

# MINUTES FOR THE 3<sup>rd</sup> PAN-ASIAN CONSORTIUM FOR TREATMENT AND RESEARCH IN ALS (PACTALS)

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The 3<sup>rd</sup> PACTALS meeting was held on 20 August 2015 at Room 405, Level 4, Kuala Lumpur Convention Centre, Kuala Lumpur, Malaysia.

The meeting began at 4pm and was presided over by Professor Nortina Shahrizaila (Malaysia) and Professor Matthew Kiernan (Australia).

1. Welcome message - Professor Nortina Shahrizaila (Malaysia)
  - a) Thanked everyone for attending and welcomed new members from the South-East Asian region
  
2. Background, structure and purpose of the PACTALS – Professor Matthew Kiernan (Australia)
  - a) Explained the inception of PACTALS 2 years earlier - Asia-Pacific region represented >60% of the world's population presenting a great opportunity for collaboration
  - b) Described the structure of PACTALS where each country has 2-3 representatives to further discussions on the Group's activities
  - c) Plans to establish a Registry for PACTALS currently underway which will investigate clinical patterns and provide a platform for future clinical trials in the region
  
3. The role of patient organisations - Carol Birks, Chair of International Alliance of ALS/MND Associations (Australia)
  - a) Explained the role of International Alliance of ALS/MND Associations
  - b) Increasing interest in the region and new members have joined the Alliance in 2015 from Malaysia, China and India.
  - c) Encouraged the involvement of new members from the region
  
4. The Australian MND Registry – A/Professor Paul Talman (Australia)
  - a) Introduced the online Australian MND Registry – incorporates data from various centres in Australia
  - b) Individual sites are given a unique identifier and patient details are de-identified
  - c) Prospectively collected more than 2000 patients to date – the key Registry questions covers the most basic information required for patient disease characteristics
  - d) Proposed how a similar platform could be utilised for PACTALS Registry
    - i. Each country will input the basic disease information as per the key Registry questions
    - ii. Scope to add further questions that is felt to be important for the different countries
    - iii. Individual countries will have a National Steering Committee which oversees the collection of data nationally – they will have access to their own dataset but not others
    - iv. The entire PACTALS Registry will be governed by a Steering Committee made up of individual country lead/representatives appointed

- v. Activities relating to the overall PACTALS registry will be with the agreement of the PACTALS Steering Committee.
- 5. Japanese Consortium for ALS (JaCALS) – Professor Gen Sobue (Japan)
  - a) Described the background of JaCALS which has collected data on more than 3000 patients in Japan
  - b) Shared the studies that have arisen from JaCALS including studies investigating genetic mutations in ALS patients and prevalence of FTD
- 6. Individual countries were invited to share their experience on MND/ALS in their country
  - a) Myanmar - Professor Win Min Thit
    - i. At present, limited information available on patients
    - ii. No standard measure of capturing data
    - iii. Keen to contribute towards the Registry
  - b) Singapore – Dr Josiah Chai
    - i. To date, over the last 6 years have captured 151 patients
    - ii. Retrospective studies ongoing to investigate the patterns seen in Singapore
    - iii. Will contribute towards Registry
  - c) Malaysia – Dr Ng Woon Fang
    - i. Development of clinical service in the last 5 years – patients are seen in multidisciplinary setting with Neurology, Palliative Care Medicine and Rehabilitation Medicine
    - ii. Since 2009, prospective data collection with almost 150 patients seen over the last 6 years
    - iii. Close relationship with MND Malaysia to reach out to patients and other Centres managing ALS
    - iv. Will contribute towards Registry
  - d) Indonesia – Premana Prebadi (ALS Indonesia)
    - i. Patient initiated blog which led to establishment of ALS Indonesia
    - ii. At present, no designated Centre that manages ALS/MND specifically
    - iii. Keen to work with PACTALS to raise awareness amongst clinicians of ALS/MND
- 7. Update of PACTALS activities – Nortina Shahrizaila
  - a) PACTALS website now available at <http://pactals.org> and members can register at the website
  - b) Recent publication of Review article by some members of the PACTALS group on ALS and motor neurone syndromes in Asia in Journal of Neurology, Neurosurgery and Psychiatry which was accompanied by a Podcast
  - c) Next Satellite meeting is planned in conjunction with the 27<sup>th</sup> International Symposium on ALS/MND in Dublin, Ireland on 7 December 2016
  - d) Plans for a dedicated scientific meeting for PACTALS (possibly pre-Congress) at the forthcoming World Congress of Neurology 17-21 September 2017

8. Closing remarks – Professor Matthew Kiernan
  - a) Plans to move forward with establishing the PACTALS Registry and further details on the progress will be discussed at the next Satellite meeting in Dublin
  
