TERMS AND CONDITIONS

APBDRF FAN NATURAL HISTORY STUDY ON THE NORD NATURAL HISTORY PLATFORM

PLEASE READ THE FOLLOWING INFORMATION CAREFULLY. IN UTILIZING THIS SERVICE, 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 THEMSELF, AND YOU ACKNOWLEDGE THAT YOU UNDERSTAND AND ACCEPT THE FOLLOWING TERMS AND CONDITIONS. IN COMPLIANCE WITH THE CHILDREN'S ONLINE PRIVACY PROTECTION ACT, YOU MUST BE AN ADULT OF LEGAL AGE TO SUBMIT PERSONAL MEDICAL DATA AND INFORMATION. IF YOU DO NOT ACCEPT THESE TERMS AND CONDITIONS, YOU MAY NOT ACCESS THIS SITE OR UTILIZE ANY OF THE SERVICES PROVIDED ON OR THROUGH THIS SITE.

The **APBDRF FAN Natural History Study** ("**APBD Patient Registry**") is a project of **Adult Polyglucosan Body Disease Research Foundation(APBD Research Foundation)** to collect patient information and medical information concerning rare diseases in order to accelerate research and find better treatments and ultimately a cure for these conditions.

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

a. General. Use of the **APBD Patient Registry** website (the "Website") and the services associated with the **APBD Patient Registry** website (the "Services") is governed by the following terms and conditions herein (the "Terms and Conditions") and the NORD Natural History Study Platform Service and Use Agreement ("Agreement") to which **APBD Research Foundation** is a signatory. All pages within the Website are owned by the National Organization for Rare Disorders, Inc. ("NORD®") and **APBD Research Foundation** owns and retains ownership of all data submitted to the **APBD Patient Registry**.

b. Purpose. The purpose of the Website is to allow individuals, families, and medical and research providers to enter certain information into the **APBD Patient Registry**. The voluntary information provided by the registrant during registration, is maintained in a secured database and identifiable data will not be shared outside **APBD Research Foundation** without the registrant's express consent. However, **APBD Research Foundation** may allow researchers and other approved third parties to search and access *pseudonymized* information.

c. Acceptance of Terms and Conditions. By using the Website, you represent that you accept and agree that you have read all of the Terms and Conditions, and been informed of the Agreement, and that you agree to accept these terms. If you do not agree to be bound by the Terms and Conditions and the Agreement, you may not submit data to the Website.

2. Intellectual Property Rights and Ownership

Adult Polyglucosan Body Disease Research Foundation owns and retains ownership of all personal data submitted to this Website, including: all personal, identifiable data and metadata collected through the Registry, and all Intellectual Property Rights thereto, except for NORD's rights to pseudonymized data. NORD owns and retains ownership of all Intellectual Property Rights in the NHS Platform, including the core data set, and any and all material that would enable the NORD NHS Platform to be reproduced, recreated, or recompiled, including the standard program templates. Unless noted otherwise in the Agreement, **APBD Research Foundation** and NORD retain right, title and interest to all of each of their own Intellectual Property.

3. Use of the Website

a. Legal Capacity. You may use the Website to register to be included in the **APBD Patient Registry** if you are at least eighteen (18) years of age, or the age of majority in your state, province, or country; that you are fully able and competent to enter into the terms and conditions set forth in these Terms and Conditions and 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 this Website.

b. True, accurate and complete information. If you register to use the Website, 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 abusive, harassing, or otherwise harmful to the **APBD Patient Registry**, **APBD Research Foundation**, or any other party or property; (ii) violates or tries to violate another party's right to privacy or; (iii) seeks to disrupt the use or operation of this Platform. You also agree that: i) you will not submit data that you know or believe to be false, fraudulent, inaccurate or misleading; ii) you will not knowingly submit data from a computer that you know or believe may contain any viruses, Trojan horses, worms, time bombs, spiders, or other computer programming routines that may damage, detrimentally interfere with, surreptitiously intercept or expropriate any system, data or personal information. In addition, you will not use the Platform to make any defamatory, libelous or threatening statements or knowingly use it to generate any spam.

d. Website for Allowable Activities (defined herein) only. The Website is for the use of registered and authorized users only. The Agreement terms control the use of all data within the Website.

e. No Unauthorized Use. You may not attempt to gain unauthorized access to this Website 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 the **APBD Patient Registry** Coordinator via email at**David Epstein, davidep45@yahoo.com** of potential unauthorized use of your password or account or any other breach of security. **APBD Research Foundation** will not be liable for any loss or damage arising from your failure to comply. Certain portions of the Website and information contained on the Website may be accessible only to authorized registered users or to affiliates, service providers, or other business partners of **APBD Research Foundation**, or may otherwise be password restricted. You agree not to (i) gain or attempt to gain unauthorized access to such portions of the Website or to information contained in such sections of the Website; (ii) obtain or attempt to obtain confidential, proprietary, and/or personal information stored on the Website; (iii) distribute passwords to unregistered or unauthorized users; or (iv) make any unauthorized use of the Website or information accessible on the Website. **APBD Research Foundation** reserves the right to deny or revoke access to the Services, in whole or in part, if **APBD Research Foundation** reasonably believes 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 solely responsible for and will exercise caution, discretion, common sense, and judgment in using and accessing both the Platform and the Website and all content contained therein. Content that is unacceptable, inappropriate, or not in compliance with these Terms and Conditions may result in termination of User's access to the Platform and to the Website. NORD and **APBD Research Foundation** have the right to edit and delete any portion of this website.

You are responsible for any content you post, publish, display, or otherwise transmit to the Website. You agree not to transmit or otherwise make available on the Website any personal information of any other individual 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 Website to the **APBD Patient Registry** Coordinator with sufficient detail identifying the abusive conduct or content, so that **APBD Research Foundation** may determine, in its sole discretion, whether to take action with respect to such alleged abuse.

