What happens when I register my twins with the MATR?
First, please know that registering with us is completely voluntary and you can withdraw from the MATR at any time. If you decide not to join, or if you register now and want to withdraw later, there will be no penalty and you will not lose any benefits to which you are otherwise entitled.

The purpose of the MATR is to facilitate twin-based health and behavior research by connecting our twins and their data with researchers conducting important twin studies. During registration, we ask for your family’s contact, demographic, zygosity, and health-related information so we can let you know about studies your family might be eligible to take part in. When the MATR has a research project that you and your twins may qualify for, we will contact you by mail, phone, email, or text with the details and invite you to participate. Participation usually involves filling out a questionnaire, completing a telephone or in-person interview, or providing a sample.

If you and your twins are invited to participate in a research study, it is always your decision whether (or not) you take part and you never have to answer any question you feel uncomfortable answering.

Registration is simple, free, and only takes a few minutes to complete by continuing with this online registration form. Twins ages 17 and younger must be registered by their parent or legal guardian and will be contacted when they turn 18 with an option to opt-out of the registry. If you prefer, you may register by mail or phone by contacting us at matr@vcu.edu or 1-800-872-8946.

What will you do with my family’s information and are there any risks?
The MATR takes your privacy and the security of your data very seriously. We will store your family’s information on VCU’s firewalled, encrypted servers and limit access to the data to qualified and trained employees and researchers. Although we have rigorous measures to protect your information, please keep in mind, whenever you share information about yourself there is always a risk of a loss of confidentiality and privacy. We do not release names or any information to employers or insurance companies, and we do not provide researchers with approval to contact you unless we have your permission first. The MATR may obtain information about you from different agencies, such as birth records, census records, and national search databases. We may use this as well as information you share with us to administer the registry and to create anonymized or de-identified datasets for research studies without asking you for additional consent. Generally, we will not give you individual results from being part of the registry. It is unlikely, but possible that authorized representatives from VCU or the Department of Health and Human Services may need to view personal information about you for the purposes of managing, monitoring, and overseeing research. Furthermore, the MATR has obtained a Certificate of Confidentiality from the National Institutes of Health as an additional measure of privacy protection. Privacy protections are not extended to information that is legally required to be reported (like child and/or elder abuse). In the future, if you decide you do not want to be a part of this registry, you can request to be removed by contacting the MATR. However, de-identified data that has already been shared with researchers will continue to be used. If you have any questions about the MATR or our research studies, please contact us at matr@vcu.edu or 1-800-URA-TWIN. If you have questions concerning your rights as a research participant, you may contact our University’s Office of Research Subject’s Protection at (804) 827-2157.

What are the benefits of participating in the MATR?
MATR participants receive our newsletters 2-3 times per year informing them about ongoing projects, study updates, twin events, and other twin-related topics of interest. As a thank you for being part of the registry, MATR twins may be entered into annual drawings for items such as $25 VISA gift cards. While you are not likely to benefit directly from participating in the registry, many people enjoy participating in MATR studies and appreciate the opportunity to contribute to scientific, health-related research.