

INSTITUTION EXOME DATA RELEASE FORM

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 Genetics 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) Request for and Consent to Release of Information from Individual's Records Form** - To be filled out by requesting institution and patient. Required for every patient.

These forms can be found on our website at: baylorgenetics.com/consent/

Once all information is compiled, please fax all documentation in its entirety to (713) 798-2787. Upon receipt of the completed data release forms, the request will be entered into our system. Only FASTQ files are available through a file transfer protocol (GoAnywhere Services) and instructions will be sent to you via email from "BCM-HGSC managed file transfer".

Please watch your email for a message from "BCM-HGSC managed file transfer".

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 1-800-411-4363.

Once the data is prepared for release, the email address listed on the data release form will receive a message stating that a new account has been created and provide the user name. A second email will be sent with a password. Newly created MFTS accounts have a 90 day lifespan after which the password expires.

Upon the release of additional data to the account within the 90 day lifespan, an email will be sent to the user by our team notifying of the new release. Additions after the 90 day lifespan will receive an email with a new password. Please keep the original email with the user name as any future releases will be sent to the same account.

You may connect to your file transfer account using your web browser, an SFTP client or a command line interface. You cannot access your account through plain FTP or FTPS. If you have trouble accessing your account, please email questions@hgsc.bcm.tmc.edu

Please download your data and save on your local system. Data files are approximately 10GB in size and will only be available on the file transfer system for 90 days from the email notification date.

After 90 days, files are removed from the file transfer system automatically. Please submit a new request form if the user intends to access the data files.

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 Genetics 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 Baylor Genetics.

INSTITUTION EXOME DATA RELEASE FORM

INSTITUTIONAL WHOLE EXOME/GENOME DATA RELEASE FORM AND CONSENT TO RELEASE OF INFORMATION FROM INDIVIDUAL'S RECORDS

Baylor Genetics will provide raw sequencing data in the form of FASTQ data files.

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 Baylor Genetics clinical report. Institutions receiving raw sequence data are strongly encouraged to share any new discoveries with our laboratory.

Baylor Genetics is not involved in the research and are not responsible for disclosures of genetic information beyond those included in the clinical report issued by the Baylor Genetics. It is the responsibility of the institution receiving the data and their clinical personnel to appropriately inform patients of research discoveries.

NOTA: The execution of this form does not authorize the release of information other than that specifically described below. This form authorizes the release of information that you specify in accordance with 5 U.S.C., Section 5701 and 7332; and 45 C.F.R., parts 160 and 164.

INSTITUTION REQUESTING RAW DATA

Institution _____ IRB or other Protocol # (Optional) _____
Person Responsible for Receipt of Raw Data _____ Phone # of Person Responsible for Receipt of Raw Data _____ E-Mail of Person Responsible for Receipt of Raw Data _____

Information Requested: **FASTQ data files from clinical exome sequencing**

Purpose(s) or need for which information is to be used by Organization of Individual to whom information is to be released _____

Investigator Name _____ Investigator Signature _____ Date (MM/DD/YYYY) _____

PATIENT INFORMATION

Proband Name _____ Proband Date of Birth (MM/DD/YYYY) _____ Baylor Genetics Lab # _____ Baylor Genetics Family # _____

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

PARENTAL INFORMATION * (ONLY AVAILABLE FOR TRIO WES)

Maternal Name _____ Maternal Date of Birth (MM/DD/YYYY) _____ Baylor Genetics Lab # _____

Paternal Name _____ Paternal Date of Birth (MM/DD/YYYY) _____ Baylor Genetics Lab # _____

AUTHORIZATION AND CERTIFICATION

I certify that this request has been made freely, voluntarily, and without coercion and that the information given above is accurate and complete to the best of my knowledge. I understand this release may not be obtained or offered as condition for treatment, payment, or other eligibility for benefits upon my signing this authorization. I may revoke this authorization at any time in writing, except to the extent that this action has already been taken to comply with it. Written revocation is effective upon receipt by the facility housing the records. Upon release, my records will no longer be protected, and re-disclosure by those receiving the information may be accomplished without my further authorization. Without my express revocation, the authorization will automatically expire upon satisfaction of the need for disclosure, under the conditions listed below, or upon this date _____ (supplied by individual/patient).

Patient/Patient's Legal Guardian Name _____ Patient/Patient's Legal Guardian Signature _____ Date (MM/DD/YYYY) _____

Mother's Signature (Required if raw data is being requested) _____ Date (MM/DD/YYYY) _____

Father's Signature (Required if raw data is being requested) _____ Date (MM/DD/YYYY) _____