MOVING? Please remember to contact the MATR if your name, address or telephone number changes by calling our toll-free number 1-800-URA-TWIN or visiting our website at www.matr.vcu.edu.

Solution may be found on the MATR website.

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Twin Matters

A Family Newsletter from the Mid-Atlantic Twin Registry

Volume XVI





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A Family Newsletter from the Mid-Atlantic Twin Registry Volume XV

A Message From The Director

Dear MATR Participants:

Salutations from Virginia Commonwealth University (VCU), home of the Mid-Atlantic Twin Registry (MATR)! As usual the MATR is enjoying a busy fall with a number of ongoing studies, including phone surveys and blood sample collections.

In this particular newsletter, we wanted to take a small break from the scientific side of the MATR and share some interesting facts and stories about twins with you. We hope you will enjoy reading this volume as much as we have enjoyed putting it together for you.

If you have any questions or comments for us, please give us a call. We always welcome your feedback and hope to hear from you soon!

Kind regards,

July I Silbey

Judy L. Silberg, Ph.D. Scientific Director Mid-Atlantic Twin Registry



We would like to say "Thank You" to our participants who are active duty military and our veterans (and their families) for their dedication, service, and sacrifice.



MATR'S NEW LOGO

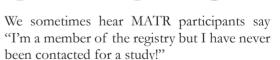
The Mid-Atlantic Twin Registry (MATR) is delighted to introduce our new Logo!



MID-ATLANTIC TWIN REGISTRY
VCU | Virginia Commonwealth University

Over the past couple of years the MATR has undergone many positive changes and we felt that it was a good time to revamp our logo. After much consideration we decided on the logo seen above! Be sure to watch for our new logo on select MATR mailings in the future. If you see this logo on a piece of mail you will know it is coming from us. We hope that you will like the new logo as much as we do!

S T U D Y SELECTION





Many times researchers are looking at specific criteria for participants in their study. For instance, the researcher may be looking for only female or only male participants or the study may have a specific age range. Whether the researcher needs twins who are identical or twins who are fraternal (zygosity) also determines which twins are eligible for the study as well as whether both twins are required for the study.

If you or your family are eligible for a study the MATR will send you a letter with information about the study then call to invite you to participate and answer any questions you might have. To guarantee that we will be able to reach you when you are selected for a study, please notify the MATR of changes to your name, address and telephone numbers either through our website, www.matr.vcu.edu or by calling 1-800-URA-TWIN (1-800-872-8946).

In this Issue:

- New MATR Logo
- Study Selection
- Meet the MATR
- On-going Studies
- Kids Corner

lirginia Commonwealth University

MEET THE MATR

Judy L. Silberg, PhD Scientific Director

Emily C. Hill Project Coordinator

Anne-Taylor Morris
Assistant Project Coordinator

Renolda Gelzinis

Database Administrator

Carol L. Williams

Participant Coordinator

Deborah A. Bratton
Fiscal Administrator

Joanna E. Penick Senior Research Interviewer

> Mary Angus Research Interviewer

> Chauntele Taylor
> Research Interviewer

Brandi Eldridge Research Interviewer

Patricia Solari Research Interviewer

Nida Cistovaite
Research Assistant

REFUSALS: STUDY vs. MATR

Occasionally when the MATR contacts an individual or family with an invitation to join in a new study we find that, due to having refused a study in the past, some participants believe they have been removed from the MATR.

Per your Rights as a Participant you may refuse any study you are not interested in; refusing a study will not remove you from the MATR. If you wish to permanently withdraw from the MATR, you should be specific about your desire to be removed.

The MATR is dedicated to respecting the rights and honoring the wishes of our participants. If the MATR is unsure of the level of a refusal we will send you a letter requesting that you clarify your desired status in the Registry.

As an alternative to withdrawal from the Registry there is also the option to take a sabbatical for a specified amount of time during which you would not be contacted for any studies.

