



PRIVACY POLICY

This Privacy Policy (the “**Policy**”) describes the type of information that CureDuchenne—a 501(c)(3) non-profit organization with a mission to extend and improve the lives of children and adults with Duchenne muscular dystrophy (“**CureDuchenne**”, “**we**” or “**our**” or “**us**”) collects from people who use the CureDuchenne Link application (the “**App**”) and CureDuchenneLink.org (the “**Site**”) (App and Site together shall be referred to as the “**Services**”), and how that information may be used and shared. Users are referred in this Policy as “you” and “your”.

This Policy is designed to ensure that you understand our practices with respect to information we collect from you throughout the Services. By using the Services, you agree to the terms of this Policy. If you do not agree to the terms of this Policy, please do not use the Services.

We will ensure that all personal information disclosed by you and that is held by us will be: (i) processed lawfully, fairly, and in a transparent manner; (ii) collected for specified, explicit, and legitimate business purposes and not further processed in a manner that is incompatible with those legitimate business purposes; (iii) adequate, relevant and limited to what is necessary; (iv) kept in a form which permits identification of data subjects for no longer than is necessary; and (v) processed in a manner that ensures appropriate security of the personal data, including protection against unauthorized or unlawful processing and against accidental loss, destruction, or damage.

We may update this Policy at any time. Any changes to the Policy will become effective upon the date of our posting of the revised Policy on the Services. We will alert you that changes have been made by indicating on the Policy the date it was last updated. We encourage you to review this Policy from time to time to make sure that you understand how any information you provide to us will be used. If we make a material change to the terms of the Policy, we will use commercially reasonable efforts to notify you of such changes. If you use any of the Services after that date, you will be deemed to have accepted the Policy’s updated terms.

1. What Types of Information Do We Collect?

The information we collect through the Services includes:

- Personally identifiable information such as first and last name, date of birth, postal address, email address, and telephone number.
- Demographic or biographical information, such as age, gender, ethnicity, and location (city, state, country);

- Condition/disease information, including diagnosis, symptoms (e.g., frequency, duration, severity), family history and other health information; and
- Any other information that you choose to provide.

Please note that your use of the Services may involve providing personal health information to us. Likewise, if you are involved in the study through a participating site, health care professionals, other caregivers, and/or clinical study managers and their associates may provide, with your approval, your personal health information to us.

Information from Cookies

We may automatically collect information about you that relates to your use of the Services but that does not directly reveal your specific identity. Such information is “passively” collected from you through browser navigational tools, such as cookies and pixel tags. These types of technologies enable us to compile statistics about our daily number of site visitors or specific page requests, while not identifying you personally, other than by your IP address, which is the Internet Protocol address of the computer that you use to access the Services. In some jurisdictions, we are not permitted to send cookies to the browser without the prior consent of the affected user. In this case, we will seek such consent. This section assumes that either the use of cookies is not restricted by applicable law, or if it is restricted that you have expressly consented to the use of the cookies. At this time, we do not track your personal information about your online activities over time and across third party websites. We also do not authorize unaffiliated third parties to collect any personal information from you for purposes of such online tracking. A cookie is a small data file that a Web site transfers to a user’s hard drive when a user visits the Web site. A cookie file can contain information such as a unique ID that the site uses to track the pages visited, and is a standard method of registering website user preferences. These preferences are stored in a file on your computer’s hard disk drive. We also use ‘analytical’ cookies. These allow us to recognize and count the number of visitors and to see how visitors move around the Services when they’re using it. This helps us improve the way our website and application work, for example by making sure users find what they need easily. Our Services uses both persistent and session cookies. Persistent cookies are cookies that stay on your computer permanently until you “manually” delete them. Session cookies delete themselves automatically when you leave a website and go to another one or shut down your browser. You can set your browser to accept all cookies, to reject cookies, or to notify you whenever a cookie is offered so that you can decide each time whether to accept it. However, refusing a cookie may in some cases preclude you from using, or negatively affect the display or function of, the Services or certain areas or features of the Services. To learn more about cookies, including how to enable cookies, change your browser settings and find and delete cookies on your hard drive, please refer to your web browser’s help menus or visit www.allaboutcookies.org. By using the Services, you are deemed to unambiguously agree to its use of any cookies that you do not disable.

When you access any of the Services through a mobile device, we may collect information about your use of the Services through your mobile device and mobile communications carrier, including, but not limited to, the identity of your mobile carrier, your mobile device, and your physical location. Use of the Services through a mobile device will cause data to be displayed and transmitted through your mobile device.

