

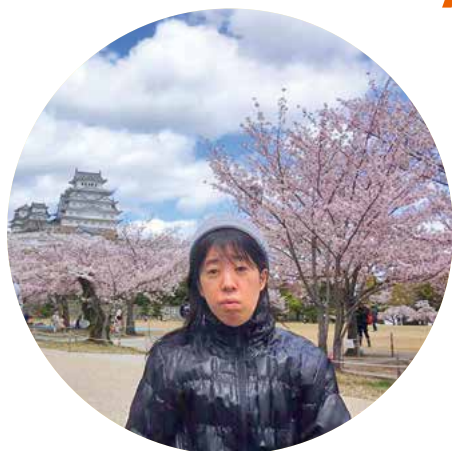


Myotonic Dystrophy Patients' Group of Japan



We are DM-family

Annual Report, 2018



<https://dm-family.net/>

With Knowledge Comes Hope



100 seats were fully packed

DM-family held a symposium to discuss the management, registry, cognitive behavioral therapy, and to share patients' experiences.

How can we prevent aspiration pneumonia?

In July 2018 in Nagoya, DM patients and their families gathered and listened attentively to a lecture by Dr. Satoshi Kuru from National Hospital Organization Suzuka National Hospital. He said: "Muscular strength, swallowing, and breathing" are crucial for daily management, and that preventing aspiration pneumonia directly aids the extension of life of DM patients.



The Significance of a Registry

Prof. Masanori P. Takahashi from Osaka University, Graduate School of Medicine talked about the latest developments in therapeutic drugs. With DM being a rare disease, patient data collected through a registry is necessary for medical advancement.



What is cognitive behavioral therapy for DM?

Prof. Osamu Imura from Osaka University, Graduate School of Human Sciences talked to patients and their families about cognitive behavioral therapy. He assured everyone present that a study has been underway in Japan.

A Session to Share and Empathize with Patients' Experiences

Three DM-family leaders talked about their experiences as patients. Participants listened sympathetically about how the three overcame their concerns and suffering to learn what they can do.



President Akane Hatano (DM1)



Vice President Minako Sato (DM1)



Vice President Yuji Akechi (DM1)



Lecture in Sapporo

Lecture meetings across Japan for CDM patients and their families.

To raise children born with CDM, we need support from people around them.

In September 2018, in Sapporo, we gave a one-day lecture to learn comprehensively about genetics, social services, the development of new medications, a registry, periodic checkups for parents, rehabilitation, as well as the children's treatment.



Dr. Yuka Ishikawa of the National Hospital Organization Yakumo National Hospital said: "Being patients themselves, parents need periodic checkups just as their children do. For that reason, support from their spouses and supporters is indispensable." She also explained how to introduce a mechanical ventilator.



Clinical Trials of Erythromycin

Assistant Professor Masayuki Nakamori of Osaka University's Graduate School of Medicine has been working on drug-repositioning of erythromycin for the development of DM treatment. He explained how DM is caused and how erythromycin works. He emphasized the necessity of a patient registry to apply for a clinical trial.



Promoting Rehabilitation

Mr. Toshihiko Miura, a physiotherapist from the National Hospital Organization demonstrated stretching and respiratory rehabilitation. He recommended doing Achilles' tendon stretches every day.



Poster displays at the Japanese Society of Neurology and Japanese Society of Child Neurology Conferences

In May 2018, both the Japanese Society of Neurology and the Japanese Society of Child Neurology held conferences in Sapporo and Makuhari respectively. To network with medical professionals, DM-family had their posters displayed.



Japanese Society of Neurology



With Dr. Tetsuo Ashizawa



Japanese Society of Child Neurology

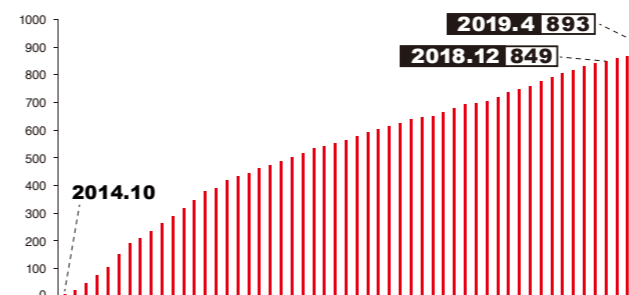
Tea Party

30 people attended a tea party held in November 2018, Tokyo, to encourage exchange among the patients and their families.



"Remudy" registration close to 900

As a patients' group, DM-family helps promote "Remudy", a Japanese patient registry, by providing information and campaigning on its importance. The registration amounted to 849 members at the end of 2018, and is expected to reach 900 in 2019.



Cooperation in a Patients' Survey

To find out what kind of medical care Japanese patients are getting, a study group sponsored by the Ministry of Health, Labour and Welfare did a survey on registered patients. DM-family cooperated to help encourage more participation.





Would you like to come to Japan?



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