

## ENROLL-HD DATA USE AGREEMENT

**THE RECEIPT AND USE OF ENROLL-HD DATA FROM CHDI FOUNDATION, INC. REQUIRES THAT THE ORGANIZATION REQUESTING ENROLL-HD DATA (THE "RECIPIENT") TO ENABLE THE RECIPIENT'S RESEARCHERS (EACH, A "RECIPIENT RESEARCHER") AGREES TO THE TERMS AND CONDITIONS OF USE SET FORTH IN THIS ENROLL-HD DATA USE AGREEMENT (THIS "AGREEMENT").**

**PLEASE READ THIS AGREEMENT CAREFULLY BEFORE REQUESTING, DOWNLOADING AND/OR USING ENROLL-HD DATA. BY CLICKING "AGREE TO/ACCEPT", THE RECIPIENT IS EXECUTING THIS AGREEMENT AND AGREEING TO BE BOUND BY THE TERMS AND CONDITIONS OF THIS AGREEMENT.**

The mission of CHDI Foundation, Inc. ("CHDI") is to facilitate and enable the development of therapeutics that will substantially improve the lives of individuals affected by Huntington's disease ("HD") as quickly as possible.

In furtherance of that mission, CHDI is funding the conduct of a global multi-site observational clinical study entitled "A Prospective Registry Study in a Global Huntington's Disease Cohort (Enroll-HD)" (the "Enroll-HD Study").

One of CHDI's objectives for funding the Enroll-HD Study is to make data collected about or from the research participants participating in the Enroll-HD Study and/or derived from the data or biological materials collected about or from such research participants, available for research related to HD or other disorders.

The Recipient desires to obtain such data to enable the Recipient's Researchers to perform research that furthers the development of treatments of HD or other disorders.

CHDI is willing to make such data available to the Recipient to facilitate the performance of such research.

This Agreement sets forth certain terms and conditions to govern the use of such data by the Recipient.

In consideration of the mutual representations, warranties and covenants contained herein and other good and valuable consideration, the receipt and sufficiency of which are hereby acknowledged, the Recipient agrees with, and for the benefit of CHDI, as follows:

1. Definitions. For the purposes of this Agreement, capitalized terms used herein but not otherwise defined shall have the meanings set forth below:

- (a) "Data" means data collected about the research participants participating in the Enroll-HD Study and/or derived from the data or biological materials collected about or from such research participants, directly or indirectly provided to, or obtained by, the Recipient from CHDI. For the avoidance of any doubt, Data does not include Research Results.
  - (b) "Research" means any activity that furthers the development of treatments of HD or other disorders other than (i) the manufacture or distribution of any product or service for sale or (ii) the sale of any product or service. For the avoidance of doubt, Research shall not include any right to (A) manufacture or distribute any product or service for sale or (B) sell any product or service.
  - (c) "Research Results" means (i) all data, formulae, outcomes or other results produced and (ii) any discovery, invention, formulation, know-how, method, technological development, enhancement, modification, improvement, work of authorship, computer software (including, but not limited to, source code and executable code) and documentation thereof, data or collection of data, whether patentable or not, or susceptible to copyright or any other form of legal protection, conceived, discovered, invented, made or first reduced to practice, in each case in the course of the Recipient's conduct of Research using the Data.
2. Acknowledgement of the Recipient of Nature of the Data. The Recipient acknowledges that CHDI, as the organization funding the Enroll-HD Study and the providing the Data, has an obligation to safeguard the identity of the the research participants participating in the Enroll-HD Study whose (a) genotypic or phenotypic data is included in the Data and/or (b) data and/or biological materials were used to derive data included in the Data.
  3. Non-Exclusive License. CHDI grants to the Recipient a non-exclusive, non-transferable, non-assignable, non-sublicensable, paid-up license throughout the world to use the Data for the sole purpose of conducting Research that is directed and overseen by the Recipient Researcher. The Recipient acknowledges and agrees that no express or implied licenses or other rights are provided to use the Data or any related patents, patent applications, trade secrets or other proprietary rights of CHDI or any third party for any purpose other than conducting Research.
  4. Limited Warranty; No Other Warranties. The Data have been collected, processed and transferred to the Recipient under this Agreement in accordance with all federal, state, local and international laws applicable to CHDI. EXCEPT FOR THE EXPRESS REPRESENTATION AND WARRANTY SET FORTH IN THIS SECTION, THE DATA ARE PROVIDED "AS-IS" AND CHDI MAKES NO OTHER REPRESENTATIONS AND EXTENDS NO OTHER WARRANTIES OF ANY KIND, EITHER EXPRESSED OR IMPLIED. THERE ARE NO EXPRESS OR IMPLIED WARRANTIES OF MERCHANTABILITY OR

