BCM-WHOLE GENOME LABORATORY
PHONE: 1-800-411-GENE | FAX: 713-798-2787 | www.bcmgeneticlabs.org

Requesting Release of Exome Data Instructions

The FASTQ data files (text-based format for storing nucleotide sequences) from the exome sequencing tests can be requested by an Institution. For FASTQ files to be released by Baylor College of Medicine to the requesting institution the following information is required for each patient:

1) Institutional Whole Exome/Genome Data Release Form - To be filled out by requesting Institution, and signed by the investigator and patient. The investigator will need to attest that the patient/patient's guardian has been provided with an informed consent document and that this informed consent document specifically authorizes the receipt and analysis of whole exome raw data.

2) BCM Authorization for Release of Protected Health Information - To be filled out by requesting insitution and patient. Required for every patient. Section 3 is to be filled out by the requesting institution and the other highlighted sections are to be reviewed and signed by the patient.

Once all information is compiled, please fax all documentation in its entirety to (713) 798-2787. Please allow up to 6 weeks for data receipt. There is currently no additional charge for this service.

For any questions, please contact us at 1-800-411-GENE (4363).

Disclaimer: Our results are reported based on our method, which has been validated using our criteria, and results are interpreted by Board Certified Directors. Given that variability exists in bioinformatics pipelines used to analyze sequence data and generate variant lists, it is possible that other pipelines will uncover potentially "clinically relevant" discoveries not included in the clinical report.

Baylor College of Medicine is not involved with analysis performed outside of the analysis included in the clinical report and is not responsible for disclosures of genetic information beyond those included in the clinical report issued by the Medical Genetics Laboratories at Baylor College of Medicine

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INSTITUTIONAL WHOLE EXOME/GENOME DATA RELEASE FORM

The Whole Genome Laboratory (WGL) at Baylor College of Medicine (BCM) will provide raw sequencing data in the form of FASTQ data files.

To release of raw data, this form and a copy of the "Authorization For Release of Protected Health Information" for each specific patient are required. Once all required documentation is received, please allow up to 6 weeks for receipt of data.

Given that variability exists in bioinformatics pipelines used to analyze sequence data and generate variant lists, it is possible that research pipelines will uncover potentially "clinically relevant" discoveries not included in the WGL clinical report. Institutions receiving raw sequence data are strongly encouraged to share any new discoveries with our laboratory.

The WGL and BCM are not involved in the research and are not responsible for disclosures of genetic information beyond those included in the clinical report issued by the Medical Genetics Laboratories (MGL) at BCM. It is the responsibility of the institution receiving the data and their clinical personnel to appropriately inform patients of research discoveries.

Institution(s) Requesting Raw Data:

Institution

IRB or other Protocol # (Optional)

Person Responsible for Receipt of Raw Data

Email Address of Person Responsible for Receipt of Raw Data

Phone # of Person Responsible for Receipt of Raw Data

Signature

Date

Patient Information:

Proband Name

Proband DOB (MM/DD/YY)

BCM Lab Number(s)*

BCM Family Number

***NOTE:** For Cancer Exome Sequencing, please provide lab numbers for both the tumor and nontumor specimens.

As the Investigator, I attest that the patient/patient's guardian has been provided an informed consent document for this research and that the informed consent document specifically authorizes the receipt and analysis of whole exome raw data.

Investigator (Print Name)	Signature of Investigator	Date
Patient/Patient's Legal Guardian (Print Name)	Signature of Patient/Patient's Legal Guardian	Date

Checklist of required documentation:

- ☐ Authorization for Release of Protected Health Information Form (to be signed by patient or legal guardian)
- ☐ Completed copy of this form

AUTHORIZATION FOR RELEASE OF PROTECTED HEALTH INFORMATION

Please complete all sections.

Section 1. **I, _____(print name) authorize the following health care provider and/or organization to disclose the following protected health information to the designated person and/or organization for the purpose(s) listed below.**

Section 2. Information disclosed by:	***Section 3.*** Information to be received by:
Baylor College of Medicine (name of health care provider/organization)	_____ (name of person or organization)
One Baylor Plaza, Houston, TX 77030 (address)	_____ (address)
713-798-2787 (facsimile number) 1-800-411-GENE (phone number)	_____ (facsimile number) _____ (phone number)
Section 4. The information to be disclosed: ___Medical record ___Billing record _X_Other (please specify) FASTQ data files from clinical exome sequencing	***Section 5.*** The information is to be: ___ mailed ____ faxed to _____ ___ e-mailed ____ phoned to _____ ___ picked up by _____ _X_ Other (please specify) Sent via secure FTP site

Section 6. The information is disclosed for the following use(s): _____

This authorization shall expire (date or event): _____

Section 7.

I do ___ do not ___ consent to the disclosure of information pertaining to psychiatric or psychological evaluation or treatment.

I do ___ do not ___ consent to the disclosure of reportable communicable diseases including sexually transmitted diseases and HIV(AIDS) evaluation or treatment.

I do ___ do not ___ consent to the disclosure of substance/alcohol abuse evaluation or treatment.

Section 8. By signing below, I understand the following:

a. I may revoke the authorization at any time (except to the extent that disclosure has already occurred in reliance upon this authorization) by sending a written revocation to the health care provider/organization designated above.
b. Any treatment, payment, or my enrollment in any health plan or my eligibility for benefits will not be affected if I do not sign this Authorization.
c. Any information disclosed by this authorization to any person/organization not a health care provider, business associate of a health care provider or health plan covered by federal and state privacy regulations could be re-disclosed by the recipient and no longer protected by those regulations.
d. I am entitled to receive a copy of this signed authorization.

Section 9.

_____ _____ _____
signature of patient) (date of birth) (date signed)

_____ _____
(address) (contact phone number/s)

_____ _____
(signature of personal representative if not signed by patient)* (date signed)

***[NOTE: Attach documents demonstrating your authority to act on behalf of the patient.]**