**THE ASHKENAZI GENOME CONSORTIUM**

**DATA ACCESS AGREEMENT**

**This agreement governs the terms on which access will be granted to the genotype data generated by the Ashkenazi Genome Consortium.**

**In signing this agreement, You are agreeing to be bound by the terms and conditions of access set out in this agreement.**

**For the sake of clarity, the terms of access set out in this agreement apply both to the User and the User’s Institution (as defined below). User Institution and User are referred to within the agreement as “You” and “Your” shall be construed accordingly.**

**Definitions:**

*Consortium* means The Ashkenazi Genome Consortium, a group of investigators, listed in the appendix. *Data* means all and any human genetic data obtained from the Consortium.

*Data Subject* means a person, who has been informed of the purpose for which the Data is held and has given his/her informed consent thereto.

*User* means a researcher whose User Institution has previously completed this Data Access Agreement and has received acknowledgement of its acceptance.

*Publications* means, without limitation, articles published in print journals, electronic journals, reviews, books, posters and other written and verbal presentations of research.

User Institution means the organization at which the User is employed, affiliated or enrolled.

**Terms and Conditions:**

In signing this Agreement:

1. You agree to use the Data only for the advancement of research, according to the consent obtained from sample donors.
2. You agree not to use the Data or any part thereof for the creation of products for sale or for any commercial purpose.
3. You agree to preserve, at all times, the confidentiality of information and the Data pertaining to the Data Subjects. In particular, You undertake not to use, or attempt to use the Data to compromise or otherwise infringe the confidentiality of information on Data Subjects and their right to privacy.
4. You agree not to attempt to link the Data provided under this agreement to identifiable information or archive data available for the Data Subjects provided, even if access to that data has been formally granted to you, or it is freely available without restriction, without specific permission being sought from the relevant access committees.
5. You agree not to transfer or disclose the Data, in whole or part, or any identifiable material derived from the Data, to others, except as necessary for data/safety monitoring or program management. Should You wish to share the Data with a collaborator outside the same Institution, the third party must make a separate application for access to the Data.
6. You agree to use the Data for the approved purpose and project described in Your application; use of the data for a new purpose or project will require a new application and approval. A new purpose includes, but not limited to, studying a disease, cohort, or sequencing/genotyping strategy not explicitly specified in the Data Access Form.
7. You agree that any use of the Data for studies directly competing with TAGC investigators would be done in collaboration with the relevant investigator(s). Research interests of TAGC investigators that are protected by this mechanism are listed in the “protected research interests” column in the Table shown in Schedule 1.
8. You agree not to use the Data for the stigmatization, defamation, or denigration of any ethnic or cultural group. You agree to comply with the standards of scientific inquiry and integrity if using the Data to pursue questions of potential political or cultural sensitivity.
9. You accept that Data will be reissued from time to time, with suitable versioning. If the reissue is at the request of sample donors and/or other ethical scrutiny, You will destroy earlier versions of the Data.
10. You agree to abide by the terms outlined in the Consortium 'Publications Policy' as set out in Schedule 2.
11. You agree to acknowledge in any work based in whole or part on the Data, the published paper from which the Data derives, the version of the data, and the role of the Consortium and the relevant primary collectors and their funders. Suitable wording is provided in the Publications Policy given in Schedule 2.
12. You accept that the Consortium, the original data creators, depositors or copyright holders, or the funders of the Data or any part of the Data supplied:
13. bear no legal responsibility for the accuracy or comprehensiveness of the Data; and
14. accept no liability for indirect, consequential, or incidental, damages or losses arising from use of the Data, or from the unavailability of, or break in access to, the Data for whatever reason.
15. You understand and acknowledge that the Data is protected by copyright and other intellectual property rights, and that duplication, except as reasonably required to carry out Your research with the Data, or sale of all or part of the Data on any media is not permitted.
16. You recognize that nothing in this agreement shall operate to transfer to the User Institution any intellectual property rights relating to the Data. The User Institution has the right to develop intellectual property based on comparisons with their own data.
17. You accept that this agreement will terminate immediately upon any breach of this agreement by You and You will be required to destroy any Data held.
18. You accept that it may be necessary for the Consortium or its appointed agent to alter the terms of this agreement from time to time in order to address new concerns. In this event, the Consortium or its appointed agent will contact You to inform You of any changes and You agree that Your continued use of the Data shall be dependent on the parties entering into a new version of the Agreement.
19. You agree that you will submit a report to the Consortium Data Access Committee, if requested, upon completion of the agreed purpose. The Consortium Data Access Committee agrees to treat the report and all information, data, results, and conclusions contained within such report as confidential information belonging to the User Institution.
20. You accept that the Data is protected by and subject to international laws, including but not limited to the US Health Insurance Portability and Accountability Act of 1996, and that You are responsible for ensuring compliance with any such applicable law. The Consortium Data Access Committee reserves the right to request and inspect data security and management documentation to ensure the adequacy of data protection measures in countries that have no national laws comparable to that which pertain in the EAA.
21. This agreement shall be construed, interpreted and governed by the laws of New York States and the United States and shall be subject to the non-exclusive jurisdiction of US courts.