FITNESS FOR A PARTICULAR PURPOSE, OR THAT THE USE OF THE DATA WILL NOT INFRINGE ANY PATENT, COPYRIGHT, TRADEMARK, TRADE SECRET OR OTHER PROPRIETARY RIGHT. IN NO CASE WILL CHDI BE LIABLE FOR ANY CONSEQUENTIAL OR INCIDENTAL DAMAGES OR FOR ANY LOST PROFITS OR LOST REVENUES DUE TO, OR ARISING FROM, THE RECIPIENT'S USE, STORAGE OR DISPOSAL OF THE DATA.

5. Ownership.

- (a) Ownership of the Data. As between CHDI and the Recipient, CHDI retains ownership of the Data.
- (b) Ownership of Research Results. As between CHDI and the Recipient, the Recipient retains ownership of all Research Results (except that, as between CHDI and the Recipient, CHDI retains ownership rights to any Data included therein). The Foundation acknowledges and agrees that the Recipient is free to file patent application(s) claiming Research Results.

6. Use of the Data.

- (a) Use of the Data by the Recipient. The Recipient agrees:
  - (i) to use the Data for the sole purpose of conducting Research that is directed and overseen by the Recipient Researcher; and
  - (ii) to use the Data in compliance with all applicable federal, state, local, international, health authority and institutional laws, rules, regulations, orders and guidelines; and
  - (iii) to maintain, store and treat the Data in the same manner, and with the same level of care (but in no event less than a reasonable level of care), as the Recipient would maintain, store and treat its own proprietary or confidential information to prevent its unauthorized transfer, disclosure or publication, as applicable; and
  - (iv) not to use the Data to attempt to determine, or determine, the identity of any of the research participants participating in the Enroll-HD Study whose (A) genotypic or phenotypic data is included in the Data and/or (B) data and/or biological materials were used to derive data included in the Data; and
  - (v) if the Recipient is established in a country outside of the European Economic Area (and, as of the effective date of this Agreement, either (A) that country does not hold a European Commission decision finding that such country provides an adequate level of

protection or (B) the Recipient does not hold a European Commission finding that it provides an adequate level of protection), to (1) agree with CHDI in its capacity as the "data exporter" (as defined in Exhibit 1) of the Data and (2) comply with each of the contractual clauses set out in Exhibit 1 in its capacity as the "data importer" (as defined in Exhibit 1) of the Data (such contractual clauses being based upon the EU standard contractual clauses published by the European Commission pursuant to Article 26(2) of Directive 95/46/EC); and

- (vi) subject to, and except as expressly permitted by, this Agreement or otherwise expressly consented to in writing by CHDI, not to transfer or disclose the Data to any third party; and
  - (vii) subject to, and except as expressly permitted by, this Agreement or otherwise expressly consented to in writing by CHDI, not to publish the Data (including any Data contained or incorporated in any Research Results); and
  - (viii) to report to CHDI any use, transfer, disclosure or publication of the Data not expressly permitted by this Agreement within 48 hours of becoming aware of any such use, transfer, disclosure or publication.
- (b) Destruction of Certain Data upon Request. From time-to-time a research participant whose (i) genotypic or phenotypic data is included in the Data and/or (ii) data and/or biological materials were used to derive data included in the Data may request that their data (including data derived from their data and/or biological materials) no longer be stored and used for research. To accommodate that circumstance, upon notice from CHDI, the Recipient will appropriately destroy or discard, and discontinue use of, all of the Data identified by CHDI in such notice.
- (c) Provision of Data to Third Parties to Replicate Published Research Results. In addition, CHDI agrees, upon the written request of the Recipient, to provide the same Data provided to the Recipient under this Agreement to any third party that desires to attempt to replicate Research Results published by the Recipient Researcher; provided, that, such third party (i) submits a request to CHDI to obtain the Data and (ii) executes a data use agreement with CHDI containing terms and conditions the same as those set forth in this Agreement.

