

## **TERMS AND CONDITIONS RARE CARE PATIENT PORTAL BY NORD**

Please read the following information carefully. In utilizing these Services, you represent that you are at least eighteen (18) years of age, or the age of majority in your state, province, or country, or have the express legal authority to act on behalf of a minor or an adult unable to act for themselves, and you acknowledge that you understand and accept the following Terms and Conditions. If you do not accept these Terms and Conditions, you may not access these Services. If these Terms and Conditions are not enforceable where you are located, you may not use the Services.

Last Updated: November 15<sup>th</sup>, 2023

The Rare Care Patient Portal is part of a program of the National Organization for Rare Disorders, Inc. (“NORD®”) to enable communication of information about your applications and awards for financial assistance.

**IMPORTANT NOTICE:** PLEASE NOTE THE ARBITRATION REQUIREMENT AND CLASS ACTION WAIVER SET FORTH BELOW, WHICH, SUBJECT TO SOME LIMITED EXCEPTIONS, REQUIRES YOU TO ARBITRATE ANY CLAIMS YOU MAY HAVE AGAINST NORD 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. PLEASE CAREFULLY REVIEW THE “DISPUTE RESOLUTION AND AGREEMENT TO ARBITRATE” SECTION BELOW FOR MORE DETAILS.

### **1. General, Purpose, and Acceptance of Terms and Conditions**

**a. General.** Use of the Rare Care Patient Portal platform operated by NORD, where these Terms and Conditions are posted (the “Platform”) and the services provided through the platform (collectively, the “Services”) are governed by the following terms and conditions (the “Terms and Conditions”). All pages within the Services are owned by NORD.

**b. Purpose.** The purpose of the Services is to allow individuals with rare diseases, their caregivers and family members to manage their applications and awards for financial assistance programs available through NORD.

**c. Acceptance of Terms and Conditions.** By using the Services, you represent that you accept and agree that you have read all the Terms and Conditions, and that you agree to accept these terms. If you do not agree to be bound by the Terms and Conditions you may not submit data to or use the Services.

**d. Additional Rules.** Certain areas, features, or functionality of the Services may be subject to different or additional terms, rules, guidelines or policies (“Additional Rules”), and we may provide such Additional Rules to you via postings, pop-up notices, links, or any other means at the time that you access or use the relevant area, feature or functionality. From time to time, such Additional Rules may conflict with these Terms and Conditions. In the event of such a conflict, the Additional Rules will control. Any reference to the “Terms and Conditions” includes the Additional Rules.

### **2. Intellectual Property Rights and Ownership**

NORD owns and retains ownership of all intellectual property rights in the Platform, including the Platform’s content, features and functionality, including, without limitation, information, text, graphics, logos, button icons, images, audio clips, video clips, data compilations and the design, selection and arrangement thereof (collectively, the “NORD Content”). All material that would enable the Platform

(including documents relating to applications and awards to be reproduced, recreated, or recompiled is the exclusive property of NORD, our licensors, or other content suppliers, and is protected by United States and international copyright, trademark, patent and other intellectual property or proprietary rights laws, and may not be used or exploited in any way without our prior written consent.

NORD is providing you with access to the Services pursuant to a limited, non-exclusive, non-sub-licensable, non-transferable, revocable license. You can use the Services for personal, non-commercial use, and subject to these Terms and Conditions. This license is available to you as long as you are not barred from the Services by applicable law and your access is not terminated by NORD. If these Terms and Conditions are not enforceable where you are located, you may not use the Services. NORD reserves all right, title, and interest not expressly granted under this license to the fullest extent possible under applicable laws.

Except as otherwise expressly stated herein, you may not modify, copy, distribute, display, reproduce, sell, license, or create derivative works from, or otherwise use or exploit, any NORD Content, in whole or in part, including any text, images, audio, and video in any manner, without the prior written authorization of NORD. Any unauthorized use of the NORD Content may violate copyright laws, trademark laws, the laws of privacy and publicity, and applicable regulations and statutes. Any unauthorized use of the Services or any NORD Content automatically terminates the limited licenses set forth in these Terms and Conditions without prejudice to any other remedy provided by applicable law of these Terms and Conditions. You agree to comply with reasonable written requests from NORD to help NORD protect our proprietary and intellectual property rights.

The name NORD, Rare Care Patient Portal, names, logos, and associated organizations, and names are trademarks of NORD and associated organizations. You agree not to display or use these trademarks in any manner without NORD's prior, written permission.

