



Twin Matters

Spring 2016 Volume XXXI

A Family Newsletter from the Mid-Atlantic Twin Registry

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MATR Twins in BBC Documentary "How to Stay Young"

Last summer Patricia 'Patty' Gamby and Teresa 'Terry' Gustafson responded to a call for identical twins to take part in a documentary; below Terry shares the adventure that response took them on.

"BBC Television seeks a pair of age 50+ identical twins who started life looking the same but now LOOK DIFFERENT, for filming in the USA in August 2015." I was immediately interested when I read this in a message sent out by the MATR in late July 2015. Although my sister, Patty, and I are identical twins and used to look exactly alike when we were kids, we are quite a bit different now.

I sent an email message to the BBC point of contact and heard nothing for almost a month. Knowing that they were planning to film in the USA in August I assumed we were not being considered. Then I got a message from the producer, Yvonne Gray, asking a series of questions and requesting some pictures. I answered and promptly got another message with more questions. Within a couple of days, we had exchanged several email messages, sent dozens of pictures, and Patty and I had both spoken to Yvonne via phone and Skype. By the end of the week, we were making plans for the BBC team to film us at our homes in Alexandria, Virginia (Patty) and Elkton, Maryland (Terry) on the first days of September.

The BBC's documentary is called "How to Stay Young." This two-part documentary explores various physiological and sociological aspects of aging. For one part of the program, they teamed up with Professor Tim Spector at the Department of Twin Research & Genetic Epidemiology at the King's College University in London who uses a process for measuring DNA methylation to gauge how an individual has aged. The results can give an idea of your "biological age" as compared to your "chronological age."

The BBC intended to use a set of identical twins that have aged differently to examine the effect of environment on aging. My slender,



stylish sister lives in the city and has a fast-paced life and a stressful job. She socializes frequently with numerous friends and neighbors and drinks coffee and alcohol on a regular basis. When the BBC film crew came to the USA, they filmed Patty hosting a gathering for about 30 friends, driving her hot little sports car on the busy freeway, and hurrying along to her office on the crowded streets of Washington, D.C. I am a good bit heavier than my sister, I wear blue jeans every day, and I have lived my whole life in the more rural town where we were born. I am retired, have a more leisurely life, and don't drink alcohol or coffee. They filmed me digging potatoes in my garden, walking my dog, and grooming and riding my horse. I believe they depicted us as high stress city twin vs the overweight country twin.

Soon after the filming at our homes, we both had blood drawn and sent to a lab in London where the DNA methylation testing was performed. Then we flew to London in late September to finish the filming. London was fantastic! It was the first time either of us had been in the UK. The BBC folks took great care of us and we all had a fantastic time filming the "American twins" in London. The main filming was done in Professor Spector's lab at St. Thomas' hospital where we were given the results of our blood tests. With much suspense and drama, they filmed us as they gave us the results. Do you want to know what we learned about how our biological age differs from our chronological age and from each other? Watch the documentary! It will be broadcast on BBC Worldwide in the spring. The MATR will share the link to the Program Page for this documentary on our website as soon as it becomes available from BBC.

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A Family Newsletter from the Mid-Atlantic Twin Registry



A token of our appreciation...

As a way to express our gratitude for your participation in the MATR, we have begun drawing names for giveaway items such as VISA gift cards and tickets to events for our twins. For the first type of drawing, all registered twins' names are entered in the pool as a way of showing our appreciation for simply being a registered member of the MATR. Another series of drawings are for registered twins or twin family members who return requested information to us, like our Update Contact Information Form, etc., or those that provide us with information, like one of our twin stories or photos, etc.

Keep an eye out on our website and the fall newsletter for updates on how these drawings go throughout the first half the year. We are very pleased to have this opportunity to show you all how much we appreciate you being part of our MATR community!

Mood & Immune Regulation in Twins (MIRT) Study Update

We just wanted to let all the twins who have been involved in MIRT know that the study has finished all of its enrollment and appointment scheduling. We greatly appreciate all the efforts twins have put forth for this study. We look forward to hearing back from the study regarding their findings and hope to have some updates on those for the fall newsletter.