7. Requests for Data from Third Parties. The Recipient agrees to refer to CHDI any request for the Data from (a) any other person within Recipient's organization other than those persons conducting Research with, and under the direction of, the Recipient Researcher or (b) any third party.

8. Assumption of Liability; Indemnification. Except to the extent prohibited by law (or, alternatively, to the extent permitted by law), the Recipient assumes all liability for damages to the extent due to or arising from the use, storage or disposal of the Data by the Recipient. CHDI will not be liable to the Recipient for any loss, claim or demand made by the Recipient, or made against the Recipient by any third party, to the extent due to or arising from the use, storage or disposal of the Data by the Recipient. Except to the extent prohibited by law (or, alternatively, to the extent permitted by law), the Recipient will defend and indemnify CHDI (and its directors, officers, employees, trustees, shareholders, members and agents) against any loss, claim or demand (including attorneys' fees and cost of defense and the enforcement of this provision) suffered by CHDI in connection with any third party action, assessment, claim, demand, proceeding or suit to the extent due to or arising from (a) a breach of any representation, warranty or covenant of this Agreement by the Recipient or (b) the use, storage or disposal of the Data by the Recipient.
  
9. Publication of Research Results; Publication Policy; Acknowledgement of the Source of the Data.
  - (a) Publication of Research Results. The Recipient and the Recipient Researcher shall have the sole and exclusive right to publish the Research Results; provided, however, the Recipient acknowledges and agrees (and shall cause the Recipient Researcher to acknowledge and agree) that the right to publish the Research Results does not, except to the extent expressly consented to in writing by CHDI, include the right to publish the Data or the codes/identification numbers assigned to the research participants participating in the Enroll-HD Study whose (i) genotypic or phenotypic data is included in the Data and/or (ii) data and/or biological materials were used to derive data included in the Data and provided with the Data. The Recipient shall use reasonable efforts (and shall cause the Recipient Researcher to use reasonable efforts) to publish, cause to be published or otherwise publicly disseminate the Research Results as soon as reasonably possible after such Research Results have been produced.
  
  - (b) Publication Policy. As described in the Enroll-HD Publication Policy (as amended from time to time), it is CHDI's position that all matters related to authorship of scientific publications resulting wholly or in substantial part from CHDI resources (financial support, data or biomaterials) should be determined in accordance with the criteria defined by the International Committee of Medical Journal Editors (<http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html>). The Recipient acknowledges that, when publishing any Research Results, the Recipient is expected to comply with the Enroll-HD Publication Policy (as amended from time to time).

- (c) Acknowledgement of the Source of the Data. The Recipient agrees that, when publishing any Research Results, the Recipient will acknowledge CHDI and the third parties specified in the Enroll-HD Publication Policy as the source of the Data in accordance with the Enroll-HD Publication Policy.
10. Termination; Effect of Termination; Survival of Certain Provisions.
- (a) Termination. This Agreement will automatically terminate upon a material breach of any representation, warranty or covenant of this Agreement by the Recipient and such breach is not remedied within 45 days of the receipt by the Recipient of notice of such breach from CHDI. In addition, to the extent the Recipient is subject to Section 6(a)(v) of this Agreement, this Agreement is also subject to the termination provisions set forth in Exhibit 1.
  - (b) Effect of Termination. Upon any termination of this Agreement, the Recipient (i) will immediately discontinue its use of the Data and (ii) will immediately and appropriately destroy or discard the Data.
  - (c) Survival of Certain Provisions. This Section 10 and each of Section 1, Section 2, Section 4 through Section 9 and Section 11 through Section 18 shall survive any termination of this Agreement.
11. Notices. Any notice required or permitted to be given by this Agreement shall be in writing and shall be delivered by personal delivery, facsimile (provided the sender has evidence of successful transmission) or next day courier service. Any notice so delivered shall be deemed to be given, delivered and received, if delivered by personal delivery, on the day of delivery and if delivered by facsimile or courier service, on the day following dispatch. All such notices are to be given or made to the parties at the following addresses (or to such other address as the Recipient or CHDI may designate by a notice given in accordance with the provisions of this section):

