

Global Commission to End the Diagnostic Odyssey for Children with a Rare Disease

Privacy Policy

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This Privacy Policy explains how Global Commission to End the Diagnostic Odyssey for Children with a Rare Disease and its affiliates (“**Global Commission**”, “**us**” or “**we**”) collects, uses, discloses, and secures personal information through our website (www.globalrareiseasecommission.com), websites we maintain for independent and any social media webpage we establish that contains a link to this Privacy Policy (each of the foregoing, a “**Site**”, and collectively, the “**Sites**”). This Privacy Policy also addresses personal information that we collect or generate concerning individuals who reach out to us directly by email, telephone, or other means.

Residents in Brazil, the European Union (“**EU**”), the European Economic Area (“**EEA**”), and the United Kingdom (“**UK**”), should refer to the body of this Privacy Policy as well as the “Jurisdiction-Specific Notices” section below for additional information that may be applicable to them.

TABLE OF CONTENTS

1. SITE TERMS OF USE
2. INFORMATION COLLECTION AND PROCESSING
3. INFORMATION SHARING
4. OUR LEGAL BASIS FOR COLLECTING PERSONAL INFORMATION
5. INFORMATION SECURITY
6. PRIVACY RIGHTS
7. LINKS TO UNAFFILIATED THIRD-PARTY WEBSITES
8. POSTING OF A REVISED PRIVACY POLICY
9. JURISDICTION SPECIFIC NOTICES
10. INTERNATIONAL TRANSFER
11. OUR EMAIL OPT-OUT POLICY
12. CONTACT US

SITE TERMS OF USE

By accessing or using the Site in any manner, you also agree to be bound by the Global Commission to End the Diagnostic Odyssey for Children with a Rare Disease Website Terms of Use, (the “**Terms of Use**”), which include well as any additional terms that are presented to you as a condition of the use of any particular aspect of the Site. Please read the Terms of Use carefully. If you do not accept all of the terms and conditions contained in or incorporated by reference into the Terms of Use, please do not use the Site.

INFORMATION COLLECTION AND PROCESSING

We collect information, including personal information, to provide better services to you and for our internal business purposes. We use the term “**Personal Information**” and “**personal information**” to refer to any information that identifies or can be used to identify you.

Contact or request submissions. When you use a Site contact or request form, we collect personal information from you to evaluate and respond to your request, and we may also use the information to improve our Sites or other aspects of our services. The information you provide may include personal identifiers, such as your name, email address, and telephone number, and the content of any messages.

Communications. We receive information you submit through your communications with us by email, phone, or physical mail and we process this information to respond to you and in the normal course of our business operations.

Social media. If you post information on a webpage we establish on a social media platform, we may use the information you provide for purposes of providing a response, to promote our business and services, and otherwise in the normal course of our business operations. We may collect personal identifiers, such as your social media username, and other personal information that you have made available to us through the webpage we established on the social media platform, in accordance with the platform rules and/or applicable law. Note that the third-party operators of social media Sites also receive such information, and their use of your personal information is governed by their own privacy policies.

Third Parties. If you provide us or our service providers with any Personal Information relating to other individuals, you represent that you have the authority to do so and acknowledge that it will be used in accordance with this Privacy Policy. If you believe that your Personal Information has been provided to us improperly, or to otherwise exercise your rights relating to your Personal Information, please contact us by using the information set out in the “Contact Us” section below.

Automated data collection; Cookies and similar technologies.

When you visit our Sites, we and our third-party partners, such as advertising partners and analytics providers (including Google Analytics), may collect information by automated means. Please see our Cookie Policy for more details

Retention period. We use the following criteria to determine the length of time for which we retain personal information subject to this Privacy Policy:

- the purposes for which the personal information is used, and the length of time for which such information is required to achieve those purposes, including for business operations, security purposes, and legal requirements;
- whether we are required to retain the category of personal information in order to: (i) comply with legal or contractual obligations; (ii) assert or defend against potential legal claims or as necessary to investigate theft, fraud, or other activities that are potentially (a) in violation of our policies and procedures applicable to you or (b) a violation of the law; (iii) ensure a secure online environment; and/or (iv) protect health and safety;
- the privacy impact on the consumer of ongoing retention; and
- the manner in which the personal information is maintained and flows through our systems and how best to manage the lifecycle of such information in light of the volume and complexity of the systems in our infrastructure and the need to maintain high integrity and availability within our systems.

INFORMATION SHARING

We may share any of the categories of personal information listed above for our commercial and other business purposes as described below.

