



**The Ehlers-Danlos Society
Privacy & Cookies Policy**

Please [see the Data Protection Policy](#) which may supersede provisions contained below. For information on the privacy policy of Network for Good, which is a nonprofit company the Society uses for donation and other data services, please visit their [privacy policy](#).

We Respect Your Confidentiality

The Ehlers-Danlos Society (hereby referred to as The Society) requires that your personal information be held in strict confidence. We use your information only for its intended Society purposes. We do not sell or trade your information to other organizations or individuals.

We Protect Your Information

The Society takes every possible measure to ensure that your information is not compromised in any way. Our privacy promise is in place in respect of our website only. Other online services will be serviced by their own privacy policies. Online information is transmitted via secure servers using encryption technology.

If you choose to send us an email, we may retain the contents of your email message, our reply and your email address as part of our ongoing customer service efforts. If you have agreed, we may send future email and/or surveys to you about The Society. You may opt out of this form of correspondence at any time if you wish to discontinue electronic communication.

We Keep Accurate Records

The Society keeps your personal information as accurate, complete, and up to date as is required to fulfill the purpose(s) for which you provided us with your personal information. Upon request in writing we will remove your personal information from our databases, except where legislation or regulation requires our retention of it (for example, charitable giving history tied to income tax receipts.)

What Are Your Data Protection Rights?

The Society would like to make sure you are fully aware of your rights. Every user is entitled to the following:

- **The right to access** You have the right to request from The Society copies of your personal data. We reserve the right to charge you a small fee for this service.
- **The right to rectification** You have the right to request that The Society correct any information you believe to be inaccurate. You also have the right to request The Society to complete information you believe is incomplete.
- **The right to erasure** You have the right to request that The Society erase your personal data, under certain conditions. Some data that is being used under certain conditions may not be able to be deleted, such as research data, however in these instances we will ensure all data being used is de-identified and cannot be linked with you.

- **The right to restrict processing** You have the right to request that The Society restrict the processing of your personal data, under certain conditions.
- **The right to object to processing** You have the right to object to The Society's processing of your personal data, under certain conditions.
- **The right to data portability** You have the right to request that The Society transfer the data that we have collected to another organization, or directly to you, under certain conditions. If you make a request, we have one month to respond to you. If you would like to exercise any of these rights, please contact us.

What Are Cookies?

When we provide services, we want to make them easy, useful and reliable. Where services are delivered on the internet, this sometimes involves placing small amounts of information on your device, for example, computer or mobile phone. These include small files known as cookies. They cannot be used to identify you personally, but are in place to collect standard internet log and visitor behavior information. When you visit our website, we may collect information from you automatically through cookies or similar technology.

How Do We Use Cookies?

The Society uses cookies to collect information about you and store your online preferences. Cookies are text files containing small amounts of information which are downloaded to your device when you visit a website. Cookies are then sent back to the website when you return to it: this is useful because it allows the website to recognize your device. To find out more about cookies please visit www.allaboutcookies.org

- Enabling a service to recognize your device so you don't have to give the same information several times during one task.
- Recognizing that you may already have given a username and/or password so you don't need to do it for every web page requested.
- Helping you to pick up where you left off when on our site
- Measuring how many people are using services, to increase usability, ensure capacity is sufficient and maintain speed and quality of services.

What Types of Cookies Do We Use?

There are a number of different types of cookies, our website uses:

- **Necessary Cookies** These cookies are essential in order to enable you to move around the Site and use its features. Without these cookies, services you have asked for (such as remembering your login details or taking a purchase to the checkout or e-billing) cannot be provided. They do not collect information about users that can be used for marketing and expire when the user leaves the website or closes their browser.
- **Performance Cookies** These cookies collect information on how people use the Site. For example, we use these cookies to help us understand how customers arrive at the Site, browse or use the Site and highlight areas where we can improve such as navigation, user experience and marketing campaigns. The data collected is only used to improve how the Site works. For example we use Google Analytics to better understand how customers use the Site. If you don't want Google Analytics to be used in your browser, you can install this Google add-on: https://tools.google.com/dlpage/gaoptout?hl=en_GB.

- **Functionality Cookies** The Society uses these cookies so that we recognize you on our website and remember your previously selected preferences. These could include what language you prefer and location you are in. A mix of first-party and third-party cookies are used.
- **Advertising Cookies** The Society uses these cookies to collect information about your visit to our website, the content you viewed, the links you followed and information about your browser, device, and your IP address. The Society sometimes shares some limited aspects of this data with third parties for advertising purposes. We may also share online data collected through cookies with our advertising partners. This means that when you visit another website, you may be shown advertising based on your browsing patterns on our website.
- **Social Media Cookies** These cookies allow you to share what you've been doing on the Site on social media such as Facebook, Instagram or LinkedIn. These cookies are not within our control. Please refer to their respective privacy policies for how their cookies work.

Third Party Cookies

This site also contains links to other sites. The Ehlers-Danlos Society is not responsible for the privacy practices or the content of such web sites.

To make it easy for you to use and share our website we embed features from other websites such as Facebook, Twitter and TripAdvisor. Browsing the The Society website may place cookies from these third party websites on your computer. The Society has no control over these cookies so it is not always possible to list them, and they are liable to change without notifying us.

We may refer to companies, organizations and public bodies and enable access to their websites directly from our website. Each company, organization or public body operates its own policy regarding the sale of personal data and the use of cookies. If you have a particular interest in, or concern regarding the way your data will be used then you are advised to read the Privacy Statement on the relevant website.

How to Manage Cookies

You can set your browser not to accept cookies, and the above website tells you how to remove cookies from your browser. However, in a few cases, some of our website features may not function as a result.

Privacy Policies of Other Websites

The Society website contains links to other websites. Our privacy policy applies only to our website, so if you click on a link to another website, you should read their privacy policy.

Policy Review and Amendments

This policy will be reviewed annually, by the end of the first quarter (Q1), to ensure that it continues to meet the needs of The Society and its community.

How to Contact Us

If you have any questions about The Society's Privacy & Cookies Policy, the data we hold on you, or you would like to exercise one of your data protection rights, please do not hesitate to contact us.

Email us at: info@ehlers-danlos.com

Call us: +1 410-670-7577 or +44 203 887 6132

Or write to us at: The Ehlers-Danlos Society Headquarters, 1732 1st Ave. #20373, New York, NY 10128, USA or The Ehlers-Danlos Society Europe Office, Office 7, 35-37 Ludgate Hill, London, EC4M 7JN, United Kingdom