

Your Rights as Participants in the Mid-Atlantic Twin Registry (MATR)

Note: For parents of juvenile twins, this document covers the rights of you and your family

The MATR is a registry of twins, other multiples, and their families who are willing to consider taking part in research on the role of heredity and the environment in causing common physical and mental health problems. While you and your family may not benefit directly from being in the MATR, your participation in research studies may benefit society by providing information that could lead to better prevention, diagnosis, and treatment of common diseases and conditions.

Your participation in the MATR is entirely voluntary and you may withdraw from our registry at any time. When you register in the MATR, you are agreeing to:

- Provide basic contact and demographic information and, if applicable, answer some questions that will help us determine whether you and your twin (or your twins/multiples) are identical or fraternal. The MATR stores this information as well as any health information you provide to help determine if you might be eligible to participate in research studies.
- Allow us to contact you periodically by mail, email or telephone to invite you to participate in health and behavior related research. Any invitation for juvenile twins to participate in research will be asked of the parent or guardian of the twins directly. The MATR does not contact juvenile twins without parental consent.
- Allow us to send you our newsletter and announcements of events for twins/multiples about 2-3 times per year.

You are not agreeing to participate in any additional research studies by registering in the MATR. You decide if you want to take part in specific research projects and you never have to answer any question that you feel uncomfortable answering. Study participation usually involves filling out a questionnaire, completing a telephone or in-person interview and perhaps providing samples.

There is no known risk and no cost to register in the MATR. If you are invited to participate in a specific research project, any risks and benefits associated with that study will be explained to you and you are always given the opportunity to ask questions regarding participation

The MATR locates information about twins/multiples and their families through birth records, national search databases, and information available to us through different agencies. We also may obtain information about your family and your neighborhood from US Census data and other publicly available information. The MATR uses data collected from twins/multiples for research purposes, such as selecting twins for research projects and in administering the registry, when contacting participants. We also may use data to create de-identified or anonymized data for use in statistical reports and research projects.

The MATR takes your privacy and the security of your data very seriously. These are just some of the steps we take to protect the confidentiality of your information.

- You will be identified by unique numbers. Names and identifying information are kept separate from any other information you or members of your family might provide.
- We do not release names or personal information to employers, insurance companies, direct marketing companies, or any mailing list.
- We do not provide your contact information to any researcher without your permission

Certificate of Confidentiality. To further protect your privacy, the MATR has obtained a Certificate of Confidentiality (COC) from the National Institutes of Health. More information about the COC is available in the MATR privacy policy which is posted on the MATR website and sent in MATR registration packets.

For information about your rights as research participants, contact Virginia Commonwealth University's Office of Research Subjects Protection. If you have questions, comments, or requests for the Twin Registry, please contact us.

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