MIBBRB IMAGE TWINS



When I was about 15 months old, my mom gave birth to identical twin boys and boy did she have her hands full with the three of us! After a while she and my dad decided to take a short break from the chaos and they went on a weekend getaway. They asked my grandmother to stay with us while they were gone. Things were going well at first; mom always dressed the twins, Chris and Tim, in color-coded clothing to be able to tell them apart. Chris always wore red and Tim always wore blue. The system worked really well, but had a flaw, which my grandmother soon found out.

It was bath time for Chris and Tim. When she finished bathing them she took them out of the tub and got ready to redress them. But wait, who was who? Beginning to panic, my grandmother tried to remember which one was dressed in red and which in blue, but by this point they were crawling around and confusing her even more. How would she be able to tell them apart? Should she guess and hope she got it right? Suddenly, she had an idea that was worth a try.

She called me into the bathroom and said to me, "Now honey, can you tell me which one is Chris and which one is Tim?" I identified them quickly without a second glance and ran off to continue to



play. My grandmother sat for a second, bemused by how easily I pointed them out and trying to decide whether to believe a 2 year old. Realizing she didn't have much of a choice, she dressed "Chris" in

red and "Tim" in blue and from then on that's how they were known.

Chris and Tim were certainly mirror-image in appearance, but this 'mirroring' effect went beyond just their faces. Over time mom noticed things like their hair curls swirled in opposite directions. As you can see from these pictures, they tended to do things oppositely, such as the direction they looked over their shoulders and which hand was dominant. It also turned out that they had opposite foot dominance, which we found out when they started playing sports.



So what causes all of this mirroring?

Chris and Tim are a type of identical twins known as mirror-image twins. Mirror-image twins occur when a single egg divides later in development

than typical identical twins - more than a week after conception. Although the egg is still very small when it splits, it already has a right side and left side. Mirror-image twins split just in time to prevent being conjoined and most conjoined twins are mirror-image.

Mirror-image twins may give hints at a very young age; even as babies one may lie curled up to the right and the other curled up to the left and then as they grow, they display other opposite behaviors/developments. Many times their first teeth come in oppositely and their fingerprints are mirror images as well. There are even rare cases where one twin has internal organs on the usual side and the other twin has them on the opposite side. In theory, if a pair of mirror image twins faced each other, they would appear to be exact reflections of one another.

Only about 25% of identical twins and 1% of the people in the entire world are mirror image twins. As you can see it's a pretty unusual phenomenon and it's neat to be able to say that my brothers are part of it. Although they have used their mirror-images to play tricks on teachers, family and friends, there was one person who could always tell them apart, and I'm happy to say it was me.

Thanks to the MATR's Project Coordinator, Emily Hill, for sharing this story about her twin brothers, Chris and Tim.

MULTIPLE BIRTH FACTS

- Twin pregnancies, whether fraternal or identical, occur spontaneously in approximately 1 in 80 pregnancies in the United States.
- An estimated 4 million women have babies each year, and over 2000 of those give birth to triplets, quadruplets or more.
- The average age of women when they give birth for the first time is 25, but the average for mothers giving birth to triplets or more is 31.
- An estimated 40% of twin births are the mother's first (63% for triplets or more). Another 32% are the second-born (28% for triplets or more); 28%, third or more (9% for triplets or more).

ON-GOING STUDIES:

National Institute of Child Health and Human Development (NICHD) – We are currently seeking identical twins, between the ages of 18 and 30 and those 60 and older, for this phase of the NICHD Development and Aging study. This study hopes to learn more about how humans age and develop by comparing changes in the genetic material of the two age groupings. The NICDH study is exploring an exciting and rapidly developing area of research called epigenetics. This

means that the researchers are looking at genes as well as the

structural changes that help regulate genes.

Genes, Environment and the Development Initiative (GEDI) – The MATR continues recruitment of twins who previously took part in the "Virginia Twin Study of Adolescent Behavioral Development" and the "Young Adult Follow-up Study" to participate in this important research. With findings from this study, researchers hope to improve their understanding of factors that trigger substance use disorders (SUD).