Astronaut (and twin), Scott Kelly returns to Earth!

After 340 days in space, Captain Scott Kelly has returned. Now, NASA's twin study on the effects of spending time in space can truly begin. Captain Kelly's identical twin brother, Captain Mark Kelly remained on earth while his twin was in space. NASA will study the twins to determine how space travel affects the body and more. To follow the research and results check out NASA's page devoted to the mission at www.nasa.gov/twins-study.

Adolescent & Young Adult Twin Study (AYATS)

Study opportunity for adolescent and young adult twins...

Researchers at VCU's Department of Psychiatry are working on a study funded by 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 MATR twin *pairs* (Caucasians, 15 through 19 years old)
- Twin pairs, including the young adult twins, need to be living full-time at home with their parent(s)
- One or both parents (or legal guardians) of the twin pair

Study participation involves:

- Parent/Guardian of adolescent twins or the adult twins (18+) completing a phone call (approximately 20 minutes) with a MATR Interviewer. This phone call will include some questions to collect basic study data and ask permission for the study to contact the parent or young adult twins directly.
- Both members of the twin pair (for adolescent twins this includes at least one of the parents/guardians) completing an appointment at VCU in Richmond, VA 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 **Adolescent & Young Adult Twin Study (AYATS)**. Please let us know the full names and DOB of the twin pair. Parents, please provide your full name as well. 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"

Message from the AYATS Principal Investigator

Thus far, my study team and I have been very pleased with the participation of twins and their families in this research. I am excited to share with you the progress AYATS has made, which is now in its third year. Our study is one of the largest studies examining environmental and genetic contributions to the risk of developing an internalizing disorder in adolescents and young adults. We are continuing to schedule participants to reach our projected goal of 450 twin pairs by **September 2016**. We also are starting Wave 2 of data collection in March 2016, which we hope to finish in about two years. We are starting to analyze the remarkable data that we have collected from our twins so far and we will share our findings



Roxann Roberson-Nay, PhD
AYATS Principal Investigator

with the scientific and clinical communities in the very near future. **It is our hope that the AYATS data will yield new insights into the causes of internalizing disorders and lead to the development of new, more effective treatments and prevention strategies. The generosity of each family's time in participating in this important research is very valued and appreciated.** The AYATS research team looks forward to future opportunities to work with you and your twins as they develop through their teenage and young adult years into adulthood. Again, a heart-felt thanks to all the parents and twins who have given their time and effort to this very important mission!

Juvenile Anxiety Study (JAS) Update

The MATR recruitment and JAS enrollment is now closed. The study is no longer enrolling participants in the main part of JAS, though the study may continue contacting families if they need to clarify information. You might also hear from them and/or their affiliates about scheduling the MRI part of the study. They have already begun compiling the data and prepping it for analysis; we'll continue to keep you up-to-date on their findings.

We'd like to give a big THANK YOU to all the families that participated in our phone calls for JAS as well as in the study itself! The MATR and study staff greatly appreciate your efforts!

First-Hand Report From a JAS Family

Though the MATR recruitment for JAS had ended, we still thought our members would enjoy reading a few first-hand remarks from a family that participated in the Juvenile Anxiety Study. The Sheltons visited VCU this year and really enjoyed their experience being part of JAS. Laura Shelton said the study was "...a very interesting experience for us, and [the twins] enjoyed it very much." Apparently the twins are already asking when they can do another study! According to Evan, "The twin study was a really fun experience. I would do a twin study again because I liked all the experiments." Addison said, "I would love to do the twin study again. Being in the twin study made me a little more interested in science." It should be no surprise that both twins seemed to enjoy the task that is set up like a game and they actually got to "earn" money. Though, their mother, Laura, really summed up what it's all about... "It's neat to think that they contributed to a study that could lead to a better understanding and treatment of anxiety and depression." And ultimately, that's what we and the research staff hope for too! Thank you to the Sheltons for sharing their time and thoughts about their experience!

