

# National Ovarian Cancer Coalition Privacy Policy

Effective Date: 1/18/2022

The National Ovarian Cancer Coalition (“**NOCC**,” “**we**,” “**us**” or “**our**”) is committed to protecting your personal information. This Privacy Policy (“**Privacy Policy**” or “**policy**”) discloses the privacy practices for the National Ovarian Cancer Coalition and applies solely to information collected by NOCC through its patient and caregiver support programs, and/or financial support programs (collectively “**NOCC programs**”), except where stated otherwise. While NOCC is not a HIPAA Covered Entity or Business Associate, we are committed to ensuring patient privacy in accordance with applicable laws and industry best practices. By using the NOCC programs, you acknowledge you have read and understood the terms and conditions of this policy. If you do not agree to the terms and conditions of this policy, please do not use the NOCC programs. Your continued use of the NOCC Website following the posting of changes to our Privacy Policy will signify your acceptance of those changes. If you have any questions about this Privacy Policy and Security Statement and/or the practices of the Website or the NOCC please feel free to contact us at [nocc@ovarian.org](mailto:nocc@ovarian.org).

## Information Collection

The NOCC provides assistance through the NOCC support programs and collects from patients certain individually identifiable information (“**personal information**”), including:

- Contact information;
- Demographic information;
- Protected health information, such as health insurance and other benefit information, financial status, medical information, and employment information;
- Upon completion of service delivery to a patient through a NOCC program the patient may be invited to Share Your Story. This is a voluntary opportunity offered to each patient and has no bearing on delivery of services to a patient through NOCC programs. Personal information is collected through Satisfaction Evaluation with an option to Share Your Story specifically to be publicly shared and demonstrate program impact for patients and their families. Only stories, and personal information, of patients who have provided authorization to NOCC are shared publicly.
- Periodically, NOCC conducts follow-up with patients served by NOCC programs to ask them questions about the services they received both from NOCC and from their medical and insurance providers. These responses help NOCC understand what matters to the patients we assist and to evaluate how our services have impacted patients receiving the services, enabling us to serve as an effective voice for change in the healthcare system. Voluntary survey and program evaluation participation has no bearing on delivery of services to a patient through NOCC programs. Survey responses are aggregated for the purposes of public reporting and no personal information is shared publicly.

## Information Use

NOCC uses the information collected from patients or their authorized representatives in order to:

- Provide assistance through its patient and caregiver support programs and/or financial support programs,
- Respond to patients and their representatives to resolve issues presented by and/or for patients,
- Send informational communications about NOCC patient programs, educational resources and upcoming events
- Solicit responses and feedback to voluntary patient and caregiver surveys as part of NOCC's ongoing program satisfaction
- And as otherwise permitted by applicable law.

It is the policy of NOCC that patients' personal information, including protected health information, may only be used after authorization by patients, or their representatives, as follows:

1. By NOCC and its representatives to provide services and support to patients seeking assistance from and enrolled in NOCC programs, including those administered by NOCC as a service provider, in order to respond to applications for assistance and/or resolve issues presented by patients seeking assistance from NOCC. Representatives may include NOCC employees, both permanent and temporary, directors, officers, NOCC legal counsel, and contracted third party service provider organizations.
2. In the NOCC Treatment Fund Disclaimer [linked here](#)
3. In the NOCC Clinical Trial Fund Disclaimer [linked here](#)

## Disclosure of Information

We may share or disclose your information to the following categories of third parties and for the following reasons:

- To third party service providers, agents or independent contractors who help us maintain our Services and provide other administrative services to us, in order to resolve issues presented by the patients, to process an application for assistance, to process a claim being made against a financial award that has been provided, as required by a partnering organization or as required by law. The patient, or the authorized representative, is notified of these disclosure practices via written program disclaimer that is provided via mail, email and/or published on the NOCC website.
- We may share your personal information in the course of any reorganization process including, but not limited to, mergers, acquisitions, and transfers of all or substantially all of our assets.

- We may disclose your personal information to law enforcement, government agencies, and other related third parties, in order to comply with the law, enforce our policies, or protect our or others' rights, property or safety.
- We may disclose information to third parties where necessary to assist in fraud protection and to minimize credit risk.

### **Collection and Use Of Information From Children**

NOCC's online services are not intended for use directly by children. We do not knowingly collect personal information directly from children, and none of our online services are designed to attract children. In the event that we learn that a person under the age of 13 has directly provided personal information to us, we will delete such personal information as soon as possible.

