

Transforming Medicine Through Genomic Research



You can make a difference in the future of medicine.

Principal Investigator Pablo V. Gejman, M.D. Director, Genomic Health Initiative



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The future depends on persons just like you helping to advance science.

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NorthShore University HealthSystem invites adult patients to join the Genomic Health Initiative, a new research project. This study investigates how an individual's genetic makeup impacts health, wellness, and the effectiveness of treatment options.

Why should I participate?

NorthShore has embarked on the next major step in advancing medicine—individualized healthcare based on an individual's comprehensive genetic profile. Hereditary makeup is transmitted through DNA, which varies in different persons, impacting health, risk for specific illnesses, and the response to many medicines. Our study will investigate these relationships to advance scientific understanding and, in turn, may lead to improvements in healthcare through genomic research.

How can I help?

We are asking all adult NorthShore patients to participate in this project, which will be fundamental to multiple genetic research studies, now and in the future. You can help by allowing NorthShore researchers to study your DNA in combination with research data obtained from your Electronic Medical Record (EMR). Participants donate a blood sample and allow us to study leftover biosamples collected for clinical reasons unrelated to this study. All DNA samples and data obtained from your EMR are de-identified and kept confidential.

Will my information be kept confidential?

To ensure confidentiality, we will replace your name with a research number that will be assigned to your study-related information, your DNA, and all biosamples. Only qualified researchers will access your study-related information. The genetic data generated by our research study will not become part of your EMR. Your name and identifying information will not be used when any findings are published.

Please know that NorthShore has an exemplary record of maintaining confidentiality with more than a

decade of experience with our EMR system. NorthShore has obtained a Certificate of Confidentiality from the National Institutes of Health (NIH) for this study.

How will you collect my blood sample for DNA?

We will take less than one extra tablespoon of your blood for this research. This can occur when you have your next clinically scheduled blood draw at any of NorthShore's hospital outpatient labs or patient service centers—see **northshore.org/lab-services/locations** for a full listing. Or if you prefer, you can come in just for this research blood draw. There is no cost to you.

What happens to my sample?

Your DNA will be stored in highly secured facilities within NorthShore. Our researchers will also access your NorthShore EMR for research purposes, including your medical history, diagnoses, procedures, imaging records, medications, and demographic information. This clinical information will be compared to the genetic data across a large number of participants to identify relationships between variation in DNA and many different health conditions.

How many people will be participating?

Our goal is to enroll tens of thousands individuals in this ongoing study. This large sample size will allow us to study the widest range of genetic variants in DNA to best inform about many different genetic and medical disorders, for example, diabetes, high blood pressure, breast cancer, asthma, obesity, abnormal heart rhythms, glaucoma, prostate cancer, psoriasis, etc.

Will I be recontacted?

The choice to be recontacted is yours. If you allow, we may contact you if we find significant results affecting your personal health. Researchers may also contact you to ask you to consider volunteering for future studies, although you have no obligation to do so. Your participation is voluntary and you may withdraw from the study at any time by contacting us.

How Can I Participate?

If you are enrolled in NorthShoreConnect, logon and click on the Genomic Health Initiative enrollment link to read and electronically sign the consent form. Or, the next time you come to the Hospital Outpatient Laboratory at Evanston or Glenbrook for a blood draw, inform the staff there that you would like to participate in the Genomic Health Initiative. They will provide a hardcopy version of the consent form. Either way, your consent allows NorthShore researchers to study your DNA and access your NorthShore EMR.

If you have further questions, please call the Genomic Health Initiative staff at **(224) 364-7470**. Or you can complete and mail the form below and researchers will contact you at your convenience. For more information please visit **northshore.org/ghi** for updates on the overall progress of the study and for selected educational materials

Send to: Genomic Health Initiative NorthShore University HealthSystem 1001 University Place Evanston, Illinois 60201 Attn.: Pablo V. Gejman, M.D., Director

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Please contact me about the Genomic Health Initiative.

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