

Terms of Service

1.1 Welcome to the Duchenne Map, a Platform as a Service (PaaS) (hereafter: “the “Duchenne Map”) operated by Duchenne Data Foundation (hereinafter ‘DDF’ or ‘We’), with Chamber of Commerce Registration Number no: 64601188 and principal address at Warmoesdreef 10, 4614 HC, Bergen op Zoom, the Netherlands.

More information about DDF you may find [here](#).

1.2 These Terms of Service (hereinafter ‘ToS’) as may be modified from time to time are legally binding and apply to all users and all services. By purchasing, subscribing to, accessing or otherwise using the Duchenne Platform, You acknowledge that you have given these Terms of Service reasonable and valuable consideration and you fully accept them.

1.3 Any modifications shall be effective upon publication. Your continued use of the Duchenne Map signifies your acceptance of the revised ToS. Substantial changes will be communicated to Users via email, while Users may communicate with us at info@duchennemap.org for any related inquiry.

2. What we do?

(DDF) is a non-profit patient initiated and managed organization. It is a worldwide collaboration in order to enhance the understanding of the course of Duchenne Muscular Dystrophy (DMD) and Becker Muscular Dystrophy (BMD), the effects of treatments, the needs and preferences of DMD/BMD patients and all other aspects relevant to the lives of DMD/BMD patients.

3. Services

The Duchenne Map allows the user to access the services.

“Services”: All services provided to Registered Users in the context of the Duchenne Map based on the user type:

For DMD Families:

- Connecting to peers
- Finding reliable information
- Finding clinical trials
- Finding DMD centers
- Finding DMD experts

For DMD Patient Organizations:

- Connecting with our Patients
- Increase your presence and impact
- Offer them better services
- Localize your efforts
- Connecting to other POs
- Capacity building
- Team building
- Knowledge transfer
- Project co creation

- Building a network of expertise (e.g. fundraising, research, etc).

For DMD Research Organizations:

- Global connection with the DMD community
- Connect with other DMD Research Centers
- Build awareness of your work
- Funding research opportunities
- Scaling up your work with Industry and PO partners
- Patient-Centered Research

For DMD Researchers:

- Global connection with the DMD community
- Connect with other Researchers
- Awareness of your work
- Funding research opportunities
- Scaling up your work with Industry and PO partners
- Patient Centered Research

For DMD Care Centers:

- Global connection with the DMD community
- Connect with other care centers
- Build awareness of your work

- Funding research
- Join projects
- Patient Centered Care
- Attract CTs and patients

For DMD Healthcare Experts:

- Global connection with the DMD community
- Connect with other HCPs and DMD experts
- Knowledge building
- Awareness of your work
- Patient Centered Care
- Attract CTs and patients

For DMD Industry:

- Global connection with the community
- Find out instantly of the patient initiatives
- Get involved in project and research
- Build awareness of your pipeline and your CTs
- Instant update of trials and trials results
- Feasibility testing

4. Your Commitments

- You must be 18 years or older to use the Duchenne Map. If you are under 18 please do not use this site;
- You are solely responsible for your conduct;
- You are solely responsible for any data, communication, contact, and evaluations thereof;
- You are solely responsible for any transaction you carry out on the Duchenne Map;
- You must not, in the use of the Duchenne Map violate any laws in your jurisdiction (including but not limited to privacy laws).

5. Registration and Validation process

All fields of the registration form are mandatory. Omission of any of these fields shall entail the inability to register successfully to Duchenne Map. You must provide with true information. The use of aliases or means to occult your identity is forbidden, unless the registration process explicitly demands the creation of a user name, nick or alias.