2. How Do We Use the Information that We Collect?

- We may use the information collected through the Services for any or all of the following legitimate purposes:
 - **Responses to Requests.** We may use information about you to respond to your requests, such as to answer your questions about using the Services, content you may have posted, your experience using the Services, and to provide you with clarifications, explanations or perhaps the benefits offered by features in the Services.
 - **Emergency.** We may use information you provide to use in the case of an emergency or other situation that we determine requires us to directly contact you.
 - **Adverse Events.** We and/or Collaborators (as defined below), may also report certain information as an adverse event and drug safety information to the U.S. Food and Drug Administration (FDA), the Centers for Disease Control and Prevention (CDC), and/or other U.S. or international governmental organizations, as well as directly to pharmaceutical and medical device companies. The information we provide may include, but is not limited to, information posted or submitted by users. In addition, certain sections of the Services may be provided with the support of Collaborators. These Collaborators may have adverse event reporting requirements that relate to regulated products that are used by users, and we may assist such Collaborators with reporting adverse events to regulatory agencies. To learn more about adverse event reporting to the US Food and Drug Administration: <http://www.fda.gov/Safety/MedWatch/>
 - **Communications with users who Subscribe.** If you join our marketing mailing list or otherwise accept to be notified of certain events and activities (by agreeing to be informed of special events, etc.), we will send you information that we believe may be of interest to you (for example, upcoming webinars, charitable events, new publications, recruiting clinical trials, certain content sponsored by our Collaborators, etc.). You may opt out of receiving such communications, as described in those communications and in Section 4 below on managing the information you provide to us.
 - **Internal Business Purposes.** We use information about you for our internal, legitimate business purposes, including in particular to help us determine usage of all of our feature groups, and help us improve our offerings. We also use your information for related internal purposes, such

as data analysis, audits, enhancing the Services, identifying usage trends and determining the effectiveness of our promotional messaging

- **Aggregated Information.** We may aggregate certain types of information you provide and report this information publicly and/or to Collaborators, such as the number of patients with a particular disease or condition, on a particular treatment, or experiencing a particular symptom. This coded information would be visible in an aggregate form by other users and potentially individuals that are not users, and great care is taken in aggregating information so that it is unlikely that someone could identify any particular user.
- **Other Information.** We use some aggregated information to help us improve the Services, such as by analyzing usage of certain pages or functions on the Services. We may also use information for other purposes, but if any such use involved combining the information with any data so that it became identifiable to you or another person, we would then treat such identifiable information in accordance with this Policy.

3. With Whom Do We Share Information Collected?

- We may share information we collect through the Services in certain circumstances for legitimate business purposes, including:
 - **Affiliates.** We may share your information with any entities that may become affiliates of CureDuchenne.
 - **Staff.** CureDuchenne Link staff or the employees of our service providers who are working on the study may sometimes need access to your information in the course of troubleshooting problems or resolving complaints.
 - **Research.** We may share or sell certain anonymized information or aggregated reports to Collaborators, including but not limited to pharmaceutical or medical device manufacturers, advocacy organizations, federated data organizations, and academic institutions that are researching and analyzing ways to better understand patient experience and improve treatment and patient outcomes.
 - **Surveys.** We may also occasionally ask you to complete voluntary surveys and/or polls about your experiences, unmet needs and/or other topics, including the various features within the platform or proposed to be included. We may use such aggregate anonymized data and combine such responses with your information and share or sell it to Collaborators.
 - **Clinical and Research Studies.** As a participant in the study, all data collected in the study will be governed by an informed consent document. Such informed consent will describe the nature of the study, the protocol, and describe how information collected from you will be used. By signing the informed consent related to the study, by agreeing to be a participant in the study, and/or by using the Services in connection with the study, you agree that we are permitted to collect, use, and share your information, as described in the informed consent and you further agree

that we have no, and shall have no, responsibility or liability to you or anyone claiming through you for any act or omission with respect to your information. Please note that CureDuchenne is not a “Covered Entity” within the meaning of the Health Information Portability and Accountability Act of 1996 (“HIPAA”).

