

**NATIONAL ORGANIZATION FOR DISORDERS OF THE CORPUS CALLOSUM**  
**PRIVACY POLICY**

**1. INTRODUCTION**

The National Organization for Disorders of the Corpus Callosum (“the NODCC,” “we,” “us” or “our”) is a non-profit 501(c)(3) entity that is organized to enhance the quality of life and promote opportunities for individuals with disorders of the corpus callosum and raise the profile, understanding and acceptance of these disorders through research, education, advocacy and networking.

The NODCC takes the security and privacy of your Personal Information very seriously. This Privacy Policy (“Policy”) describes how we process Personal Information that we collect through our website, located at <<https://nodcc.org/>>, as well as any other applications operated and controlled by us from which you are accessing this Policy (the “Site”). The Policy also describes how we process Personal Information that we collect through offline activities such as postal mail, in-person, or over the phone (e.g., donations), the NODCC conference, local gatherings of families, or any other NODCC-sponsored or affiliated programs or events (the “Offline Services”). By accessing and using the Site or Offline Services, you agree to the terms and conditions of this Policy.

**2. INFORMATION WE COLLECT**

- 2.1 **Personal Information**: “Personal Information” is the information that identifies you as an individual or relates to an identifiable individual, such as: name, postal address, telephone number, email address and credit or debit card number.
- 2.2 **Personal Information You Submit**: We collect and process Personal Information when you submit it to us through the Site or Offline Services, including but not limited to when you: (i) submit a donation; (ii) register for or subscribe to certain events, products, or services; (iii) register to maintain an account with us or create a profile on the Site; (iv) participate in a contest or fundraiser; (v) participate in a voluntary survey; (vi) use an interactive feature on the Site; or (vii) participate in one of our forums, message boards, networking groups, and other interactive features on the Site (collectively, the “Forums”).
- 2.3 **Traffic Data**: Through your use of the Site, we may also gather certain information about your use of the Site that does not identify you individually, but may identify your computer or device. Generally, this information is collected through what we refer to herein as “Traffic Data.” We may collect and store such Traffic Data automatically whenever you interact with the Site. For example, we may collect your IP address, the hostname of your computer, browser information and reference site domain name every time you use the Site. We may collect information regarding user traffic patterns and Site usage. This Traffic Data does not, however, contain anything that can personally identify you, though it may identify your computer or device; it is used to analyze and improve the Site and to provide our users with a better experience. Please see the section below in this Policy regarding Passive Information Collection for more information about our use of cookies and other technologies.
- 2.4 **Combination of Data**: We may combine your Personal Information with other information we have collected from you, whether on- or offline, including, for example, your purchase history or Traffic Data. We may also combine your Personal Information with information we receive about you from other sources, such as our affiliates, publicly available information sources, and third parties. We treat the combined information as Personal Information.
- 2.5 **Other Personal Data**: We may inform you of other Personal Information collected by or through the Site or Offline Services at the point of collection.

**3. PASSIVE INFORMATION COLLECTION, USE, AND CHOICES**

3.1 As you navigate the Site, certain Traffic Data may be passively collected, meaning it is gathered without your actively providing it. This is done using the following technologies in the following ways:

3.1.1 **Through your browser:** Certain information is collected by most browsers, such as your Media Access Control (MAC) address, computer type and operating system type and version screen resolution, and Internet browser type and version.

3.1.2 **Through your device:** If you access the Site through a mobile device or other network-connected product, certain information may be collected about that device, including your device type, network service provider, and other identifiers. We may collect unique device identifiers (such as IDFA and AID tags and UUID and UDID identifiers) associated with the device you use to access the Site.

3.1.3 **Using cookies:** The NODCC may use cookies, which are comprised of small bits of data that often include an anonymous unique identifier. A cookie is a small data file that most major web sites write to your computer's hard drive for record keeping purposes when you visit them. Cookies allow us to measure activity on the Site and to improve your user experience and make updates based on which areas are popular and which are not, for example by remembering your passwords and viewing preferences. We will make available cookies, containing non-personally identifiable information such as IP addresses and pages viewed, regarding your activity on the Site to certain third party providers with whom we work, in order to show advertisements relating to the Site that may be of interest to you. If you would like more information about this practice and to know your choices about not having this information used by these companies, please let us know by contacting us as described in the **Contact Us** section below.

