



Taiwan MND Association's Efforts in Promoting ALS Research

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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



- 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.



WAN MND Association
漸凍人研究獎
ALS
Research Award



你是我的家人!?! | 2018/6/20 記者會
第三屆漸凍人研究獎頒獎







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%**



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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*.
- <https://www.ncbi.nlm.nih.gov/pubmed/31155482>

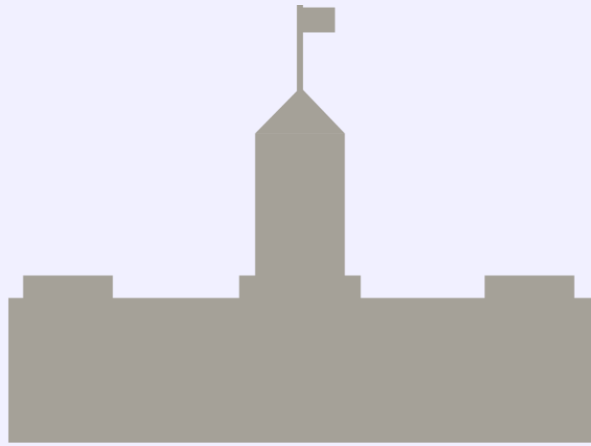


Brainwave Study

- 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.



衛生福利部

Ministry of Health and Welfare





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

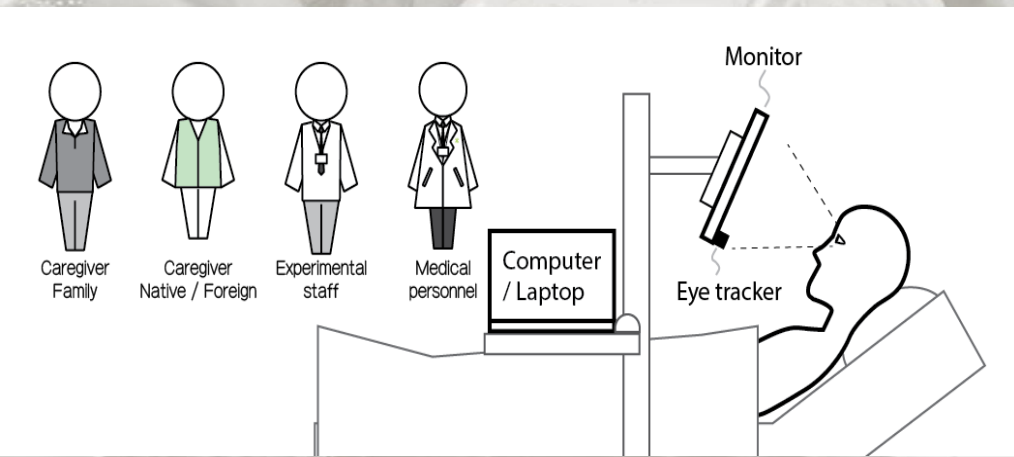


(4) Voice banking based on Chinese mandarin language

(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

聽見 愛還在



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謝謝妳為我做一切



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- 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

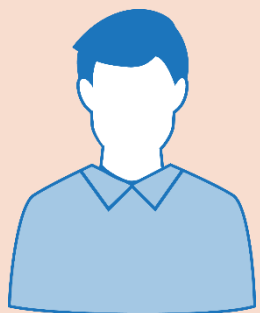
CEO of Patient Autonomy Research Center



病人自主研究中心

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
- Signature



Advance Directives (AD)

- Accept/Refuse which treatment
- Witness/ Notary
- Notation

臨床條件

Clinical Conditions

- 末期病人
Terminal Patients
- 處於不可逆轉之昏迷狀況
Irreversible Comas
- 永久植物人狀態
Permanent Vegetative States
- 極重度失智
Advanced Dementia
- 其他經中央主管機關公告之疾病
Other disorders officially recognized as intolerable and incurable.

Health

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'

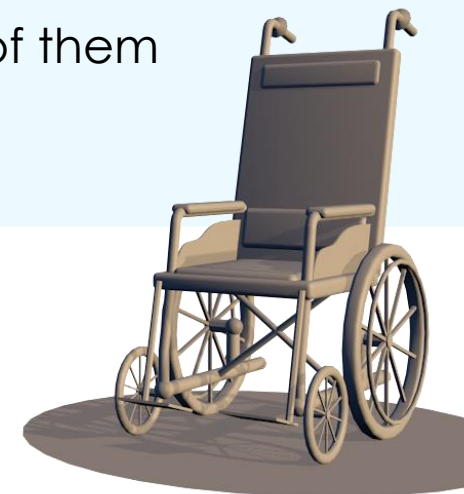


<https://www.scmp.com/lifestyle/health/article/3012578/fight-her-life-right-die-taiwan-activist-patient-autonomy-law>



Recent ALS statistics in Taiwan

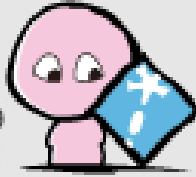
- According to the National Health Insurance Research Database survey in the years from 2008 to 2015.
- The incidence rates of ALS approximately 0.33% to 0.44% (per 100,000 people).
- The average yearly number of people in Taiwan diagnosed with ALS was 116 people.
- The average age of first diagnosis 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.

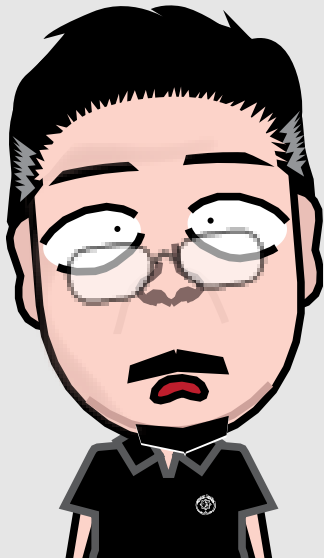
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THANK YOU



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