Taiwan MND Association’s Efforts in Promoting ALS Research

Lung Kuo
Executive director of Taiwan MNDA
Taiwan Motor Neuron Disease Association (TMNDA) is a service-based organization that aims to provide better care and support to patients with amyotrophic lateral sclerosis (ALS) or motor neuron disease (MND).

In addition to providing services to such patients, we also undertake initiatives that involve working with government authorities and research institutes.
Four Main ALS genes in Taiwan

- Dr. Yi-chun Lee, M.D., the winner of 2017 Research Awards, discovered four main ALS genes in Taiwanese patients with ALS, namely,
  - SOD1 ----- 7%
  - C9orf72 ---- 4%
  - TARDBP --- 4%
  - FUS ------ 2%
Gene Therapy Research

- The principal investigator Dr. Jun-an Chen, whose team members have received the research award two years in a row. Under his instruction, the team devoted to gene therapy focus on MICRORNA MIR-17-92.

- The team research results were published this year in the Cell Stem Cell journal under the title of Mir-17∼92 Confers Motor Neuron Subtype Differential Resistance to ALS-Associated Degeneration.

Brainwave Study

- As for the development of technological assistive devices, Professor Yi-hung Liu, the 2018 winner, has been researching communication through brain waves. Professor Liu’s research has increased recognition accuracy to 85% through the use of artificial intelligence.
- This study developed an alternative communication channel for patients in a later stage of ALS who are unable to open the eyes.
Long-term care as a national policy in Taiwan

Because of Taiwan’s rapidly aging population, its government is dedicated to including the provision of long-term care as a national policy.

The development of science and technical aid for long term care is a key investment item among government projects where a lot of fund and resources were pulled in.
In September 2018, the minister of science and technology inaugurated the LIFE-FIX project, which aimed at establishing a smart communication system for patients with ALS.

The minister of science and technology of Taiwan
Mr. Liang-Gee Chen
The Chairman of TMNDA
Mr. Yun-Yi Lin

Department of Foresight and Innovation Policies, MOST
Hsiu-Ya Yang
Director General
Project LIFE-FIX comprises six sub-projects (2018/9-2019/8)

1. Brain-Computer-Interface communication system
2. Eye-Control for home appliance
3. Design and production of brain electrode cap for PALS
4. Voice banking based on Chinese mandarin language
5. Multimode human-computer interface design for PALS
6. Evaluating usability of clinical PALS user
TMNDA role in this project, including:
1. Delivering care-taking instructions.
2. Presenting deeper knowledge of the disease.
3. In charge of communication between patients and the research teams.
4. Promote the greater support and participation of the project among patients and their families.
5. The medical staff of the association to arrange and supervise the experimental test.
2019 年 621 全球漸凍人日 記錄
聽見愛還在

中華民國運動神經元疾病病友協會
Taiwan Motor Neuron Disease Association
漸凍人協會
A massive crowd appeared on the same day of the initiation of the campaign to donate their voices.

A Taiwanese pop singer, “Where Chou”, offered to endorse the campaign for free and shoot a promotion video.

Three months after the campaign, two mainstream television media outlets, the Public Television and Formosa Television, each produced a thirty-minute programs on the topic to raise awareness of patients with ALS among the Taiwanese people.
Patient Right to Autonomy Act

Yu-Hsin Yang
CEO of Patient Autonomy Research Center
Standard Operating Procedure (SOP) for Patient Right to Autonomy Act

- **Patient**
  - Adults with behavioral competence
  - Adults with mental/cognitive capacity

- **Advance Care Planning (ACP)**
  - Make the decision together: Medical Center, the patient, the lasting power of attorney or the family
  - Specific Clinical Conditions

- **Advance Directives (AD)**
  - Accept/Refuse which treatment
  - Witness/Notary
  - Notation

- **Signature**

**Clinical Conditions**
- **Terminal Patients** (けんていびょうびょう)
- **Irreversible Comas** (いりけいひるるな
- **Permanent Vegetative States** (ひんながいしゅうぶてきせき)
- **Advanced Dementia** (こうでんばつ）
- **Other disorders officially recognized as intolerable and incurable.** (おうわどおりしんしんけんにしあつめられたひんようとしんかげん）
The fight of her life – for the right to die. Taiwan activist on patient autonomy law, the first in Asia

・Rose Yang learned at 19 she would spend the rest of her life in a wheelchair. Straight away she started helping people like her make the most of their lives

・Now she is celebrating Taiwan’s passage of the first right-to-die law in Asia, which she championed and, one day, will use; until then she’ll ‘live life well’
Recent ALS statistics in Taiwan

- According to the National Health Insurance Research Database survey in the years from 2008 to 2015.
- The incidence rates of ALS approximately 0.33% to 0.44% (per 100,000 people).
- The average yearly number of people in Taiwan diagnosed with ALS was 116 people.
- The average age of first diagnosis was 58.8 years old.
- Male to female ratio was 1.3
- The mean overall survival was 6.05 years.
- In addition, the current number of patients with ALS in Taiwan is 596, and 400 of them have joined in the association.
We would like to give credit to the ALS Research Awards for the research achievement so far. The award has brought researchers and the association closer and increased the government's attention toward the TMNDA—a small but impactful association.
THANK YOU

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