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Lecture

Introduction of the special lecture of Mrs. Shannon M. Lord

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Following are the full contents of the special lecture by Mrs. Shannon M. Lord which were addressed to the nursing students of the Aino Gakuin at Aino Hall on October 11th, 2001, on the occasion of the 3rd International Myotonic Dystrophy Conference (IDMC-3).

IDMC-3 was organized on October 9–11, 2001, at The Miyako, Kyoto under the chairmanship of Nakaaki Ohsawa, M. D., the Aino Institute for Aging Research. The IDMC is a unique international conference entirely devoted to the incurable disease by name of myotonic dystrophy and the participants included both biologists and clinicians. The IDMC aims to stimulate new international and scientific collaborations of new therapeutic approaches on myotonic dystrophy. The IDMC-1 was held in Paris, France, in 1997 and IDMC-2 at Research Triangle, North Carolina, USA in 1999. Both conferences were very successful.

Now we remember those days of IDMC-3 Kyoto. At that time we unexpectedly faced to the serious situations, since the period was just after the September 11th tragedy. We were afraid that many foreign participants could not fly over from abroad, and we, the organizers, might be forced to cancel the meeting. Thanks to all, it turned out needless worry. Many expected foreign participants including Mrs. Shannon Lord joined us and the IDMC-3 proceeded with great success, providing many fruitful contributions to myotonic dystrophy research.

After the IDMC-3 Kyoto, the lecture meeting on the care of myotonic dystrophy was held in the afternoon of October 11th, 2001 at Aino Hall. This meeting was planned in connection with IDMC-3, in order to give the nursing students of the Aino Gakuin a chance to obtain brand new knowledge on the care of the patient with this incurable disease by two distinguished speakers, professor Ashizawa and Mrs. Lord.

First, Dr. Ashizawa, professor of neurology, Baylor university, USA, the world famous authority gave us the introductive review on the disease. Then, Mrs. Shannon M. Lord, the president of the Hunter Research Fund talked on her idea about how to cope with this difficult disease from the stand point of the patient. The title of her lecture was "Speech to Nursing Students at the Aino Gakuin: A Patient Perspective of Myotonic Dystrophy".

The speech of Mrs. Lord not only greatly impressed all participants at IDMC-3 in Kyoto, but also her lecture to nursing students deeply moved the audience in Aino Hall. So we wanted to publish her lecture in Aino Journal. We greatly appreciate Mrs. Shannon M. Lord to give us kindly the permission of publication of her special lecture.

Mrs. Shannon M. Lord is a housewife, an artist, a writer and a child care specialist, and also a patient with myotonic dystrophy. She has two sons with the same disease, whose symptoms are more severe than her symptoms. She always thinks about how to cope with myotonic dystrophy from the patient's view and she decided to promote the funding for the research by establishing the Hunter Research Fund. As the president, she generously supported the travel costs of many participants to IDMC-3 Kyoto from USA and Canada.

Her perspective of myotonic dystrophy as a patient which tries to promote the cooperations of patients and all members of medical services (including medical doctors, nurses, researchers etc.) in order to overcome this difficult disease will be in good concert with Koyama's symbolic idea of the Aino Gakuin, the symmedical system, which emphasizes

the importance of the symphony of patient-centered medical services.

Notes

Myotonic dystrophy (DM) is a hereditary autosomal dominant disease which reveals various systemic symptoms, such as muscle dystrophy, myotonia, endocrine disorders, diabetes mellitus, cataract, arrhythmia, dementia etc. and is thought to simulate premature aging. DM is one of the triplet repeat diseases. The pathology is due to the increased number of repeats of CTG triplet in DMPK (dystrophia myotonica protein kinase) gene located on chromosome 19. The number of CTG repeats are less than 50 in normals, whereas 100, 1000 or more in patients with myotonic dystrophy, which is believed to cause various abnormalities. No effective therapeutic method has been established at present yet.