

Privacy Policy

Cure NDD — Consortium for Understanding, Research, and Education in X-linked Neurodevelopmental Disorders, doing business as "Cure NDD." Cure NDD will be referred to as such throughout this Policy.

Effective Date: August 1, 2026

Cure NDD ("we," "us," or "our") respects your privacy and is committed to protecting your personal information. This Privacy Policy ("Policy") describes how we collect, use, disclose, and safeguard your data when you visit our website, participate in our programs, or interact with us through other digital or in-person means (collectively, the "Services"). By using the Services, you agree to the collection and use of information in accordance with this Policy.

Cure NDD is a nonprofit research and education consortium. We are not a "covered entity" under the Health Insurance Portability and Accountability Act of 1996 ("HIPAA"), and we do not provide clinical care, diagnosis, or treatment. Any optional health-related information you choose to share with us (such as diagnosis or symptom information) is collected for research, education, and community-building purposes as described in this Policy, and is generally not "Protected Health Information" regulated by HIPAA. If you participate in a clinical trial or research study that we sponsor, conduct, or facilitate, that participation is governed separately by a study-specific informed consent document approved by an Institutional Review Board ("IRB"), and, where applicable, a HIPAA research authorization — not by this Policy alone.

Unless otherwise defined here, capitalized terms have the meaning given to them in the Cure NDD Terms of Use. We may update this Policy periodically; the date of the most recent revision appears above as the "Effective Date." Significant changes will be communicated by email or a prominent notice on our website.

Information We Collect

Personal Data You Provide

We may collect the following information when you register, communicate, or participate in Cure NDD programs:

- Name, title, and organization;

- Email address and phone number;
- Address, city, state, and ZIP code;
- Professional role, school, or institution affiliation;
- Disease or research area of interest;
- Demographic information (such as pronouns, age range, or gender identity); and
- Optional health-related information (such as diagnosis or symptoms), which we collect only with your explicit consent.

Automatically Collected Data

When you visit our website, we may automatically collect your IP address, browser type, operating system, the date and time of your visit, referring website, pages viewed, device information, and usage statistics. We use cookies and similar technologies to enhance site performance and understand how visitors use the Services. You can instruct your browser to refuse cookies, though some features of the Services may not function properly without them.

Payment Information

If you make a donation or payment to Cure NDD, your payment is processed by a third-party payment processor. We do not store your full payment card details; that information is provided directly to our payment processor, whose use of your information is governed by its own privacy policy.

Clinical Trials and Research Participation

Cure NDD's mission includes supporting and facilitating research into X-linked neurodevelopmental disorders, which may include clinical trials or research studies that we sponsor, conduct, or facilitate, and which may include both adult and pediatric (child) participants. Participation in any clinical trial or research study is always voluntary and separate from your general use of the Services. If you or your child are invited to participate in such a study, the collection, use, and disclosure of information for that study — including any sharing with a study sponsor, investigators, an Institutional Review Board, or regulatory authorities such as the U.S. Food and Drug Administration — will be described in a separate, study-specific informed consent document (and, for pediatric participants, a parental permission form and, where appropriate to the child's age and maturity, the child's own assent) and, where applicable, a HIPAA research authorization. Studies involving children are subject to additional protections under 45 C.F.R. Part 46, Subpart D, and, where the study involves an FDA-regulated product, 21 C.F.R. Part 50, Subpart D. That documentation, and not this Policy, will govern information collected for purposes of that study.

How We Use Your Data

We use personal data to:

- Operate and improve our website and programs;
- Communicate with you about events, research, and partnership opportunities;
- Process membership applications and manage consortium activities;
- Send newsletters, updates, and fundraising communications;
- Facilitate participation in studies or surveys, with your consent; and
- Comply with applicable laws and protect our rights.

We will never sell your personal information.

Sharing Your Information

We may share limited personal information only in the following circumstances:

- **With Service Providers:** For website management, email communication, payment processing, and event logistics; these providers are contractually obligated to protect your information and use it only to perform services on our behalf.
- **With Consortium Partners:** When necessary for collaborative research or advocacy efforts, and only with your consent.
- **For Legal Reasons:** If required by law, subpoena, or regulatory authority.
- **In Case of Merger or Transition:** If we merge with, or transition our operations to, another organization, your data may transfer as part of that process, and we will provide notice before your data becomes subject to a different privacy policy.

