

EU Privacy Policy

Effective 5/25/18

Introduction

The National Urea Cycle Disorders Foundation takes your privacy seriously. Our Privacy Policy describes how we collect and use personal information you provide to us. With this knowledge, you can make informed decisions about using our site and services. We will not use or share your information with anyone except as described in this Privacy Policy. If you have any queries about this policy, please contact NUCDF Data Controller at datacontrol@nucdf.org

What information do we collect?

When you visit our website, you may provide us with two types of information: (1) personal information you knowingly choose to disclose that is collected on an individual basis (i.e., information you enter on a membership form, or newsletter subscription), and (2) website use information that is aggregated with other users about the way you browse our website. For this website use information, NUCDF's web server automatically recognizes but does not collect or use your IP address. (See Website Use Information below).

Personal Information you share with us

Registration information

You are not required to provide any personal information on our website unless you choose to do so. You may provide us with personal information on our membership form to help us provide you with services, support or information. We will never share your membership form with anyone. You may contact us to give us permission to share specific information contained in your membership form, for example your name and email address to network you with other families with the same condition. You may provide personal information on donation pages to properly enable donation transaction processing, when you register for NUCDF events and webinars, or when you subscribe to NUCDF e-newsletters or other notifications. webinars. NUCDF will never sell or trade your personal information with any other entity. When you donate to NUCDF online, pay an event registration fee online or purchase a product online, you provide NUCDF with your name, address, and email address in order to communicate with you about those activities. When you choose to participate in various NUCDF fundraising, awareness campaigns or volunteer activities, you may choose to provide us with additional information including, but not limited to, your name, contact information, images or photographs, and stories or narratives authored by you.

Email Information

If you choose to correspond with us through email, we may retain the content of your email messages together with your email address and our responses. Our website does not automatically recognize your email address and requires that you enter it in any email communication submission form.

Website Use Information

NUCDF's web server automatically recognizes but does not collect or use your domain name (IP address). Similar to other nonprofit and commercial websites, our website utilizes a standard technology called "cookies" (see description below) and web server logs to collect information about how our website is used. Information gathered through cookies and web server logs may include the date and time of visits, the pages viewed, time spent on our website, and the websites visited just before and just after our website.

What is a "cookie"?

A cookie is a very small text document that often includes an anonymous unique identifier. When you visit a website, the web server asks your computer for permission to store this file in a part of your hard drive specifically designated for cookies. Each website can send its own cookie to your browser if your browser's

preferences allow it, but (to protect your privacy) your browser only permits a website to access the cookies it has already sent to you, not the cookies sent to you by other sites.

How do we use information collected from “cookies”?

As you visit our website, the site uses its cookies to differentiate you from other visitors. In some cases, cookies are used to recognize you as a return visitor. Cookies, in conjunction with our web server's log files, allow us to calculate the aggregate number of people visiting our website and which parts of the site are most popular. This helps us gather feedback in order to constantly improve our website and better serve our mission. Cookies do not allow us to gather any personal information about you and we do not store any personal information that were provided by your cookies. NUCDF uses Google Analytics to aggregate and analyze data collected from the use of cookies. With this information, we are able to provide NUCDF website users with a better website experience. Most browsers allow you to opt out of third party cookies, while leaving first party cookies switched on. Third party cookies are issued by web services other than the website you're looking at the time and can allow those web services to track you as you browse from site to site. Facebook and Google do this routinely, as do a number of other advertising networks. If you wish to turn off third party cookies, please go to your browser settings to make the adjustment.

What about another website linked from our website?

We use links to outside resources, and sites that store our website video content. These are called “external sites.” We are not responsible for the practices employed by the websites linked to or from our website, nor the information or content contained therein. Links to other websites are provided solely as pointers to information on topics or resources that may be useful to the users of our website. Please remember that when you use a link to go from our website to another website, our Privacy Policy is no longer in effect. Your browsing and interaction on any other website, including websites which have a link on our website, is subject to that website's own rules and policies. Please read over that website's privacy policies before proceeding.

