

## Informed consent (electronic)

Protocol Number: UX001-CL401  
Date/Version: 23 May 2013/2

1. Do we have your permission to store your data in the international HIBM registry (in a form identifiable only by a code) where it may be used for research and for the planning of clinical trials?

Yes                      No

2. If we receive information on HIBM related projects or other information related to your condition which might be relevant to you, would you like to be informed about this?

Yes                      No

3. If we receive information about a clinical research or trial which you might be eligible for, would you like to be informed about this?

Yes                      No

(Please note that even if the coordinators of a clinical trial believe that you might be eligible for the trial, based on the data about you stored in the registry, it is possible that later on it will turn out that you do not meet the trial inclusion criteria after all. Please also be aware that if we inform you about the existence of a trial, this does not imply that we endorse it. In order to participate in any trial, you will need to fill out a separate informed consent form.)

4. So that we can keep the registry up to date, we will need to contact you and ask about any changes in your medical condition. Do you agree to receive and complete follow-up forms once or twice a year by logging into the registry database and registering any changes in your medical condition?

Yes                      No

5. If there are any changes in your data (e.g. change of address, or changes in medical condition, such as loss of ambulation) that occur in the period between updates, are you willing to inform us?

Yes                      No

I understand that relevant sections of my medical notes and data collected during the study may be looked at by researchers from the study, by regulatory authorities (such as FDA or DHHS or from NHS trust), where it is relevant to my taking part in this research. I give my permission for these individuals to have access to my records.

Yes                      No

I,....., have understood the patient information and informed consent form. The nature of the registry has been fully explained to me. I have had the opportunity to ask questions, and all my questions have been answered to my satisfaction. Upon reflection, I agree to take part in this registry.

6 . I give my permission to contact the following clinic/hospital or laboratory to request a copy of my genetic and/or biopsy test result:

Yes

No

Your doctor (consultant or physician): **(Text box for the name and contact details)**.

\_\_\_\_\_

Date

\_\_\_\_\_

Signature