- **Third Party Service Providers.** We may share information with unaffiliated third parties who provide us with services, such as third-party service providers assisting us with the study, the developer and designer of the Site or App, to provide technology, data analysis, or similar services.
- **Third Parties for Marketing.** We do not share your information with unaffiliated third parties for their own marketing purposes. Please note that CureDuchenne may reach out to you on behalf of third parties, should we receive information about a clinical trial or study targeting recruitment to a cohort of potentially eligible participants, or for other reasons for which we feel may be valuable to you.
- **Acquirers or Assignees.** In the event of any reorganization, merger, sale, joint venture, assignment, transfer or other disposition of all or any portion of CureDuchenne, any of their respective affiliates, or their respective assets, CureDuchenne may transfer any and all information collected from Site users to the acquiring party or assignee.
- **Entities Entitled Under Law.** We may disclose information about you to others as we believe to be appropriate in the following circumstances: (i) when required by applicable law, including laws outside your country of residence; (ii) to comply with legal process (iii) to respond to requests from public and government authorities; (iv) to enforce the terms and conditions for use of the Site, including this Policy; (v) to protect and defend our rights and property; (vi) to protect the interests and safety CureDuchenne, or others; and (vii) to permit us to pursue available remedies or limit the damages that we may sustain. We have no obligation to notify you of such disclosures, except as required by applicable law.
- **Based on your consent.** We may also share your information when we have your consent to do so.
- **Other Information.** We may share non identifiable information, such as the Site or App usage patterns of visitors on an aggregate basis, with third parties.

4. How Can You Manage Information We Maintain?

- **Managing Communications With You.** If you no longer wish to receive emails from us on a going-forward basis, you may opt-out of receiving such emails by following the “unsubscribe” directions on the e-mails, or by sending an e-mail to CDLink@cureduchenne.org with the subject line “Unsubscribe.” We will endeavor to comply with your request as soon as reasonably practicable. We may also in the future send you certain non-promotional communications regarding

CureDuchenne, to the extent permitted by law, you will not be able to opt-out of those communications (e.g., communications regarding updates to this Policy).

- **Updating or Correcting Information.** If you would like to review, correct, or update information about you that you previously provided to us (other than your birth date), you may do so by visiting your user account settings. If you are unable to locate that page, please inform us by sending us an e-mail. For your protection, we will only implement such requests with respect to the information associated with the particular email address that you use to send us your request, and we may need to verify your identity before implementing your request.

5. How Do We Protect and Maintain Information Collected Through the Site?

- **Security.** We use reasonable organizational, technical and administrative measures to help protect against the loss, misuse and alteration of the information under our control. However, no data transmission over the Internet or data storage system can be guaranteed to be 100 percent secure. Please exercise caution in sending us any information you consider confidential. It is your personal responsibility to secure your own copies of your passwords and related access codes for our online resources.
- **Data Integrity and Retention.** We will retain information about you for the period necessary to fulfill the purposes outlined in this Policy or our data retention policies unless a longer retention period is required by law. Additionally, we cannot guarantee the integrity or authenticity of any data that other users may provide us about themselves.

6. Collection of Information by Others Through the Services

We do not allow others (except for our service providers or third parties operating on our behalf) to collect the information of visitors to the Services by tracking the usage of either the App, Site or other websites. However, you should use discretion when providing information about yourself or others on the Services, even though third parties are not permitted to collect information of visitors to the Services (except for our service providers or third parties operating on our behalf) we cannot guarantee absolute privacy, confidentiality, or security. This Policy is only applicable to the Services and will not apply to any third-party sites.

7. CALIFORNIA PRIVACY RIGHTS

Pursuant to Section 1798.83 of the California Civil Code, a California resident who has provided Personal Information to a business with whom he/she has established a business relationship for personal, family, or household purposes (“California Customer”) is entitled to request information about whether the business has disclosed Personal Information to any third parties for the third parties’ direct marketing purposes. Upon receipt of a request by a California Customer, the business is required to provide a list of all third parties to whom Personal Information was disclosed in the preceding calendar year, as well as a list of the categories of Personal Information that were disclosed. You

can make a request for this information by emailing us or by writing to us at the address given at the bottom of this policy.

The California Consumer Privacy Act (CCPA) provides California consumers with the right to request access to their personal data, additional details about our information practices and deletion of their personal information (subject to certain exceptions). California consumers also have the right to opt out of sales of personal information, if applicable. We describe how California consumers can exercise their rights under the CCPA below. Please note that you may designate an authorized agent to exercise these rights on your behalf by providing written materials demonstrating that you have granted the authorized agent power of attorney. Please note that if an authorized agent submits a request on your behalf, we may need to contact you to verify your identity and protect the security of your personal information. We will not fulfill your CCPA request unless you have provided sufficient information for us to reasonably verify you are the consumer about whom we collected personal information. We will not discriminate against you if you choose to exercise your rights under the CCPA.