If to CHDI to:

CHDI Foundation, Inc.  
c/o CHDI Management, Inc.  
350 Seventh Avenue, Suite 200  
New York, NY 10001  
Facsimile: 212-239-2101  
Attention: Chief Administrative Officer

With a copy to:

CHDI Foundation, Inc.  
c/o CHDI Management, Inc.  
350 Seventh Avenue, Suite 200  
New York, NY 10001  
Facsimile: 212-239-2101  
Attention: Chief Legal Officer

If to the Recipient, to the addresses for the Recipient and the Recipient Researchers maintained in each Recipient Researcher's Enroll-HD Clinical Access Account.

12. Assignment. The Recipient may not assign this Agreement without the prior written consent of CHDI.
13. Incorporation of Appendices, Exhibits and Schedules; Entire Agreement; Amendment. The appendices, exhibits and schedules identified in this Agreement are incorporated herein by reference and made a part hereof. If anything in any appendix, exhibit or schedule attached to this Agreement (other than Exhibit 1) or any notice, invoice or other document delivered by a party under this Agreement conflicts with any terms or conditions set forth in the body of this Agreement, the terms and conditions set forth in the body of this Agreement shall control. This Agreement constitutes the entire agreement among the parties hereto relating to the subject matter hereof and all prior understandings and agreements relating to the subject matter hereof are superseded hereby. This Agreement may not be amended except by a document signed by the Recipient and CHDI.
14. No Waiver. Any failure of either the Recipient or CHDI to enforce any provision of this Agreement shall not be deemed a waiver of its right to enforce such provision on any subsequent occasion. No waiver of any provision of this Agreement shall be valid unless it is in writing and is executed by the party against whom such waiver is sought to be enforced. A waiver by either the Recipient or CHDI of any provision of this Agreement will not be construed to be a waiver of any succeeding breach thereof or of any other provision of this Agreement.
15. Severability. Whenever possible, each provision of this Agreement shall be interpreted in such manner as to be effective and valid under applicable law. In the event a court of competent jurisdiction holds any provision of this Agreement to be invalid, such holding shall have no effect on the remaining provisions of this Agreement, and they shall continue in full force and effect.
16. Interpretation; Headings. The word "including" shall mean "including without limitation". All pronouns and any variations thereof refer to the masculine, feminine or neuter, singular or plural, as the context may require. All terms

defined in this Agreement in their singular or plural forms have correlative meanings when used herein in their plural or singular forms, respectively. Headings used in this Agreement are for convenience of reference only and are not intended to influence the interpretation hereof.

17. Governing Law. This Agreement shall be governed by and construed in accordance with the domestic laws of the State of New York without giving effect to any choice or conflict of law provision or rule (whether of the State of New York or any other jurisdiction) that would cause the application of the laws of any jurisdiction other than the State of New York unless the Recipient is prohibited by applicable law from so agreeing in which case this Agreement will be governed by such law as determined by a court of competent jurisdiction.
18. Authority to Execute this Agreement. The individual executing this Agreement on behalf of the Recipient represents and warrants that he or she has the authority (corporate or otherwise) to execute and deliver this Agreement on behalf of the Recipient.

[End of Enroll-HD Data Use Agreement]



**Exhibit 1 to Enroll-HD Data Use Agreement**

**(Standard Contractual Clauses – Transfer of Personal Data Outside the Community)**

**Controller to Controller Transfers**

References to "this Agreement" in this Exhibit 1 refer to the Data Use Agreement to which this Exhibit 1 is attached.

References to a "party" and the "parties" are to CHDI and the Recipient individually and collectively, as applicable.