Notice of Compelled Disclosure. If we receive a subpoena, court order, or other legal demand for your health-related information, we will, except where prohibited by law, make reasonable efforts to notify you before we respond, so that you have an opportunity to object or seek a protective order.

Data Retention

We retain personal data only as long as necessary to fulfill the purposes described in this Policy, comply with legal or contractual obligations, or maintain membership and research records. Where you have consented to provide optional health-related information, you may withdraw that consent and request deletion of that information at any time, as described below, except where we are required to retain records for a study you have separately enrolled in under its own informed consent terms.

Your Privacy Rights

Regardless of where you live, we extend the following rights to you as a matter of policy:

- The right to know what personal information we have collected about you, and to access it;
- The right to request correction of inaccurate personal information;
- The right to request deletion of your personal information, subject to our legal and research recordkeeping obligations;
- The right to opt out of non-essential data collection or communications, such as newsletters and fundraising emails; and
- The right not to be discriminated against for exercising any of these rights.

If you are a California resident, these rights are also provided to you under the California Consumer Privacy Act ("CCPA"). If you are a resident of Virginia, Colorado, Connecticut, Utah, Texas, Oregon, Montana, or another U.S. state with a comprehensive consumer privacy law, these rights are also provided to you under that state's law, to the extent applicable. We do not sell personal information or use automated decision-making to produce legal or similarly significant effects concerning our users. To exercise any of these rights, contact us through our website at curendd.org/contact-us. We will respond within the time required by applicable law (generally forty-five (45) days, extendable once by an additional forty-five (45) days with notice to you), and, where required by law, will offer an appeal process if we deny your request.

Do Not Track Signals

As required by the California Online Privacy Protection Act ("CalOPPA"), we note that our website does not currently respond to "Do Not Track" browser signals, as there is no common industry standard for how online services should respond to them. We will update this section if that changes.

California "Shine the Light" Law

Under California Civil Code Section 1798.83 ("Shine the Light"), California residents with an established relationship with us may request information once a year about our disclosure, if any, of personal information to third parties for those third parties' direct marketing purposes. We do not make such disclosures. To make a request, contact us using the information below.

California Minors' Right to Removal

Under California Business and Professions Code Section 22581, California residents under the age of 18 who are registered users of the Services may request removal of content or information they have publicly posted. To make such a request, contact us using the information below and include the email address associated with the relevant account. This request does not guarantee complete or comprehensive removal of the content in all circumstances permitted by law.

Data Security

We use secure, encrypted technologies and limit access to authorized personnel. However, no system is completely secure, and we encourage you to exercise caution when transmitting personal information online.

Children's Privacy

Cure NDD may collect limited information from parents, guardians, and researchers regarding minors involved in our research, advocacy, or family community, but we do not knowingly collect personal information directly from children under 13 through the Services without verified parental consent, consistent with the Children's Online Privacy Protection Act ("COPPA"). If you believe we have inadvertently collected information from a child under 13 without appropriate consent, please contact us so we can address it. Separately, if a child participates in a clinical trial or research study, the additional pediatric research protections described in "Clinical Trials and Research Participation" above apply to that participation.

International Access

Cure NDD is a United States-based organization, and this Policy is written for a United States audience. We do not direct, market, or target our Services to individuals in the European Economic Area ("EEA"), the United Kingdom, Switzerland, or any other jurisdiction outside the United States. Because our website is hosted online, it may nonetheless be accessible from other countries. If you choose to access or use the Services from outside the United States, you do so on your own initiative, your information will be transferred to and processed in the United States, and you are responsible for compliance with the laws applicable to you in your location. We do not represent that the Services are appropriate, compliant with local law, or available for use in every jurisdiction. If our approach to serving individuals outside the United States changes — for example, if we begin marketing or directing our Services specifically to

individuals in the EEA, UK, or Switzerland — we will update this Policy and put in place the additional protections required by applicable law before doing so.

Links to Other Websites

Our website may contain links to external sites. We are not responsible for their content, policies, or data handling practices, and we encourage you to review each site's privacy policy.

Changes to This Policy

We may update this Privacy Policy periodically. The "Effective Date" will reflect the latest revision. Significant changes will be communicated by email or a prominent notice on our website.

Contact Us

If you have questions about this Privacy Policy, or would like to exercise any of the rights described above, please contact us at:

Cure NDD — curendd.org/contact-us