

## UK DUCHENNE MUSCULAR DYSTROPHY REGISTRY

### TERMS OF USE

#### 1. ACCEPTANCE OF TERMS

The services that the UK Duchenne Muscular Dystrophy Registry (the Registry) provides are subject to the following Terms of Use ("TOU"). The Registry reserves the right to update the TOU at any time without notice to the user. The most current version of the TOU can be reviewed by clicking on the "Terms of Use" hypertext link located on the Account button on our web pages.

- A. This Agreement is applicable to the Registry. By using the Registry, the user agrees to comply with all of the terms and conditions hereof. The right to use the Registry (www.dmdregistry.org) is personal to the user and is not transferable to any other person or entity. The user is responsible for all use of the user's Account (under any screen name or password) and for ensuring that all use of the user's Account complies fully with the provisions of this Agreement. The user shall be responsible for protecting the confidentiality of the user's password(s), if any.
- B. The Registry shall have the right at any time to change or discontinue any aspect or feature of the Registry, including, but not limited to, content, hours of availability, and equipment needed for access or use.
- C. It shall be recognized that these TOU are implemented for the purpose of protecting participant's data from unauthorized disclosure under obligations placed on the Registry by the Data Protection Act (1988) and the Computer Misuse Act (1990).
- D. For those Persons who are not Participants, or their Guardians this document will include, supplemental terms and conditions (Supplemental Terms") governing the use of material contained in the Registry and associate documents.

#### 2. CHANGED TERMS

The Registry shall have the right at any time to *reasonably* change or modify the terms and conditions applicable to the user's use of the Registry, or any part thereof, or to impose new conditions, including, but not limited to, adding fees and charges for use for non-participants, whilst such terms are admitted by the governance procedures of the Registry. Such changes, modifications, additions or deletions shall be effective immediately upon notice thereof, which may be given by means including, but not limited to, posting on the Registry, or by electronic or conventional mail, or by any other means by which the user obtains notice thereof. Any use of the Registry by the user after such notice shall be deemed to constitute acceptance by the user of such changes, modifications or additions.

#### 3. DESCRIPTION OF SERVICES

Through its Web property, the Registry provides the user with access to a variety of resources, including viewing, processing, modifying and extracting information (collectively "Services"). The Services, including any updates, enhancements, new features are subject to the TOU.

## 4. USER CONDUCT

- A. The user shall use the Registry for lawful purposes only. The user shall not post or transmit through the Registry any material which violates or infringes in any way upon the rights of others or otherwise violate any law, or which, without The Registry's express prior approval, contains advertising or any solicitation with respect to products or services. Any conduct by the user that in the Registry's discretion restricts or inhibits any other the user from using or enjoying the Registry will not be permitted. The user shall not use the Registry to advertise or perform any commercial solicitation.
- B. The Registry contains copyrighted material and other proprietary information, including, but not limited to, data, text, software, and the entire contents of the Registry are copyrighted as a collective work under the UK copyright laws. The Registry owns a copyright in the selection, coordination, arrangement and enhancement of such content, as well as in the content original to it. The user may not modify, publish, transmit, participate in the transfer or sale, create derivative works, or in any way exploit, any of the content, in whole or in part. Except as otherwise expressly permitted under copyright law, no copying, redistribution, retransmission, publication or commercial exploitation of downloaded material will be permitted without the express permission of the Registry and the copyright owner. In the event of any permitted copying, redistribution or publication of copyrighted material, no changes in or deletion of author attribution, trademark legend or copyright notice shall be made. The user acknowledges that it does not acquire any ownership rights by downloading copyrighted material.

## 5. USE OF SERVICES

The user agrees to use the Services only to post, send and receive material that are proper and, when applicable, and to the best of their knowledge accurate. By way of example, and not as a limitation, the user agrees that when using the Services, the user will not:

- Violate the legal rights (such as rights of privacy and publicity) of others.
- Publish post, upload, distribute or disseminate any inappropriate, profane, defamatory, obscene, indecent or unlawful topic, name, material or information.
- Upload, or otherwise make available information protected by intellectual property laws, copyright or trademark laws, or data protection laws unless the user own or control the rights thereto or have received all necessary consent.
- Advertise or offer to sell or buy any goods or services for any business purpose, unless such Communication Services specifically allows such messages.
- Download any information posted that the user knows, or reasonably should know, is protected by intellectual property laws, copyright or trademark laws, or data protection laws.
- Falsify information in the Registry.
- Create, Update or Delete any information posted that the user know, or reasonably should know, is protected by intellectual property laws, copyright or trademark laws, or data protection laws.
- Restrict or inhibit any other the user from using and enjoying the Registry.
- Violate any code of conduct or other guidelines which may be applicable for any particular Service.
- Harvest or otherwise collect information about others, including personal information
- Violate any applicable laws or regulations.
- Create a false identity for the purpose of misleading others.

