

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

## Website Terms of Service

Last updated: May 8, 2024

Please read the following Website Terms (“**Terms**”) carefully.

These Terms are entered into by and between you and Global Commission to End the Diagnostic Odyssey for Children with a Rare Disease (“**Global Commission**”, “**us**”, or “**we**”) and apply to any information services we provide (“**Services**”) on a website or application that Global Commission maintains, including <https://globalrareiseasecommission.com/>, which links to these Terms (collectively referred to as the “**Site**”). These Terms include the terms and conditions set forth below as well as any additional terms that are presented to you as a condition of the use of any particular aspect of the Site (“**Additional Terms**”), which Additional Terms are hereby incorporated by reference.

By using the Site, you agree to these Terms. If you do not agree to these Terms, you should not use the Site or the Services.

PLEASE READ THE “DISPUTE RESOLUTION; ARBITRATION; GOVERNING LAW; CLASS ACTION WAIVER” SECTIONS BELOW CAREFULLY. THOSE SECTIONS AFFECT HOW DISPUTES ARE RESOLVED. IF YOU DO NOT AGREE TO THOSE DISPUTE RESOLUTION PROVISIONS, DO NOT ACCESS OR USE THE SITE OR THE SERVICES.

### 1. **Provision of the Site.**

You understand and agree that the Site is provided “as-is” and that Global Commission assumes no responsibility for the availability or functionality of the Site, or for the timeliness, deletion, mis-delivery or failure to store any user communications or personalization settings. Note that collection and use of personal information in connection with the Site or the Services is described in our Privacy Policy.

### 2. **Use of Site; License to Global Commission.**

a. The Site and the Services are for personal use only. You agree not to use the Site for commercial purposes. You are responsible for all data, text, messages or other materials that you post, transmit or otherwise make available to the Site.

b. In addition to any licenses and rights granted to Global Commission pursuant to Additional Terms, you grant Global Commission and related entities a royalty-free, perpetual, irrevocable, non-exclusive right and license to use, copy, modify, publish, transmit, distribute, and create derivative works from all data, text, messages or other materials that you post, transmit, or otherwise make available to the Site or the Services in any form. You grant all rights described in this paragraph in consideration of your use of the Site and the Services and without an expectation of compensation of any sort.

### 3. **Site Ownership; Trademarks.**

a. The Site is owned and operated by Global Commission. The visual interfaces, graphics, other content, design, compilation, computer code (including source code and object code), and other elements of the Site (“**Materials**”) are protected by intellectual property and other laws. All Materials are the property of Global Commission or our third-party licensors. Global Commission reserves all rights in and to the Materials.

b. Global Commission’s logos and product and service names are trademarks of Global Commission and/or its affiliates, or Global Commission. All rights in and to such trademarks are fully reserved by Global Commission. You agree not to display or otherwise use any such trademarks in a manner that constitutes trademark infringement or unfair competition.

4. **No Reproduction or Publication.** Images, text, or other information posted or found on the Site are solely for use in connection with the Site in accordance with these Terms and may not be used, reproduced, or published for any other purpose, commercial or otherwise, without the express written permission of Global Commission and the owner of the images, text, or other information.

5. **Health-Related Content.** The materials provided on or through our Site are not meant to be used for self-diagnosis or to replace the services of a medical professional. While Global Commission endeavors to keep the materials on our Site current, healthcare-related information changes rapidly and thus, the materials on our Site should not be relied upon to be comprehensive, up-to-date, or error free. Global Commission does not recommend, endorse, or make any warranties or representations of any kind with regard to the accuracy, completeness, timeliness, quality, efficacy or non-infringement of any of the programs, materials, products, or other information provided on our Site or by the companies or organizations linked or referred to on our Site. Global Commission does not advocate that you attempt to treat or diagnose yourself, your family or someone you know. Global Commission encourages you to seek the guidance of a healthcare provider if you feel that you, your family, or someone that you know has a condition that is addressed or described on our Site.

6. **Third-Party Services and Linked Websites.** The Site may provide links to other websites or Internet resources. Global Commission has no control over such websites and resources and is not responsible for the availability or content of such external websites or resources. Global Commission shall not be responsible or liable for any damage or loss caused or alleged to be caused by or in connection with use of or reliance on any such content, goods, or services available on or through any such website or resource.

