## Terms and Conditions for the Monogenic Hub website and the Monogenic Portal

These Terms and Conditions constitute a binding agreement made between you, whether personally or on behalf of an entity ("you") and the GP2 Monogenic Hub ("we," "us" or "our"), concerning your access to and use of the <a href="themonogenic.com">themonogenic.com</a> website as well as any other media form, media channel, mobile website or mobile application related, linked, or otherwise connected there to (collectively, the "Site").

You agree that by accessing the Site, you have read, understood, and agree to be bound by all of these Terms and Conditions.

This site includes the Monogenic Hub website as well as the Monogenic Portal through which clinical and genetic data will be shared.

# **Data sharing**

- 1. The Parties will comply with all laws, rules, regulations and policies applicable to the handling, use and disposal of the data.
- 2. Data will only be used for the following research project: The Global Parkinson's Genetics Program (GP2) ("Research Project"). You herewith understand and agree that in accordance with this Research Project:
- 3. Information and data provided to us under these Terms and Conditions may be shared with members of the Global Parkinson's Genetic Program (GP2) (https://www.parkinsonsroadmap.org/gp2/);
- 4. Data provided to us under this Agreement may be shared with GP2-designated genetic data generation centers, including, but not limited to, the National Institute on Aging (part of the National Institutes of Health, a component of the United States Department of Health and Human Services) and Psomagen, Inc.
- 5. Data generated or derived using information provided to us under this Agreement will be deposited into a data repository such as the Accelerating Medicines Partnership Parkinson's Disease ("AMP-PD") data portal (https://amp-pd.org/), which approved researchers can gain access to. The MATERIAL being experimental in nature must not be used in humans, in clinical trials, for diagnostic, prognostic, treatment purposes or purposes involving human subjects or animals unless where applicable explicitly admitted by an ethics committee or regulations on the treatment of laboratory animals.
- 6. The data must not be used for any commercial purposes, including selling, commercial screening, or transferring data to a third party for commercial purposes.

# Confidentiality

1. All information to be deemed confidential that is transferred between the Parties under this Agreement will be clearly marked "CONFIDENTIAL" by the disclosing Party ("Confidential Information") and maintained in confidence by the receiving Party for a period of three (3) years from the date of receipt. Any Confidential Information that

is orally disclosed must be reduced to writing and marked "CONFIDENTIAL" by the providing Party and such notice must be provided to the receiving Party within thirty (30) days of the oral disclosure. We shall hold the Confidential Information in strict confidence, and use the Confidential Information solely for the Purpose and shall not disclose or permit disclosure of the Confidential Information to anyone except if only to the extent that such disclosure is necessary to the Investigator's evaluation of his/her interest in participating in the study(ies) and unless otherwise permitted by you. We will use best efforts to safeguard such Confidential Information. In the event you permit us to disclose the Confidential Information for the Purpose to a third party, we shall ensure such third party is bound by confidentiality obligations similar to those contained herein prior to disclosure. If we are required by law, regulation, rule or order of any governmental authority or agency to disclose any Confidential Information, we may disclose such Confidential Information provided that we provide you, as applicable, maximum prior written notice and an opportunity to file a protective order. Each party agrees that it will promptly notify the other should it conclude that it is no longer interested in pursuing the Purpose for which such Confidential Information was provided. Immediately following transmission or receipt by us of any such notice or upon request from you, we shall return the Confidential Information; provided, however, that we may retain one (1) copy of Confidential Information for archival purposes and thereafter shall not use the Confidential Information for any purpose whatsoever.

2. The term "Confidential Information" shall not include information which: (i) at the time of disclosure is information published, generally known or available to the public, or after the time of disclosure becomes generally available through no wrongful act of us; (ii) was rightfully in our possession (as evidenced by written records) prior to being disclosed by you; (iii) is obtained from any third party lawfully in possession of the information and not in violation of any legal obligation with respect to the information; or (iv) is independently developed by or for us without the use of your Confidential Information, as evidenced by written records.

#### **User representations**

By using the Site, you represent and warrant that:

- (1) all registration information you submit will be true, accurate, current, and complete;
- (2) you will maintain the accuracy of such information and promptly update such registration information as necessary;
- (3) you have the legal capacity and you agree to comply with these Terms and Conditions;
- (4) you will not access the Site through automated or non-human means, whether through a bot, script, or otherwise;
- (5) you will not use the Site for any illegal or unauthorized purpose;
- (6) your use of the Site will not violate any applicable law or regulation.

If you provide any information that is untrue, inaccurate, not current, or incomplete, we have the right to suspend or terminate your account and refuse any and all current or future use of the Site (or any portion thereof).

## **Privacy policy**

We care about data privacy and security. By using the Site, you acknowledge that you have read our Privacy Policy. Please be advised the Site is hosted in Lübeck, Germany.

If you access the Site from the United States, Asia, or any other region of the world with laws or other requirements governing personal data collection, use, or disclosure that differ from applicable laws in Europe, then through your continued use of the Site, you are transferring your data to Europe, and you expressly consent to have your data transferred to and processed in Europe.

#### **Data Protection**

The parties undertake to know and comply with the relevant national (federal and state) and international regulations in their current version, in particular

REGULATION (EU) 2016/679 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation - GDPR)

#### **User registration**

You are required to register with the monogenic website. You agree to keep your password confidential and will be responsible for all use of your account and password. We reserve the right to remove, reclaim, or change a username you select if we determine, in our sole discretion, that such username is inappropriate or otherwise objectionable.

Provided that you are eligible to use the Site, you are granted a limited license to access and use the Site of any portion of the Content to which you have properly gained access solely for your personal, non-commercial use.

#### **Online Forms**

The monogenic website uses online forms to gather specific information from our site visitors. This 'contact us' form to send messages to our staff is used to collect typical information as the visitor's name, contact information, and a brief message. Data is then stored locally or on our email marketing platform.

## **Third-Party Websites and Other Sites**

This site may contain links to third-party web sites or services that are not owned or controlled or endorsed by the Site. These third-party websites may use cookies and collect your personal information through their privacy policies.

The Site has no control over, and assumes no responsibility for, the content, privacy policies, or practices of any third-party web sites or services. You further acknowledge and agree that the Site shall not be responsible or liable, directly or indirectly, for any damage or loss caused or alleged to be caused by or in connection with use of or reliance on any such content or services available on or through any such web sites or services.

## Changes

We reserve the right, in our sole discretion, to make changes or modifications to these Terms and Conditions at any time and for any reason. We will alert you about any changes by updating the "Last updated" date of these Terms and Conditions, and you waive any right to receive specific notice of each such change.

#### **CONTACT US**

In order to resolve a complaint regarding the Site or to receive further information regarding use of the Site, please use the contact form.