Pursuant to Section 6 of this Agreement, the Recipient is required to enter into and comply with the clauses set forth in this Exhibit 1 if the Recipient is established outside of the European Economic Area and that country does not, as of the effective date of this Agreement, hold a European Commission decision finding that such third country, nor the Recipient, provides an adequate level of protection.

**Recitals**

- (a) The Recipient acknowledges that CHDI is subject to certain European Union ("EU") laws which govern the collection and use of personal data.
- (b) The Recipient further acknowledges that certain of the Data provided by CHDI to the Recipient includes personal data within the meaning of EU data protection laws.
- (c) The purpose of this Exhibit 1 is to legitimize the processing of personal data by the Recipient as required under EU data protection laws by ensuring it is given an "adequate level of protection" within the meaning of those laws.
- (d) The details of the transfer (as well as the personal data covered) are specified in Annex B to this Exhibit 1, which forms an integral part of the clauses set forth in this Exhibit 1.

**Definitions**

For the purposes of the clauses:

- (a) "personal data", "special categories of data/sensitive data", "process/processing", "controller", "processor", "data subject" and "supervisory authority/authority" shall have the same meaning as in Directive 95/46/EC of 24 October 1995 (whereby "the authority" shall mean the competent data protection authority in the territory in which the data exporter is established).

- (b) "the data exporter" shall mean the controller who transfers the personal data to the data importer.
- (c) "the data importer" shall mean the controller who agrees to receive from the data exporter personal data for further processing in accordance with the terms of these clauses and who is not subject to a third country's system ensuring adequate protection.
- (d) "clauses" shall mean the contractual clauses set forth in this Exhibit 1.

The details of the transfer (as well as the personal data covered) are specified in Annex B to this Exhibit 1, which forms an integral part of the clauses.

### **Data Protection Clauses**

#### **I. Obligations of the Data Exporter**

The data exporter warrants and undertakes that:

- (a) The personal data have been collected, processed and transferred in accordance with the laws applicable to the data exporter.
- (b) It has used reasonable efforts to determine that the data importer is able to satisfy its legal obligations under these clauses.
- (c) It will provide the data importer, when so requested, with copies of relevant data protection laws or references to them (where relevant, and not including legal advice) of the country in which the data exporter is established.
- (d) It will respond to enquiries from data subjects and the authority concerning processing of the personal data by the data importer, unless the parties have agreed that the data importer will so respond, in which case the data exporter will still respond to the extent reasonably possible and with the information reasonably available to it if the data importer is unwilling or unable to respond. Responses will be made within a reasonable time.
- (e) It will make available, upon request, a copy of the clauses to data subjects who are third party beneficiaries under clause III, unless the clauses contain confidential information, in which case it may remove such information. Where information is removed, the data exporter shall inform data subjects in writing of the reason for removal and of their right to draw the removal to the attention of the authority. However, the data exporter shall abide by a decision of the authority regarding access to the full text of the clauses by

data subjects, as long as data subjects have agreed to respect the confidentiality of the confidential information removed. The data exporter shall also provide a copy of the clauses to the authority where required.

II. Obligations of the Data Importer

The data importer warrants and undertakes that:

- (a) It will have in place appropriate technical and organizational measures to protect the personal data against accidental or unlawful destruction or accidental loss, alteration, unauthorized disclosure or access, and which provide a level of security appropriate to the risk represented by the processing and the nature of the data to be protected.
- (b) To the extent the data exporter consents to the data importer transferring the personal data to, or providing access to the personal data to, a third party, it will have in place procedures so that any third party it authorizes to have access to the personal data, including processors, will respect and maintain the confidentiality and security of the personal data. Any person acting under the authority of the data importer, including a data processor, shall be obligated to process the personal data only on instructions from the data importer. This provision does not apply to persons authorized or required by law or regulation to have access to the personal data.
- (c) It has no reason to believe, at the time of entering into these clauses, in the existence of any local laws that would have a substantial adverse effect on the guarantees provided for under these clauses, and it will inform the data exporter (which will pass such notification on to the authority where required) if it becomes aware of any such laws.
- (d) It will process the personal data for purposes described in Annex B to this Exhibit 1, and has the legal authority to give the warranties and fulfil the undertakings set out in these clauses.
- (e) It will identify to the data exporter a contact point within its organization authorized to respond to enquiries concerning processing of the personal data, and will cooperate in good faith with the data exporter, the data subject and the authority concerning all such enquiries within a reasonable time. In case of legal dissolution of the data exporter, or if the parties have so agreed, the data importer will assume responsibility for compliance

with the provisions of clause I(e).