7. **Termination of Access and Use; Discontinuation and Modification of the Site.** If you violate any provision of these Terms, our permission for you to use the Site automatically terminates. In addition, Global Commission may in its sole discretion terminate your access to the Site at any time for any reason or no reason, with or without notice. We also reserve the right to modify or discontinue any Services including the Site at any time (including by limiting or discontinuing certain features of the Site), temporarily or permanently, with or without notice. Upon the termination of your right to use the Site, and upon any discontinuation of the Site by us in whole or in part, Global Commission may delete any content you submitted to or through the Site.

8. **Procedure for Unlawful Material.**

a. **General.** If you believe that any material posted on the Site does not conform to these Terms, please notify us at [info@globalrarediseasecommission.com](mailto:info@globalrarediseasecommission.com).

b. **DMCA Notification.** We comply with the provisions of the Digital Millennium Copyright Act (the “DMCA,” 17 U.S.C. §512, as amended) as applicable to the Site. If you have any copyright or other intellectual property rights complaint about material posted on the Site, you may contact our designated agent at the following address:

Global Commission

Attn: Holland & Knight LLP

787 Seventh Avenue, 31st Floor, New York, NY 10019

212-513-3243

[info@globalrarediseasecommission.com](mailto:info@globalrarediseasecommission.com)

Please note that, under applicable law, if you knowingly give false, misleading or inaccurate information that material is infringing, you may be subject to civil or criminal penalty. Any notice under the DMCA alleging that materials hosted by or distributed through the Site infringe intellectual property rights must include all of the information required by the DMCA for such notices.

9. **Prohibited Conduct.** You agree not to, directly or indirectly:

a. use or access the Site (i) from a jurisdiction where such use or access is not authorized, (ii) for any illegal purpose, or (iii) in violation of any local, state, national, or international law;

b. conduct activities that may be harmful to others or that could damage Global Commission’s reputation;

c. violate, or encourage others to violate, any right of a third party, including by infringing or misappropriating any third-party intellectual property right or violating any third party privacy right or right of publicity;

d. post, upload, or distribute marketing or advertising links or content that is unlawful, defamatory, libelous, or that a reasonable person could deem to be objectionable, profane, pornographic, harassing, threatening, embarrassing, hateful, or otherwise inappropriate;

e. use scrapers, robots, or other data gathering devices not provided by Global Commission on or through the Site;

f. interfere with security-related features of the Site, including by: (i) disabling or circumventing features that prevent or limit use or copying of any content; or (ii) reverse engineering, decompiling, or otherwise attempting to discover the source code of any portion of the Site, except to the extent that such activity is expressly permitted by applicable law notwithstanding this restriction;

g. interfere with the operation of the Site or any user's enjoyment of the Site, including by: (i) uploading or otherwise disseminating any virus, adware, spyware, worm, or other malicious code; (ii) making any unsolicited offer or advertisement to another user of the Site; (iii) attempting to collect personal information or other information about another user or third party without their consent; or (iv) interfering with or disrupting any network, equipment, or server connected to or used to provide the Site, or violating any regulation, policy, or procedure of any such network, equipment, or server;

h. perform any fraudulent activity including impersonating any person or entity, claiming a false affiliation or accreditation, or accessing any other Services account without permission;

i. modify, translate, or create derivative works, adaptations or compilations of, or based on, the Site or part thereof, or use, copy or reproduce the Site or any part thereof other than as expressly permitted in these Terms or by applicable law (e.g., as to fair use under copyright law); or

j. attempt to do any of the acts described in this Section 9 or assist or permit any person in engaging in any of the acts described in this Section 9.