## 6. MEMBER, ACCOUNT PASSWORD AND SECURITY

When opening an account to use the Registry, the user must complete the registration process by providing The Registry with current, complete and accurate information as prompted by the applicable registration form. The user also will choose a password and a user name. The user is entirely responsible for maintaining the confidentiality of the user's password and account. The user will be responsible for updating passwords periodically as required by The Registry security policy. Furthermore, the user is entirely responsible for any and all activities that occur under the user's account. The user agrees to notify the Registry immediately of any unauthorized use of the user's account or any other breach of security. The Registry will not be liable for any loss that the user may incur as a result of someone else using the user's password or account, either with or without the user's knowledge. The user may not use anyone else's account at any time, without the permission of the account holder.

The user must ensure that after being logged they log off, or secure their machine using a password protected screen saver for the duration of being logged into the Registry. Further that the user does nothing that could knowingly lead to data being made available. The Registry must not be accessed from a public place such as internet-café.

## 7. NOTICE SPECIFIC TO DATA AVAILABLE ON THE REGISTRY WEB SITE.

Permission to use Data (such as Personal Details, Participant Medical Records, Participant Assessments, Participant Interventions) from the Services is granted, provided that (1) written agreement is gained from the Registry (2) the below copyright notice appears in all copies, (3) use of such Documents from the Services is for informational and non-commercial or personal use only and will not be copied or posted on any network computer or broadcast in any media, and (3) no modifications of any Information are made (4) that all Information is made irreversibly anonymous, such that no name, reference or id is made available.

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## 8. NOTICES REGARDING SOFTWARE, DOCUMENTS AND SERVICES AVAILABLE ON THE REGISTRY WEB SITE

IN NO EVENT SHALL THE REGISTRY AND/OR ITS RESPECTIVE SUPPLIERS BE LIABLE FOR ANY SPECIAL, INDIRECT OR CONSEQUENTIAL DAMAGES OR ANY DAMAGES WHATSOEVER RESULTING FROM LOSS OF USE, DATA OR PROFITS, WHETHER IN AN ACTION OF CONTRACT, NEGLIGENCE ARISING OUT OF OR IN CONNECTION WITH THE USE OR PERFORMANCE OF SOFTWARE, DOCUMENTS, PROVISION OF OR FAILURE TO PROVIDE SERVICES, OR INFORMATION AVAILABLE FROM THE SERVICES BY A USER.

## 9. MATERIALS PROVIDED OR POSTED TO THE REGISTRY WEB SITE

The Registry does not claim ownership of the materials the user provides to The Registry. However, by posting, uploading, inputting, providing or submitting (“Posting”) the user’s submission the user is granting the Registry, its affiliated companies and necessary sub licensees permission to use the user’s submission in connection with the operation of the Registry under the Data Protection Act (1988) and solely for the published purposes of the Registry.

No compensation will be paid with respect to the use of the user’s submission, as provided herein. The Registry is under no obligation to post or use any submission the user may provide and the Registry may remove or change any submission at any time in its sole discretion. By Posting a submission the user warrants and represents to own or otherwise control all of the rights to the user’s submission as described in these TOU including, without limitation, all the rights necessary for the user to provide, post, upload, input or submit the submissions.

