

# Clinical Summary Form for *Adult Patient*

Specimen No. (for NCNP use only)

Patient name: (in English) \_\_\_\_\_ Medical record No.: \_\_\_\_\_  
(in Japanese/Chinese) \_\_\_\_\_

Date of birth: \_\_\_\_\_ [D/M/Y] (Age: \_\_\_\_\_ yrs \_\_\_\_\_ mos) Sex: M / F

Clinical diagnosis : \_\_\_\_\_

Site of muscle biopsy: (R L) \_\_\_\_\_ (Performed on: \_\_\_\_\_ [D/M/Y])

Hospital\*: \_\_\_\_\_ Department\*: \_\_\_\_\_

Address\*: \_\_\_\_\_  
\*Use Japanese for Japanese hospitals

TEL: \_\_\_\_\_ FAX: \_\_\_\_\_

Attending physician\*: \_\_\_\_\_ E-mail: \_\_\_\_\_

Chief complaint: \_\_\_\_\_

Present illness: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Past history: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Underlying disease(s) \_\_\_\_\_

Medication (s) (N / Y name and period used \_\_\_\_\_)

Steroid (N / Y name and period used \_\_\_\_\_)

Developmental history (Normal Abnormal \_\_\_\_\_)

## Family history:

Parental consanguinity N / Y \_\_\_\_\_

\_\_\_\_\_  
Neuromuscular disease N / Y \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

## Physical examination:

Height: \_\_\_\_\_ cm Weight: \_\_\_\_\_ kg

Skin abnormality ( N / Y \_\_\_\_\_)

Spine deformity ( N lordosis scoliosis )

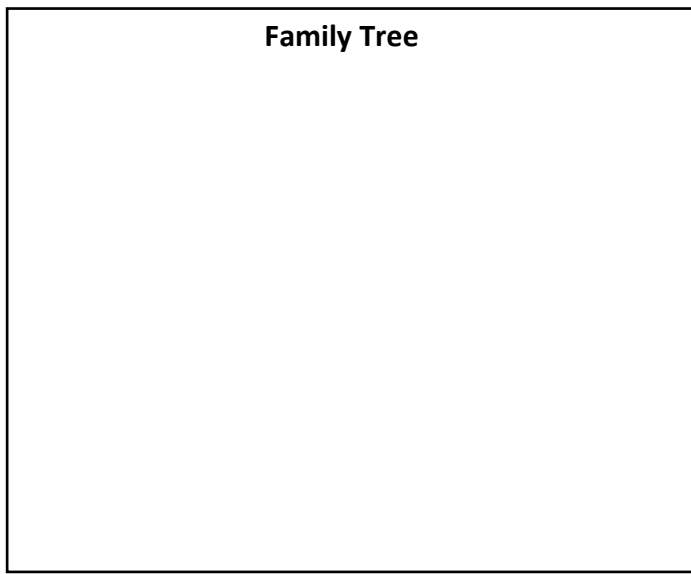
Chest deformity ( N pigeon funnel )

Joint contracture ( N / Y site \_\_\_\_\_)

High-arched palate ( N / Y narrow wide )

Minor anomaly ( N / Y \_\_\_\_\_ )

Respiratory insufficiency ( N / Y ) Mechanical ventilation ( N / Y since \_\_\_\_\_, NPPV or TPPV )



**Neurological findings:**

Intelligence ( normal borderline low ) Cognitive function ( MMSE HDS-R \_\_\_\_\_ )  
 Cranial nerve: Ptosis ( N / Y ) Ophthalmoplegia ( N / Y \_\_\_\_\_ )  
 Facial muscle involvement ( N / Y )  
 Dysarthria / dysphonia ( N / Y \_\_\_\_\_ ) Dysphagia ( N / Y \_\_\_\_\_ )  
 Motor system: Grip power ( R \_\_\_\_\_ kg / L \_\_\_\_\_ kg )  
 Walking ( N / Y possible with assistance tool \_\_\_\_\_ )

MMT		Neck	Shoulder	Elbow	Wrist	Fingers	Hip	Knee	Ankle
Flexion	R		abduction						
	L		abduction						
Extension	R		/						
	L								

