

Introduction

This document provides information on how to request PPMI whole exome sequencing data in FASTQ and/or BAM format. Due to the size of these data, they are available only via sets of loaner hard drives.

Background

Whole exome sequencing was performed on whole-blood extracted DNA samples collected according to the *PPMI Research Biomarkers Laboratory Manual*. Details about the exome data may be found in the *Exome Sequencing Methods* document, available in the Genetic Data Download section of the [PPMI data repository](#). Genomic VCF (gVCF) data files generated from the exome sequencing process are currently available to authorized PPMI investigators from within the PPMI data repository hosted by the Laboratory of Neuro Imaging (LONI). However, due to the size of the files the entire dataset cannot be reasonably distributed over the Internet, so the FASTQ and BAM files will be disseminated per user request via sets of external drives.

Your Responsibilities

In order to receive the BAM/FASTQ exome sequencing data you are required to maintain your PPMI data use account under the provisions of the PPMI [Data Use Agreement](#) including protecting data from unauthorized access and following all aspects of the PPMI [Publications Policy](#). In addition, you must agree to the terms of the **Whole Exome Sequencing Data Agreement** (below).

Please contact ppmi@loni.usc.edu to be added to the requestor queue. A scanned copy of the Whole Exome Sequencing Agreement (below) must accompany your request. Data requests will be filled in the order received. LONI will contact you when the hardware becomes available to verify shipping information.

You will be responsible for making arrangements for shipping and insurance, including all associated costs (***If located outside the US, refer to the section on international shipments*). If funding is needed for shipping costs please contact MJFF at ppmi@michaeljfox.org. Depending on the files requested, the data will be shipped on between 1 and 4 external hard drives valued at \$325.00 each, which you will need to replace if they are lost or damaged.

Once you receive the shipment, please copy the data to your local system and return the hardware within 3 weeks of receipt. Each hard drive will be labeled with the return address, which is also shown below:

Attn: Data Coordinator
Laboratory of Neuro Imaging Institute for Neuroimaging and Informatics (INI)
Keck School of Medicine at University of Southern California
2001 North Soto Street, SSB1-102,
Los Angeles, CA 90032

****For International Shipments**

When shipments are sent internationally, they often will require additional documentation, such as commercial invoices. Before making shipping arrangements, contact your designated courier service about supplemental forms required for shipments into and out from the US. This will ensure that the shipment clears U.S. Customs.



Whole Exome Sequencing Data Agreement

I am requesting PPMI whole exome data. I will:

- maintain the genetic data in confidence with the same degree of care I hold my own confidential information.
- not attempt to use the data to identify PPMI subjects.
- not transfer or redistribute the data in any way.
- follow all provisions of the PPMI [Data Use Agreement](#), the PPMI [Publications Policy](#) and my institution's rules and regulations.
- return the hardware on which the data is provided in good working condition, within the assigned time period.
- replace any lost or damaged hardware within 30 days.

Additionally:

- Nothing in this document shall be construed as granting you a license to any patent rights or other intellectual property rights.
- Any significant violation of the points in this document will lead to suspension of data access privileges.

I agree to the terms of this agreement and am requesting the data selected below (check one). I acknowledge that I am responsible for returning the hardware in:

Entire Set (FASTQ and BAM)

FASTQ only

BAM only

Signature:

Printed Name:

Date:

Email address of authorized PPMI account holder:

Email address for communicating status:

Shipping address: