

**HIPAA¹ AUTHORIZATION TO USE AND DISCLOSE
INDIVIDUAL HEALTH INFORMATION FOR RESEARCH PURPOSES**

Purpose. As a research participant, I authorize Antoinette Moran, MD, John Wagner, MD and Brandon Nathan, MD and staff to use and disclose my individual health information for the purpose of conducting the research project entitled **Natural History Study** (HSC # 0305M47349).

2. Individual Health Information to be Used or Disclosed. My individual health information that may be used or disclosed to conduct this research includes: demographic information, results of histories and physical exams, results of blood tests and other diagnostic medical procedures, and results of questionnaires.

3. Parties Who May Disclose My Individual Health Information. Drs. Moran, Wagner, and Nathan and staff may obtain my individual and diagnostic test information from Fairview-University Medical Center and from other hospitals, clinics, health care providers and health plans that provide my health care during the study.

4. Parties Who May Receive or Use My Individual Health Information. The individual health information disclosed by parties listed in item 3 and information disclosed by me during the course of the research may be received and used by Drs. Moran, Wagner, and Nathan and staff, the George Washington University Biostatistics Center, and the National Institutes of Health (a Federal agency).

5. Right to Refuse to Sign this Authorization. I do not have to sign this Authorization. If I decide not to sign the Authorization, I may not be allowed to participate in this study or receive any research related treatment that is provided through the study. However, my decision not to sign this authorization will not affect any other treatment, payment, or enrollment in health plans or eligibility for benefits.

6. Right to Revoke. I can change my mind and withdraw this authorization at any time by sending a written notice to Antoinette Moran, MD, MMC 404, 420 Delaware St. SE, Minneapolis, MN 55455 to inform her of my decision. If I withdraw this authorization, the researcher may only use and disclose the protected health information already collected for this research study. No further health information about me will be collected by or disclosed to the researchers for this study.

7. Potential for Re-disclosure. My individual health information disclosed under this authorization may be subject to re-disclosure outside the research study and be no longer protected. For example, researchers in other studies could use my individual health information collected for this study without contacting me if they get approval from an Institutional Review Board (IRB) and agree to keep my information confidential.

7A. Also, there are other laws that may require my individual health information to be disclosed for public purposes. Examples include potential disclosures if required for mandated reporting of abuse or neglect, judicial proceedings, health oversight activities and public health measures.

This authorization does not have an expiration date.

I am the research participant or personal representative authorized to act on behalf of the participant.

I have read this information, and I will receive a copy of this authorization form after it is signed.

signature of research participant or research participant's representative

date

printed name of research participant or research participant's
personal representative

description of personal representative's authority to act on behalf
of the research participant (if applicable)

¹ HIPAA is the Health Insurance Portability and Accountability Act of 1996, a federal law related to privacy of health information.