Muscle atrophy ( N / Y \_\_\_\_\_ ) Winged scapula ( N / Y \_\_\_\_\_ )  
 Muscle hypertrophy ( N / Y GC tongue other \_\_\_\_\_ ) Muscle tone ( normal ↓ ↑ )  
 Myotonia ( N / Y \_\_\_\_\_ ) Strength fluctuation ( N / Y diurnal within a week within a month )  
 Myalgia ( N / Y site \_\_\_\_\_ time between exercise and onset of myalgia \_\_\_\_\_ )  
 Neck movement limitation ( N / Y flexion extension rotation ) DTR ( normal ↓ absent ↑ \_\_\_\_\_ )  
 Involuntary movement ( N / Y \_\_\_\_\_ ) Cerebellar sign ( N / Y \_\_\_\_\_ )  
 Sensory system ( normal / abnormal \_\_\_\_\_ )  
 Autonomic system ( normal / abnormal \_\_\_\_\_ )  
 Fundus examination \_\_\_\_\_ Others \_\_\_\_\_

**Laboratory result:**

CK at rest \_\_\_\_\_ (Normal range: \_\_\_\_\_ ) Aldolase \_\_\_\_\_ (Normal range: \_\_\_\_\_ )  
 AST \_\_\_\_\_ ALT \_\_\_\_\_ CRP \_\_\_\_\_ ESR \_\_\_\_\_ ACE \_\_\_\_\_ M proteinemia ( N / Y λ type κ type )  
 Serum lactate \_\_\_\_\_ (normal range: \_\_\_\_\_ ) CSF lactate \_\_\_\_\_  
 Serum pyruvate \_\_\_\_\_ (normal range: \_\_\_\_\_ ) CSF pyruvate \_\_\_\_\_  
 Autoantibodies \_\_\_\_\_  
 Infection HBV HCV HTLV-1 HIV Other \_\_\_\_\_  
 Endocrinological disease \_\_\_\_\_  
 Forearm exercise test \_\_\_\_\_  
 EMG \_\_\_\_\_  
 NCS/ RNS \_\_\_\_\_  
 Imaging findings (send imaging data if possible)  
 Muscle imaging ( CT MRI ultrasound ) \_\_\_\_\_  
 Brain/ spine imaging ( CT MRI ) \_\_\_\_\_  
 EKG \_\_\_\_\_ Echocardiogram \_\_\_\_\_  
 Respiratory function VC \_\_\_\_\_ L % VC \_\_\_\_\_ % ( Sitting Supine )  
 Others \_\_\_\_\_

**Record by:** \_\_\_\_\_ **Date:** \_\_\_\_\_ [D/M/Y]

## Additional clinical information for *Myositis*

(When myositis is suspected, also fill this form)

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### CLINICAL FINDINGS

**Skin lesion:** Gottron sign ( N / Y )

Mechanic's hands ( N / Y )

Heliotrope rash ( N / Y )

Other ( N / Y \_\_\_\_\_ ) Skin biopsy ( N / Y \_\_\_\_\_ )

**Motor system:** Myalgia ( N / Y )

Dysphagia ( N / Y )

### LABORATORY FINDINGS

**CBC:** WBC \_\_\_\_\_ / $\mu$ l

Hb \_\_\_\_\_ g/dl

Plt \_\_\_\_\_ / $\mu$ l

**Urinalysis:** Protein ( N / Y )

<b>Antibody testing:</b> Anti ARS Ab	( N / Y / not tested )	Anti Jo-1 Ab	( N / Y / not tested )
Anti SRP Ab	( N / Y / not tested )	Anti mitochondrial M2 Ab	( N / Y / not tested )
Anti HMGCRAb	( N / Y / not tested )	Anti TIF1 $\gamma$ Ab	( N / Y / not tested )
Anti MDA5 Ab	( N / Y / not tested )	Anti Mi-2 Ab	( N / Y / not tested )
Anti NXP-2 Ab	( N / Y / not tested )	Anti SAE Ab	( N / Y / not tested )
Anti SS-A Ab	( N / Y / not tested )	Anti SS-B Ab	( N / Y / not tested )
Anti RNP Ab	( N / Y / not tested )	Anti Scl-70 Ab	( N / Y / not tested )
Anti DNA Ab	( N / Y / not tested )	Anti nuclear Ab titer	_____ / not tested