**10. Indemnity.** To the fullest extent permitted by applicable law, you will defend and indemnify Global Commission and its members, managers, officers, directors, employees, affiliates, agents, representatives, licensors, and service providers from and against every claim, liability, damage, loss, and expense, including reasonable attorneys' fees and costs, arising out of: (a) your access to or use of the Site; (b) your violation of these Terms or any applicable law; (c) your violation of any third-party right, including any intellectual property right or publicity, confidentiality, other property, or privacy right in connection with your use of the Site; (d) any dispute or issue between you and any third party concerning the Site; and (e) all claims pertaining to the Site or your use of the Site that arise from or allege negligence, fraud, or intentional misconduct committed by you. Without limiting the foregoing, we reserve the right, at our own expense, to assume the exclusive defense and control of any matter otherwise subject to indemnification by you (without limiting your indemnification obligations with respect to that matter), and in that case, you agree to cooperate with our defense of that claim.

#### **11. Disclaimers; No Warranties.**

a. THIS SITE AND ALL MATERIALS, PRODUCTS, AND CONTENT AVAILABLE THROUGH THE SITE ARE PROVIDED "AS IS" AND ON AN "AS AVAILABLE" BASIS, WITHOUT WARRANTY OR CONDITION OF ANY KIND, EITHER EXPRESS OR IMPLIED. TO THE FULLEST EXTENT PERMISSIBLE UNDER APPLICABLE LAW, WE DISCLAIM ALL WARRANTIES OF ANY KIND, WHETHER EXPRESS, IMPLIED, OR STATUTORY, RELATING TO THE SITE AND ALL MATERIALS, PRODUCTS, AND CONTENT AVAILABLE THROUGH THE SITE, INCLUDING WITHOUT LIMITATION: (A) ANY IMPLIED WARRANTY OF MERCHANTABILITY, FITNESS FOR A PARTICULAR PURPOSE, TITLE, QUIET ENJOYMENT, OR NON- INFRINGEMENT; AND (B) ANY WARRANTY ARISING OUT OF COURSE OF DEALING, USAGE, OR TRADE. GLOBAL COMMISSION DOES NOT WARRANT THAT THE SITE OR ANY PORTION OF THE SITE, OR ANY MATERIALS OR CONTENT OFFERED THROUGH THE SITE, WILL BE UNINTERRUPTED, SECURE, OR FREE OF ERRORS, VIRUSES, OR OTHER HARMFUL COMPONENTS.

b. SOME JURISDICTIONS MAY PROHIBIT A DISCLAIMER OF WARRANTIES PROVIDED OR IMPLIED BY LAW OR A DISCLAIMER OF OTHER WARRANTIES, AND IN THAT CASE THE ABOVE PARAGRAPH SHALL ONLY APPLY TO THE FULLEST EXTENT PERMITTED UNDER APPLICABLE LAW. YOU MAY HAVE OTHER RIGHTS THAT VARY FROM JURISDICTION TO JURISDICTION.

## 12. **Limitation of Liability.**

a. IN NO EVENT WILL WE OR ANY OF OUR MEMBERS, MANAGERS, OFFICERS, DIRECTORS, EMPLOYEES, AFFILIATES, AGENTS, REPRESENTATIVES, LICENSORS, OR SERVICE PROVIDERS BE LIABLE TO YOU FOR ANY INDIRECT, INCIDENTAL, SPECIAL, CONSEQUENTIAL OR PUNITIVE DAMAGES (INCLUDING WITHOUT LIMITATION DAMAGES FOR INCREASED COSTS, DIMINUTION IN VALUE OR LOST BUSINESS, PRODUCTION, REVENUES, OR PROFITS, GOODWILL, REPUTATION, OR ANY OTHER INTANGIBLE LOSS) ARISING OUT OF OR RELATING TO THESE TERMS OR YOUR ACCESS TO OR USE OF, OR YOUR INABILITY TO ACCESS OR USE, THE SITE, THE SERVICES, OR ANY MATERIALS, OR ANY DELAY IN THE RECOVERY OF ANY DATA, INABILITY TO RECOVER ANY DATA, OR BREACH OF DATA OR SYSTEM SECURITY, WHETHER BASED ON WARRANTY, CONTRACT, TORT (INCLUDING NEGLIGENCE), STATUTE, OR ANY OTHER LEGAL THEORY, AND WHETHER OR NOT WE (OR ANY OTHER PERSON OR ENTITY AGAINST WHICH LIABILITY IS ASSERTED) HAVE BEEN INFORMED OF THE POSSIBILITY OF DAMAGE.

