

# Report on the 15<sup>th</sup> Annual Scientific Meeting of the Asian and Oceanian Myology Center, Hsinchu 2016

The Asian and Oceanian Myology Center (AOMC) was established as an organisation in Tokyo in 2001. Its aims and objectives have been to promote scientific and clinical research, to provide a forum to advance and distribute knowledge for the benefit of patients, to provide educational opportunities for young investigators and clinicians and to promote the achievement of high standards in clinical practice in myology and neurology as they relate to neuromuscular diseases in the Asian and Oceanian regions.

The 15<sup>th</sup> Annual Scientific Meeting of AOMC was held in conjunction with the 20<sup>th</sup> Taiwan Child Neurology Society Annual Meeting in Hsinchu, Taiwan, on 26<sup>th</sup> to 29<sup>th</sup> May, 2016 with the venue for the meeting being the Lecture Theatres and Meeting Rooms of the Microelectronic and Information Systems & Research (MIRC) Building at the National Chiao Tung University.

Dr. Yuh-Jyh Jong (AOMC Executive Board Member), AOMC 2016 Chairman and Conference President, along with AOMC International Consulting Members and a large team of Local Committee Members, organised the meeting for AOMC, along with the Taiwan Child Neurology Society and the National Chiao Tung University, as well as, an additional 10 Taiwan Medical, Allied Health and Research Societies/Organisations and the Japan Foundation for Neuroscience and Mental Health as co-organisers. Delegate registrations totalled 338 with 119 international participants from 22 Countries and Autonomous Regions, some, such as Indonesia and Myanmar represented for the first time. Altogether, for both the AOMC and TCNS clinico-scientific presentations and seminars, there were 31 speakers from Australia, Finland, Mainland China, Hong Kong, India, Japan, Korea, Malaysia, Netherlands, Philippines, Taiwan, Thailand and the United States. Six individuals were awarded

Fellowships to attend the conference through grants from the Japan Foundation for Neuroscience and Mental Health, as facilitated by AOMC president, Dr. Ikuya Nonaka. These were: Dr. Michelle Farrar (AU), Dr. Yun Yuan (CN), Dr. Chuanzhu Yan (CN), Dr. Kazunari Momma (JP), Dr. Dae-Seong Kim (KO) and Dr. Fumi Takeuchi (JP).

Dr. Yuh-Jyh Jong chaired the Opening Ceremony, introducing the President of the National Chiao Tung University, Dr. M.C. Frank Chang, who welcomed all attendees followed by Drs Ikuya Nonaka and Yuh-Jyh Jong who greeted AOMC and TCNS delegates, respectively. Dr. Arthur H.M. Burghes then opened the scientific program with an “Overview and update of SMA” in the first Plenary Session which was entitled, Spinal Muscular Atrophy, SMA. Presentations, “Neuromuscular deficits and drug discovery in Spinal Muscular Atrophy” by Dr. Chien-Ping Ko and “Diagnosis and management of SMA in a new therapeutic era” by Dr. John T. Kissel, followed. Spinal Muscular Atrophy being a major focus of the meeting, a vigorous Panel Discussion on Asian and Oceanian experiences of Diagnosis, Standards of Care and Clinical Trials then occurred. There was much excitement in regard to recent advances in the treatment of SMA with some 19 potential therapeutic drugs in development or well advanced in clinical trials.

Plenary Session 2 involved Distal Myopathies where Dr. Bjarne Udd gave presentations on “Titinopathy” and “Laing Myopathy”. Dr. Ichizo Nishino’s presentation in this session was on “GNE Myopathy (Distal Myopathy with Rimmed Vacuole or hIBM)”. Both Titinopathy and Laing Myopathy are proving to be more complex clinical entities with unusual phenotypes dependent on the specific genetic variation. At this stage, therapies other than personalised genetic engineering cannot be foreseen. By contrast, knowledge of GNE Myopathy, as for SMA, seems to have reached the point where therapeutic intervention by simple drug treatment can be envisaged.

Updates in several Neuromuscular Disease areas were presented on the second day of the meeting in Plenary Session 3. Dr. Carsten G. Bönnemann discussed “Recent advances of Ullrich Congenital Muscular Dystrophy” and Dr. Silvère M. van der Maarel presented “Recent advances of Facioscapulohumeral Muscular Dystrophy”. At last the genetics and epigenetics of FSHD are being unravelled and some clues to potential therapy are being revealed. Likewise, theoretically at least, some cases of Ullrich Congenital Muscular Dystrophy might be amenable to therapy that reduces production of an aberrant form of collagen type VI. Dr. Shin’ichi Takeda in his “Updated treatment of Duchenne Muscular Dystrophy” presentation, however, brought the most disappointing news of the meeting, that the United States Food and Drug Administration (FDA) had just (in May) severely criticised the clinical trial of the drug Eteplirsen. This setback has come very soon after the FDA’s rejection (in January) of the drug Drisapersen due to severe side effects and notification (in February) that Translarna™ (Ataluren, PTC124) did not meet the FDA’s standards on efficacy. On the other hand, more efficient and less toxic drugs are in development while entirely new methods of gene therapy (for example, genetic engineering using CRISPR) have recently been found to be effective in Muscular Dystrophy in mice.

From early afternoon, on the second day of the meeting, the usual Clinico-Pathological Case Conference was held during which 10 of the most interesting and unusual cases were chosen by the conference organisers and presented. Sets of original microscope slides relating to these cases were available for viewing throughout the meeting. These sessions are invariably greatly appreciated and enthusiastically received by both novices and experienced researchers, frequently with extensive discussion and divergent opinions before reaching a final diagnosis or concluding that further information/biochemistry/genetic analysis is required. Also, on this occasion, some 75 posters were mounted for display covering most areas of Neuromuscular Disease. In two one-hour dedicated sessions and during coffee

breaks, these were individually the site of considerable animated discussion as crowds of interested viewers and anonymous judges moved from poster to poster. Five prizes were awarded for the best domestic posters to Dr. Wen-Chin Weng, Dr. Wen-Chen Liang, Dr. Chia-Jui Hsu, Dr. Shan-Fu Ou and Mr. Te-Lin Lin.

On the final day of the joint AOMC/TCNS meeting, several of the AOMC lecturers gave variations of their earlier presentations tailored to the more clinically oriented audience, and Dr. Jun Kimura presented his experiences in the “Electrodiagnosis of Pediatric Neuromuscular Diseases”. His talk included a number of extremely interesting and informative anecdotes and case histories.

There were then eight short oral presentations on a variety of topics and the meeting concluded with Lectures by Dr. Shih-Hwa Chiou on “The translational research of induced pluripotent stem cells in personalised medicine” and by Dr. Lee-Jun Wong on “Molecular diagnosis of mitochondrial diseases”.

At its Executive Board meeting, AOMC members agreed to accept the proposal from Singapore to host the 16<sup>th</sup> annual scientific meeting of AOMC from 6<sup>th</sup> to 8<sup>th</sup> August, 2017, immediately preceding Singapore’s National Day on 9<sup>th</sup> August, to be organised by Drs Josiah Chai and Umapathi Thirugnanam. Further information on AOMC and future meetings may be obtained by visiting the web site:

[www.aomc.info](http://www.aomc.info)

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