Twin Matters

A Family Newsletter from the Mid-Atlantic Twin Registry

Volume XVII

RESEARCH STUDY UPDATES

GENES, ENVIRONMENT AND THE DEVELOPMENT OF SUBSTANCE USE DISORDER (GEDI)

The first phase for Drs. Eaves' and Silberg's "Genes, Environment and the Development of Substance Use" study is almost complete. This study is part of a multi-site project called the Genes, Environment and Development Initiative (GEDI) of the National Institute on Drug Abuse (NIDA). For this first phase, participants from several study sites, including the MATR, have provided samples from which genetic material will be isolated for analysis.

For the next phase of the study, investigators will begin something called "genotyping" (determining the genetic make up) of the samples they've received for their analysis. Through their analysis the researchers are hoping to determine which genes and/or combination of genes most likely play a role in whether or not an individual may develop substance use issues. There is also evidence to suggest that at different developmental periods (childhood, adolescence, and young adulthood) there are differing likelihoods that an individual might develop substance use issues. Keeping this in mind, ultimately the researchers hope to answer which genes, which environments, and which developmental transitions together predict the start and progression for which drug of abuse an individual might be susceptible to. While this research will take several years to complete, in the end we hope to gain a better understanding regarding the development of substance use issues, which in turn will allow scientists to investigate interventions and prevention programs that are most likely to be successful.

Currently, we have collected approximately 830 samples out of our 1000 sample goal. Though this first phase of sample collection is ramping down, there is still time to participate. If you have already been contacted by us and have yet to schedule your blood draw appointment, please try to do so as soon as possible. Feel free to contact us if you need help arranging your appointment. For twins that might be interested in participating in this study, the main requirement is that you participated in either the "Virginia Twin Study of Adolescent Behavioral Development" (VTSABD) or the "Young Adult Follow-up Study" (YAFU); some of

(continued on Page3)

A Message From The Director

Dear MATR Participants;

Greetings from the MATR! We hope that you are all doing well and are having a great summer! We are looking forward to some exciting projects and wanted to update everyone on the progress of our current studies.

We have also completely updated our website and are very excited about the changes this will bring! By the time you receive this newsletter the first changes should be posted and we will be adding new features, so check it out at www.matr.vcu.edu – any comments or suggestions are always welcome. We hope you enjoy it!

And as always, thank you for your continued support of the MATR!

Regards,

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

EMAIL ADDRESSES NEEDED!

We would like to, again, thank everyone who has already provided us with their email addresses. We are still collecting email addresses, (from members over 18 years old and parents of younger twins). 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 (800-872-8946) and leave a message. You can also email us at matr@vcu.edu. As with all information you provide, we will not share your email address with anyone and you may ask that your email address be removed at any time.

In this Issue:

VCU

Virginia Commonwealth University

KIDS CORNER!

Start →

DID YOU KNOW THAT . . .

- the word "twin" comes from the Anglo-Saxon getwinn, which means "that which is divided"
- twins born to members of the Galoa, an African tribe, are always named Wora and Veno. Wora means "first born" and Veno means "second born"
- identical twins **do not** have identical fingerprints. Fingerprints are not just a genetic characteristic; fingerprints are influenced by environmental factors during pregnancy like nutrition, blood pressure and growth rate. Fingerprints of identical twins although similar, as with any fingerprints, no two are exactly the same!

MOVING?

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

Twin Matters

A Family Newsletter from the Mid-Atlantic Twin Registry

Volume XVII

VCU

Virginia Commonwealth University

MID-ATLANTIC TWIN REGISTRY
VCU | Virginia Commonwealth University
MATR

http://www.matr.vcu.edu
1-800-URA-TWIN (872-8946)
PO Box 980617, Richmond VA 23298

Return Service Requested

Nonprofit
Organization
U.S. Postage
PAID
Permit No. 869
Richmond, VA

WE VALUE YOU.

The Mid-Atlantic Twin Registry (MATR) greatly values its participants and strives to treat you with consideration and respect. We have the same expectations for researchers that interact with our twins. If at any time you have feedback 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 our Participant Coordinator, Carol Williams, at 804-828-8116 and we will address your concern immediately. You can also email us at matr@vcu.edu.

TWIN PHOTOS AND STORIES

Please continue to send photographs 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. We all enjoy learning about other multiples' experiences, so be sure to fill us in! Thank you to everyone who has already sent in photos and stories!

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 (800-872-8946), so they can join the thousands of multiples who are willing to consider participating in health-related research.

POLYCYSTIC OVARY SYNDROME (PCOS)

Over the last few years, the MATR has collaborated with the National Institute of Environmental Health Studies and Duke University for a study of Polycystic Ovary Syndrome (PCOS). This study is beginning to wind down its data collection at this time. Thank you to all of our twins who participated in this study!

NATIONAL INSTITUTE OF CHILD HEALTH & HUMAN DEVELOPMENT STUDY (NICHD)

Participant recruitment for The National Institute of Child Health & Human Development's (NICHD) "Development & Aging" study is still in the early phases and will likely continue for quite some time. This study is investigating factors that affect human development and aging. A person's environment and lifestyle choices influence their aging process as well as their risk for developing certain age-related diseases, such as heart disease and diabetes. As we age, we see some evidence of the aging process, such as gray hair or wrinkles, but there are also changes in our cells that aren't visible. Another factor in whether or not people develop age-related disorders is how our cells are programmed to change. "Biological clocks" are the programs in our cells that impact how we age and develop. How these biological clocks work is directly related to our DNA or genes. Certain chemicals in our cells help regulate these "aging genes." These chemicals can help turn certain genes on or off and thus influence whether a particular gene is active or inactive at a given point in our development. This gene regulation in turn influences our biological clocks and ultimately how we age.