You may request, no more than twice in a twelve (12) month period, access to the specific pieces of personal data we have collected about you in the last twelve (12) months. You may also request additional details about our information practices, including the categories of personal information we have collected about you, the sources of such collection, the categories of personal information we share for a legitimate business or commercial purposes, and the categories of third parties with whom we share your personal information. You may make these requests by contacting using the contact information provided below in the “Contacting Us” Section below. After submitting your request, please monitor your email for a verification email. We are required by law to verify your identity prior to granting access to your data in order to protect your privacy and security.

You may request, no more than twice in a twelve (12) month period, transportable copies of your personal information that we have collected about you in the last twelve (12) months. You may make these requests by contacting using the contact information provided below in the “Contacting Us” Section. After submitting your request, please monitor your email for a verification email. We are required by law to verify your identity prior to granting access to your data in order to protect your privacy and security.

You may request that we delete the personal information we have collected about you. Please note that we may retain certain information as required or permitted by applicable law or as detailed in the informed consent documents. You may make these requests by contacting us using the contact information provided below in the “Contacting Us” Section below. After submitting your request, please monitor your email for a verification email. We are required by law to verify your identity prior to granting access to your data in order to protect your privacy and security.

California residents are entitled to ask us for a notice identifying the categories of personal information which we share with our affiliates and/or third parties for marketing purposes and providing contact information for such affiliates and/or third parties.

8. EUROPEAN ECONOMIC AREA DATA SUBJECT RIGHTS

If you are a citizen or resident of a country within the European Economic Area (“Data Subject”), the following additional rights as expressed under Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 known as the General Data Protection Regulations (“GDPR”) are applicable to you: Personal Data: For the purposes of this section, “Personal Data” means collectively your information, Unique Identifiers, Advertising Identifiers, and Location Data which you have provided to, or otherwise collected when you use and otherwise access the platform.

Basis for Processing Data: Site relies on the consent of the Data Subject to process personal information. Data Subjects must be at least the age of 16 to consent to the processing of their Personal Data. Data Subjects under the age of 16 must obtain their parent’s or legal guardian’s permission to consent to the processing. On other occasions, we may process information when we need to do so to fulfill a contract, provide services or where we are required by law to do so.

Access/Portability: You may access, correct, or modify the Personal Data you provided to website and associated with your account. Note that we may request to verify your identification before fulfilling your request. You can also request that your personal information is provided to you in a commonly used electronic format so that you can share it with other organizations. You may do so by contacting our privacy team and they will send you the appropriate documentation to process your request.

Forgotten: You may request to have your Personal Data erased, or otherwise request that your Personal Data not be processed. Please note that the Service, or parts of the Service, may become inaccessible or otherwise not function properly if you request to have your Personal Data erased or not be processed. You may do so by contacting our privacy team as described below.

Object, Restrict, or Withdraw Consent: You may withdraw consent you previously provided to website or otherwise object to or restrict the processing of your Personal Data You may do so by contacting our Privacy Team. They will send you the appropriate documentation to process your request.

Supervisory Authority: If you have a concern with the handling of your Personal Information, you have the right to notify your local Data Protection Authority in the country in which you reside.

If you would like to exercise the above EU General Data Protection Regulation (GDPR) rights about your personal information we hold about you, please submit a written

request using the information provided in the “Contacting Us” section below. Our privacy team will examine your request and respond to you as quickly as possible.

9. Use of Site by Children

These Services may not be used by children under the age of 18 and we do not knowingly collect information from any individuals under age 18 without their parent or legal guardian’s consent. If we discover that we have obtained information from a child under age 18, we will delete it. Notwithstanding the foregoing, we may collect information in the context of studies intended to enroll children as subjects. In such circumstances, the written informed consent document shall describe the information collected by the Services and shall be signed by the subject and their parent(s) or their legal guardian(s). Please review the clinical trial information above in Section 3.

10. International Transfers and Processing of Information

We are a United States based entity and our servers are located in the United States. By providing your information through the Services you fully understand and unambiguously consent to the transfer of such information to, and the collection, retention and processing of such information in the United States and other countries or territories. If you do not wish to transfer your information to the United States, please contact us using the information in the “Contacting Us” section below.

11. Contacting Us

If you have any questions or concerns related to this Policy or the information practices of this Site, please send us an e-mail at CDLink@cureduchenne.org or contact us via telephone at (888) 235-4655.

Last Updated: March 10, 2021