

## **Privacy Policy**

This Privacy Policy applies to your use of www.EHDN.org, all its sub-domains and all associated services including, but not limited to, e-mail received from EHDN.org, any of our computer systems, databases or networks connected to EHDN.org and all its sub-domains (collectively, the "Website"). The Website is being made available for your use by EHDN represented by the University Hospital of Ulm (<http://www.uniklinik-ulm.de/struktur/kliniken/neurologie/home/spezialsprechstunden/morbus-huntington.html>). We are committed to protecting the privacy and security of your visits to the Website and comply with all applicable data protection laws. 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.

You are only permitted to browse or otherwise use the Website, if 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. You are only permitted to use the Website after any such modifications are made if you acknowledge, and agree with, the Privacy Policy, as modified.

When using our Website or services we may collect some information that can be directly associated with you. We call this information "Personal Information". We will process Personal Information to the extent necessary to justify and execute our Website or services and transfer Personal Information to third parties only for the purposes of fulfilling contracts or with your consent.

### **Collection of Information and Use**

If you elect to (a) join one of our mailing lists, (b) obtain an EHDN Access Account to gain access to REGISTRY, apply for EHDN membership or provide services to EHDN and/or (c) register for conferences through the Website, we collect some Personal Information.

If you elect to join our "EHDN General Information Mailing List" to electronically receive information sent out by EHDN about EHDN activities including, but not limited to, EHDN newsletters, information about meetings and conferences, information about other HD networks, information about grant opportunities, information about Huntington's disease related research and information and information about the Enroll-HD Study (e.g., the *Enroll!* Newsletter and monthly bulletins), we will collect your email address and your name. The registration for this mailing list occurs through a "double-opt-in process". After joining this mailing list, you will receive a confirmation e-mail in which you are asked to verify your request to receive information sent out by EHDN about EHDN activities by clicking on a link contained inside that confirmation e-mail.

You will only receive such information once you have given that verification by clicking on the link. 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 this mailing list by sending an email to [unsubscribe@euro-hd.net](mailto:unsubscribe@euro-hd.net) or by following the instructions set out in our e-mails.

If you elect to obtain an EHDN Access Account in order to 1) enable you to access the REGISTRY Electronic Data Capture (EDC) and REGISTRY Study documents, EHDN working group/committee documents and updates, and/or certification training, 2) apply for EHDN membership, or 3) provide services to EHDN 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 to communicate directly with you and to give you access to, or provide you with, REGISTRY EDC and REGISTRY Study documents, EHDN working group/committee documents and updates, and motor certification training.

If you elect to join our "EHDN Conference Registration Mailing List" so that you can register to attend EHDN conferences through the Website, we will collect your name, address and email address. The registration for this mailing list occurs through a "double-opt-in process". After joining this mailing list, you will receive a confirmation e-mail in which you are asked to verify your request to join this mailing list so that you can register to attend EHDN conferences through the Website by clicking on a link contained inside that confirmation e-mail. You will only receive information relating to EHDN conference registration once you have given that verification by clicking on the link. For credit card payments, you will be directed to a secure payment website for payment. You may revoke the permission you have given us to use your Personal Information to send you emails ("opt-out") for this mailing list by sending an email to [unsubscribe@euro-hd.net](mailto:unsubscribe@euro-hd.net) or by following the instructions set out in our e-mails.

### **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 [unsubscribe@euro-hd.net](mailto:unsubscribe@euro-hd.net).

### **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 and only if necessary to perform our contractual obligations or if you have explicitly consented to such transfer. 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 if necessary to perform our contractual obligations or if you have explicitly consented to such transfer. 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 and all applicable data protection laws 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 or consented to by you.

If you consent to allowing your Personal Information to be given to CHDI Foundation, Inc. (CHDI) for use by CHDI, your Personal Information will be disclosed to CHDI.

### **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 as all such data is anonymized.

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, deletion, and rectification of, your Personal Information by contacting us at [info@euro-hd.net](mailto:info@euro-hd.net).

Any consent given can be revoked at any time with immediate effect.

If you have any questions about this privacy policy or our Personal Information practices, you may likewise contact us at [info@euro-hd.net](mailto:info@euro-hd.net).

University Hospital of Ulm

**(<http://www.uniklinik-ulm.de/struktur/kliniken/neurologie/home/spezialsprechstunden/morbus-huntington.html>)–**

[www.EHDN.org](http://www.EHDN.org) – Privacy Policy

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