### **3. Use of the Services**

**a. Legal Capacity.** You may use the Services to register and manage applications and awards that have been included on the Platform, if you are 1) at least eighteen (18) years of age, or the age of majority in your state, province, or country; 2) are fully able and competent to enter into the terms and conditions set forth in these Terms and Conditions and 3) are otherwise capable of forming legally binding agreements under applicable law; and that you agree to be bound by these Terms and Conditions. If you are not competent to form legally binding agreements, do not use the Services.

**b. True, accurate and complete information.** If you register to use the Platform and Services, you agree to provide true, accurate, and complete registration information.

**c. Lawful Use.** By accepting these Terms and Conditions, you agree to refrain from prohibited conduct, defined here as any conduct that: (i) is harmful, threatening, tortious, vulgar, obscene, hateful, or racially, ethnically or otherwise objectionable, abusive, harassing, or otherwise harmful to NORD or any other party or property, as determined by NORD in its sole discretion; (ii) is designed to interrupt, destroy or limit the functionality of, the Services, this Platform or any computer software or hardware or telecommunications equipment (including by means of software viruses or any other computer code, files or programs); (iii) infringes any copyright, trademark, trade secret, patent or other right of any party, or defames or invades the publicity rights or the privacy of any person, living or deceased (or impersonates any such person); (iv) consists of any unsolicited or unauthorized advertising, promotional materials, "junk mail," "spam," "chain letters," "pyramid schemes," or any other form of solicitation; (v) causes NORD to lose (in whole or in part) the services of our Internet service providers or other suppliers; (vi)

links to materials or other content, directly or indirectly, to which you do not have a right to link; (vii) copies, modifies, creates a derivative work of, reverse engineers, decompiles or otherwise attempts to extract the source code of the software underlying the Services or any portion thereof; or (viii) violates, or encourages anyone to violate these Terms and Conditions or the Privacy Policy or any applicable local, state, national, or international law. You also agree that: i) you will not submit data that you know or believe to be is false, fraudulent, inaccurate or misleading; ii) you will not knowingly submit data from a computer that you know or believe may contain any viruses or other computer programming routines that may damage or detrimentally interfere with the Services or the NORD Content.

**d. No Unauthorized Use.** The Services are for the use of registered and authorized users only. You may not attempt to gain unauthorized access to this Platform or any services, other accounts, computer systems, or networks connected to any server or to any of the Services, through hacking, password mining, or any other means.

#### **4. User Conduct and Responsibility**

**a. Security.** You are solely responsible for the security of your password and your account and are fully responsible for all activities that occur under your password or account with or without your knowledge. You may not knowingly provide your login and password information to another person. You agree to immediately change your password and notify NORD at [NORDPatientPortalTech@rarediseases.org](mailto:NORDPatientPortalTech@rarediseases.org) of potential unauthorized use of your password or account or any other breach of security. NORD will not be liable for any loss or damage arising from your failure to comply. Certain portions of the Services and information contained on the Services may be accessible only to authorized registered users, or other business partners of NORD, or may otherwise be password restricted. You agree not to (i) gain or attempt to gain unauthorized access to the Services or to information contained in the Services; (ii) obtain or attempt to obtain confidential, proprietary, and/or personal information stored on the Services; (iii) distribute passwords to unregistered or unauthorized users; or (iv) make any unauthorized use of the Services or information accessible on the Services. NORD reserves the right to deny or revoke access to the Services, in whole or in part, if there is reasonable belief that you are in breach of these Terms and Conditions or are otherwise using or accessing the Services in any manner inconsistent with the Terms and Conditions.

#### **b. User Submitted Content.**

You are responsible for any content you post, publish, display, or otherwise transmit to the Platform. You agree not to transmit or otherwise make available on the Platform any personal information of any other individual for whom you are not authorized to do so or any material protected by copyright, trademark, publicity, privacy, or other proprietary right without the express permission of such individual or the owner of such rights, respectively. The burden of determining that transmission of the information is permissible, or that the material is not protected by such rights, is on you, the user.

You further understand and acknowledge that you may be exposed to information that is inaccurate or otherwise objectionable, and you may report abuses of the Services to NORD at [NORDPatientPortalTech@rarediseases.org](mailto:NORDPatientPortalTech@rarediseases.org) with sufficient detail identifying the abusive conduct or content, so that NORD may determine, in its sole discretion, whether to take action with respect to such alleged abuse.

**c. Cooperation.** You agree to cooperate fully with NORD to investigate any suspected or actual activity that is in breach of these Terms and Conditions.