## 10. DISCLAIMER OF WARRANTY; LIMITATION OF LIABILITY

- A. THE USER EXPRESSLY AGREES THAT USE OF THE REGISTRY IS AT THE USER’S SOLE RISK. NEITHER THE REGISTRY, ITS AFFILIATES NOR ANY OF THEIR RESPECTIVE EMPLOYEES, AGENTS, THIRD PARTY CONTENT PROVIDERS OR LICENSORS WARRANT THAT THE REGISTRY WILL BE UNINTERRUPTED OR ERROR FREE; NOR DO THEY MAKE ANY WARRANTY AS TO THE RESULTS THAT MAY BE OBTAINED FROM USE OF THE REGISTRY, OR AS TO THE ACCURACY, RELIABILITY OR CONTENT OF ANY INFORMATION, SERVICE, OR MERCHANDISE PROVIDED THROUGH THE REGISTRY.
- B. THE REGISTRY IS PROVIDED ON AN “AS IS” BASIS WITHOUT WARRANTIES OF ANY KIND, EITHER EXPRESS OR IMPLIED, INCLUDING, BUT NOT LIMITED TO, WARRANTIES OF TITLE OR IMPLIED WARRANTIES OF MERCHANTABILITY OR FITNESS FOR A PARTICULAR PURPOSE, OTHER THAN THOSE WARRANTIES WHICH ARE IMPLIED BY AND INCAPABLE OF EXCLUSION, RESTRICTION OR MODIFICATION UNDER THE LAWS APPLICABLE TO THIS AGREEMENT.
- C. THIS DISCLAIMER OF LIABILITY APPLIES TO ANY DAMAGES OR INJURY CAUSED BY ANY FAILURE OF PERFORMANCE, ERROR, OMISSION, INTERRUPTION, DELETION, DEFECT, DELAY IN OPERATION OR TRANSMISSION, COMPUTER VIRUS, COMMUNICATION LINE FAILURE, THEFT OR DESTRUCTION OR UNAUTHORIZED ACCESS TO, ALTERATION OF, OR USE OF RECORD, WHETHER FOR BREACH OF CONTRACT, TORTIOUS BEHAVIOR, NEGLIGENCE, OR UNDER ANY OTHER CAUSE OF ACTION. THE USER SPECIFICALLY ACKNOWLEDGES THAT THE REGISTRY IS NOT LIABLE FOR THE DEFAMATORY, OFFENSIVE OR ILLEGAL CONDUCTS OF OTHER THE USERS OR THIRD-PARTIES AND THAT THE RISK OF INJURY FROM THE FOREGOING RESTS ENTIRELY WITH THE USER.
- D. IN NO EVENT WILL THE REGISTRY, OR ANY PERSON OR ENTITY INVOLVED IN CREATING, PRODUCING OR DISTRIBUTING THE REGISTRY OR THE REGISTRY SOFTWARE, BE LIABLE FOR ANY DAMAGES, INCLUDING, WITHOUT LIMITATION, DIRECT, INDIRECT, INCIDENTAL, SPECIAL, CONSEQUENTIAL OR PUNITIVE DAMAGES ARISING OUT OF THE USE OF OR INABILITY TO USE THE REGISTRY THE USER HEREBY ACKNOWLEDGES THAT THE PROVISIONS OF THIS SECTION SHALL APPLY TO ALL CONTENT ON THE SITE.

- E. IN ADDITION TO THE TERMS SET FORTH ABOVE NEITHER, THE REGISTRY, NOR ITS AFFILIATES, INFORMATION PROVIDERS OR CONTENT PARTNERS SHALL BE LIABLE REGARDLESS OF THE CAUSE OR DURATION, FOR ANY ERRORS, INACCURACIES, OMISSIONS, OR OTHER DEFECTS IN, OR UNTIMELINESS OR UNAUTHENTICITY OF, THE INFORMATION CONTAINED WITHIN THE REGISTRY, OR FOR ANY DELAY OR INTERRUPTION IN THE TRANSMISSION THEREOF TO THE USER, OR FOR ANY CLAIMS OR LOSSES ARISING THEREFROM OR OCCASIONED THEREBY. NONE OF THE FOREGOING PARTIES SHALL BE LIABLE FOR ANY THIRD-PARTY CLAIMS OR LOSSES OF ANY NATURE, INCLUDING, BUT NOT LIMITED TO, LOST PROFITS, PUNITIVE OR CONSEQUENTIAL DAMAGES.

## 11. MONITORING

The Registry shall have the right, but not the obligation, to monitor the content of the Registry, to determine compliance with this Agreement and any operating rules established by the Registry and to satisfy any law, regulation or authorized government request. The Registry shall have the right in its sole discretion to edit, refuse to post or remove any material submitted to or posted on the Registry. Without limiting the foregoing, the Registry shall have the right to remove any material that the Registry, in its sole discretion, finds to be in violation of the provisions hereof or otherwise objectionable.

## 12. TERMINATION

Either the Registry or the user may terminate this Agreement at any time. Without limiting the foregoing, the Registry shall have the right to immediately terminate the user's Account in the event of any conduct by the user which the Registry, in its sole discretion, considers to be unacceptable, or in the event of any breach by the user of this Agreement.