**SCHEDULE 1**

**TAGC Investigators and their research interests**

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| Investigator | Affiliation | Protected research interests | Additional interests |
| Gil Atzmon | Albert Einstein College of Medicine/Haifa University | Longevity, aging, epigenetics in disease, epigenomics, and lipid profile |  |
| Susan Bressman | Beth Israel Medical Center | Dystonia; Typical and Atypical Parkisonian Syndromes: Parkinson Disease (PD), PD with dementia, Progressive supranuclear palsy, Corticobasal degeneration, multiple system atrophy, diffuse Lewy body disease; Essential Tremor; Frontotemporal dementia (FTD); and Amyotrophic Lateral Sclerosis (ALS) |  |
| Judy Cho | Ichan School of Medicine at Mount Sinai | Inflammatory Bowel Disease |  |
| Lorraine Clark | Columbia University Medical Center | Neurodegenerative diseases including but not restricted to Dystonia; Typical and Atypical Parkisonian Syndromes: Parkinson Disease (PD), PD with dementia, Dementia with Lewy body, Progressive supranuclear palsy, Corticobasal degeneration, multiple system atrophy, diffuse Lewy body disease; Essential Tremor; Frontotemporal dementia (FTD); and Amyotrophic Lateral Sclerosis (ALS). |  |
| Ariel Darvasi | Hebrew University of Jerusalem |  | Type I diabetes, Type II diabetes, Colorectal cancer, Breast cancer, Prostate cancer, Alzheimer’s disease, Parkinson’s disease, Multiple sclerosis, Migraine, Hypertension, Asthma, Coronary artery disease, Schizophrenia, Bipolar disorder, Schizoaffective disorder, and Rheumatoid arthritis |
| Todd Lencz | The Feinstein Institute for Medical Research | Schizophrenia, Schizoaffective disorder, and Bipolar disorder |  |
| Kenneth Offit | Memorial Sloan-Kettering Cancer Center | Breast and ovarian cancer, colon cancer, prostate cancer, and Lymphoma |  |
| Harry Ostrer | Albert Einstein College of Medicine | Cancer genetics, metastasis genomics, radiogenomics, rare disorders |  |
| Laurie Ozelius | Ichan School of Medicine at Mount Sinai | Dystonia; Typical and Atypical Parkisonian Syndromes: Parkinson Disease (PD), PD with dementia, Progressive supranuclear palsy, Corticobasal degeneration, multiple system atrophy, diffuse Lewy body disease; Essential Tremor; Frontotemporal dementia (FTD); and Amyotrophic Lateral Sclerosis (ALS). |  |
| Itsik Pe’er | Columbia University |  | Population genetics, demographic inference, statistical genetics, identical-by-descent segments |
| Inga Peter | Ichan School of Medicine at Mount Sinai | Inflammatory Bowel Disease |  |

**SCHEDULE 2**

**Publications Policy**

The primary purpose of the Ashkenazi Genome Consortium is to accelerate efforts to identify genomic variants influencing human morbidity in the Ashkenazi Jewish and other populations. This goal is implemented through large-scale genome sequencing of a cohort of control individuals. Additional objectives include addressing questions in population genetics and evolutionary biology as well as the development of methods appropriate to achieve the goals of the project. The data may also be used to study the population history of the Ashkenazi Jewish population as well as other, Jewish and non-Jewish populations.

The Consortium anticipates that data generated from the project will be used by others. Potential applications include: association studies in diseases beyond the scope of the consortium members; clinical evaluation and prioritization of genomic variants; imputation of large cohorts of sparsely genotyped individuals for the purpose of studies in medical and evolutionary genetics; development of new analytical methods; and study of patterns of polymorphism in the Ashkenazi Jewish and other populations and their interrelation with demographic and evolutionary parameters.

Authors who use data from the project must acknowledge TAGC using the following wording "This study makes use of data generated by The Ashkenazi Genome Consortium.”

Users should note that the Consortium bears no responsibility for the further analysis or interpretation of these data, over and above that published by the Consortium.

**For and on behalf of User:**

**Name of**

**Applicant(s):** \_Dr. Alexei Fedorov\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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**Signature of**

**Applicant(s):** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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**Date:** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**For and on behalf of User Institution:**

**Signature of**

**Institutional or**

**Administrative** Chairman of the Department of Medicine,

**Authority:**  The University of Toledo

**Print name:** Dr. Lance Dworkin

**User Institution:** The University of Toledo

**Date:** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

WHEN SUBMITTING THIS DOCUMENT, PLEASE INCLUDE ALL PAGES OF THE AGREEMENT WITH THIS SIGNATURE PAGE.