**d. Risk of Using the Services.** You acknowledge and agree that any uploads or transmission through the Services may be intercepted and used by an unauthorized third party and that all the risk associated with these activities is solely yours.

## **5. Disclaimer of Medical Advice**

All Services content is for general informational purposes only and is not intended to be a substitute for independent professional medical judgment, advice, diagnosis, or treatment. Any questions regarding your health should be directed to your physician or a qualified health provider, and you should neither disregard nor delay seeking medical advice relating to treatment or standard of care because of information featured on or transmitted through the Services. You understand and agree that the Services are provided to you on an AS IS and AS AVAILABLE basis. We disclaim all responsibility and liability for the availability, timeliness, security or reliability of the Services, the accuracy of any opinion or information contained on the Services, or the availability and reliability of any software on the Services. Your use of the Services does not create a professional-client relationship between you and NORD or any of its employees. You agree that access to and use of the Services and the content thereof is at your own risk. The language of this section in no way limits the applicability of any other disclaimers or liability limitations found elsewhere in these Terms and Conditions.

## **6. Disclaimer of Warranties**

TO THE FULLEST EXTENT PERMITTED UNDER LAW AND SAVE FOR THE RIGHTS GRANTED UNDER APPLICABLE LAWS, THE SERVICES AND THE CONTENT ON THE SERVICES ARE PROVIDED "AS IS." THERE IS NO WARRANTY OF ANY KIND WHATSOEVER TO YOU OR ANY OTHER PERSON RELATING IN ANY WAY TO THE SERVICES OR THE CONTENT OR COMMUNICATIONS ON THE SERVICES, OR ANY WEBSITE OR OTHER CONTENT OR SERVICE THAT MAY BE ACCESSIBLE DIRECTLY OR INDIRECTLY THROUGH THE SERVICES, TO THE EXTENT PERMITTED BY LAW, INCLUDING NO WARRANTY THAT THE SERVICES WILL BE UNINTERRUPTED OR ERROR-FREE, ARE OF SATISFACTORY QUALITY, ACCURATE, TIMELY, FIT FOR A PARTICULAR PURPOSE OR NEED, NON-INFRINGEMENT, OR THAT DEFECTS IN THE SERVICES WILL BE CORRECTED, THAT ANY INFORMATION CONTAINED ON OR TRANSMITTED THROUGH THE SERVICES IS COMPLETE, ACCURATE OR CURRENT, THAT USER OR OTHER INFORMATION WILL BE COMPLETELY SECURE FROM UNAUTHORIZED ACCESS OR DISCLOSURE, OR THAT ANY INFORMATION IS FREE OF VIRUSES OR OTHER ROGUE PROGRAMMING. WE DO NOT GUARANTEE THAT THE SERVICES THAT MAY BE OBTAINED WILL BE EFFECTIVE, RELIABLE, AND ACCURATE OR MEET YOUR REQUIREMENTS. WE DO NOT GUARANTEE THAT YOU WILL BE ABLE TO ACCESS OR USE THE SERVICES (EITHER DIRECTLY OR THROUGH THIRD-PARTY NETWORKS) AT ALL TIMES OR LOCATIONS OF YOUR CHOOSING.

NO ORAL OR WRITTEN INFORMATION OR ADVICE GIVEN BY NORD OR A REPRESENTATIVE SHALL CREATE A WARRANTY.

## **7. Limitation of Liability and Indemnification**

TO THE FULLEST EXTENT PERMITTED UNDER LAW, NORD WILL HAVE NO OBLIGATION OR LIABILITY (WHETHER ARISING IN CONTRACT, WARRANTY, TORT, INCLUDING NEGLIGENCE, PRODUCT LIABILITY, OR OTHERWISE) FOR ANY DAMAGES OR LIABILITIES, INCLUDING DIRECT, INCIDENTAL, INDIRECT, SPECIAL, OR CONSEQUENTIAL (INCLUDING ANY LOSS OF DATA, REVENUE OR PROFIT OR DAMAGES ARISING FROM

PERSONAL INJURY/WRONGFUL DEATH) ARISING WITH RESPECT TO YOUR USE OF THE SERVICES, EVEN IF WE HAVE BEEN ADVISED OF THE POSSIBILITY OF SUCH DAMAGES. THIS LIMITATION APPLIES TO DAMAGES ARISING FROM (i) USE OF OR INABILITY TO USE THE SERVICES, (ii) COST OF PROCUREMENT OF SUBSTITUTE GOODS AND SERVICES, (iii) UNAUTHORIZED ACCESS TO OR ALTERATION OF YOUR TRANSMISSIONS BY THIRD PARTIES, (iv) ANY OTHER MATTER RELATING TO THE SERVICES. NORD SHALL NOT BE LIABLE TO ANY THIRD-PARTY ARISING FROM YOUR INAPPROPRIATE USE OF THE WEBSITE OR SERVICES.