- (f) At the request of the data exporter, it will provide the data exporter with evidence of financial resources sufficient to fulfil its responsibilities under Clause III (which may include insurance coverage).
- (g) Upon reasonable request of the data exporter, it will submit its data processing facilities, data files and documentation needed for processing to reviewing, auditing and/or certifying by the data exporter (or any independent or impartial inspection agents or auditors, selected by the data exporter and not reasonably objected to by the data importer) to ascertain compliance with the warranties and undertakings in these clauses, with reasonable notice and during regular business hours. The request will be subject to any necessary consent or approval from a regulatory or supervisory authority within the country of the data importer, which consent or approval the data importer will attempt to obtain in a timely fashion.
- (h) It will process the personal data, at its option, in accordance with the data processing principles set forth in Annex A to this Exhibit 1.
- (i) It will not disclose or transfer the personal data to a third party data controller located outside the European Economic Area ("EEA") without the prior written consent of the data exporter and
  - (i) the third party data controller processes the personal data in accordance with a Commission decision finding that a third country provides adequate protection, or
  - (ii) the third party data controller becomes a signatory to these clauses or another data transfer agreement approved by a competent authority in the EU, or
  - (iii) data subjects have been given the opportunity to object, after having been informed of the purposes of the transfer, the categories of recipients and the fact that the countries to which data is exported may have different data protection standards, or
  - (iv) with regard to onward transfers of sensitive data, data subjects have given their unambiguous consent to the onward transfer.

III. Liability and Third Party Rights

- (a) Each party shall be liable to the other party for damages it causes by any breach of these clauses and that liability as between the parties is limited to actual damage suffered. Punitive damages (i.e. damages intended to punish a party for its outrageous conduct) are specifically excluded. Each party shall be liable to data subjects for damages it causes by any breach of third party rights under these clauses. This does not affect the liability of the data exporter under its data protection law.
- (b) The parties agree that a data subject shall have the right to enforce as a third party beneficiary this clause and clauses I(b), I(d), I(e), II(a), II(c), II(d), II(e), II(h), II(i), III(a), V, VI(d) and VII against the data importer or the data exporter, for their respective breach of their contractual obligations, with regard to his personal data, and accept jurisdiction for this purpose in the data exporter's country of establishment. In cases involving allegations of breach by the data importer, the data subject must first request the data exporter to take appropriate action to enforce his rights against the data importer; if the data exporter does not take such action within a reasonable period (which under normal circumstances would be one month), the data subject may then enforce his rights against the data importer directly. A data subject is entitled to proceed directly against a data exporter that has failed to use reasonable efforts to determine that the data importer is able to satisfy its legal obligations under these clauses (the data exporter shall have the burden to prove that it took reasonable efforts).

IV. Law Applicable to the Clauses

These clauses shall be governed by the law of the country in which the data exporter is established, with the exception of the laws and regulations relating to processing of the personal data by the data importer under clause II(h), which shall apply only if so selected by the data importer under that clause.

V. Resolution of Disputes with Data Subjects or the Authority

- (a) In the event of a dispute or claim brought by a data subject or the authority concerning the processing of the personal data against either or both of the parties, the parties will inform each other about any such disputes or claims, and will cooperate with a view to settling them amicably in a timely fashion.
- (b) The parties agree to respond to any generally available non-

binding mediation procedure initiated by a data subject or by the authority. If they do participate in the proceedings, the parties may elect to do so remotely (such as by telephone or other electronic means). The parties also agree to consider participating in any other arbitration, mediation or other dispute resolution proceedings developed for data protection disputes.

