Project Leader Yuki Nakayama **ALS Nursing Care Project**

Improving the Quality Of Life of Patients with Amyotrophic Lateral Sclerosis

"Our mission is to establish the best practices for respiratory and communication management for ALS patients in a community-based setting . We have established a multidisciplinary research team to develop a Brain Machine Interface for ALS patients."

Matsuda C, Shimizu T, Nakayama Y, and Haraguchi M. (2018) "Cough peak flow decline rate predicts survival in patients with amyotorophic lateral sclerosis." *Muscle Nerve.* 2018 Aug 14.

Shimizu T, Bokuda K, Kimura H, Kamiyama T, Nakayama Y, Kawata A, Isozaki E, and Ugawa Y.(2018) "Sensory cortex hyperexcitability predicts short survival in amyotrophic lateral sclerosis." *Neurology* 1 ;90(18):e1578-e1587.
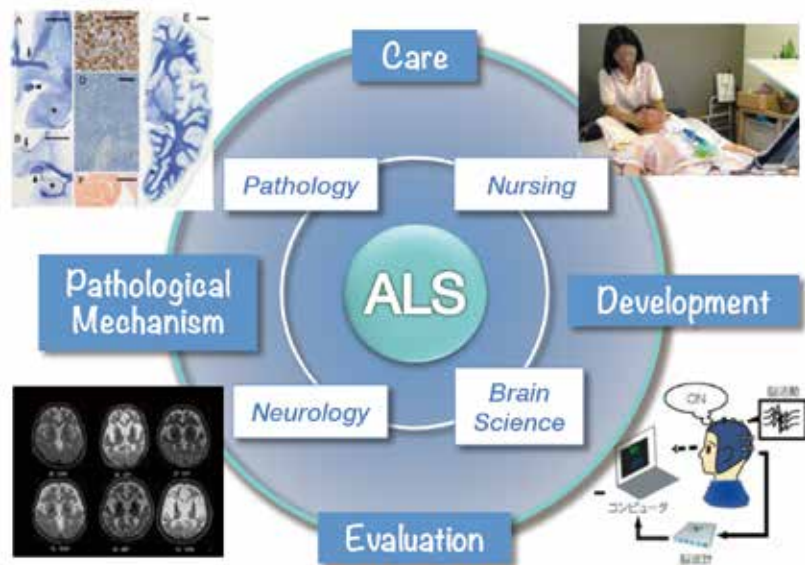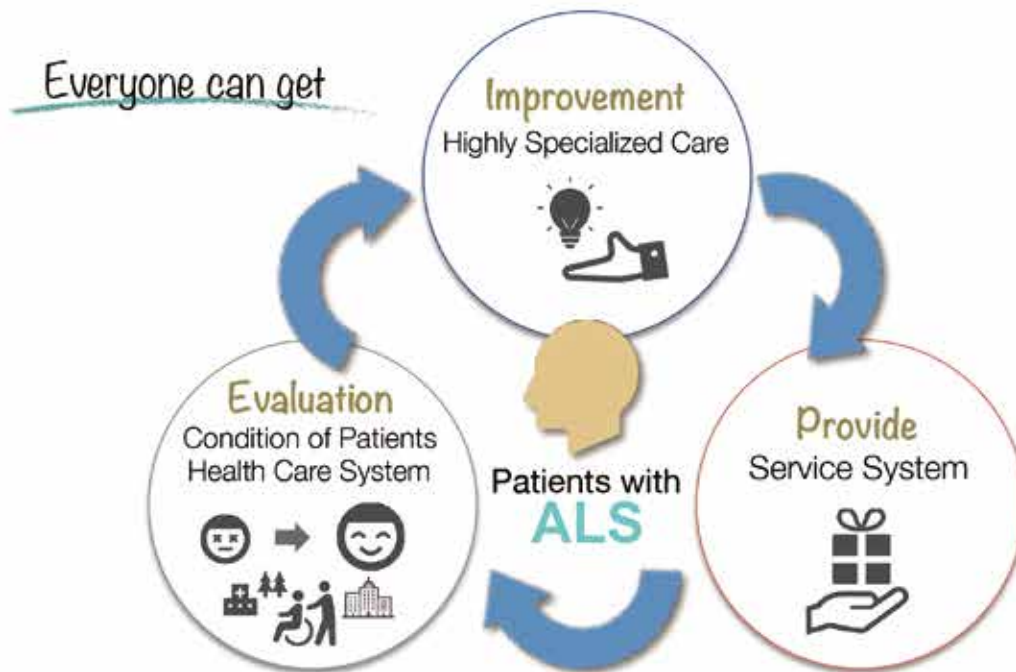
Nakayama Y, Shimizu T, Matsuda C, Haraguchi M, Hayashi K, Mochizuki Y, Nagao M, Kawata A, and Isozaki E.(2018) "Non-motor manifestations in ALS patients with tracheostomy and invasive ventilation." *Muscle Nerve.* 57(5):735-741.

Nakayama Y, Shimizu T, Mochizuki Y, Hayashi K, Matsuda C, Nagao M, Watabe K, Kawata A, Oyanagi K, Isozaki E, and Nakano I. (2016) "Predictors of impaired communication in amyotrophic lateral sclerosis patients with tracheostomy invasive ventilation." *Amyotroph. Lateral Scler. Frontotemporal Degener.* 17(1-2):38-46.

Matsuda C, Shimizu T, Nakayama Y, Haraguchi M, Hakuta C, Itagaki Y, Ogura A, Murata K, Taira M, Numayama T, and Kinoshita M.(2016) "Macroglossia in advanced amyotrophic lateral sclerosis." *Muscle Nerve.* 54:386-390.

Multidisciplinary research team

ALS

Care

Pathology

Nursing

Development

Brain Science

Neurology

Evaluation

Pathological Mechanism

ALS Nursing Care

ALS Nursing Care Project Ground design

Everyone can get

Improvement
Highly Specialized Care

Evaluation
Condition of Patients
Health Care System

Patients with
ALS

Provide
Service System

Administration of Community-Based Nursing

How many visiting nurse stations are there in this community?
" Do Patients live well? "

Akiko Ogura, Ph.D.

Quality Assurance of Home Care

Collaboration between visiting Nurse and care workers.
Risk management on Home Mechanical Ventilation, and Construction of
information system for Medical Near-miss/adverse event.
Needs of Nursing Support in Outpatient Department on Patients with ALS.

Michiko Haraguchi, Ph.D.

Establishing specialized Oral Nursing care system for advanced amyotrophic lateral sclerosis patient

Chiharu Matsuda, Ph.D.

Multivariate analysis for the occurrence of macroglossia
by logistic regression

Variables	Odds ratio	95% CI	P-value
Age at beginning of TIV use, years	0.937	0.845–1.041	0.225
Duration of TIV use, months	1.022	1.000–1.044	0.050
ALSFRS-R score	0.822	0.314–2.146	0.314
Body mass index, kg/m²	1.653	1.150–2.376	0.007
Energy intake, kcal/d	1.001	0.995–1.006	0.784
Stages of communication impairments (I, II–IV, V)	3.771	1.150–12.370	0.029

Patients with Intractable Diseases Analyze their physical and psycho-social Data

Yumi Itagaki, M.S.

ALS Nursing Care