In addition, when using the Services, information will be transmitted over a medium which is beyond the control and jurisdiction of NORD, its partners, advertisers, or any other third party mentioned on the Services. Accordingly, NORD assumes no liability for or relating to the delay, failure, interruption, or corruption of any data or other information transmitted in connection with use of the Services.

SOME JURISDICTIONS DO NOT ALLOW THE EXCLUSION OR LIMITATION OF CERTAIN DAMAGES, SO THE ABOVE LIMITATION OR EXCLUSION MAY NOT APPLY TO YOU.

You agree to defend (at NORD's option), indemnify, and hold NORD harmless from and against any and all liabilities, claims, damages, costs, and expenses, including attorneys' fees and costs, arising from or related to your misuse of the Services or any breach by you of these Terms and Conditions. We reserve the right, at our expense, to assume exclusive defense and control of any matter otherwise subject to indemnification by you and, in any case, you agree to cooperate with us if and as requested by us in the defense and settlement of such matter.

## **8. International Users**

NORD make no claims that information on the Services are appropriate or may be downloaded outside of the United States. Access to the Services may not be legal in certain countries or for certain persons. If you access the Services from outside of the United States, you do so voluntarily at your own risk and are responsible for compliance with the laws of your jurisdiction regarding online conduct and acceptable content. User personal information that is submitted to these Services will be collected, processed, stored, disclosed, and disposed of in accordance with applicable U.S. law and our Privacy Policy.

## **9. General Practices Regarding Use and Storage**

You agree that NORD does not have any responsibility or liability for the deletion or failure to store any messages and other communications or other NORD Content maintained or transmitted by the Services. You further acknowledge that NORD reserves the right to modify these general practices and limits from time to time.

## **10. Confidentiality and Use**

NORD maintains commercially reasonable physical, electronic, and procedural safeguards and personnel policies that are designed to guard the Services, our systems and your personal information, in accordance with our Privacy Policy. No data transmissions over the Internet can be guaranteed to be 100% secure.

NORD staff will have access to all data provided on the Services. NORD staff access will be restricted to individuals engaged in activities related to the function, upgrades, support, maintenance, audit, quality control of the Services and the generation of Platform-wide participation metrics. As part of the registration process, you will be asked to provide information about the patient, which may be you or an

individual with a rare disease that you are a guardian for. The data that will be collected includes name, date of birth, sex, and country of residence, etc. These fields will be used to create a system generated global identifier that will prevent duplication within the Services.

You agree that these Terms and Conditions and the Privacy Policy governs the collection, use and sharing of personal and non-personal information from you when using the Services. NORD or the organization sponsoring the assistance program on the Services may disclose, or be required to disclose, certain information if they have a good faith belief that such disclosure is required by applicable law.

## **11. Termination**

You agree that your account and access to the Platform may be immediately terminated, with or without cause, without prior notice, and regardless of award statuses. Without limiting the foregoing, the following will lead to a termination by NORD of a user's use of the Platform: (a) breaches or violations of these Terms and Conditions, (b) requests by law enforcement or other government agencies, (c) a request by you (self-initiated account deletions), (d) unexpected technical issues or problems, and (e) extended periods of inactivity. We may change, restrict access to, suspend or discontinue the Services, or any portion of the Services, at any time and at our sole discretion. You agree that all terminations shall be made in NORD's sole discretion, and that NORD shall not be liable to you or any third-party for any termination of your account or access to the Website or the Services.

## **12. Communications from NORD**

From time to time, NORD will notify users of valuable information about the Services and related program updates. By registering on the Services, users consent to being contacted by NORD and to receiving such updates and information.

## **13. No Cost to Participate**

There is no cost to register on the Platform and Services.

## **14. Governing Law**

Any dispute that arises out of the use of the Platform or the Services or these Terms and Conditions will be governed by the law of the Commonwealth of Massachusetts, regardless of conflict of law principles.

## **15. Statute of Limitations**

Any cause of action you may have with respect to use of the Services must be commenced within one (1) year after the claim or cause of action arises.