- (c) Each party shall abide by a decision of a competent court of the data exporter's country of establishment or of the authority which is final and against which no further appeal is possible.

**VI. Termination**

- (a) In the event that the data importer is in breach of its obligations under these clauses, then the data exporter may temporarily suspend the transfer of personal data to the data importer until the breach is repaired or this Agreement is terminated.
- (b) In the event that:
  - (i) the transfer of personal data to the data importer has been temporarily suspended by the data exporter for longer than one month pursuant to paragraph (a);
  - (ii) compliance by the data importer with these clauses would put it in breach of its legal or regulatory obligations in the country of import;
  - (iii) the data importer is in substantial or persistent breach of any warranties or undertakings given by it under these clauses;
  - (iv) a final decision against which no further appeal is possible of a competent court of the data exporter's country of establishment or of the authority rules that there has been a breach of the clauses by the data importer or the data exporter; or
  - (v) a petition is presented for the administration or winding up of the data importer, whether in its personal or business capacity, which petition is not dismissed within the applicable period for such dismissal under applicable law; a winding up order is made; a receiver is appointed over any of its assets; a trustee in bankruptcy is appointed, if the data importer is an individual; a company voluntary arrangement is commenced by it; or any equivalent event

in any jurisdiction occurs

then the data exporter, without prejudice to any other rights which it may have against the data importer, shall be entitled to terminate this Agreement (including these clauses), in which case the authority shall be informed where required. In cases covered by (i), (ii), or (iv) above, the data importer may also terminate this Agreement (including these clauses).

- (c) Either party may terminate these clauses if (i) any Commission positive adequacy decision under Article 25(6) of Directive 95/46/EC (or any superseding text) is issued in relation to the country (or a sector thereof) to which the data is transferred and processed by the data importer, or (ii) Directive 95/46/EC (or any superseding text) becomes directly applicable in such country.
- (d) The parties agree that the termination of these clauses at any time, in any circumstances and for whatever reason (except for termination under clause VI(c)) does not exempt them from the obligations and/or conditions under the clauses as regards the processing of the personal data transferred.

#### VII. Variation of These Clauses

The parties may not modify these clauses except to update any information in Annex B to this Exhibit 1, in which case they will inform the authority where required. where required. This does not preclude the parties from adding additional commercial clauses,

#### VIII. Description of the Transfer

The details of the transfer and of the personal data are specified in Annex B to this Exhibit 1. The parties may amend this Agreement to incorporate additional annexes to cover additional transfers, which will be submitted to the authority, where required. Annex B to this Exhibit 1 may, in the alternative, be drafted to cover multiple transfers.

The parties agree that Annex B to this Exhibit 1 may contain confidential business information which they will not disclose to third parties, except as required by law or in response to a competent regulatory or government agency, or as required under clause I(e). The parties may execute additional annexes to cover additional transfers, which will be submitted to the authority where required. Annex B to this Exhibit 1 may, in the alternative, be drafted to cover multiple transfers.

**Annex A to Exhibit 1 to Data Use Agreement**

**(Data Processing Principles)**

1. **Purpose Limitation**: Personal data may be processed and subsequently used or further communicated only for purposes described in Annex B to this Exhibit 1 or subsequently authorized by the data subject.
2. **Data Quality and Proportionality**: Personal data must be accurate and, where necessary, kept up to date. The personal data must be adequate, relevant and not excessive in relation to the purposes for which they are transferred and further processed.
3. **Transparency**: Data subjects must be provided with information necessary to ensure fair processing (such as information about the purposes of processing and about the transfer), unless such information has already been given by the data exporter.
4. **Security and Confidentiality**: Technical and organizational security measures must be taken by the data controller that are appropriate to the risks, such as against accidental or unlawful destruction or accidental loss, alteration, unauthorized disclosure or access, presented by the processing. Any person acting under the authority of the data controller, including a processor, must not process the data except on instructions from the data controller.
5. **Rights of Access, Rectification, Deletion and Objection**: As provided in Article 12 of Directive 95/46/EC, data subjects must, whether directly or via a third party, be provided with the personal information about them that an organization holds, except for requests which are manifestly abusive, based on unreasonable intervals or their number or repetitive or systematic nature, or for which access need not be granted under the law of the country of the data exporter. Provided that the authority has given its prior approval, access need also not be granted when doing so would be likely to seriously harm the interests of the data importer or other organizations dealing with the data importer and such interests are not overridden by the interests for fundamental rights and freedoms of the data subject. The sources of the personal data need not be identified when this is not possible by reasonable efforts, or where the rights of persons other than the individual would be violated. Data subjects must be able to have the personal information about them rectified, amended, or deleted where it is inaccurate or processed against these principles. If there are compelling grounds to doubt the legitimacy of the request, the organization may require further justifications before proceeding to rectification, amendment or deletion. Notification of any rectification, amendment or deletion to third parties to whom the data have been disclosed need not be



