

HISTORY OF NEUROLOGY

Neuromuscular disorders in Asia and Oceania: A history of the Asian and Oceanian Myology Center (AOMC)

Allan H. Bretag

School of Pharmacy and Medical Sciences, University of South Australia, Adelaide, Australia

BEGINNINGS

In 1971, individual patient/parent organisations in Europe convened the European Alliance of Neuromuscular Disorders Associations (EAMDA).¹ Eventually, as the success of EAMDA grew, members of its executive board, Ysbrand Poortman of the Netherlands (Vereniging Spierziekten Nederland, VSN), Giovanni Nigro of Italy (Unione Italiana Lotta alla Distrofia Muscolare, UILDM) and Reinhardt Rüdell of Germany (Deutsche Gesellschaft für Muskelkranke, DGM) began to envisage the establishment of a European centre of excellence for the initiation and co-ordination of neuromuscular research.² By late 1987, Poortman, as vice-president responsible for medical research, was presenting the case to the EAMDA board. Together with Bernard Barataud and Pierre Birambeau (the initiators of the very financially successful Telethon of the Association Française contre les Myopathies, AFM), and support from the Muscular Dystrophy Group of Great Britain and Northern Ireland (MDGGB), the idea of the centre was realised in mid December 1988.² The first workshop of the European Neuromuscular Centre (ENMC) was held in Paris on the 18th of February 1989. Of significance here, is that Alan Emery was employed by the fledgling ENMC as its Research Director from 1st April 1990.² Funding of ENMC has been provided through contributions from European national patient/parent and other organisations. The aims of ENMC have been to hold workshops on specific neuromuscular diseases (NMDs) in relation to diagnostic criteria, genetic screening, disease registers, tissue banking, clinical trials, biomarkers, outcome measures and standards of care. Subsequently, numerous publications have been produced.

During the years 1990 to 2000, the reach of

ENMC was expanded and included invitations to clinicians and scientists in parts of the world outside Europe to attend ENMC's specific disease workshops. Beginning in the early to mid 1990s, Japanese and Australian researchers with relevant expertise were the first from the Asian and Oceanian region to be invited to participate in these workshops. Among these were, Kiichi Arahata, Kyugo Hirabayashi and Kiichiro Matsumura (Japan), and Nigel Laing and Kathryn North (Australia).

ESTABLISHMENT OF AOMC

Although the Asian and Oceanian Myology Center was established only in 2001 its antecedents go back well before that time, to a period when patient/parent groups began to gather for mutual support. Perhaps the earliest of these was the Muscular Dystrophy Association of South Australia founded in 1954. Soon neuromuscular research in the region was flourishing, particularly in Japan and Australia, often with substantial support from patient/parent organisations. In 1971, the II International Congress on Muscle Diseases was held in Perth, Australia, the XI International Congress of Neuropathology in Kyoto, Japan, in 1990 and the XIII International Congress of Neuropathology in Perth in 1997. In the same period, the VIII International Congress on Neuromuscular Disorders, was held in Kyoto in 1994 and the IX International Congress on Neuromuscular Disorders, in Adelaide, Australia in 1998. The last two of these major scientific/clinical congresses were accompanied by large lay conferences of the leaders of international patient/parent organisations (under the auspices of the World Alliance of Neuromuscular Disorder Associations, WANDA) along with patients and parents, themselves. Latest research developments were conveyed to the lay conferences by specialist

Address correspondence to: Allan H. Bretag, School of Pharmacy and Medical Sciences, University of South Australia, Adelaide, SA 5000, Australia.
Email: a.bretag@unisa.edu.au

speakers from the scientific/clinical congresses. By then the stage was set.

In June 1999, at the 70th ENMC Workshop on Nemaline Myopathy in Naarden, the Netherlands, Alan Emery, who was about to retire from his position as ENMC Research Director, suggested to participants from Japan (Ikuya Nonaka) and Australia (Edna Hardeman, Nigel Laing, Kathryn North, Kristen Nowak) that they might consider forming an Asian and Oceanian equivalent of ENMC. Ikuya Nonaka took the idea back to Japan and together with suggestions and help from Hideo Sugita (then president emeritus of the National Center for Neurology and Psychiatry, Tokyo) began contacting potential national representatives throughout Asia and Oceania to determine their interest in forming a regional organisation similar to ENMC. Having ascertained broad support by mid 2000, they convened a meeting in Tokyo for January 20-21, 2001.