Affiliates. We may share personal information with our affiliates, and any successors thereto in the normal course of our business operations. We do so for business purposes, such as to communicate with you and to promote and provide our services. Such affiliates will only use your personal information in a manner that is consistent with this Privacy Policy.

Vendors and service providers. We share personal information with vendors and service providers that process such information to perform services for us in connection with this Site. We require that such vendors and services providers will only use your personal information in a manner that is consistent with this Privacy Policy.

Legal and similar disclosures. We may share personal information with law enforcement, the courts, our advisors, attorneys, and others who participate in legal processes or proceedings, if we believe doing so is required or appropriate to: comply with legal requirements and law enforcement requests (such as a court order or subpoena); comply with legal process (such as discovery); or protect your, our, or others' rights, property, or safety.

Merger, sale, or other asset transfers. If we are involved in a merger, acquisition, financing due diligence, reorganization, bankruptcy, receivership, sale of company assets, or transition of service to another provider, your personal information may be shared with the other parties and advisors involved under an obligation of confidentiality in connection with the negotiation of such transaction, and your personal information may be transferred as part of such a transaction (subject to compliance with applicable laws).

OUR LEGAL BASIS FOR COLLECTING PERSONAL INFORMATION

Whenever we collect Personal Information from you, we may do so on the following legal bases:

1. Your consent to such collection and use;
2. Out of necessity for the performance of an agreement between us and you, such as your agreement to use our services or your request for services;
3. Our legitimate business interest, including but not limited to the following circumstances where collecting or using Personal Information is necessary for:
 - Intra-organization transfers for administrative purposes;
 - Product development and enhancement, where the processing enables Global Commission to enhance, modify, personalize, or otherwise improve our services and communications for your benefit, and to better understand how people interact with our Site;
 - Fraud detection and prevention;
 - Enhancement of our cybersecurity, including improving the security of our network and information systems; and
 - General business operations and diligence.

Provided that, in each circumstance, we will weigh the necessity of our processing for the purpose against your privacy and confidentiality interests, including taking into account your reasonable expectations, the impact of processing, and any safeguards which are or could be put in place. In all circumstances, we will limit such processing for our legitimate business interest to what is necessary for its purposes.

INFORMATION SECURITY

Global Commission maintains reasonable administrative, technical and physical safeguards designed to protect Personal Information and other information against accidental, unlawful or unauthorized destruction, loss, alteration, access, disclosure or use. Information you send by email is not secure, so please avoid including Personal Information in any email you send us. No method of electronic transmission or storage is 100% secure. Therefore, we cannot guarantee absolute security of your information.

PRIVACY RIGHTS

Certain jurisdictions have specific legal requirements and grant privacy rights with respect to personal information, and we will comply with restrictions and any requests you submit as required by applicable law. For example, you may have the right to review, correct, and delete personal information we have about you, or to consent or withdraw consent to certain uses or sharing of personal information. You also have the right to not be discriminated against for exercising your privacy rights. If you seek to exercise your rights under the law of a specific jurisdiction, please contact us by using the contact information in the Contact Us section below.

Please note that, when you make a request, we may require that you provide information and follow procedures so that we can verify your identity (and the applicable jurisdiction). The verification steps we take may differ depending on your jurisdiction and the request. Where possible, we will attempt to match the information that you provide in your request to information we already have on file to verify your identity. If we are able to verify your request, we will process it. If we cannot verify your request, we may ask you for additional information to help us do so.

We will respond to your request within the time period required by applicable law. However, we may not always be able or required to comply with your request, in whole or in part, and we will notify you in that event.

LINKS TO UNAFFILIATED THIRD-PARTY WEBSITES

The Sites may contain links to unaffiliated third-party websites. This Privacy Policy does not apply to the practices of such other Sites, and we are not responsible for the actions and privacy policies of the third parties that operate or interact with those Sites.

NO USE BY CHILDREN

The Sites are not intended for use by children. In particular, if you are under the age of 18, you may not use our Sites. We do not knowingly collect, maintain, or use personal information from children under 18 years old. If we believe that any information has been posted by a child under the age of 18, we will promptly delete that information. Parents may contact us using the methods set forth below to request that information concerned their child be removed from our records.

POSTING OF A REVISED PRIVACY POLICY

We may make changes to this Privacy Policy from time to time, and the revised version will be effective when it is posted and will apply to personal information received after that date. If the changes are material, we will provide a more prominent notice for a reasonable period. We encourage you to review this Privacy Policy periodically.