### **Notice Regarding Public Posting Areas**

Please note that any information you include in a message you post to any chat room, forum or other public posting area is available to anyone with Internet access. If you do not want people to know your email address, for example, do not include it in any message you post publicly. PLEASE BE EXTREMELY CAREFUL WHEN DISCLOSING ANY INFORMATION IN CHAT ROOMS, FORUMS AND OTHER PUBLIC POSTING AREAS. WE ARE NOT RESPONSIBLE FOR THE USE BY OTHERS OF THE INFORMATION THAT YOU DISCLOSE IN CHAT ROOMS, FORUMS AND OTHER PUBLIC POSTING AREAS.

### **Third-Party Links**

You might find links to third party websites on our website. These websites should have their own privacy policies which you should check. We do not accept any responsibility or liability for their policies whatsoever as we have no control over them.

### **Media Release Form**

Certain patients may be contacted by NOCC in reference to participation in public appearances, media interviews, and other outreach activities. These voluntary activities have no bearing on delivery of services to patients through NOCC programs. Before participating in such activities, patients must complete a media release form. Only patients who have provided authorization to NOCC to share their personal information publicly will be engaged in media events and opportunities.

### **Information Ownership and Sharing**

NOCC is the sole owner of the personal information collected through NOCC programs, except in certain programs where NOCC is in partnership with another organization to deliver a program.

NOCC collects information that patients voluntarily provide or that is given to us by patients' authorized representatives and providers, including but not limited to family members, caregivers, guardians, medical providers, pharmacies, health care facilities, diagnostic laboratories, medical equipment providers, health and welfare benefit plans, insurance companies, benefit administrators and employers.

## **Security**

We implement reasonable security measures to ensure the security of your personal information. Please understand, however, that no data transmissions over the Internet can be guaranteed to be 100% secure. Consequently, we cannot ensure or warrant the security of any information you transmit to us and you understand that any information that you transfer to us is done at your own risk. If we learn of a security systems breach we may attempt to notify you electronically so that you can take appropriate protective steps. By providing personal information to us, you agree that we can communicate with you electronically regarding security, privacy and administrative issues relating to your use of the NOCC programs. We may post a notice via our websites if a security breach occurs. We may also send an email to you at the email address you have provided to us in these circumstances. Depending on where you live, you may have a legal right to receive notice of a security breach in writing.

## **International Data Transfers**

We are based in the United States. If you choose to provide us with information, please understand that your personal information may be transferred to the United States and that we may transfer that information to third parties, across borders, and from your country or jurisdiction to other countries or jurisdictions around the world. If you are visiting from the EU or other regions with laws governing data collection and use that may differ from US law, please note that you are transferring your personal information to the United States and other jurisdictions which may not have the same data protection laws as the EU. We put in place appropriate operational, procedural and technical measures in order to ensure the protection of your personal information. You acknowledge that by providing your personal information: (i) your information will be used for the uses identified above in accordance with this Privacy Policy; and (ii) your information may be transferred to the US and other jurisdictions as indicated above, in accordance with applicable law.

## **Access to and Updates of Your Information**

Patients may request a printed copy of their personal information that is electronically stored at NOCC and/or provide updates to their personal information by contacting us via email [nocc@ovarian.org](mailto:nocc@ovarian.org), by calling 1-888-682-7426, or by writing to National Ovarian Cancer Coalition, Attn: Privacy Policy, 12221 Merit Drive, Suite 1950 Dallas, Texas 75251. NOCC does not delete entire patient records that are electronically stored upon request.

## **Opt Out of Future Contacts**

Patients may opt out of any future contacts from NOCC at any time. To do so, contact us via email [nocc@ovarian.org](mailto:nocc@ovarian.org), by calling 1-888-682-7426, or by writing to National Ovarian Cancer Coalition, Attn: Privacy Policy, 12221 Merit Drive, Suite 1950 Dallas, Texas 75251.

### **Dispute Resolution and Agreement To Arbitrate**

Except where and to the extent prohibited by law, by using the NOCC programs, you and NOCC agree that, if there is any controversy, claim, action, or dispute arising out of or related to your use of the NOCC programs or the breach, enforcement, interpretation, or validity of this policy or any part of it ("Dispute"), both parties shall first try in good faith to settle such Dispute by providing written notice to the other party describing the facts and circumstances of the Dispute and allowing the receiving party thirty (30) days in which to respond to or settle the Dispute. Notice shall be sent to:

- Us, at National Ovarian Cancer Coalition, 12221 Merit Drive, Suite 1950 Dallas, Texas 75251 or
- You, at the address we have on file for you.