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

d. Research Studies. The value and relevance of the information provided by the **APBD Patient Registry** is directly linked to the information provided by users. It is your responsibility to provide complete, accurate, and updated information to the Website.

e. Risk of Using the Website. You acknowledge and agree that any uploads or transmission you make to, from, or through these means may be intercepted and used by an unauthorized third party and that all of the risk associated with these activities is solely yours.

f. Links to Other Websites. The **APBD Patient Registry** and NORD NHS Platform may contain links to related websites. The inclusion of any link does not imply endorsement by **APBD Research Foundation**, the **APBD Patient Registry** or by NORD. It is up to you to take precautions to ensure that whatever you select for your use is free of viruses, worms, Trojan horses, and other items of a destructive nature.

5. Disclaimer of Medical Advice

All Website content is for 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 Website.

6. Disclaimer of Warranties

THERE IS NO WARRANTY THAT THE WEBSITE WILL BE UNINTERRUPTED OR ERROR-FREE OR THAT DEFECTS IN THE WEBSITE WILL BE CORRECTED, THAT ANY INFORMATION CONTAINED ON OR TRANSMITTED THROUGH THE WEBSITE 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.

7. Limitation of Liability

NEITHER **APBD RESEARCH FOUNDATION** NOR NORD SHALL BE LIABLE TO ANY THIRD-PARTY ARISING FROM YOUR INAPPROPRIATE USE OF THE WEBSITE OR PLATFORM, AS SET FORTH IN SECTION 3 AND SECTION 4, ABOVE.

8. Copyright

You agree that content contained on, and the intellectual property by which the Website is produced may not be modified, copied, distributed, framed, republished, downloaded, displayed, or sold in any form or by any means, in whole or in part, without the prior written consent and approval of **APBD Research Foundation** or NORD, as applicable, for a particular purpose.

9. Trademarks

The name **Adult Polyglucosan Body Disease Research Foundation** (**APBD Research Foundation**), **APBDRF FAN Natural History Study** (**APBD Patient Registry**), **APBD Patient Registry** logo, and other **APBD Research Foundation** logos, associated organizations, and names are trademarks of the **Adult Polyglucosan Body Disease Research Foundation** and associated organizations. You agree not to display or use these trademarks in any manner without **Adult Polyglucosan Body Disease Research Foundation's** prior, written permission. The name NORD, NORD Natural History Studies Program ("NHS Program") and Natural History Studies Platform ("NHS Platform") and other related logos are the property of NORD. You agree not to use or display these trademarks in any manner without NORD's prior, written permission.

10. International Users

The **APBD Patient Registry** and NORD make no claims that information on the Website is appropriate or may be downloaded outside of the United States. Access to the Website may not be legal in certain countries or for certain persons. If you access the Website 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 ("Information") that is submitted to this Website will be collected, processed, stored, disclosed, and disposed of in accordance with applicable U.S. law and our Privacy Policy.

11. General Practices Regarding Use and Storage

You agree that neither the **APBD Patient Registry** nor NORD has any responsibility or liability for the deletion or failure to store any messages and other communications or other Content maintained or transmitted by the Website. You acknowledge that the **APBD Patient Registry** reserves the right to log off accounts that are inactive for an extended period of time. You further acknowledge that the **APBD Patient Registry** reserves the right to modify these general practices and limits from time to time.

12. Confidentiality and Use

You agree that the Agreement governs the collection, use and sharing of personal and non-personal information from you when using the Website. **Adult Polyglucosan Body Disease Research Foundation** and/or NORD may disclose, or be required to disclose, certain information if they have a good faith belief that such disclosure is required by applicable law.

13. Termination

You agree that your account and access to the Website or Services may be immediately terminated, with or without cause and without prior notice. Without limiting the foregoing, the following will lead to a termination by the **APBD Patient Registry** of a user's use of the Website or the Services: (a) breaches or violations of these Terms and Conditions or Agreement, (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. You agree that all terminations shall be made in the **APBD Patient Registry's** sole discretion and that neither the **APBD Patient Registry** nor NORD shall be liable to you or any third-party for any termination of your account or access to the Website or the Services.

14. Communications from the APBD Patient Registry

From time to time, the **APBD Patient Registry** or other related entities will notify users of updates and other valuable information about the **APBD Patient Registry**, the Website, and related clinical and research studies. By using the Website or registering or subscribing for services provided on or through the Website, users consent to being contacted by the **APBD Patient Registry** and related entities, and to receiving such updates and information. Users acknowledge and agree that users must always accept email transmissions from the **APBD Patient Registry**, in order to continue to use the Website or the Services.

15. No Cost to Participate

There is no cost to submit data to the **APBD Patient Registry**. Both registration and use of an account on the **APBD Patient Registry** are free.

16. Governing Law

Any dispute that arises out of the use of the Website or the Services or these Terms and Conditions will first be mediated prior to resorting to other remedies at law or in equity. Mediation and resolution will be governed by the law of the Commonwealth of Massachusetts, regardless of conflict of law principles. Sole and exclusive jurisdiction and venue over any dispute arising out of or relating to these Terms and Conditions shall lie in the appropriate federal or state court in Massachusetts.

17. Statute of Limitations

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

18. Contacting the APBD Patient Registry Coordinator

If you have any medical, research, treatment, or patient referral questions, contact the **APBD Patient Registry** Coordinator at: **APBD Patient Registry, David Epstein, davidep45@yahoo.com**.

If you have questions about the **APBD Patient Registry**, or to report violations of these Terms and Conditions, please email the Registry Coordinator at: **David Epstein, davidep45@yahoo.com**.