User Type	Step 1 Account Activation	Step 2 User Data Validation	Step 2 Who can validate who	Result
Patient	Same process for all user types	Account Activation / User Data Validation	HE / CC / PO If not match ? Contact WDO	Send to Contact Email and approve or cancel the user validation process
Researcher		Account Activation / User Data Validation	CC / PO / RO	
Healthcare Expert (HE)		Account Activation / User Data Validation	CC / PO / RO	
Care Center (CC)		Account Activation / User Data Validation	PO / RO – WDO notification email when the	

			CC validates	
Research Organization (RO)		Account Activation / User Data Validation	PO / CC – WDO notification emails when the RO validates	
Patient Organization (PO)		Account Activation / Notify user will be validated by WDO and don't go to validation form	WDO only	
Industry		Verify account / Notify it will be validated by WDO and don't go	WDO only	

		to validation form		
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5.2 Access details

It is important that you keep your access details secret. You shall be solely liable for the use of your personal account and thus you commit to use your information with due diligence, not to share it with third parties and communicate any loss or theft.

In order to keep your information up to date, you shall communicate any modification and/or rectification as soon as possible by email to info@duchennemap.org. You can also update your personal data through the corresponding settings of your account.

6 Platform security

The security of your Personal Information is important to us, but remember that no method of transmission over the Internet, or method of electronic storage, is 100% secure. While we strive to use commercially acceptable means to protect your Personal Information, we cannot guarantee its absolute security.

7 Intellectual Property

7.1 All content available such as text, data, database, analyses, graphics, user interfaces, visual interfaces, photographs, trademarks, trade name, trade dress, logos, artwork, and software source code, formats of any kind, user's scores, reviews and any related data and metadata (collectively, "Content"), including but not limited to the design, structure, selection, coordination, expression, "look and feel" and arrangement of such content, the overall know how and methods contained on the Duchenne Map is owned, controlled or licensed by or to Us. We retain all rights, title and interest in and to the Content and any portion thereof and it is protected by

copyright, patent and trademark laws, and various other intellectual property rights, trade secret and unfair competition laws. The Content is provided 'as is' for your information and personal use according to the present ToS.

7.2 Except as expressly provided in these Terms of Service, no part of the Duchenne Map and no Content may be copied, reproduced, republished, rewritten, used as a news source, uploaded, posted, publicly displayed, encoded, translated, transmitted or distributed in any way (including "mirroring") to any other computer, server, website or other medium for publication or distribution or for any commercial enterprise or commercially exploited, without Our express prior written consent.

8. Duchenne Map Access & Use

8.1 The following are just examples of the kind of conduct that is illegal or prohibited on the Duchenne Map, that a) is

defamatory, harassing, threatening, or an invasion of a right of privacy of another person, otherwise harms or can reasonably be expected to harm any person or entity; b) is illegal or encourages or advocates illegal activity or the discussion of illegal activities with the intent to commit them; c) violates or attempts to violate the privacy rights, publicity rights, copyrights, trademark rights, contract rights or any other rights of any person; d) using the Platform in a manner inconsistent with any and all applicable law;

8.2 Users may not install, upload and/or distribute any content that contains a virus or other harmful component, or otherwise tampers with, impairs or damages the Duchenne Map or any connected network, or otherwise interferes with any person or entity's use or enjoyment of the Duchenne Map.

9. DDF Community

We understand DDF as a community that allows its members to inspire and support each other, to share data, experience and knowledge, to exchange ideas and generate supportive channels. Users are solely responsible for, and will exercise caution, discretion, common sense and judgment in, using the Duchenne Map, disclosing personal information to other users and entering in any kind of transactions.

10. Disclaimers & Indemnification

10.1 In no event shall DDF be liable to any user or third party for any direct indirect, consequential, exemplary incidental, special or punitive damages arising from your use of the Duchenne Map and/or any transactions among Registered Users taking place herein.

10.2 Given the internet's design and architecture DDF does not warrant that any content will be error – free, that access hereto will be uninterrupted, that defects will be

corrected or that any site service or the servers that make such content available are free of viruses or other harmful components.

11. Miscellaneous

11.1 ToS describe the general binding agreement between DDF and You, complementary to any License Agreement or special terms, when applicable. In the event that any clause or portion of ToS was declared null and void for any reason whatsoever, the rest of the ToS shall remain in full force and effect.

11.2 Unless explicitly stated, Terms Of Use and any rights granted hereof may not at any circumstances be subject of transfer or assignment without DDF's prior written consent.

11.3 You agree that no joint venture, partnership, employment, or agency relationship exists between You

and DDF as a result of your access to and use of the
Duchenne Map.