

Cure NDD Privacy Policy

Effective Date: 2025

Legal Entity: Cure NDD

1. Introduction

Cure NDD Consortium (“we,” “us,” “our”) respects your privacy and is committed to protecting your personal information. This Privacy 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.

By using our services, you agree to the collection and use of information in accordance with this Policy.

2. Definitions

- **“You”** refers to an individual accessing or using our website or participating in Cure NDD programs.
 - **“Personal Data”** means any information that identifies or can be used to identify an individual.
 - **“Service”** refers to the Cure NDD website and related activities, including consortium membership, events, and research collaborations.
 - **“Service Provider”** means any third-party entity assisting us in operating the Service.
 - **“Cookies”** are small files stored on your device that help us improve functionality and track usage patterns.
 - **“CCPA”** refers to the California Consumer Privacy Act.
-

3. Information We Collect

a. Personal Data You Provide

We may collect the following personal 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 (e.g., pronouns, age range, gender identity)
- Optional health-related data (e.g., diagnosis, symptoms) with explicit consent

b. Automatically Collected Data

When you visit our website, we may automatically collect:

- IP address, browser type, operating system
- Date and time of visit, referring website, and pages viewed
- Device information and usage statistics

We use cookies and similar technologies to enhance site performance and user experience.

4. 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 consent)
- Comply with applicable laws and protect our rights

We will never sell your personal data.

5. Sharing Your Information

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

- **With Service Providers:** For website management, email communication, and event logistics.
 - **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 Cure NDD merges with another organization, your data may transfer as part of that process, with notice provided.
-

6. Data Retention

We retain personal data only as long as necessary to fulfill the purposes outlined in this Policy, comply with legal obligations, or maintain membership and research records.

7. Your Rights

Under the **California Consumer Privacy Act (CCPA)** and other applicable laws, you have the right to:

- Access and request a copy of your personal information
- Request correction or deletion of your data
- Opt out of non-essential data collection or communications
- Not be discriminated against for exercising privacy rights

Requests can be made through our **Contact Us** form: <https://www.curendd.org/contact-us>

8. Data Security

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

9. Children's Privacy

Cure NDD may collect limited data from parents, guardians, and researchers regarding minors involved in research or advocacy, but we do not knowingly collect personal data directly from children under 13 without verified parental consent.

10. Links to Other Websites

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

11. 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 notice on our website.

12. Contact Us

If you have questions about this Privacy Policy, please contact us
<https://www.curendd.org/contact-us>