b. SOME JURISDICTIONS DO NOT ALLOW THE EXCLUSION OR LIMITATION OF LIABILITY FOR CONSEQUENTIAL OR INCIDENTAL DAMAGES. ACCORDINGLY, THE ABOVE LIMITATION MAY NOT APPLY TO YOU. NOTHING IN THESE TERMS LIMITS OR EXCLUDES ANY LIABILITY THAT CANNOT BE LIMITED OR EXCLUDED BY LAW. EACH PROVISION OF THESE TERMS THAT PROVIDES FOR A LIMITATION OF LIABILITY, DISCLAIMER OF WARRANTIES, OR EXCLUSION OF DAMAGES IS INTENDED TO AND DOES ALLOCATE THE RISKS BETWEEN THE PARTIES UNDER THESE TERMS.

c. THIS ALLOCATION IS AN ESSENTIAL ELEMENT OF THE BASIS OF THE BARGAIN BETWEEN THE PARTIES, AND THE LIMITATIONS IN THIS SECTION 12 WILL APPLY EVEN IF ANY LIMITED REMEDY FAILS OF ITS ESSENTIAL PURPOSE. EACH OF THE ABOVE PROVISIONS OF THIS SECTION 12 IS SEVERABLE AND INDEPENDENT OF ALL OTHER PROVISIONS OF THESE TERMS, AND EACH SUCH PROVISION SHALL ONLY BE EFFECTIVE TO THE EXTENT PERMISSIBLE UNDER APPLICABLE LAW.

13. **Modification of these Terms.** We reserve the right to change these Terms on a going-forward basis at any time. Please check these Terms periodically for changes. If a change to these Terms materially modifies any user rights or obligations, we will endeavor to post notice of the modification on the Site for a reasonable period of time. Any disputes concerning or related to the Site will be resolved in accordance with the version of these Terms that was in effect at the time the dispute arose.

14. **Dispute Resolution; Informal Resolution; Class Action Waiver.** In order to expedite and control the cost of disputes, you and Global Commission agree that any legal or equitable claim concerning or arising under these Terms (referred to as a “**Claim**”) will be resolved as follows:

a. **Informal Resolution:** You and Global Commission will first attempt to resolve any Claim informally. In the event that any dispute between Global Commission and you arises out of or concerns these Terms, the applicability of these Terms, to the use of the Site, or the breach or enforcement, interpretation or validity of these Terms, you and we agree to try to promptly resolve any such dispute informally. Please send a written notice describing the dispute to [info@globalrarediseasecommission.com](mailto:info@globalrarediseasecommission.com).

15. **Governing Law and Venue.** These Terms are governed by the laws of the State of Delaware without regard to conflict of laws principles. Subject to the dispute resolution provision set forth in Section 14, if a lawsuit or court proceeding is permitted under these Terms, then you and Global Commission agree to submit to the exclusive jurisdiction of the state courts and federal courts located within the State of Delaware for the purpose of litigating any dispute, and you hereby consent to the personal jurisdiction and venue thereof.

16. **Limited Time to File Claims.** To the fullest extent permitted under applicable law, no action arising out of, in connection with, or relating to these Terms shall be brought by you more than one (1) year after the accrual of the Claim. This period shall not be extended for any reason, except by the written consent of both parties. All statutes or provisions of law which would toll or otherwise affect the running of the period of limitation are hereby waived, and no such statute or provision of law shall operate to extend the period limited in this paragraph, to the fullest extent permitted under applicable law.

17. **Contact Information.** The Site is offered by Global Commission to End the Diagnostic Odyssey for Children with a

Rare Disease. You may contact us by emailing us at [info@globalrarediseasecommission.com](mailto:info@globalrarediseasecommission.com) or writing to us at c/o Holland & Knight – 787 Seventh Avenue, 31st Floor, New York, NY 10019.

18. **General Information.** The failure of Global Commission to exercise or enforce any right or provision of these Terms shall not constitute a waiver of such right or provision. If any provision of these Terms is found by a court of competent jurisdiction to be invalid, the parties agree that the court should try to give maximum effect to the parties' intentions as reflected in the provision and the other provisions of these Terms shall remain in full force and effect.