Most browsers are initially set up to accept cookies. If you would prefer, you can set yours to refuse cookies or to alert you when cookies are being sent. Your browser may allow you to block or limit cookies. You will need to do this on each browser and device that you use. However, it is possible that some parts of the Site will not function properly if you do so. To learn more about cookies, please visit <http://www.allaboutcookies.org>.

3.1.4 **Using Monitoring Tools:** The Site may utilize pixel tags, web beacons, clear GIFs, Flash Shared Objects, HTML5 Local Storage, HTML5 Mini Databases, and other similar technologies, both on certain aspects of the Site and in HTML-formatted e-mail messages to you. These monitoring tools are used for the purpose of, among other things, compiling statistics about Site usage and response rates, and tracking the activities of users of the Site and e-mail recipients.

3.1.5 **IP Address:** We collect IP addresses through the Site. An IP Address is a number that is automatically assigned to your computer that you are using by your Internet Service Provider. Web servers, the computers that "serve up" web pages, automatically identify your computer by its IP address, and when you request a page from the Site, our servers log your IP address. An IP Address is identified and logged automatically in our server log files whenever a user visits the Site, along with the time of the visit and the page(s) that were visited. Collecting IP Addresses is standard practice on the Internet and is done automatically by many online service providers, including website operators. We use IP Addresses for purposes such as calculating Site usage levels, helping diagnose server problems, and administering the Site. The Site does not link IP addresses to anything personally identifiable, so although your session will be logged, you will remain anonymous to us.

3.1.6 **Analytic Tools:** We also use tools and third-party services to collect information about usage of the Site, including Google Analytics. To learn more about privacy and Google Analytics please consult the Google Analytics overview provided by Google at: <http://www.google.com/intl/en/analytics/privacyoverview.html>. Generally speaking, Google Analytics collects information on how often users visit the Site, what aspects of the Site they visit when they do so. You may prevent your data from being collected and used by Google Analytics by opting out through the use of the [Google Analytics Opt-out Browser Add-on](#).

Although our use of passive collection technologies may change over time as technology evolves, the above descriptions are designed to provide you with additional detail about our current approach to information collected from passive technologies.

This Site does not process Do-Not-Track (DNT) headers transmitted by Web browsers.

#### 4. CHILDREN AND PRIVACY

- 4.1 We will not knowingly market to or collect Personal Information from children under the age of 13. We reserve the right to delete any information identified as having been provided by such persons at our discretion.

#### 5. HOW WE USE YOUR PERSONAL INFORMATION

- 5.1 We use the Personal Information we collect for the purposes set forth herein and as otherwise described to you at the point of collection. Specifically, we may use Personal Information in the following ways:

- To improve the quality of our services or to ensure that content from the Site is presented in the most effective manner for you and for your computer.
- To provide you with information, products or services that you request from us or that we feel may interest you. For example, the NODCC may from time to time send promotional materials or notifications related to our products, events, and services and/or the products, events, and services of third parties to the email or postal address you provided.
- To complete and fulfill your purchase, for example, to process your payments, donations, have your order delivered to you, communicate with you regarding your purchase, and provide you with related customer service.
- To allow you to participate in interactive features of our service, when you choose to do so.
- To notify you about changes to our Site, products, events, and services.
- To create and manage your personal account with us.
- To prevent misuse or improper use of the Site.
- To communicate with you and respond to your inquiries.
- To send you surveys regarding your satisfaction with our services (performed by the NODCC or by third parties on our behalf), products, events, and overall experience in connection with the NODCC.
- For our purposes, such as data analysis, audits, developing new products and features, enhancing our website, improving our products and services, identifying Site usage trends, and determining the effectiveness of our promotional campaigns.
- As we believe to be necessary or appropriate: (a) under applicable law, including laws outside your country of residence; (b) to comply with legal process; (c) to respond to requests from public and government authorities, including public and government authorities outside your country of residence; (d) to enforce our terms and conditions; (e) to protect our operations or those of any of our affiliates; (f) to protect our rights, privacy, safety or property, and/or that of our affiliates, you, or others; and (g) to allow us to pursue available remedies or limit the damages that we may sustain.
- For any other purpose specified at the point of collection.