This first meeting saw some 22 participants from 11 different countries/regions in attendance (Figure 1). Those present included: from Australia, Byron Kakulas; from China, Dingguo Shen; from Chinese Taipei, Yuh-Jyh Jong; from India, Veena Kalra; from Indonesia, Sangkot Marzuki; from Japan, Hideo Fukunaga, Yu-ichi Goto, Yukiko K. Hayashi, Tadayuki Ishihara, Hisanobu Kaiya, Ichizo Nishino, Ikuya Nonaka, Eijiro Ozawa, Eijiro Satoyoshi, Hideo Sugita, Shin'ichi Takeda;

from Korea, Yong Seung Hwang; from Malaysia, Kum-Thong Wong; from Singapore, Woon Chee Yee; from Thailand, Siwaporn Chankrachang, Rawiphan Witoonpanich; from the Philippines, Raymond Rosales. This group then determined to name itself the Asian and Oceanian Myology Center and to hold annual scientific meetings. From among the participants an Executive Board of country representatives was appointed with Alan Emery (not present at the meeting) as an Advisory Board Member.

AOMC CONFERENCES

The aims of AOMC were necessarily different from those of ENMC largely due to an absence of the ready financial support from national NMD patient/parent organisations that was available in Europe. None of the countries in the region had patient/parent groups with the wealth of their large and successful European counterparts. Many developing countries in the Asia/Pacific did not even have established patient/parent groups. It was decided, therefore, that rather than holding many small workshops to co-ordinate and facilitate research in specialised fields, the function of AOMC would be largely educational, providing research updates and training workshops for young clinicians, medical scientists, allied health workers and nurses. AOMC would promote the highest



Figure 1. First AOMC Meeting, Tokyo, January 20-21, 2001. Front row from left: Yukiko Hayashi, Veena Kalra, Eijiro Ozawa, Byron Kakulas, Hideo Sugita, Eijiro Satoyoshi, Ikuya Nonaka, Woon Chee Yee. Back row from left: Ichizo Nishino, Raymond Rosales, Yuh-Jyh Jong, Yu-ichi Goto, Yong Seung Hwang, Hisanobu Kaiya, Hideo Fukunaga, Sangkot Marzuki, Shin'ichi Takeda, Dingguo Shen, Rawiphan Witoonpanich, Siwaporn Chankrachang, Kum-Thong Wong, Tadayuki Ishihara (photo courtesy of Dr. Eijiro Ozawa).

Table 1: The yearly AOMC conferences

AOMC Scientific Meetings	Organiser/s	Main NMD Themes*
1st Meeting, January 20-21, 2001 Tokyo Interim Meeting, November 9-10, 2001 Chiang Mai	Ikuya Nonaka, Hideo Sugita Rawiphan Witoonpanich, Siwaporn Chankrachang	NMDs in General Mitochondrial Myopathy
2nd Meeting, September 17-19, 2002 Beijing	Dingguo Shen	Myopathies, Muscle Channelopathies, Gene Therapy of NMDs
3rd Meeting, January 8-9, 2004 Singapore	Woon Chee Yee	DMD New & Future Therapy Glycogen Storage Diseases
4th Meeting, March 3-4, 2005 Kaohsiung	Yuh-Jyh Jong	Myotonic Dystrophy, Spinal Muscular Atrophy
5th Meeting, May 25-27, 2006 Cebu	Raymond Rosales	EMG & Nerve Conduction, Inflammatory Myopathies, Metabolic Myopathies, Basic Myopathology
6th Meeting, June 21-23, 2007 Penang	Kum Thong Wong, Khean Jin Goh	Congenital MDs, Congenital Myopathies, Immunotherapy of Peripheral Neuropathies
7th Meeting, November 13-14, 2008 Melbourne	Andrew Kornberg	Congenital Myopathies & MDs, Inherited Myopathy Therapy, Acquired Myopathies, Inherited Neuropathies
8th Meeting, May 23-24, 2009 Mumbai	Satish Khadilkar	Radiology & Histopathology, Molecular Therapy in DMD, Inflammatory Myopathies, Myasthenia Gravis
9th Meeting, March 25-26, 2010 Seoul	Young-Chul Choi, Dae-Song Kim	Muscular Dystrophies, Metabolic Myopathy, Autoimmune NMDs
10th Meeting, February 25-26, 2011 Auckland	David Hutchinson	Molecular Mechanisms & Diagnostic Methods in NMDs, Acquired Myopathies. Limb Girdle MD
11th Meeting, June 7-8, 2012 Kyoto	Ikuya Nonaka, Ichizo Nishino	Glycogenoses, Lipid & Mitochondrial Dysmetabolism, Care and Management of NMDs
12th Meeting, June 6-8, 2013 Xi'an	Dingguo Shen, Liying Cui, Chuanqiang Pu	Inflammatory Myopathies, Metabolic Myopathies, Clinical Trials in NMDs, Diagnostic techniques in NMDs, GNE Myopathy
13th Meeting, May 15-17, 2014 Manila	Ludwig Damian, Raymond Rosales	Muscular Dystrophies, Mitochondrial & Metabolic Myopathies, Channelopathies & Toxic Myopathies, Treatment Strategies in NMDs
14th Meeting, March 1-4, 2015 Bangkok	Charunghai Dejthevaporn, Rawiphan Witoonpanich	Congenital Myasthenic Syndrome, Childhood-onset Myopathy, Autoimmune Myopathy
15th Meeting, May 26-28, 2016 Hsinchu	Yuh-Jyh Jong	Spinal Muscular Atrophy, Distal Myopathies
16th Meeting, August 6-8, 2017 Singapore	Umapathi Thirugnanam, Josiah Chai	Inflammatory Myopathies, Multidisciplinary Management of Chronic NMDs, Paediatric Myology & Asian Perspectives
17th Meeting, July 23-25, 2018 Kuala Lumpur	Khean Jin Goh, Kum Thong Wong	Inflammatory Myopathies, Translational Medicine, Paediatric NMDs