Both you and NOCC agree that this dispute resolution procedure is a condition precedent that must be satisfied before initiating any litigation or filing any claim against the other party. IF ANY DISPUTE CANNOT BE RESOLVED BY THE ABOVE DISPUTE RESOLUTION PROCEDURE, YOU AGREE THAT THE SOLE AND EXCLUSIVE JURISDICTION FOR SUCH DISPUTE WILL BE DECIDED BY BINDING ARBITRATION ON AN INDIVIDUAL BASIS. ARBITRATION ON AN INDIVIDUAL BASIS MEANS THAT YOU WILL NOT HAVE, AND YOU WAIVE, THE RIGHT FOR A JUDGE OR JURY TO DECIDE YOUR CLAIMS, AND THAT YOU MAY NOT PROCEED IN A CLASS, CONSOLIDATED, OR REPRESENTATIVE CAPACITY. Other rights that you and we would otherwise have in court will not be available or will be more limited in arbitration, including discovery and appeal rights.

The arbitrator, and not any federal, state, or local court or agency, shall have exclusive authority to resolve any dispute arising under or relating to the interpretation, applicability, enforceability, or formation of this policy, including any claim that all or any part of this policy is void or voidable.

### **How We Respond To Do-Not-Track Signals**

At this time our websites do not recognize automated browser signals regarding tracking mechanisms, which may include "Do Not Track" instructions.

### **Cookies and Pixels**

A "cookie" is a small file that a website may send to your browser and which may then be stored on your hard drive. The NOCC website uses cookies to improve our visitors' online experience and simulate a continuous connection to the NOCC website by letting us "remember" your preferences on our site. No personally identifiable information is stored in these cookies. You can manually delete

all cookies within your browser's privacy settings. You can also set your browser to not accept cookies. For more information about how to disable cookies, refer to the "help" section of your browser application. In addition, The NOCC website uses "pixels," or transparent GIF files, to help manage online advertising. These pixels do not collect identifying information.

### **Your California Privacy Rights**

California Civil Code Section 1798.83 permits users who are California residents to request certain information regarding our disclosure of personal information to third parties for their direct marketing purposes. We do not share personal information with third parties for their direct marketing purposes.

### **Printed Copy of this Policy**

To request a printed copy of this policy, or any NOCC program disclaimer, contact us via email [nocc@ovarian.org](mailto:nocc@ovarian.org), by calling 1-888-682-7426, or by writing to National Ovarian Cancer Coalition, Attn: Privacy Policy, 12221 Merit Drive, Suite 1950 Dallas, Texas 75251.

### **Donor Policy**

The National Ovarian Cancer Coalition guarantees that we will not trade, sell or share any donor's personal information with anyone else, nor send donor mailings on behalf of other organizations. This policy applies equally to online donors via the NOCC website and NOCC website donation platform, as well as to offline donors making contributions via cash, check, money order, ACH, third party, and any additional offline methods of contribution.

### **Collect Payment Information**

NOCC does not collect credit and debit card information directly and kindly asks you not to share this information with us when submitting requests for additional information

NOCC does use third-party credit card processors ("Payment Processors") to process online as well as other donations to our organization. Please note that your credit and debit card information (number, expiration date, security code) is provided directly to the Payment Processor and is stored by the Payment Processor and not by us, and as such, it is important to review the Payment Processor's privacy policy and terms of use to understand their information security practices. The Payment Processor may share all or some of the following information with us so that we may reach out to you in the future about our organization: first and last name, physical address, email address, phone number, donation amount, and dedication information if applicable (i.e. description of dedication, contact information, and dedication message). Here is a list of our current Payment Processors and links to their policies:

Donor Drive privacy policy: <https://www.donordrive.com/donordrive-platform-privacy-policy/>

## **Data Deletion**

In order to delete your data, please contact us via email [nocc@ovarian.org](mailto:nocc@ovarian.org), by calling 1-888-682-7426, or by writing to National Ovarian Cancer Coalition, Attn: Privacy Policy, 12221 Merit Drive, Suite 1950 Dallas, Texas 75251. Note some of your data may still be stored on third-party sites."

## **Questions or Concerns**

If you have any questions regarding this Privacy Policy, or would like more information on our privacy practices, simply send your inquiry to us via certified mail at:

National Ovarian Cancer Coalition  
12221 Merit Drive, Suite 1950 Dallas, Texas 75251

## **Notification of Patient Privacy Policy Changes**

The current Patient Privacy Policy is posted at [www.ovarian.org](http://www.ovarian.org). We reserve the right to modify this policy at any time. When we do so, we will update the "Effective Date" above. You will be notified of any material changes to this policy via a posting on the website.