JURISDICTION SPECIFIC NOTICES

EU, EEA, or UK Residents

Global Commission believes that it is important that individuals are given the opportunity to exercise choice with respect to how their Personal Information is collected and used. Some data protection laws, including the European Union's General Data Protection Regulation ("GDPR"), provide you with certain rights in connection with Personal Information you have shared with us. We rely on the legal bases set forth in the "Our Legal Basis for Collecting Personal Information" section to process your Personal Information. If you are resident in the EU, EEA, or the UK, you have the following rights:

- **The right to be informed.** You are entitled to be informed of the use of your Personal Information. This Privacy Policy provides such information to you.
- **The right of access.** You have the right to request a copy of your Personal Information which we hold about you.
- **The right of correction:** You have the right to request correction or changes of your Personal Information if it is found to be inaccurate or out of date.
- **The right to be forgotten:** You have the right to request us, at any time, to delete your Personal Information from our servers and to erase your Personal Information when it is no longer necessary for us to retain such data. Note, however, that deletion of your Personal Information will likely impact your ability to use our services.
- **The right to object (opt-out):** You have the right to opt-out of certain uses of your Personal Information, such as direct marketing, at any time.
- **The right to data portability:** You have the right to a “portable” copy of your Personal Information that you have submitted to us. Generally, this means your right to request that we move, copy or transmit your Personal Information stored on our servers / IT environment to another service provider’s servers / IT environment.
- **The right to refuse to be subjected to automated decision making, including profiling:** You have the right not to be subject to a decision and insist on human intervention if the decision is based on automated processing and produces a legal effect or a similarly significant effect on you.
- **The right to lodge a complaint with a supervisory authority.** You may also have the right to make a GDPR complaint to the relevant Supervisory Authority. A list of Supervisory Authorities is available here: http://ec.europa.eu/justice/data-protection/bodies/authorities/index_en.htm.

If you need further assistance regarding your rights, please contact us using the contact information provided below and we will consider your request in accordance with applicable law. To make these requests, you may contact us using the contact information in the "Contact Us" section below, and we will consider your request in accordance with applicable laws. For your protection, we may need to verify your identity before responding to your request, such as verifying that the email address from which you send the request matches your email address that we have on file. If we no longer need to process Personal Information about you in order to provide our services or our Site, we will not maintain, acquire or process additional information in order to identify you for the purpose of responding to your request.

In some cases our ability to uphold these rights for you may depend upon our obligations to process personal information for security, safety, fraud prevention reasons, compliance with regulatory or legal requirements, or because processing is necessary to deliver the services you have requested. Where this is the case, we will inform you of specific details in response to your request.

Brazil Residents

If you are a resident of Brazil, the following Brazil-specific provisions apply to our processing of your personal information in addition to the relevant sections of the Privacy Policy:

- We rely on the legal bases set forth in the “Our Legal Basis for Collecting Personal Information” section to process your Personal Information.

- Our Site is not directed to children under the age of 18 and we do not knowingly collect personal information from children under the age of 18 on our Site.

If you are resident of Brazil, you have certain rights, including the right to be informed, right to access, right of correction, right of erasure, right to object/opt-out of certain uses of personal information, right to data portability, and right to not be subject to automated decision-making. If you need further assistance regarding your rights, please contact us using the contact information provided in the " Contact Us" section below.

INTERNATIONAL TRANSFER

We may, directly or indirectly through third-party entities around the world, process, store, and transfer the information you provide, including your Personal Information, as described in this Privacy Policy. Specifically, the information and Personal Information that we collect may be transferred to, and stored at, a location outside of your jurisdiction. It may also be processed by staff, service providers, or third parties operating outside of your jurisdiction in connection with the activities outlined in this Privacy Policy. By submitting your Personal Information using the Site, you agree to this transfer, storing or processing. We will take all steps necessary to ensure that your Personal Information is treated securely and in accordance with this Privacy Policy. We have put in place commercially reasonable technical and organizational procedures to safeguard the information and Personal Information we collect on the Site.

OUR EMAIL OPT-OUT POLICY

By providing an email address on or through the Global Commission Site, you agree that we may contact you in the event of a change in this Privacy Policy, with regard to any submissions you have provided, or to provide you with information about our events, invitations, or related educational information.

We currently provide the following opt-out opportunities: At any time, you can follow a link provided in offers, newsletters or other email messages received from us to unsubscribe.

Notwithstanding anything else in this Privacy Policy, please note that we always reserve the right to contact you in the event of a change in this Privacy Policy, or to provide you with any service-related notices.

CONTACT US

If you have questions about this Privacy Policy or if you would like to make a suggestion about our privacy practices, please send an email to info@globalrarediseasecommission.com.