

Study of Rheumatoid Arthritis (RA): Recruitment Continues!

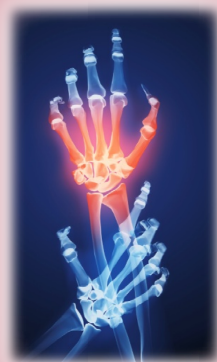
Dr. Jose U. Scher & colleagues at New York University's Hospital for Joint Diseases continue their collaboration with the MATR to help learn more about rheumatoid arthritis (RA).

Who's needed? Adult twin pairs—*Identical OR Fraternal*—where one or both members of the pair have rheumatoid arthritis.

Why is this study needed? This is not a treatment study but rather one that seeks to collect important data and samples that will help improve scientists' understanding of RA with the goal of advancing treatment options and perhaps even one day preventing RA.

Interested in learning more? Contact the MATR at 1-800-URA-TWIN (1-800-872-8946) and leave us a message with your name and best way to contact you or email us at matr@vcu.edu. The MATR will tell you more about the study and then you decide whether you want to be contacted by the study staff. It is okay to decide you don't want to participate; the study staff will not be given any information about you without your permission.

Dr. Scher and his team wish to thank those twins that have already participated or contacted him about the study and look forward to continuing their collaboration with the MATR Community!



MATR Events

This has been a year filled with opportunities to connect with many of our long time participants and to welcome new families into the MATR. We are always delighted to meet and say thank you to those of you who continue to give your time in support of our research.

We are excited to be attending the Mid-Atlantic Parents of Multiples Convention in Charles Town, WV April 27 - 29, 2012.

This summer will once again host Multiples Family Day at Kings Dominion in VA, June 16, 2012! Back by popular demand, we will host a Multiples Family Day at Carowinds in NC, on September 15, 2012! Be sure to SAVE the DATES to 'Double Your Fun' with the MATR staff at these two great parks!

For more information on these and other events watch our website, www.matr.vcu.edu, for updates.

Do Not Call Registry and the MATR...

In this day and age, when you get a call from a number that you don't recognize, you might automatically think, with dread...telemarketer! We understand how irritating it can be to have someone call and try to sell you something you don't want or need. Many of you participate in 'The National Do Not Call Registry' in order to try and prevent these kinds of calls. As you may know, the 'Do Not Call Registry' does not apply to the MATR or other not-for-profit organizations. Be assured that the MATR is not a telemarketing organization: we never call to try to sell you anything and we do not give any of your information to any organization without your permission. When the MATR calls you, we are usually doing so to provide you with information about a twin study we are conducting or with other information about twin-related events. We may also sometime call you to help us update your contact information. It is always up to you whether or not you want to provide information or participate in a study. As always, when you do hear from us and are not interested in participating please feel free to (politely) let us know. We greatly appreciate our participants and do what we can to minimize unwanted contact - you are always welcome to contact us directly to update your level of willingness in the MATR. We try to make your participation with us enjoyable and we welcome your suggestions to ensure our contact with you is a pleasant experience.

MATR Update

If you are a twin who participated in a study with us years ago, it may have been some time since you have heard from us. We recently updated many of our records and realize this might be the first point of contact you've had from us in a few years, so we wanted to extend our hand to welcome you back into the swing of things. We apologize for not updating our records sooner, but are happy to get you back in the loop of Twin Matters! We encourage you to check out archived MATR newsletter volumes on our website, www.matr.vcu.edu. We also encourage all MATR members to read over your Rights as Research Participants and the MATR Privacy Policy to learn more about how we protect your information. This information is available on our website or if you prefer, you may request a mailed copy.

The MATR recognizes twins and other multiples as a unique and valuable resource to health and behavior-related research and we have a great appreciation for all who are willing to participate in twin studies. These studies work towards the betterment of health care for generations to come. We take many steps to ensure that your participation with us is always pleasant and that you feel there are open lines of communication with us at all times. If you have any questions, you may contact us at any time by leaving a message at 1-800-URA-TWIN (872-8946), emailing us at matr@vcu.edu, or contacting us through our website listed above. Please include detailed information on how to reach you so we can respond promptly to your inquiry. Thank you for continued interest in twin research and we are glad to be back in touch!

Stress and Aging Study

Some of you are participating in Dr. Colleen Jackson-Cook or Dr. Timothy York's studies looking at the impact that certain factors, such as aging or childhood stress, have on an individual's chromosome structure later in life. Your participation may have begun some time ago and perhaps you didn't have a chance to complete the study and provide your samples. If you still have a blood collection kit, the study may contact you to see if you'd still like to participate (remember though, participation is not required, you're welcome to tell them if you've changed your mind). You're also welcome to contact the research staff directly if you know you'd still like to complete the study. If you no longer have their information, feel free to contact the MATR at 1-800-URA-TWIN or email us at matr@vcu.edu.



