

MINUTES FOR THE 2ND ASIA-PACIFIC ALS/MND CONSORTIUM MEETING

The second Asia-Pacific ALS/MND Consortium meeting was held on 11 December 2015 at Room Cordova 6, Marriot Hotel, Orlando, Florida.

The meeting began at 1pm and was presided over by Professor Matthew Kiernan (Australia) with support from Professor Gen Sobue (Japan), Carol Birks (Chair of the International Alliance of ALS/MND Associations) and Kiki Qu (Taiwan MND Association).

1. Welcome message - Professor Matthew Kiernan
 - a) Increasing interest in developing collaborations within various regions; references made to the European and North American consortiums— referred to as ENCALS and NEALS respectively
 - b) The Asia-Pacific region represents more than 60% of the world's population and therefore a great opportunity for collaboration
2. Background on the existing work that is being performed in Japan – Professor Gen Sobue
 - a) Patient information is captured on a three-monthly basis
 - b) Acquisition of biological specimens and linking this with clinical information
3. Carol Birks, Chair of International Alliance of ALS/MND Associations:
 - a) Welcomed the development of this collaboration.
 - b) Increasing interest in the region and new members have joined the Alliance in 2015 from Malaysia, China and India.
 - c) The Alliance is committed to supporting the development of patient organisations in the region.
4. Minutes of last meeting approved
5. Model and structure of the Asia-Pacific ALS/MND consortium
 - a) Each member country shared their experience of establishing a national Registry
 - i. The purpose of collecting data across the region
 - ii. Funding systems in place that may facilitate further growth
 - b) The need for key registry questions to be addressed
 - i. JACALS (Japan) – identifying mutations in different ethnic groups represented by the group
 - ii. Establishing the frequency of FTD in ALS patients from the Asia-Pacific countries
 - c) Professor Kaji as Vice-President of World Federation of Neurology indicated interest from World Federation of Neurology and discussed launch of the recent Asian

initiative. Potentially, the WFN could facilitate the Asia-Pacific ALS/MND Consortium by engaging other member countries

6. Proposal for development of Asia-Pacific website and web-based patient registry
 - a) General agreement for the need of a simple website and establishing the common metrics for capturing patient data in the Registry
 - b) Possibilities of sources of funding
 - i. Clinical trials
 - ii. WFN
 - iii. International Alliance
 - iv. Support from individual member countries
 - v. Philanthropic funds

7. Individual countries were invited to share their experience on the National Registry
 - a) China - Professor Liying Cui
 - i. Hospital-based Registry
 - ii. Information from Registry confirmed differences i.e lower incidence of FTD and *C9orf72* mutations
 - iii. Instrumental in advancing ALS research in the country

 - b) Korea - Professor Seung Hyun Kim
 - i. Identified 2,500 Koreans have MND
 - ii. Database includes acquisition of DNA and skin biopsy samples
 - iii. Established the low prevalence of *C9orf72* mutations in Koreans

 - c) Australia – Associate Professor Rob Henderson
 - i. The Australian MND Registry captures 40% of population and gathers information on phenotypes/health utilisation/medical interventions
 - ii. Expressed interest in comparing between individual countries

 - d) Taiwan - Professor Ching-Piao Tsai and Kiki Qu
 - i. Hospital based registry recording clinical information and also
 - ii. Registry was modelled on existing Multiple Sclerosis database

8. Calls for suggestion of a group name
 - a) PACTALS – Pan Asian Consortium for Treatment and Research in ALS
 - b) APAC – Asia-Pacific ALS/MND Consortium

➤ Following discussion and voting, majority voted for PACTALS

9. Proposal for the next satellite meeting to be held at the Asia Oceania Congress of Neurology in Kuala Lumpur, Malaysia (18-21 August 2016) – to be organised and chaired by Nortina Shahrizaila (Malaysia)