- 5.2 We may use non-personal, non-individual statistics or demographic information in aggregate form without restriction, and we may share such information with our marketing partners, advertisers or other third-parties for research purposes.

#### 6. HOW WE SHARE YOUR INFORMATION

- 6.1 **Information Disclosed through Forums:** Certain features on the Site give you an opportunity to interact with us and others, including on the Forums, which include discussion boards, networking centers, chats, and creating community profiles on the Site. When you use these features, you should be aware that any information you submit, including your name, location and email address, is made available to others who have registered to participate in the Forums. We do not have any control over how those other users may use and disclose the information that you share on the Forums. It is possible that they could make

your information publicly available. We are not responsible for any information you choose to submit through these interactive features.

## **6.2 Our Disclosure of Personal Information:**

6.2.1 We may disclose your Personal Information to any member of our affiliates and subsidiaries for the purposes described in this Policy.

6.2.2 We may disclose your Personal Information to third parties:

- Who assist us to administer the Site (such as our Internet services providers) or to provide and manage the services you are requesting. These third parties must at all times provide the same levels of security for your Personal Information as NODCC.
- Who are service providers that perform functions on our behalf. For example, we may make your Personal Information available to certain third-party service providers who help us: (i) manage or provide our products, events and services; (ii) send email messages on our behalf; (iii) process payments; (iv) fulfill product orders; (v) deliver packages; (vi) provide customer service; (vii) analyze data or statistics; and (viii) provide marketing assistance and customized advertising. These service providers have access to Personal Information needed to perform their functions, but are contractually prohibited from using it for other purposes. Further, they must process the Personal Information in accordance with this Policy and as permitted by applicable data protection laws.
- In the event of any reorganization, merger, sale, joint venture, assignment, transfer, or other disposition of all or any portion of our business, assets, or stock (including in connection with any bankruptcy or similar proceeding).
- If we are under a duty to disclose or share your Personal Information in order to comply with any legal obligation, or in order to: (i) protect or defend the legal rights or property of the NODCC or of its affiliates, employees, agents, contractors, and others (including enforcement of our agreements); (ii) protect the safety and security of users of our products, events, and services or members of the public; (iii) protect against fraud or for risk management purposes; (iv) comply with the law or legal process, including laws outside your country of residence; or (v) to respond to requests from public and government authorities including public and government authorities outside your country of residence.

## **7. PRIVACY POLICY CHANGES**

7.1 **Privacy Policy Changes.** The NODCC may modify this Policy from time to time. When we do, we will let you know by posting the changed Policy on this page with a new “Last Updated” date. In some cases, we may also tell you about changes by additional means, such as by posting a notice on the Site or sending an e-mail to the e-mail address we have on file for you.

## **8. CROSS-BORDER TRANSFER**

8.1 Personal Information may be stored and processed in any country where we have facilities or in which we engage service providers, and by using the Site and/or our products and services, you consent to the transfer of information to countries outside of your country of residence, including outside of the United States, which may have different data protection rules than in your country of residence. The laws of the United States and other countries governing data protection may not be as comprehensive or as protective as the laws in the country where you live.

## **9. DATA RETENTION**

9.1 We will retain your Personal Information for the period necessary to fulfill the purposes outlined in this Policy unless a longer retention period is required or allowed by law.