9. List of registered members to date  
(Inaugural meeting in Brussels 2014, 2<sup>nd</sup> meeting in Orlando 2015, 3<sup>rd</sup> meeting Kuala Lumpur)

Name	Country	Name	Country
Ali, David	Australia	Morimotoa, Satoku	Japan
Ahmad-Annuar, Azlina	Malaysia	Morita, Mitsuya	Japan
Aliling, Nicole	Philippines	Nagano, Seiichi	Japan
Atsuta, Naoki	Japan	Nagashima, Kazuaki	Japan
Ang, Mavis	Singapore	Nash, Janet	Australia
Auon, Samar	Australia	Ni, Feng	China
Bae, Jong Seok	South Korea	Ni, Richard	China
Banno, Haruhiko	Japan	Ng, Woon Fang	Malaysia
Birks, Carol	Australia	Ogino, Mieko	Japan
Blizzard, Catherine	Australia	Ogino, Yutaka	Japan
Bokuda, Kota	Japan	Oh, Kiwook	Japan
Caga, Jashelle	Australia	Ono, Suzuka	Japan
Chai, Josiah	Singapore	Paranjape, Amneta	India
Chang, Hao-Teng	Taiwan	Panggabean, Reggy	Indonesia
Connors, Karol	Australia	Park, Jenseok	Korea
Cui, Liying	China	Park, Jin Sung	Korea
De Roxas, Ranhel	Philippines	Patterson, Rachel	Int Alliance
Devenney, Emma	Australia	Perera, Nirma	Australia
Dickson, Tracey	Australia	Po, Chih Chen	Taiwan
Endo, Fumito	Japan	Porlas, Romeo	Philippines
Fan, Dongsheng	China	Prado, Mario	Philippines
Geevasinga, Nim	Australia	Premadi, Premana	Indonesia
Goh, Khean-Jin	Malaysia	Puvanarajah, Santhi	Malaysia
Gourie-Devi, M	India	Qu, Kiki	Taiwan
Hadano, Shinji	Japan	Reardon, Katrina	Australia
Hasegawa, Yukiyo	Japan	Rogers, Mary-Louise	Australia
Henderson, Robert	Australia	Rutter, Richard	Singapore
Hiew, Fu Liong	Malaysia	Ryoicho, Nakamura	Japan
Hirose, Takahiko	Japan	Schultz, David	Australia
Hogden, Anne	Australia	Shahrizaila, Nortina	Malaysia
Hu, Char-Jong	Taiwan	Sheean, Rebecca	Australia
Hutchinson, Nicole	Australia	Shibuya, Kazumoto	Japan
Iguchi, Yohei	Japan	Shimizu, Toshio	Japan

Inoue, Haruhisa	Japan	Simon, Neil	Australia
Iwasaki, Yasuo	Japan	Skeels, Andrew	Australia
Kaji, Ryuji	Japan	Sobue, Gen	Japan
Kano, Osamu	Japan	Sonoo, Masahiro	Japan
Katayama, Hideo	Japan	Sujipto, Alice	Indonesia
Kennerson, Marina	Australia	Tada, Saduro	Japan
Khosama, Herlyani	Indonesia	Tan, Rachel	Australia
Kiernan, Matthew	Australia	Talman, Paul	Australia
Kim, Seung Hyun	South Korea	Tenashima, Tomoya	Japan
Kimura, Fumiharu	Japan	Thirugnanam, Umapathi	Singapore
King, Anna	Australia	Tsai, Ching-Piao	Taiwan
Kokubo, Yasumasa	Japan	Turner, Brad	Australia
Komai, Kiyonobu	Japan	Vijayan, Joy	Singapore
Kuang Ming	Taiwan	Vohino, Akiko	Japan
Kuniani, Nani	Indonesia	Vucic, Steve	Australia
Kuwabara, Satoshi	Japan	Watanabe, Seiji	Japan
Kwak, Shia	Japan	Watanabe, Yasuhiro	Japan
Latif, Lydia	Malaysia	Watson, Beth	New Zealand
Lee, Michael	Australia	Weston, Richard	Australia
Lee, Yi Chung	Taiwan	Win Min Thit	Myanmar
Leung, Jacqueline	Australia	Yamanaka, Koji	Japan
Liu, Xiaolu	China	Yerbury, Justin	Australia
Loh, Ee Chin	Malaysia	Yin Isabel	Taiwan
Mangelsdorf, Marie	Australia	Yu, Joyce	Taiwan
Matsuo, Tsuyoshi	Japan		
Mitchell, Kathy	Canada		