NICHD participants ascertained through the Mid-Atlantic Twin Registry need to be complete twin pairs from two main age categories - ages 18 to 30 and over 60. Currently we are focusing on ascertaining identical twins (monozygotic), but as the study progresses we will likely seek fraternal twins (dizygotic) as well. While twins for this study can be any sex or race, there are some criteria that would exclude twins from participating. For example, if the individual has an active autoimmune disorder or is taking certain medications, they cannot participate because those factors might overly influence the results of the analysis. Because of this, if we contact you about the study we will need to ask you some health-related questions to determine your eligibility. Some of you that have already been contacted about this study might be contacted again to determine if you're still eligible and willing to participate.

For this research, analysis will be done on the DNA as well as other genetic material and proteins in the samples. From this analysis, the researchers hope to learn more about how an individual's genetic makeup and lifestyle choices influence their aging process and in turn how aging influences gene expression. To do this the researchers will look at the genes themselves as well as the structures and chemicals that help regulate how active a gene is at a given time. This research falls into the category of "epigenetics". In the world of genetics studies, this is a relatively new and exciting area of research, and, at least for this study, results could very well shed light on what leads to the progression of certain age-related diseases.

STUDY COMPENSATION

Some of our studies may offer you a token of appreciation for your participation, such as money, a gift, or an informational report. Typically, you should receive the gift within 1-2 months after completing the study, unless you are told otherwise by the study interviewer. Though it is rare, sometimes our participants do not receive their compensation due to circumstances beyond our control; for instance, items are lost in the mail or the participant moves and we do not have their updated address. If you do not receive your gift within a reasonable amount of time, please notify the study or the MATR right away.

Although the compensation is the study's responsibility, the MATR wants to ensure you receive them in a timely manner. Unfortunately, once a study ends, the MATR is no longer able to provide compensation or reports promised by a specific study.

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 of all ages and ethnicities 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).

FACTORS IN HUMAN AGING (FHA)

As we age, our genetic material (genes and chromosomes) ages as well. Because of this, over our lifetime our genetic material changes in many different ways; including changes to our chromosomes. Some of these chromosomal changes seemingly do not have any affect on us while some are likely involved in certain age-related conditions. Learning more about the causes that lead to increased numbers of chromosomal changes can help researchers learn more about how people develop certain age-related conditions.

This study aims to help answer whether these chromosomal changes are more likely caused by an individual's genetics or their environment; or a combination of the two. In order to help answer this question, the researchers invited both male and female identical and fraternal twins from ages 9 to 80 to participate in the Factors in Human Aging (FHA) study. These participants provided blood samples from which the researchers obtained the cells and genetic material needed to identify the presence and frequency of chromosomal changes for each twin in the study.

As expected, the researchers found that as a person ages the frequency of changes to their chromosomes increases. They also observed that fraternal twins are more likely to have greater differences in the frequency of chromosomal changes than identical twins. This indicates that there is, at least to some degree, something that predisposes certain individuals to develop more chromosomal changes than others. But, the researchers also determined that there was too much variation in the number of chromosomal changes within identical twin pairs to be able to confirm genetics as the only reason for the changes. This means that environmental factors must also play a role in the differences of chromosomal changes observed in the participants.

One particular environmental factor that the researchers looked at was the role smoking might play on the development of these changes. Participants that had smoked had significantly greater frequencies of chromosomal changes than those that did not. Again, this indicated that environmental exposures are a factor in the occurrence of chromosomal changes.

These findings have provided insight into the relationship between a person's genetics and their environmental factors; both of which play a role in the frequency of chromosomal changes in individuals. The next step for this research is to look into how some of the molecules that are part of our genetic makeup might play a role in the development of chromosomal changes. This would shed light on why some individuals are predisposed to these changes more than others.

Quaternary Marriages

It does not happen often, however there are cases where identical twins marry other identical twins. These marriages are called "quaternary marriages". Estimates indicate that there are 250-300 sets of identical twins married to identical twins in the world.

Cousins or siblings; when identical twins marry identical twins, technically their children are first cousins, however their genetic makeup is the same as that of full siblings, this occurs only when identical twins marry identical twins (since identical twins share nearly 100% of the same DNA).

The children of non-twin siblings or fraternal twins who are married to identical twins are genetic half-siblings as they share the same DNA from one parent, but not the other.

ESTIMATING FETAL AND MATERNAL GENETIC CONTRIBUTIONS TO PREMATURE BIRTH

It has been reported that 12% of births are premature (pre-term). Dr. York, in collaboration with researchers from VCU, has been analyzing pregnancy histories from the children of twins to determine risk factors that might lead to premature births. The researchers have been particularly interested in understanding how a person's genes and their environment affect pregnancy outcomes. It is difficult to make informed conclusions about the role environmental factors and genes have on whether a birth will be preterm or not. This is partially because the researchers have to take into account the mother's genes as well as the genes of the fetus and how their genetic effects might combine to affect the outcome of a pregnancy. The researchers also have to estimate the role environmental factors have. As you can see, this creates a complicated set of circumstances with multilayered factors that contribute to a birth being pre-term or full-term.

In approaching these multilayered factors the researchers needed to develop a method of analysis that would allow them to better examine this complex data. To accomplish this they used a combination of computer programs and statistical models that allowed them to estimate the different effect of the environment, the mother's genes, and the fetus's genes. As a product of this method, the researchers were able to conclude that both a mother's genes and the genes of the fetus influence the risk of a pregnancy ending in a pre-term delivery. These results, along with establishing their innovative research method, will allow the researchers to further understand the influence genes and the environment have on the outcome of pregnancies.

(continued from Page 1)

you may remember these as the "MCV Twin Studies." If you think you participated in these studies and we have not yet contacted you, please call us and make sure we have your updated contact information in case we do not already.