## **10. THIRD PARTY WEBSITES**

10.1 The Site may also be linked to sites operated by third parties, and may carry advertisements or offer content, functionality, games or applications developed and maintained by third parties. Some of these third party sites may be co-branded with the NODCC logo, even though they are not operated or maintained by us. The NODCC is not responsible for the privacy practices of any such third parties, and once you leave our Site via a third party link, enable a third-party service, or click an advertisement, you should check the applicable privacy policy of the third-party site. We do not control the use of cookies or the collection of information by these third parties, nor how they manage such information. The availability of, or inclusion of a link to or interface with, any third-party service on the Site does not imply endorsement of it by us or by our affiliates. Your use of those other sites and services is subject to the privacy policies of those sites.

## **11. THIRD PARTY PAYMENT PROCESSOR**

11.1 The NODCC uses a third party payment processor to assist us in processing your personally identifiable payment information securely. The information collected for payment purposes, such as your credit card number and expiration date, is collected by the third party payment processor. Such third party processor's use of your Personal Information is governed by its own separate Policy, which may or may not contain privacy protections as protective as this Policy. We will inform you which payment processor is used when processing your payments.

## **12. SOCIAL MEDIA**

12.1 Some aspects of the Site may allow you to interface with other websites, social media, and other online services, such as Facebook. We will diligently work to identify these aspects of the Site to you, for example, by identifying them with the applicable third party logos or trade names. By using these interfaces, you will allow us to access information about you from those other online services, including information and other content that you submit to those online services. If you interface with the Site through your social media account, we may contact you or enable you to share your experience and content via your social media account, which information may be publicly viewed by other users of those services. For a description on how such social media services and other third party platforms, plug-ins, integrations, and applications handle your information, please refer to their respective privacy policies and terms of use, which may permit you to modify your privacy settings with that service or platform.

## **13. SECURITY**

13.1 The NODCC uses commercially reasonable and appropriate administrative, technical, and organizational measures to safeguard Personal Information in its possession against loss, theft and unauthorized use, disclosure or modification. Unfortunately, no transmission of data over the Internet is guaranteed to be completely secure. It may be possible for hackers or other third parties not under the control of the NODCC to intercept or access transmissions or private communications or to gain access unlawfully to information that we store. While we strive to protect your personal information, the NODCC cannot ensure or warrant the security of any Personal information. Any transmission of such information to us is done at your own risk. If you have reason to believe that your interaction with us is no longer secure (for example, if you feel that the security of any account you have with us has been compromised), please immediately notify us of the problem.

## **14. HOW TO ACCESS, CORRECT OR UPDATE YOUR INFORMATION**

14.1 You can access or modify your information and modify your preferences by contacting us as indicated in the **Contact Us** section below.

## **15. CONTACT US**

- 15.1 If you have any questions regarding this Policy or the use of your Personal Information under this Policy, you can contact us at [info@nodcc.org](mailto:info@nodcc.org) or at the address below.

NODCC  
PMB 363, 18032-C Lemon Dr.  
Yorba Linda, CA 92886

## 16. OPTING-OUT

- 16.1 You may request to stop receiving electronic or postal notifications from the NODCC at any time by contacting us at [info@nodcc.org](mailto:info@nodcc.org). In the subject field, type "Opt Out" and provide us your name and the e-mail, phone or postal address you wish to be removed. We will seek to comply with your request(s) as soon as reasonably practicable. In addition, you may opt out of receiving promotional e-mails from us by following the unsubscribe instructions provided in any such messages. Please note that if you opt out of receiving promotional messages from us, this does not impact other transactional and administrative messages which you will continue to receive (such as emails relating to billing and payment information or changes to this Policy).
- 16.2 If you would like to request that we withhold your information from any third-party, please e-mail us at [info@nodcc.org](mailto:info@nodcc.org). In the subject field, type "Third-Party Opt Out" and provide us your name and the e-mail, phone or postal address you wish to be removed. We will seek to comply with your request(s) as soon as reasonably practicable.

Last Updated: **January 25, 2020**

Copyright © 2019 NATIONAL ORGANIZATION FOR DISORDERS OF THE CORPUS CALLOSUM

All rights reserved.