*In addition to the Main Themes at each conference, updates on many different NMDs were provided, new research was communicated in plenary lectures, oral and poster sessions and a number of clinical cases were always presented.

quality in standards of care and encourage basic and clinical research in the NMD field. Each year the AOMC conference would be moved from country to country throughout the region to avoid undue travel expenses for young local participants while faculty members would generally have to provide for their own travel and accommodation costs. Where possible, AOMC would solicit funds to provide travel grants to young participants from developing countries and would provide poster and oral presentation prizes, as funds allowed. As well as the conference moving from country to country, each year several symposium themes would be selected, typically of relevance to the host country (Table 1), with major presentations invited from among AOMC faculty and from experts chosen from elsewhere. General methods and advances in the understanding and diagnosis of NMDs and in their therapy would be a common feature of each meeting. Three fixed components of these conference are: (1) to begin, a basic course in fields of Electrophysiology, Imaging, Muscle Biopsy Procedures and Processing, and Myopathology; (2) to conclude, a Clinico-Pathological Conference; (3) an AOMC Executive Board meeting. Frequently, AOMC scientific meetings have been held alongside and partly supported by meetings of the neuroscience or neurology societies of the country in which the AOMC meeting is being held. In Table 1, themes from these parallel meetings that have fallen outside the field of NMDs have not been listed.

Meetings have been very successful with some hundreds of delegates attending each of the last AOMC conferences. During its existence there have been four presidents of the organisation, Hideo Sugita, Byron Kakulas, Ikuya Nonaka and Raymond Rosales. Recent years have seen the passing of AOMC Executive Board members Woon Chee Yee (in 2011), long-term Secretary and later Vice-President of AOMC, and John Mc.C. Howell (in 2017) who wrote the reports on each AOMC meeting as published annually in the journal *Neuromuscular Disorders* until 2011. In addition to the clinical and scientific proceedings, relevant cultural experiences have often been included at the Welcome Reception, during the Opening Ceremony, at the Gala Dinner or otherwise attached to the meeting. To mention just a few: Look Choop (a Thai dessert, coloured and flavoured mung bean paste miniature fruits and flowers once reserved for Thai royalty) for morning tea in Chiang Mai; a meal at a traditional Peking duck restaurant in Beijing; a performance of the bamboo dance “tinikling” in the Philippines;

a short classical music concert in Hsinchu; a guided walking tour around old Georgetown (Penang); a demonstration of Japanese ink brush calligraphy by a DMD patient in Kyoto; a performance of “A Song of Everlasting Sorrow” at the Huaqing Palace near Xi’an; an address by CMT patient Yip Pin Xiu, winner of three swimming Gold Medals in Paralympic Games, in Singapore.

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