Adolescent & Young Adult Twin Study (AYATS) Update



The AYATS Research Staff
Audrey Anderson, Laura Hazlett, and Jennifer Cecilione

The MATR is continuing its recruitment efforts for AYATS ("meet" the study Principal Investigator on the opposite page). This study dovetails nicely with the Juvenile Anxiety Study (JAS) but has twin participants in an older age range that includes adolescents and young adults. Both studies hope to learn more about internalizing disorders like depression and anxiety with the ultimate goal to improve prevention and treatment plans for these mood states that greatly undermine a person's, and often their family's and friends', quality of life. Read what the AYATS Principal Investigator, Roxann Roberson-Nay PhD, has to say about the study thus far. You can also learn more about Dr. Roberson-Nay at go.vcu.edu/pibio.



How we collect information online

We have recently revamped (or are in the process of doing so) many of our online surveys to make them even more secure. We value the information you provide us and treat it as *strictly confidential*. Because of this, we use online applications that have state-of-the-art security protocols. The main online application we are now using is known as Research Electronic Data Capture (REDCap). This web-based tool was developed by an international consortium of universities and other partners for the purpose of collecting and managing research data in a secure environment. Please visit <http://project-redcap.org/> if you'd like to learn more. Currently, both of our online registration surveys (adult and juvenile) are on REDCap. We have also recently revised our online 'update contact information' links to direct users to a REDCap update form and we are very pleased to now use REDCap as a means for you to share your stories (go.vcu.edu/matrstory) and photos (go.vcu.edu/matrphoto) with us: similar to what you have seen in this newsletter.



If you have not already, please take a minute to like our page to stay up to date on studies, twins in the news and events for twins! Check us out at www.facebook.com/twinsmatr or by searching "The Mid-Atlantic Twin Registry of VCU."

How We Work

From time-to-time, we are asked what the MATR does as a registry so we are providing a short summary here to give folks an overview of how we work. The MATR connects twins and their families with researchers who conduct twin research. We are essentially the gatekeepers of our twins' information and only allow researchers to contact them with our twins' consent. We take privacy and confidentiality very seriously and are rigorously committed to maintaining it.

There is no cost to be part of the MATR and it's easy to join. Participants enjoy knowing that there is never an obligation to participate in a study they are not interested in and they can withdraw from the MATR any time. Once we partner with a research group we contact parents of juvenile twins and/or adult twins to tell them about the research. Those interested in learning more give us permission to turnover contact information and they are contacted by the study staff; if a participant isn't interested in learning more, then they are removed from the calls for that study. Involvement in studies can be as simple as completing a survey to more involved studies that consist of other data collection elements. MATR members that go on to participate in research find fulfillment in knowing that their efforts are contributing to helping others and also appreciate that most studies provide incentives and/or compensation for their time. MATR participants also enjoy staying up-to-date with the bi-annual *TWIN MATTERS* newsletter, updates to our website, and posts on our Facebook page (<https://www.facebook.com/twinsmatr>). They also have fun at events, such as the MATR Multiples Family Day at Kings Dominion. MATR participants enjoy being part of a group that fosters a community of twins and research discovery.

Multiples Family Day

Start your summer by joining other families of twins, triplets and more, for Multiples Family Day at Kings Dominion on **Saturday, June 18th 2016!**

To purchase Special Discount Tickets (\$34.50 plus processing) (2 years and under admitted free) just go to our website www.matr.vcu.edu and click on the "Events" button and follow the directions for purchasing tickets provided there. The discount tickets will be sold **online only**; this price **will not be available at the park**.

Join us for photos, new games and contests with lots of fun for everyone from 10am-4pm at Kings Dominion in Doswell, VA (Exit 98 off I-95 between Richmond VA and Washington DC).

The MATR is grateful to Kings Dominion for allowing us this opportunity to say "Thank You" for your participation in the MATR. We look forward to seeing you, your family and friends at the park!