- a) Matters to be discussed at the meeting:
 - i. Model for Registry that can be utilised by member countries
 - ii. Models for funding
- b) Suggestion to review current registries and identify common questions
 - i. To be initiated by Nortina Shahrizaila and Korean ALS researchers
- c) Future meetings after Satellite meeting in Kuala Lumpur
 - i. The 27th International Symposium on ALS/MND in Dublin, Ireland from 7-9 December 2016
 - ii. World Congress of Neurology, Kyoto, Japan in 2017 (dates to be confirmed)
 - iii. Aim for the first dedicated meeting of the Consortium in 2017, possibly in Beijing

10. List of registered members to date

(Inaugural meeting in Brussels 2014 and 2nd meeting in Orlando 2015)

Name	Country	Name	Country
Ali, David	Australia	Morimotoa, Satoku	Japan
Atsuta, Naoki	Japan	Morita, Mitsuya	Japan
Auon, Samar	Australia	Nagano, Seiichi	Japan
Bae, Jong Seok	South Korea	Nagashima, Kazuaki	Japan
Banno, Haruhiko	Japan	Nash, Janet	Australia
Birks, Carol	Australia	Ni, Feng	China
Blizzard, Catherine	Australia	Ni, Richard	
Bokuda, Kota	Japan	Ogino, Mieko	Japan
Caga, Jashelle	Australia	Ogino, Yutaka	Japan
Chang, Hao-Teng	Taiwan	Oh, Kiwook	
Connors, Karol	Australia	Ono, Suzuka	Japan
Cui, Liying	China	Amneta Paranjape	India
Devenney, Emma	Australia	Park, Jenseok	
Dickson, Tracey	Australia	Perera, Nirma	Australia
Endo, Fumito	Japan	Po, Chih Chen	Taiwan
Fan, Dongsheng	China	Qu, Kiki	Taiwan
Geevasinga, Nim	Australia	Reardon, Katrina	Australia
Goh, Khean-Jin	Malaysia	Rogers, Mary-Louise	Australia
Hadano, Shinji	Japan	Rutter, Richard	Singapore
Henderson, Robert	Australia	Nakamura, Ryoicho	Japan
Hogden, Anne	Australia	Schultz, David	Australia
Hu, Char-Jong	Taiwan	Shahrizaila, Nortina	Malaysia
Hutchinson, Nicole	Australia	Sheean, Rebecca	Australia
Iguchi, Yohei	Japan	Shibuya, Kazumoto	Japan
Inoue, Haruhisa	Japan	Shimizu, Toshio	Japan
Iwasaki, Yasuo	Japan	Skeels, Andrew	Australia
Kaji, Ryuji	Japan	Sobue, Gen	Japan

Kano, Osamu	Japan	Sonoo, Masahiro	Japan
Katayama, Hideo	Japan	Tada, Saduro	Japan
Kiernan, Matthew	Australia	Tan, Rachel	Australia
Kim, Seung Hyun	South Korea	Tenashima, Tomoya	Japan
King, Anna	Australia	Tsai, Ching-Piao	Taiwan
Kokubo, Yasumasa	Japan	Turner, Brad	Australia
Komai, Kiyonobu	Japan	Vohino, Akiko	Japan
Kuang Ming	Taiwan	Watanabe, Seiji	Japan
Kuwabara, Satoshi	Japan	Watanabe, Yasuhiro	Japan
Kwak, Shia	Japan	Watson, Beth	New Zealand
Latif, Lydia	Malaysia	Weston, Richard	Australia
Lee, Michael	Australia	Yamanaka, Koji	Japan
Leung, Jacqueline	Australia	Yerbury, Justin	Australia
Liu, Xiaolu		Yin Isabel	Taiwan
Loh, Ee Chin	Malaysia	Yu, Joyce	Taiwan
Mangelsdorf, Marie	Australia		
Matsuo, Tsuyoshi	Japan		
Mitchell, Kathy	Canada		