Aging and Genomic Changes: Role of Environment/ Genetics (FHA) – For this study we are looking for twins, male pairs and female pairs, of all ages and zygosity. The FHA study is collecting information to measure how frequently our chromosomes change as we age and to determine how much these changes are influenced by genes and/or the environment. This information is important because changes in our chromosomes are thought to be key in the development of many health conditions, including cancer, heart disease, Alzheimer's disease, diabetes and arthritis. The information gained from this study should allow investigators to recognize frequencies or chromosomal patterns of acquired changes that can hopefully be used for preventative health screenings.

Genetic and Environmental Causes of Polycystic Ovary Syndrome (PCOS) – Researchers at Duke University are studying the genetic and environmental causes of Polycystic Ovary Syndrome (PCOS). Knowing what causes PCOS can help scientists develop new treatments and ways to lower a woman's chance of developing PCOS, especially if PCOS runs in her family. It may also lead to information on how to lower the rates of other conditions that are associated with PCOS such as obesity, diabetes, high cholesterol, high blood pressure, heart disease and certain cancers.

See a Study You Are Interested In? If there is a study you feel you are eligible for and would be interested in participating in please contact the MATR by calling 1-800-URA-TWIN (1-800-872-8946) or go to our website www. matr.vcu.edu and send us a message. When you contact us please provide the name of the study you are interested in, your name, current address and the phone number (and time) where it is best to reach you.

We Value You.

The Mid-Atlantic Twin Registry (MATR) values your participation greatly and strives to interact with our community with consideration and respect. We have the same expectations for researchers that interact with our twins. If at any time you have questions or concerns regarding your experiences with MATR staff or research staff for any study, please do not hesitate to call 1-800-URA-TWIN (800-872-8946) or call the Participant Coordinator for the MATR, Carol Williams, at 804-828-8116 and we will address your concern immediately.

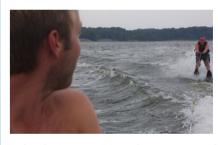
Twin Photos and Stories

Thank you to everyone who has sent in photographs and stories. Please continue to send photos and stories about your experiences as a multiple. Once we receive them you will be asked to sign a permission form which allows us to use them in publications. Who knows, your picture and/or story could show up in upcoming newsletters, or even on our website! We all enjoy learning about other multiples' experiences, so be sure to fill us in!

Do you know twins who want to register with us?

If so, please ask them to visit our website at www.matr.vcu.edu and drop us a note, or call us at 1-800-URA-TWIN (1-800-872-8946), so they can join the thousands of twins who are willing to consider participating in health-related research.

THE LAND OF TWINS



The frequency of identical twins is about the same around the world; however the rate of fraternal twins varies, not only from family to family but across the world. For example, twins are very rare in Japan (0.8 percent) but quite common in

Nigeria (5 percent). Igbo-Ora, a small farming community in southwest Nigeria welcomes visitors with a sign proclaiming "The Land of Twins". There is hardly a family there without a set of twins.

One theory of why in the 1960's about 1 of every 20 births resulted in twins but has now slowed to about 1 in every 42 births is diet. Yoruba women used to eat a lot of yams (sweet potatoes). The Nigerian version of yams is rich in natural chemicals that cause more than one egg to be released making it much easier, and more likely, to produce fraternal twins. In more recent years the Yoruba's diet has changed to fewer yams and more rice, milk, sugar, and bread.

Although the yam theory is just a guess, wouldn't it be interesting if eating more sweet potatoes meant having more twins?

ATTENTION TWINS: EMAIL ADDRESSES NEEDED!

Again, we would like to thank everyone who has already sent us their email addresses. We will continue collecting email addresses, from members over 18 years old and parents of younger twins, in an effort to start conducting web-based surveys and we hope more of you would like to take part in this process. If you are interested, please visit our website at www.matr. vcu.edu and drop us a note or call us at 1-800-URA-TWIN (1-800-872-8946) and leave a message. As with all information you provide us, we will not share your email with anyone and you may ask to be removed at any time.