Mid-Atlantic Twin Registry Survey

Available to all interested adult
MATR participants!



What is it?

The MATR has launched a new survey which will enrich our Registry as a potential resource for researchers. This survey will ask questions about your health habits, health conditions and demographic characteristics. It will also ask questions about your personality as well as your social and political attitudes.

How is this different from other MATR surveys?

For the first time we will be offering the option of taking this survey online! The survey and data will be housed on a secure server and you only need internet access to complete the survey.

How do I get involved?

To participate, you need to be a registered, adult twin (over 18) or other multiple in our Registry (if you're not yet registered but want to participate, feel free to contact us to register!). You can let us know you're interested in participating in the survey by sending us an email or calling us at 1-800-URA-TWIN and leaving a message for us on our voicemail. Feel free to let us know if you have any questions. Remember, as with all MATR related activities, participation is voluntary and you can withdraw at any time. Plus, you do not have to answer any question that you're not comfortable answering!

How will my participation help?

Though you may not benefit directly from taking part, your participation will hopefully result in improving our understanding of certain health conditions and behaviors. We hope that with this improved understanding the scientific community will be better equipped to develop enhanced prevention methods and treatment plans.

Successful Launch for the MATR Online Survey!

As many of you may recall from the Spring Newsletter, the MATR has a new, online survey for our adult twins that covers questions about a wide range of topics including health, personality, and social attitudes. Our first wave of invitations has gone out and we are very pleased with how willing participants have been to complete the survey. We are also happy to report that 100% of the twins who provided feedback indicated they had an overall 'excellent' or 'good' survey experience!

The answers MATR participants provide to this survey are a valuable resource to researchers who are interested in conducting twin studies and we wanted to share some of what's been reported thus far. Some examples of the interesting statistics from the different categories of questions include: health conditions (7% of survey respondents thus far have asthma), demographics (68% live in suburban areas), personality (43% see themselves as extraverted), social attitudes (32% rate themselves as moderate, while 29% rate themselves as liberal), and health habits (29% exercise moderately 4-6 times per week). The survey also allows the MATR to learn more about what our participants feel comfortable with—for example, 71% of respondents would be willing to provide their DNA for genetics studies.

We plan on inviting as many of our participants as possible to complete the survey so these figures will probably change over time as more and more of you complete the survey- we just wanted to share a sample of results with you now! We are very excited about the initial success of the survey and will be sending out another round of invitations again soon, so be sure to keep an eye out for an invitation from us.

If we have a current email address for you then your invitation will likely come by email from matrsurvey@vcu.edu (please add this email address to your address book so that the invitation is less likely to be sent to spam/junk folders). If we don't have your current email address you may receive an invitation by traditional mail. If you are interested in taking the survey, please see the advertisement in this newsletter for additional details on how to volunteer.

A BIG THANK-YOU TO ALL OF OUR
TWINs FOR MAKING THE MATR SURVEY
A GREAT SUCCESS!



Neuroimaging for Anxiety Disorders

Dr. Jack Hettema, MD, PhD has just published the results from his MATR study, "Neuroimaging of Monozygotic Twins Discordant for Anxiety Disorders" in the journal, *Depression & Anxiety*.

This National Institute of Mental Health (NIMH) funded project is the first in MATR history to use neuroimaging techniques to study psychiatric conditions. Over a period of several years, Dr. Hettema collected data from 34 twins using an MRI scanner at the VCU Medical Center. Half of these twins had generalized anxiety disorder. The data showed that there are changes in the structure and chemistry of certain brain regions that are related to this condition, and that these changes might indicate an underlying genetic predisposition to developing issues with anxiety. Dr. Hettema is very grateful for the time and effort provided by the twins who participated and looks forward to further research in this direction.



www.matr.vcu.edu

1-800-URA-TWIN (872-8946)

PO Box 980617, Richmond VA 23298

Return Service Requested

Twin Matters

A Family Newsletter from the Mid-Atlantic Twin Registry

Volume XXII

VCU



Virginia Commonwealth University

Calling All Parents of Twins

We have several researchers who might be interested in inviting parents of juvenile twins to participate in their research studies, but would like for the MATR to send out invitations by email. If you are interested in possibly being contacted by email for a study, please send us your email address as soon as you can using our 'Update Your Contact Info' form on our website at www.matr.vcu.edu. If you prefer, you may leave us a message with your email address (spelled twice please), name, and date of birth at 1-800-872-8946 or email us directly at matr@vcu.edu. Thank you and we hope to hear from you soon!

