

## Patient Self-Report *Registration and Consent Questionnaire (I)* “The International Dysferlinopathy Registry”

### 1. PATIENT 'S INFORMATION

1.1 First/Given name: \_\_\_\_\_

1.2 Last/Family name: \_\_\_\_\_

1.3 Postal address: \_\_\_\_\_

\_\_\_\_\_

1.4 City: \_\_\_\_\_

1.5 State/Province (*optional*): \_\_\_\_\_

1.6 Postal/Zip code (*optional*): \_\_\_\_\_

1.7 Country: \_\_\_\_\_

1.8 Phone number (*optional*): \_\_\_\_\_

1.9 E-mail address (*optional for paper registration*): \_\_\_\_\_

1.10 Date of birth: Day: \_\_\_\_\_ Month: \_\_\_\_\_ Year: \_\_\_\_\_

1.11 Gender:  Male  Female

1.12 We aim to harmonise existing dysferlinopathy registries. Therefore, we would like to know if you have signed up with other registries.

- No
- Yes, with the Jain Foundation Registry
- Yes, with another registry (*please specify*): \_\_\_\_\_
- I am not sure or I don't know
- I choose not to answer this question

### 2. PARENT'S OR GUARDIAN'S INFORMATION

If you are filling in this questionnaire on behalf of the patient, please give your details below and explain your relationship to the patient. If you are the patient, but are younger than 18 years of age, please have your parent/guardian fill in this section. If you are the patient and 18 years of age or over, skip this question and proceed directly to section 3.

Ms  Mr

2.1 First/Given name: \_\_\_\_\_

2.2 Last/Family name: \_\_\_\_\_

2.3 Postal address: \_\_\_\_\_  
\_\_\_\_\_  
2.4 City: \_\_\_\_\_  
2.5 State/Province (optional): \_\_\_\_\_  
2.6 Postal/Zip code (optional): \_\_\_\_\_  
2.7 Country: \_\_\_\_\_  
2.8 Phone number (optional): \_\_\_\_\_  
2.9 E-mail address (optional for paper registration): \_\_\_\_\_

2.10 The patient is:

- My ward  
 My child  
 My sister or brother  
 My nephew or niece  
 Other (please specify): \_\_\_\_\_  
 I choose not to answer this question

### 3. PHYSICIAN/MEDICAL CENTRE INFORMATION

Please provide us with contact information for medical doctor(s) / medical institution(s) who will have information about your muscle problem diagnosis and symptoms. Please enter contact information for as many doctors or medical centres as necessary. For each contact person / medical centre, please enter at least one form of contact information (complete postal address or e-mail or phone number).

Physician    Neurologist    Consultant    Medical Centre    Others (please specify): \_\_\_\_\_

3.1 Name of your contact person (if applicable): \_\_\_\_\_

3.2 Name of medical centre / hospital (if applicable): \_\_\_\_\_

3.3 Postal address: \_\_\_\_\_  
\_\_\_\_\_

3.4 City: \_\_\_\_\_

3.5 State/Province (optional): \_\_\_\_\_

3.6 Postal/Zip Code (optional): \_\_\_\_\_

3.7 Country: \_\_\_\_\_

3.8 Phone number (optional): \_\_\_\_\_

3.9 E-mail address (optional): \_\_\_\_\_

Physician    Neurologist    Consultant    Medical Centre    Others (please specify): \_\_\_\_\_

3.1 Name of your contact person (if applicable): \_\_\_\_\_

3.2 Name of medical centre / hospital (if applicable): \_\_\_\_\_

3.3 Postal address: \_\_\_\_\_

3.4 City: \_\_\_\_\_

3.5 State/Province (optional): \_\_\_\_\_

3.6 Postal/Zip Code (optional): \_\_\_\_\_

3.7 Country: \_\_\_\_\_

3.8 Phone number (optional): \_\_\_\_\_

3.9 E-mail address (optional): \_\_\_\_\_

#### 4. AUTHORIZATIONS

4.1 I give the International Dysferlinopathy Registry my permission to:

- a) contact the doctor(s) / medical institution(s) that I indicated in section 3 of this questionnaire in order to obtain the genetic and other medical information on my dysferlinopathy that are requested by this registry;
- b) store all my contact details and medical data – that have been provided by me or by those doctor(s) / medical institution(s) – in this registry, where they may be used for research and for the planning of clinical trials and research studies;
- c) store all my anonymous medical data in the UMD-DYSF mutation database and make readily consultable a part of these data on the UMD-DYSF web portal (see point 7 in the *Information for Patients* document);
- d) send me a follow-up email/letter/form once a year asking me to register any changes in my medical condition and personal details in order to keep the registry up-to-date.

YES

NO. I do not wish to register with the International Dysferlinopathy Registry.

4.2 If there are any major changes in my data that occur in the period between the yearly updates (for example change of address, participation to another registry/scientific research study/clinical trial, identification of new genetic data), I am willing to inform the International Dysferlinopathy Registry.

YES

NO

4.3 I allow the International Dysferlinopathy Registry to send me information on dysferlinopathies that might be relevant to me, including information about any clinical trials or research studies in dysferlinopathies that I might be eligible for.

YES

NO

4.4 I allow the International Dysferlinopathy Registry to share my data with the Jain Foundation, and by agreeing to share my data I understand that I will automatically be registered with the Jain Foundation, that I will have access to all the services the Jain Foundation offers and that I may directly be contacted by the Jain Foundation.

YES (I am not already registered with the Jain Foundation).

YES (I am already registered with the Jain Foundation Registry and I agree to share all my registry information between the two registries).

NO

## 5. CONSENT

5.1  I am the patient, I am 18 years of age or over and able to consent by myself.

The nature of the International Dysferlinopathy Registry has been fully explained to me. I have understood the *Information for Patients* document. I have had the opportunity to ask questions, and all my questions have been answered to my satisfaction. Upon reflection, I agree to participate in this registry.

Patient's name and signature:

Date:

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5.2  The patient is under 18 years of age or otherwise not able to consent by himself/herself, and I am his/her parent/guardian.

I am the patient's parent/guardian and the nature of the International Dysferlinopathy Registry has been fully explained to me. I have understood the *Information for Patients* document. I have had the opportunity to ask questions, and all my questions have been answered to my satisfaction. Upon reflection, I agree that my child/dependent participates in this registry.

Parent or guardian's name and signature:

Date:

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OPTIONAL:  I am the patient and I have understood the *Information for Patients or Children* documents and discussed this information with my parent/guardian. I agree to her/him entering my data in the International Dysferlinopathy Registry and to giving authorisations and consent on my behalf.

Patient's name and signature:

Date:

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Please send this *Registration and Consent Questionnaire (I)*, correctly completed and signed to:

The International Dysferlinopathy Registry, Inserm UMR 910, Aix-Marseille Université, 27 boulevard Jean Moulin, 13385 Marseille Cedex 05, FRANCE.