

# Consent Form for Sample Analysis, Preservation and Research

To the President of the National Center of Neurology and Psychiatry.

Patient Name: \_\_\_\_\_ Age: \_\_\_\_\_ Date: \_\_\_\_\_

Patient Address: \_\_\_\_\_

**SIGNATURE (Patient or a representative):** \_\_\_\_\_

If the consent is given by a representative due to the patient is not capable of making a judgement, please fill out the following.

Name of the representative: \_\_\_\_\_ Relationship to the patient: \_\_\_\_\_

Address of the representative: \_\_\_\_\_

Sample type (Circle all that apply) : Skeletal muscle / Peripheral nerve / Skin / Blood / Other

Need of cultivation (Circle one) : Yes / No

## Pathological / Biochemical Analysis

If you consent to the following with your acknowledgement after you have obtained sufficient explanation from your attending physician, please check the box.

- With my sample indicated above, the National Center of Neurology and Psychiatry conduct a diagnostic analysis. If my sample includes a frozen muscle, it is applied with Pompe enzyme activity screening. Where necessary, my sample is sent to collaborative research facilities for further specialized analyses.

## Genetic Analysis

If you consent to the followings with your acknowledgement after you have obtained sufficient explanation from your attending physician, please check the appropriate boxes/circles. ( mandatory,  optional)

- With my sample indicated above, the National Center of Neurology and Psychiatry conduct a diagnostic analysis, and the analysis result is explained to me by my attending physician, and where necessary a sufficient genetic counselling is provided to me prior to the explanation. (Please select the range of your analysis from the following two options)
- Please conduct genetic analysis for any possible disorder.
- Please conduct genetic analysis for a specific disorder (Specify the name of the disorder: \_\_\_\_\_)

- Where necessary, part of my analysis is outsourced to domestic/foreign external companies with my identification anonymized.
- My genetic sequencing data as well as disease information are in principle registered into public databases.

- I wish to be informed about any incidental finding that could significantly harm my health.

<<Disclaimer>> Even when a large genome sequencing is performed, the subsequent analysis to interpret the raw sequencing data is limited to targeted regions/targeted genes aiming to elucidate disease causation and pathogenesis, therefore it is not certain that all kinds of health-harming information can be obtained. Also, such information like a patient's vulnerability to various disorders is usually not detected, as our analysis does not intend to serve such a purpose.

## Preservation / Research Use

If you consent to the followings with your acknowledgement after you have obtained sufficient explanation from your attending physician, please check the appropriate boxes/circles. ( mandatory,  optional)

- Part of my sample indicated above is preserved for the elucidation of disease causation and pathogenesis of neuromuscular disorders. My sample as well as my clinical information (clinical history and findings) is used for researches including genetic sequencing, provided that such a usage is approved by Ethics Committee.
- My anonymized data is used for academic and educational presentations.
- My anonymized genetic sequencing data and disease information is in principle registered into public databases.

- My sample is used by foreign research institutes.
- My sample is offered to public banks.
- My sample is offered to researches conducted by domestic and foreign commercial enterprises.

- I wish to be informed about any incidental finding that could significantly harm my health.

<<Disclaimer>> Even when a large genome sequencing is performed, the subsequent analysis to interpret the raw sequencing data is limited to targeted regions/targeted genes aiming to elucidate disease causation and pathogenesis, therefore it is not certain that all kinds of health-harming information can be obtained. Also, information such as a patient's vulnerability to various disorders is usually not detected, as our analysis does not intend to serve such a purpose.

## Physician Statement

I have fully explained to my patient above including the contents of the Patient's Handbook and obtained his/her voluntary consent. Upon the receipt of any diagnostic results from the Analysis Conductor, I accept responsibility for explaining the results to the patient together with providing sufficient genetic counselling.

PHYSICIAN SIGNATURE: \_\_\_\_\_ Printed Name: \_\_\_\_\_ Specialty: \_\_\_\_\_

Hospital Name: \_\_\_\_\_

Hospital Address: \_\_\_\_\_

The Analysis Conductors and the Administrators of Samples and Bioresources

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Approved by Ethics Committee on 24 February, 2017  
Modified in conformity with the revised ethical policy, on 30 May, 2017