

Privacy Policy

This Privacy Policy applies to your use of www.Enroll-HD.org, all its sub-domains and all associated services including, but not limited to, e-mail received from [Enroll-HD.org](http://www.Enroll-HD.org), any of our computer systems, databases or networks connected to [Enroll-HD.org](http://www.Enroll-HD.org) and all its sub-domains (collectively, the "Website"). The Website is being made available for your use by [CHDI Foundation, Inc.](http://www.ChDI.org).

We are committed to protecting the privacy and security of your visits to the Website. This is our online Privacy Policy. If you have questions about this Privacy Policy, please let us know. If you do not agree with this Privacy Policy, please do not access or use the Website.

If you browse or otherwise use the Website, you accept this Privacy Policy. We reserve the right to modify this Privacy Policy at any time by posting such change here. We encourage you to refer back to this page and review this Privacy Policy often for the latest information and the effective date of any modifications. If we decide to change this Privacy Policy, we will post a new policy on the Website and change the revision number and effective date at the bottom. Changes to this Privacy Policy will not apply retroactively. Your continued use of the Website after any such modifications are made constitutes your acknowledgement of, and agreement with, the Privacy Policy, as modified.

Collection of Information and Use

If you elect to (i) join our mailing list, (ii) obtain a Clinical Access Account or (iii) obtain a Training Access Account through the Website, we collect some information that can be directly associated with you. We call this information "Personal Information".

If you elect to join our mailing list to electronically receive the *Enroll!* Newsletter, we will collect your email address. By joining our mailing list, you have granted us permission to use your Personal Information to send you emails ("opt-in") relating to the Enroll-HD Study (including the *Enroll!* Newsletter) and other Huntington's disease related research and information. If you have received an email from us, our records indicate that you joined our mailing list. Because we respect your time and attention, we make every effort to control the frequency of our emails. You may revoke the permission you have given us to use your Personal Information to send you emails ("opt-out") for the mailing list by sending an email to AccountSetup@Enroll-HD.org or by following the instructions set out in our e-mails.

If you elect to obtain a Clinical Access Account in order to enable you to access and obtain clinical data and biosamples taken as part of the Enroll-HD Study to be used as part of your research, we will collect your name, title, email address, phone number and the name and address of the company or research institution with which you are affiliated and a description of your research project. This Personal Information is used to verify that you are employed by the company or research institution with which you indicate

you are affiliated and to communicate directly with you and to give you access to, or provide you with, any requested clinical data or biosamples. If you elect to access or obtain clinical data and biosamples, a brief description of your research project (which is provided by you) and your name and the name of the company or research institution with which you are affiliated will be posted on the Website.

If you elect to obtain a Training Access Account in order to enable you to access and use training courses/materials relating to your conduct of the Enroll-HD Study, we will collect your name, title, email address, phone number and the name and address of the company or research institution with which you are affiliated. This Personal Information is used to verify that you are employed by the company or research institution with which you indicate you are affiliated and that such company or research institution is a study site in the Enroll-HD Study and to communicate directly with you and to give you access to, or provide you with, any requested training courses/materials. If you elect to obtain a Training Access Account and access the training courses/materials, we will collect information about which training courses/materials you have accessed, the dates you accessed and completed any such accessed training courses/materials and the test scores (or pass/fail results) that you obtain through the completion of any training assessments included in any such accessed training courses. This information will be entered into the Enroll-HD Electronic Data Capture (EDC) system as a record of whether you have completed training courses required for your conduct of the Enroll-HD Study as well as whether you have passed each such training course. Your test scores (or pass/fail results) may be shared with the company or research institution with which you indicate you are affiliated and/or CHDI Foundation, Inc. for the purpose of confirming your eligibility to conduct the Enroll-HD Study.

Additionally, we may aggregate Personal Information in a manner such that the end-product does not personally identify you or any other user of the Website. For example, we may use the aggregated Personal Information to calculate the percentage of the Training Access Account users who pass/fail a specific training course. Such aggregate information/end-product may be used for any purpose.

Anti-Spam

If you believe you have received unwanted, unsolicited email from us sent via the Website or purporting to be sent via the Website, please forward a copy of that email to AccountSetup@Enroll-HD.org.

Privacy and Sharing of Your Personal Information

Except where otherwise expressly noted or contemplated in this Privacy Policy, it is our general policy not to make Personal Information available to anyone other than our personnel, website administrators, service providers and agents and the company or research institution with which you indicate you are affiliated. We may share your Personal Information with our personnel, website administrators, service providers and agents that carry out certain functions on our behalf, such as website hosting, data processing and order fulfillment. We may share your Personal Information with the

company or research institution with which you indicate you are affiliated for the purpose of confirming your eligibility to conduct the Enroll-HD Study. Some of these personnel, website administrators, service providers and agents may be located in jurisdictions (including the United States) that may not have the same or as strict privacy laws as your country of residence. We require that our personnel, website administrators, service providers and agents comply with this Privacy Policy when processing or handling Personal Information on our behalf.

Without your prior consent except as permitted or required by law, we will not disclose your Personal Information for purposes other than those expressly noted or contemplated in this Privacy Policy. In the event of a sale, amalgamation, re-organization, transfer or financing of some or all of our operations, your Personal Information may be disclosed to an acquiring organization, either as part of due diligence or on completion of the transaction. If Personal Information is disclosed in this context, we will require the acquiring organization to comply with this Privacy Policy in its processing and handling of such Personal Information.

Security

We maintain a variety of physical, electronic and procedural safeguards to protect your Personal Information. As mentioned above, it is our general policy to restrict access to Personal Information to our personnel, website administrators, service providers and agents.

The Website may have links to other websites that we do not control. You should know that we have no control over the content, privacy policies or security of any of these websites you elect to visit or interact with. Furthermore, we are not responsible for the content, privacy policies or security of any of these websites you elect to visit or interact with and you should check those policies on such websites.

Browser Information Collected on the Website

We log IP addresses, which are the locations of computers or networks on the Internet, and analyze them in order to improve the utility of the Website. We also collect aggregate numbers of page hits in order to track the popularity of certain pages and improve the utility of the Website. We do not gather, request, record, require, collect or track any users' Personal Information through these processes.

We use cookies on the Website. A "cookie" is a tiny text file that we store on your computer to customize your experience and support some necessary functions. We also use cookies to better understand how users use the Website. Our cookies contain no Personal Information and are neither shared nor revealed to other websites. We do not look for or at other websites' cookies on your computer.

You also have choices with respect to cookies. By modifying your browser preferences, you can accept all cookies, be notified when a cookie is set, or reject all cookies (for more information on how to block or filter cookies, see

<http://www.cookiecentral.com/faq>). However, if you reject some or all cookies, your experience at the Website may not be complete.

Use of Web Beacons

When we send emails to users of the Website, we may include a web beacon to allow us to determine the number of users who open our emails. When you click on a link in an email we have sent to you, we may record this individual response to allow us to customize our offerings to you. Web beacons collect only limited information, such as a cookie identifier, time and date of a page being viewed, and a description of the page on which the Web Beacon resides (the URL).

Web Beacons can be refused when delivered via email. If you do not wish to receive Web Beacons via email, you will need to disable HTML images or refuse HTML (select Text only) emails via your email software.

Contacting Us

You have a right to request access to, and rectification of, your Personal Information by contacting us at AccountSetup@Enroll-HD.org. If you have any questions about this privacy policy or our Personal Information practices, you may likewise contact us at AccountSetup@Enroll-HD.org.

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