findings:** It was found that the association between maternal depression and child depression was primarily explained by the family environment. There were genetic effects on child depression, but they were different from the genes for maternal depression.  
**Journal Article:** Silberg, JS, et al. (2010), Genetic and environmental influences on the transmission of parental depression to

children’s depression and conduct disturbance: an extended Children of Twins study. Journal of Child Psychology and Psychiatry, and Allied Disciplines, 6:734-44

**Study Title:** Virginia Twin Study of Adolescent Behavioral Development (VTSABD)  
**• Study PI and Institution:** Dr. Lindon Eaves, Virginia Commonwealth University  
**Topic of this analysis:** childhood behavioral health  
**Findings:** It was found that parental neglect was a genuine environmental risk factor for children’s behavioral health over and above any genes shared between mothers and their children.  
**Journal Article:** Eaves LJ, et al. (2010), The mediating effect of parental neglect on adolescent and young adult antisociality: A longitudinal study of twins and their parents (LTAP). Behavior Genetics, 40:425-37.

**• Study Investigator and Institution:** Dr. Elizabeth Prom-Wormley, Virginia Commonwealth University  
**Topic of this analysis:** genes and conduct disorder  
**Findings:** Certain forms of a gene conveyed a protective effect on the risk to develop conduct disorder in children exposed to childhood adversity  
**Journal Article:** Prom-Wormley E, et al.(2009), Monoamine oxidase A and childhood adversity as risk factors for conduct disorder in females. Psychological Medicine, 39:579-590.

**• Study PI and Institution:** Dr. Lindon Eaves, Virginia Commonwealth University  
**Topic of this analysis:** sleep problems  
**Findings:** This analysis found moderate heritability for sleep problems in children and adolescents. There also seems to be a genetic association with depression and anxiety for this age group.  
**Journal Article:** Gehrman, P.R., et al. (2011), Heritability of insomnia symptoms in youth and their relationship to depression and anxiety. Sleep, 34, 1641-1646.

New Study opportunity for juvenile twins...

Researchers at VCU’s Department of Psychiatry are working with the National Institutes of Health in hopes of learning more about how certain conditions, such as anxiety and depression develop.

Participants the study will need include:

- ➔ Generally healthy same-sex, juvenile 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 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*,
- ➔ smart phone users:



Getting Greener

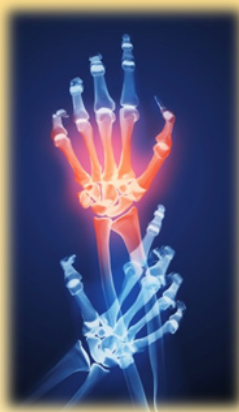
Until now families of juvenile twins have received one copy of our Twin Matters Newsletter per household, while adults (18+) have received one copy each, even if they live at the same address. In keeping with VCU’s efforts to Go Green, from now on the MATR will send only one Twin Matters Newsletter to multiples living at the same address, regardless of age.

address associated with that organization, please take a few minutes to make sure your email address with us is up to date. It’s also helpful if you add the MATR to your email address book.

Simply scan the barcode with your Smartphone or go to the *Update Your Contact Info* form on the MATR website at www.matr.vcu.edu, fill in the blanks, submit, and you’re done!



Rheumatoid Arthritis Study



The MATR continues its collaboration with Dr. Jose U. Scher and his team at New York University’s Hospital for Joint Disease to learn more about the causes, onset, and progression of rheumatoid arthritis, a very painful health condition that typically affects joint health.

The first phase of the study involved the MATR contacting over 300 twins with an invitation to complete a brief phone survey. Eligible twin pairs were then invited to participate in the study on RA. We are continuing to recruit participants for this exciting study. Our next phase of recruitment will be to send letters to adult MATR twins with information about the RA study and an invitation to take part. Currently, the study needs full identical twin pairs where one twin has RA and the other does not. As more twin pairs participate, the study will advance further into its

analysis in hopes of helping to answer such questions as: why do some individuals develop RA and others do not; why is RA more severe in some affected individuals than others; what’s different in the biology of a person that has RA from one who does not? By answering these types of questions the researchers hope to move closer towards their

Twins in the News

The MATR staff is always excited to read about twins and higher order multiples in the news so we would like to share some of our favorite stories with you! Next time you’re online check out *Twins in the News*, under *Resources*, on the MATR website - www.matr.vcu.edu.

ultimate goal of helping the scientific and medical communities improve RA treatment and prevention plans.

Thank you to all the twins who have participated in the phone survey and the RA study as well as all who have spent time on the phone talking to MATR and NYU-HJD staff about this crucial health research.

A Call for New and Updated Emails!!

For many of you, email is one of the best ways to be contacted. So, we are actively collecting email addresses as a way to keep in touch and let you know about events for twins, MATR announcements, and twin studies. As with all of the information you provide, we will treat each email address as confidential information. We will not share your information without your permission and we’ll only send you occasional emails. On top of that, you can always remove yourself from our email list.

Please share your email address with us as we’d love to use this increasingly popular communication method with you. If you recently graduated, changed jobs, changed internet providers and no longer use the email