### EXTRAMUSCULAR MANIFESTATIONS

Interstitial pneumonia ( N / Y )      KL-6 \_\_\_\_\_      Cardiac abnormality ( N / Y \_\_\_\_\_ )

Chest X-ray \_\_\_\_\_

Chest CT \_\_\_\_\_

Concurrent malignancy ( N / Y Diagnosis \_\_\_\_\_ )

History of malignancy ( N / Y Diagnosis \_\_\_\_\_ Time of onset before myositis \_\_\_\_\_ )

Other connective tissue disease ( N / Y symptoms and findings \_\_\_\_\_ )

Statin use ( N / Y : currently , in the past ), provide the name and period of use \_\_\_\_\_

(when the blood sample is submitted, please also provide the date of drawing blood \_\_\_\_/\_\_\_\_/\_\_\_\_)

Current use of steroid / immunomodulatory drugs ( N / Y \_\_\_\_\_ )

Other active inflammation (including flu, allergy, and trauma) \_\_\_\_\_

## Additional clinical information for **FSHD**

(When FSHD is suspected, also fill this form)

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**Family History** ( N / Y ) If yes (Y), draw a pedigree in the clinical summary form

### Symptoms:

Sleep with eyes half open ( N / Y ) since age \_\_\_\_ yrs      Difficulty closing eyes ( N / Y ) since age \_\_\_\_ yrs  
Difficulty whistling ( N / Y ) since age \_\_\_\_ yrs      Difficulty sucking with straw ( N / Y ) since age \_\_\_\_ yrs  
Difficulty closing mouth ( N / Y ) since age \_\_\_\_ yrs      Difficulty raising arms ( N / Y ) since age \_\_\_\_ yrs  
Difficulty placing things on overhead shelves ( N / Y ) since age \_\_\_\_ yrs  
Difficulty doing pullover on gymnastic bar ( N / Y ) since age \_\_\_\_ yrs  
Able to stand up from a chair without any difficulty ( N / Y )  
Able to stand up from a chair using hands to support ( N / Y )  
Able to walk but unable to stand up from a chair ( N / Y )  
Unable to walk ( N / Y )

### Physical findings:

Winged scapula ( N / Y )      Scapula elevation on shoulder abduction ( N / Y )      Beevor sign ( N / Y )  
Ciliary sign ( N / Y )      Tongue atrophy ( N / Y )      Dysphagia ( N / Y )      Funnel chest ( N / Y )      Lumbar lordosis ( N / Y )

<Muscle weakness/atrophy>

Orbicularis oculi	( Normal / R>L / R<L / R=L )	Quadriceps femoris	( Normal / R>L / R<L / R=L )
Orbicularis oris	( Normal / R>L / R<L / R=L )	Hamstrings	( Normal / R>L / R<L / R=L )
Biceps brachii	( Normal / R>L / R<L / R=L )	Tibialis anterior	( Normal / R>L / R<L / R=L )
Deltoid	( Normal / R>L / R<L / R=L )	Gastrocnemius	( Normal / R>L / R<L / R=L )
Pectoralis major	( Normal / R>L / R<L / R=L )	R>L: Weakness predominantly in the right	

<Extramuscular abnormalities>

Audiometry ( ND / Normal / Impaired R \_\_\_\_ dB L \_\_\_\_ dB)      Retinal vessel abnormality ( N / Y )  
Others \_\_\_\_\_

**Association with autoimmune disease** ( N / Y \_\_\_\_\_ )

Anti-AChR Ab ( N / Y )      Anti SRP Ab ( N / Y )      Others ( N / Y \_\_\_\_\_ )

Other findings (Describe any findings that led to the clinical diagnosis of FSHD) \_\_\_\_\_

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