**The Pan-Pacific Alliance of the MSA Coalition: Clinicogenetic analyses**

**Memorandum of Understanding**

**Background**

Multiple system atrophy (MSA) is a neurodegenerative disease in which effective treatments are unavailable. Genetic factors are an important component of variance in any biological system, although there are only a small number of families with multi-incident MSA, a meta-analysis of relatively rare genetic variability identified by high-throughput sequencing (HTS) technologies is worthwhile.

**Specific Aims**

1. Prospective cross-sectional and longitudinal data-sharing including neurological, clinical, biomarker and genetic data between Project members.
2. To establish appropriate criteria for authorship and acknowledgments.

**1. Prospective cross-sectional and longitudinal data-sharing including neuropsychological, neurological, clinical, biomarker and genetic data between Project members.**

1. To develop an ethical and legal framework to enable all parties, Investigators and their institutions, to share data and to work as a distributed team.
2. To create a web forum for project communication amongst research professionals, including a meta-data directory of expertise, resources and data with an elected steering committee.
3. Clinical and genetic data sets would be surveyed to ascertain diagnostic criteria applied, which scales/instruments and whether any genetic analysis had been performed.
4. We plan to assess performance on candidate loci and in exploratory analyses of harmonized clinicogenetic data, with stratification by MSA subtype, duration and disability as quantitative traits, adjusting for age and gender.

**2. To establish criteria of authorship.**

*Authorship, Usage of Data*

*The Pan-Pacific Alliance of the MSA Coalition* is to be inclusive. All raw data is to be made available to all Project members, including access to the website, biomarker and genetic results. However, no data will be made available beyond the Project without prior agreement of its members.

We follow recent ICMJE criteria on authorship (Alfonso et al. 2017). Funding agencies will be acknowledged on all manuscripts. Nevertheless, all investigators have the right to share their own data as they wish and publish it independently. As a courtesy, prior approval should be sought before such publication.

*Institutional Review Board/Ethical Approvals*

Documentation of appropriate IRB/Ethics Board approval for each study participant is required. The informed consent should include sharing of de-identified clinical and other data. All studies involving research on human subjects must work in accordance with the World Medical Association Declaration of Helsinki and de-identified data provided by participating members must be collected with the participant’s informed consent.

*Intellectual Property*

No investigator seeks to gain financially from the successful outcome of the Project studies, but funding must be sought. All findings will be publicly disclosed on completion of the study. By signing this agreement to participate in *The Pan-Pacific Alliance of the MSA Coalition*, members acknowledge they have been made aware of these provisions.

*In conclusion*

By signing this agreement to participate in *The Pan-Pacific Alliance of the MSA Coalition*, members acknowledge they have been: 1) made aware of these provisions; 2) agree to take part in the studies described, and; 3) will provide the above requested data according to ethical standards.

**Signed: Date:**

**Investigator name:**

**Institution:**

**Institutional official: Date:**