

A. Consent document on 'Muscle Disease Diagnostic Support (normal)'

Ichizo Nishino, Project Manager

I have fully explained and understood the following 'Muscle Disease Diagnostic Support' by means of the explanatory document. I participate in this project of my own free will.

A. 'Muscle Disease diagnostic support'

Items explained and understood (Agreement to all items from ☐1 to ☐12 is required to receive diagnostic support).

☐1 Participate in muscle disease diagnostic support (as part of broader practice) (Explanatory document: 2-(1)-(4))

☐2* Participation in screening for known causative genetic mutations of muscle disease in all cases of diagnosed muscle pathology (Explanatory document: 2-(2)).

**Not required to be checked if muscle biopsy is not performed (invalid even if checked).*

☐3 Purpose and significance (Explanatory document: 3)

☐4 Method of implementation and duration of the project (Explanatory document: 4)

☐5 Use of anonymized data for academic and educational purposes (Explanatory document: 4)

☐6 Burdens, risks and benefits that may arise (Explanatory document: 5)

☐7 Financial burden (Explanatory document: 6)

☐8 Withdrawal of consent after provision of materials (specimens and various clinical information) (Explanatory document: 7)

☐9 Handling of personal and other information (Explanatory document: 8)

☐10 Conflicts of interest of funding sources, researchers, etc. (Explanatory document: 9)

☐11 Obtaining or viewing business plans and other documents (Explanatory document: 10)

☐12 If you have any queries regarding support for the diagnosis of muscle diseases (Explanatory document: 13)

Information is provided when critical health findings are accidentally discovered or when important findings are obtained.
(Select one of the options)

☐ Please provide the information.

☐ Do not provide the information. (Explanatory document: 2-(4))

Subject signature

Date of agreement Month/Year _____ Signature (patient) _____

Address _____

Signature of substitute (If the subject is unable to give consent on his/her own with full understanding)

I have fully explained and understood the above matters concerning the 'Muscle Disease Diagnostic Support' in which
(subject name) _____ will participate, by means of the explanatory document. I confirm that the
subject will not be disadvantaged and agree that the subject will participate in this project.

Date of agreement Month/Year _____

Signature (patient) _____ (Continuity _____)

Address _____

Doctor-in-charge

Signature (patient) _____

Hospital name _____ Department name _____

Explainer (Project manager) Ichizo Nishino, Department of Neuromuscular Research, National Institute of

Neuroscience

B. Consent document on 'Preservation and Research Use (Muscle repositories)'

Ichizo Nishino, Project Manager

I have been fully informed of and understand the following information on 'Preservation and Research Use (Muscle Repositories)' by means of the Explanatory Memorandum. I participate in this project of my own free will.

B. 'Preservation and Research Use'.

Items explained and understood (Agreement to all items ☐ 1 to ☐ 17 is required to participate the project)

- ☐ 1 Purpose and significance of 'preservation of materials' (Explanatory document: 1-(1))
- ☐ 2 Purpose and significance of 'research use of materials' (Explanatory document, 1-(2))
- ☐ 3 Purpose and significance of 'Use of materials for academic and educational purposes' (Explanatory document: 1-(3))
- ☐ 4 Methods of implementation and duration of the project with regard to preservation and research use (Explanatory document: 2)
- ☐ 5 Provision of specimens to public databases, tissue banks, commercial companies, etc. (Explanatory document: 2)
- ☐ 6 Research use of materials (explanatory document: 2)
- ☐ 7 Burdens, risks and benefits that may arise from preservation and research use (explanatory document: 3)
- ☐ 8 Financial burden associated with provision of materials (Explanatory document: 4)
- ☐ 9 Withdrawal of consent for 'Preservation and Research Use' of materials (Explanatory document: 5)
- ☐ 10 Handling of personal and other information in storage and research use (Explanatory document: 6)
- ☐ 11 Methods for storage and disposal of materials (Explanatory document: 7)
- ☐ 12 Conflicts of interest of funding sources, researchers, etc. in preservation and research use (Explanatory document: 8)
- ☐ 13 Handling of research results for those who provided materials (Explanatory document: 9)
- ☐ 14 Compensation for damage to health caused by storage and research use (Explanatory document: 10).
- ☐ 15 Information disclosure on 'Preservation and Research Use' (Explanatory document: 11)
- ☐ 16 Obtaining or viewing the project plan and documents related to the research project (Explanatory document: 12)
- ☐ 17 If you have any queries regarding storage and research use (Explanatory document: 15)

※ materials: specimens and various clinical information

Subject signature

Date of agreement Month/Year _____ Signature (patient) _____

Address _____

Signature of substitute (If the subject is unable to give consent on his/her own with full understanding)

I have fully explained and understood the above matters concerning the 'Muscle Disease Diagnostic Support' in which (subject name) _____ will participate, by means of the explanatory document. I confirm that the subject will not be disadvantaged and agree that the subject will participate in this project.

Date of agreement Month/Year _____

Signature (patient) _____ (Continuity _____)

Address _____

Doctor-in-charge

Signature (patient) _____

Hospital name _____ Department name _____

Explainer (Project manager) Ichizo Nishino, Department of Neuromuscular Research, National Institute of Neuroscience