How do we use the information you provide to us?

We use personal information for purposes of communicating with you to notify you about important changes to our website, information you may have requested, and news concerning our research, awarenessness, support, education programs, as well as fundraising and other events. You may contact us at unsubscribe@nucdf.org to be removed from this communication.

Sharing information with third parties

NUCDF does not sell or trade your personal information with any organization or entity, nor does NUCDF send mailings on behalf of other any organizations or commercial entities. You are not required to provide any personal information on our website unless you choose to do so. We do ask for personal information on our online donation pages to properly enable donation transaction processing. We use this information to acknowledge receipt of your donation for tax purposes. We may publicly acknowledge your gift on NUCDF.org domains if you give us consent to do so. If you give a gift to NUCDF, your name and address will be placed on our donor mailing list. If you do not wish to receive mailings we send to our donor mailing list or wish to be removed from our donor mailing list, please contact us at unsubscribe@nucdf.org.

Certain Disclosures

We may disclose your personal information if required to do so by law or subpoena or if we believe that such action is necessary to (a) conform to the law or comply with legal process served on us or Affiliated Parties; (b) protect and defend our rights and property, the site, the users of the site, and/or our Affiliated Parties; or (c) act under circumstances to protect the safety of users of the site, us, or third parties.

How do we protect your information?

We have strict policies and procedures in place to keep your information private and secure. It is protected from unauthorized access by firewalls and other industry best practices. Only NUCDF staff who need access to personal identifiable information to perform a specific function are granted access to that information. We do not share your information with third parties or publicly. If you email us, please remember that email is not recognized as a secure medium of communication.

Some of the information you may enter on our website may be transmitted securely (e.g. information used to complete an online credit card transaction). Outside of these secure transmissions, NUCDF cannot, however, ensure or warrant the security of any information you transmit to us or guarantee that your information on the website may not be accessed, disclosed, altered, or destroyed by breach of any of our physical, technical, or managerial safeguards. Please email us at any time at datacontrol@nucdf.org if you have any questions or concerns.

How can you access and correct your information?

You may request access to all your personally identifiable information that we collect and maintain in our database. To correct or change your contact information, please contact datacontrol@nucdf.org. You may opt out of email communications at any time by clicking the unsubscribe link that is included at the bottom of email communications from NUCDF. You may also contact us at unsubscribe@nucdf.org to be removed from email communication.

When do we delete information?

We retain your personal information for the period necessary to fulfill the purposes outlined in this Privacy Policy unless a longer retention period is required or permitted by law. We will periodically review and remove invalid physical addresses, email addresses, and phone numbers as we become aware of them and remove contacts that are inactive or irrelevant to our work. We will also anonymize donations at the donor's request.

Your Privacy Rights

By using our website, you consent to our collection and use of your personal information as described in this Privacy Policy. If we change our privacy policies and procedures, we will post those changes on our website to keep you aware of what information we collect, how we use it, and under what circumstances we may disclose it. As a member or supporter of NUCDF, or user of our services who gives us permission to collect your personal data, you have rights. These include the right to review the data we have collected, the right to have your data removed, and the right to contact a supervisory authority if you would like to lodge a complaint. Only authorized NUCDF staff are responsible for managing your personal data. The data is used to increase the efficiency and quality of communications between authorized NUCDF staff and our NUCDF members, service recipients, supporters and donors. You have the right at any time to withdraw consent from NUCDF to retain your personal data. Withdrawal of consent can be done by emailing datacontrol@nucdf.org.

Children's Privacy

Protecting the privacy of young children is critically important to us. For that reason, we do not knowingly collect or solicit personal information from anyone under the age of 13 or knowingly allow such persons to register. If you are under 13, please do not send any information about yourself to us, including your name, address, telephone number, or email address. No one under age 13 is allowed to provide any personal information to us on our website. In the event that we learn that we have collected personal information from a child under age 13 without verification of parental consent, we will delete that information as quickly as possible. If you believe that we might have any information from or about a child under 13, please contact us.