made when this involves a disproportionate effort. A data subject must also be able to object to the processing of the personal data relating to him if there are compelling legitimate grounds relating to his particular situation. The burden of proof for any refusal rests on the data importer, and the data subject may always challenge a refusal before the authority.

6. Sensitive Data: The data importer shall take such additional measures (e.g. relating to security) as are necessary to protect such sensitive data in accordance with its obligations under Clause I.
7. Data Used for Marketing Purposes: Where data are processed for the purposes of direct marketing, effective procedures should exist allowing the data subject at any time to "opt-out" from having his data used for such purposes.
8. Automated Decisions: For purposes hereof "automated decision" shall mean a decision by the data exporter or the data importer which produces legal effects concerning a data subject or significantly affects a data subject and which is based solely on automated processing of personal data intended to evaluate certain personal aspects relating to him, such as his performance at work, creditworthiness, reliability, conduct, etc. The data importer shall not make any automated decisions concerning data subjects, except when:
  - (a) both (i) such decisions are made by the data importer in entering into or performing a contract with the data subject and (ii) the data subject is given an opportunity to discuss the results of a relevant automated decision with a representative of the parties making such decision or otherwise to make representations to that parties.

Or

  - (b) where otherwise provided by the law of the data exporter.

**Annex B to Exhibit 1 to Data Use Agreement**

**(Description of the Transfer)**

**Data Subjects**

The personal data transferred concern the following categories of data subjects: research participants.

**Purposes of the Transfer**

The transfer is made for the following purposes: to conduct research in the interest of contributing to and promoting the public good and welfare. The data importer's use of the personal data shall be limited to what is permitted pursuant to Section 3 (Non-Exclusive License) of this Agreement.

**Categories of Data**

The personal data transferred fall within the following categories of data: **[THE LIST BELOW TO BE EDITED TO REFLECT THE CONTENTS OF THE DATASET.]**

- **[personal details;**
- **family details;**
- **lifestyle and social circumstances;**
- **genetic data;**
- **financial details;**
- **employment and education/training details;**
- **goods and services; and**
- **employment and education details.]**

**Recipients**

The personal data transferred may be disclosed only to the following recipients or categories of recipients:

- persons which have signed agreements incorporating these clauses or which are located in a country providing an adequate level of data protection.

- Within these companies the personal data may only be disclosed to such individuals that are involved in the performance of the tasks detailed above.

### **Sensitive Data**

The personal data transferred fall within the following categories of sensitive data: **[THE LIST BELOW TO BE EDITED TO REFLECT THE CONTENTS OF THE DATASET.]**

- **[physical or mental health details;**
- **sexual life;**
- **racial or ethnic origin;**
- **trade union membership;**
- **religious or other beliefs of a similar nature;**
- **offences and alleged offences; and**
- **genetic data.]**

### **Data Protection Registration Information of Data Exporter**

CHDI Foundation, Inc. is registered at the Information Commissioner's Office with Registration Number ZA031615.

### **Additional Useful Information**

None.

### **Contact Points for Data Protection Enquiries**

Data protection enquiries can be directed to each party in accordance with Section 11 (Notices) of this Agreement.

[End of Exhibit 1 to Enroll-HD Data Use Agreement]