## **16. Dispute Resolution and Agreement to Arbitrate**

By using the Services, you and NORD agree that, if there is any controversy, claim, action, or dispute arising out of or related to your use of the Services or the breach, enforcement, interpretation, or validity of these Terms and Conditions or any part of them ("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:

- **Notice to NORD:** You must send notice (1) by electronic mail to [iamrare-help@rarediseases.org](mailto:iamrare-help@rarediseases.org) and (2) by first-class or certified mail to NORD to ATTN: LEGAL at 1900 Crown Colony Drive, Suite 310, Quincy, MA 02169 or

- **Notice to You:** We will send notice by (1) first class or certified mail to the physical address we have on file for you (if any) and (2) by electronic mail to the email address we have on file for you (if any). If we do not have a physical or email address on file for you, or if we are, for any reason, unable to provide notice via the contact information on file, we reserve the right to provide notice by such means as we deem reasonable.

Both you and NORD 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 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 TO HAVE A JUDGE OR JURY TO DECIDE YOUR CLAIMS, AND THAT YOU MAY NOT PROCEED IN A CLASS, CONSOLIDATED, COLLECTIVE 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.

All such Disputes shall be exclusively submitted to Judicial Arbitration and Mediation Services (JAMS) ([www.jamsadr.com](http://www.jamsadr.com)) for binding arbitration under its rules then in effect (as modified by this agreement to arbitrate), before one arbitrator to be mutually agreed upon by both parties. The arbitration shall be conducted in accordance with the JAMS Consumer Arbitration Minimum Standards (<https://www.jamsadr.com/consumer-minimum-standards/>) if it is determined by JAMS or the arbitrator that these standards are applicable to the Dispute. The location of any hearings will be determined by the applicable JAMS rules, provided that if the claim is for \$10,000 or less, you may choose to have the arbitration conducted (1) solely on the basis of the documents submitted to the arbitrator or (2) through a non-appearance based hearing by teleconference or videoconference.

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 these Terms and Conditions, including any claim that all or any part of these Terms and Conditions are void or voidable. For the avoidance of doubt, you and NORD agree that the arbitrator shall have the exclusive power to rule on his or her own jurisdiction, including any objections with respect to the existence, scope, or validity of this agreement to arbitrate or the arbitrability of any claim or counterclaim. The arbitrator may award (on an individual basis) any relief that would be available in a court. The award rendered by the arbitrator may be confirmed and enforced in any court having jurisdiction thereof.

Notwithstanding the foregoing, in lieu of arbitration either you or NORD may (1) bring an individual claim in small claims court in the United States consistent with any applicable jurisdictional and monetary limits that may apply and (2) file an individual claim in court to enjoin the infringement or other misuse of its intellectual property rights, provided that any such claim is brought and maintained on an individual basis.

## **17. Modification and Termination**

We reserve the right to modify these Terms and Conditions at any time. When we do so, we will update the "Effective Date" above. By continuing to use the Services, or any portion thereof, after we post any such changes, you accept these Terms and Conditions, as modified.

## 18. Miscellaneous

- A. No waiver.** Our failure to act with respect to a breach by you or others does not waive our right to act with respect to a subsequent or similar breach or breaches. If NORD does not exercise or enforce any legal right or remedy which is contained in these Terms and Conditions (or which NORD has the benefit of under any applicable law or regulation), such action or inaction shall not be taken to be a formal waiver of NORD's rights, and all such rights or remedies shall still be available to NORD.
- B. Severability.** If any provision of these Terms and Conditions is held to be invalid by a court having competent jurisdiction, the invalidity of such provision shall not affect the validity of the remaining provisions of these Terms and Conditions, which shall remain in full force and effect.
- C. Entire Agreement.** These Terms and Conditions and any Additional Rules set forth the entire understanding and agreement between us with respect to your use of the Services.
- D. Assignment.** You may not assign, transfer, or sublicense any or all of your rights or obligations under these Terms and Conditions without our express prior written consent. We may assign, transfer, or sublicense any or all of our rights or obligations under these Terms and Conditions without restriction.
- E. No Relationship.** These Terms and Conditions do not, and shall not be construed to, create any partnership, joint venture, employer-employee, or agency relationship between you and NORD.

## 19. Contacting NORD

If you have questions about the Services or need to report violations of these Terms and Conditions, please email NORD at: [NORDPatientPortalTech@rarediseases.org](mailto:NORDPatientPortalTech@rarediseases.org) For general, non-Services related questions, you can reach out to NORD's information services department at 1-800-259-7178.