

AUTHORIZATION FOR RELEASE OF GENOMIC DATA FOR RESEARCH PURPOSES FORM



Title of Research Project:			
Purpose of Research Project:			
Patient Name:		Date of Birth:	
Principal Investigator:			
Mailing Address of Investigator:			
Research Institution:			

Exome data will be emailed as a link to a secure file sharing site. (*indicates required field)

Preferred Format of Data: CRAM and VCF VCF only

Name*: _____

Street: _____ City: _____ State: _____ Zip: _____

Business Phone: _____ Fax Number: _____

Email*: _____

I, _____, hereby authorize GeneDx, LLC (GeneDx) to disclose (release) my health information that identifies me for the research project identified above. My health information may be shared with the principal investigator, sub-investigators, and research institution and research team (the Researchers) conducting the research project. I understand such use or disclosure may also include disclosure to research collaborators, research project sponsors, and/or Institutional Review Boards or Data Safety and Monitoring Boards.

The Researchers are solely responsible for providing me with information regarding the research project, answer my questions about the research project, and obtaining my informed consent to participate in research project. I understand that GeneDx is not involved in the research project. I understand and authorize that the health information that GeneDx may disclose to the Researchers under this authorization form includes:

- Laboratory Results (e.g., blood work, molecular tests, and other diagnostics)
- Clinical information (e.g., symptoms and features of any disorder, review of systems results, and medical records)
- Other: _____

I understand that my health information may be collected and used to conduct the research project and to determine research results. I also understand that my health information may be used to develop new tests, procedures and commercial products. Finally, I understand that the research project sponsor may add my research project data to research databases so that it can design better research studies in the future or gain a better understanding of disease.

I understand that my health information can be used or disclosed when required by law, and that it may be shared with a public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, and conducting public health surveillance, investigations or interventions.

I understand that my health information may be included in scientific publications and educational presentations, but no publication or public presentation about the research described above will reveal contain my name, address or date of birth without another authorization from me.

GeneDx is required by law to protect my health information. By signing this document, I authorize GeneDx to disclose (release) my health information

to the Researchers. I understand that those persons who receive my health information may not be required by federal and state privacy laws (such as the Privacy Rule) to protect it and may share my information with others without my permission, if permitted by laws governing them.

If I am a resident of New York and experience discrimination because of the use or disclosure of HIV/AIDS-related information, I may contact the New York State Division of Human Rights at 212.480.2493 or the New York City Commission of Human Rights at 212.306.7450. These agencies are responsible for protecting my rights. **UNLESS YOU SIGN HERE, NO INFORMATION ABOUT ALCOHOL/SUBSTANCE ABUSE, HIV/AIDS, OR MENTAL HEALTH WILL BE DISCLOSED:**

YES, DISCLOSE THIS INFORMATION * _____ NO, DO NOT DISCLOSE THIS INFORMATION * _____

I understand that I do not have to sign this Authorization and refusal to sign will not affect services that I may receive from GeneDx.

I understand I may change my mind and revoke (take back) this Authorization at any time. Unless I revoke the Authorization, it will not expire. Even if I revoke this Authorization, I understand that the Researchers may still use or disclose health information they already have obtained about me as necessary to maintain the integrity or reliability of the current research. To revoke this Authorization, I understand that I must provide written notice to:

GeneDx, LLC
Attention: Privacy Officer at 207 Perry Parkway
Gaithersburg, MD 20877

I understand revocation of this Authorization is effective upon receipt by GeneDx. I understand that if I revoke this Authorization as described above, GeneDx will stop providing my health information to the Researchers for the research project. However, in the event of a revocation of this Authorization, the Researchers will be able to use my health information that it already collected, and information already sent to the research project sponsor cannot be withdrawn.

By signing this Authorization I agree to the following:

- I have read and understood this Authorization and had ample opportunity to ask questions;
- I certify that this request has been made freely, voluntarily, and without coercion; and
- I understand that I will receive a copy of this form after I sign it.

Participant

Signature: _____

Printed Name: _____

Date: _____

Personal Representative of Participant (if applicable)

Signature: _____

Printed Name: _____

Date: _____

Description of authority to sign for participant:

PLEASE RETURN THIS FORM TO GENEDX BY FAX, MAIL OR EMAIL:
PATIENT RECORDS RELEASE: 207 PERRY PARKWAY, GAITHERSBURG, MD 20877
FAX: 301-519-2892 | EMAIL: SUPPORT@GENEDX.COM CALL US AT 301-519-2100 WITH QUESTIONS.