Study Update: Type 1 Diabetes and Kidney Complications

The MATR is collaborating with Drs. Caramori and Mauer from the University of Minnesota to better understand kidney complications that sometimes develop in those that have type 1 diabetes. By completing an identical (monozygotic) twin study, the researchers hope to learn more about why some individuals with type 1 diabetes develop these kidney problems and others do not. This study is currently enrolling identical twin pairs where at least one member of the pair has type 1 diabetes. They are comparing these twin pairs to twin pairs in which neither twin is affected with diabetes (called the control pair). Many MATR twins called to volunteer as control pairs (neither twin has diabetes) but for now the study is holding off on enrolling any more from this group. However they do plan to continue enrolling control twin pairs at some point in the future, so they still might give you a call even if they haven't yet. So far, the study has been very pleased with the great response from willing MATR twins and sends their thanks for your enthusiasm! Please see the ad placed in this newsletter to learn more!



A Family Newsletter from the Mid-Atlantic Twin Registry

Volume XXII

Twin Matters

Greetings from the MATR!

We hope all of our twins and their families had a wonderful summer and that you are enjoying the long-awaited cooler weather!

We are happy to report that the MATR had a great summer and we were able to meet quite a few of our participants at events for twins that we either attended or hosted. Our Multiples Family Day at Kings Dominion was a great success-over 1100 tickets were sold and we were thrilled to see so many of your smiling faces! Save the date on your calendar for June 16, 2012 when we host next summer's Multiples Family Day at Kings Dominion! We also attended the State Fair of VA this fall and enjoyed getting to meet all of the twins and their families there too. We love your enthusiasm and appreciate your support at these events!

We've also recently started the process of some much-needed cleaning up of old files. This means that some of you may be hearing from us for the first time in years. In fact, some of you may not have heard from us since the Virginia Twin Registry and the North Carolina Twin Study became the Mid-Atlantic Twin Registry (MATR). If it's been a while since you've been contacted, please see our article titled "MATR Update" to learn more and please accept our apologies for not getting back in touch with you sooner.

As always, we'd like to send a big thanks to all of our twins and their families for their continued support of our research efforts. Without you, this fascinating research would not be possible!

Warm Regards,

Judy L. Silberg

Judy Silberg, PhD
MATR Scientific Director

In This Issue:

- MATR Online Survey
- Rheumatoid Arthritis Study
- The Human Microbiome and Female Health
- Neuroimaging for Anxiety Disorders
- Diabetes Study Update

The Human Microbiome and Female Health

The Vaginal Microbiome Study, conducted by Dr. Gregory Buck (VCU) and his colleagues, continues to make new and exciting observations about the microbiome and its relationship with female reproductive health. Investigators have already found evidence that suggests certain bacterial groups might be associated with pre-term labor and have identified potential connections between a person's demographics (age, race, etc.) and their microbiome profiles. They've even discovered and genetically sequenced new groups of bacteria associated with vaginal microbiota. These are just a few examples of the remarkable observations being made by the research teams involved in this study. This study is part of a larger National Institutes of Health (NIH) project, called the Human Microbiome Project (HMP) whose aim is to understand the impact our microbiome has on our overall health and the development/prevention of many human disease conditions. The MATR is particularly excited to be part of this study given that VCU is one of the few research sites that utilizes the twin study design to help learn more about how each person's genetic make-up influences their microbiome. Other research groups that are part of the HMP are also very interested in this twin research component. Findings from this twin research which have been presented at HMP meetings, such as the Human Microbiome Research Conference in St. Louis, MO, have been very well received in the scientific community.



Microbiome Study

FEMALE TWINS NEEDED FOR STUDY OF WOMEN'S REPRODUCTIVE HEALTH

The MATR is conducting a new study on women's reproductive health with Dr. Gregory Buck at VCU. We are currently looking for pairs of female twins ages 18 and older that would be willing to travel to Richmond, Virginia to participate. You will be reimbursed for your time and travel. Dr. Buck hopes this study will lead to improved treatment and healthcare for women. If you are interested, please contact the MATR for more information at 1-800-URA-TWIN (1-800-872-8946).

Needless to say, the MATR is very pleased to be part of this research effort and looks forward to continuing our collaboration with Dr. Buck and his colleagues.

Please see the advertisement in this newsletter to learn more about how adult female twin pairs can participate in this study!

