

MSBase Scientific Leadership Group Regulations

10th June 2014

Article I – Introduction: The MSBase Registry and the MSBase Foundation

The MSBase registry formed in 2003 and was initially governed by a steering committee. In June 2004 the steering committee became known as the MSBase Scientific Advisory Board (SAB), an advisory board to the new owner of the MSBase registry, the MSBase Foundation Ltd (MSBF). The MSBF is a charitable organisation incorporated as a company limited by guarantee in Australia.

The amended MSBF Constitution of 2013 recognised the new name adopted by the SAB in 2006, the Scientific Leadership Group (SLG). According to the MSBase Constitution of 2013 the role of the SLG remained to:

- (a) Provide scientific assistance to the Foundation with respect to the Foundation's database and website;
- (b) Make recommendations to the Foundation with respect to financing of projects
- (c) act as custodians of the data on the Foundation's database; and
- (d) Become a self-constituting entity, subject to the Project Regulations, Observational Plan and any other requirements of the Foundation,

together with such other matters as the Foundation determines from time to time.

The MSBF provides financial and logistical support to maintain the database.

The Foundation's intention is to support this international MS registry over the long-term.

The Foundation indemnifies the SLG members against legal proceedings and compensation claims arising out of their direct activities as SLG members, except if such claims arise as a result of their gross negligence or wilful misconduct.

Article II – Regulations of the MSBase Scientific Leadership Group

1. Introduction:

As a scientific advisory group to the MSBF, the SLG reviews and advises on matters relating to the MSBase Registry and associated research activities. All members, including the chairperson of the SLG, are chosen among neurologists, scientists and nurses with senior experience in the field of multiple sclerosis. Membership of the SLG is managed and approved by the existing members of the group.

The SLG may form subcommittees as required to efficiently discharge its role.

2. Quorum:

There is no maximum number of members of the SLG. A quorum is defined as a minimum of 2/3 of all members.

3. Election and removal of members

- a. The MSBase SLG is self-constituting.
- b. All decisions regarding the appointment of a new member, or the dismissal or replacement of an existing member shall be made by a 2/3 majority of the votes cast. If requested by a member, the vote will be secret.
- c. All members are required to complete a Competing Interest Form annually to be reviewed by the SLG CI committee.

4. Term of appointment

- a. Members of the SLG are appointed for a two year period. The initial period commenced June 27-2004 and concluded June-2006. From 2014 the two year term will finish at the end of the face to face meeting held in conjunction with ECTRIMS.
- b. At the beginning of each term members will be requested to sign the regulations to confirm that they are able to fulfil the requirements of an SLG member.

5. Named Officers of the SLG

a. Chair

- i. The Chairperson is responsible for setting the agenda of each meeting and the review and distribution of meeting minutes
- ii. The chairperson shall lead the SLG and chair each meeting.
- iii. In their absence, a meeting shall be chaired by the deputy chair
- iv. The Chairperson shall be elected for a term of two years, commencing at the end of the face to face meeting at ECTRIMS every even year.
- v. The Chairperson can be re-elected to a second two-year term.

b. Deputy Chair (Chair-elect)

- i. The Deputy Chair is the Chair-elect of the SLG, and will replace the Chair in his/her position after two years
- ii. The deputy chair shall be elected for a term of two years, commencing at the end of the face to face meeting at ECTRIMS every even year.

c. Past Chair

- i. The past chair will remain for two years
- ii. In general, the role of the past chair is to provide administrative assistance for the purpose of ensuring continuity of business to the chair and vice-chair.

6. Election of Officers

- a. All SLG members may nominate for the position of deputy chair when it becomes vacant, and for the position of chair if the deputy chair is unable or unwilling to fill the position. In case of multiple nominations, there will be a secret ballot of all SLG members, conducted by the chair. The nominee with the most votes is appointed to the position. In case of a tie, the position will be decided by the drawing of lots.
- b. Members are allowed to nominate a proxy if they cannot attend a specific meeting. This proxy does have voting rights.

7. Meeting frequency

- a. The SLG shall meet by teleconference 3-5 times annually and one face to face meeting held in conjunction with ECTRIMS. Meeting frequency for the coming year will be determined at the annual meeting.
- b. Members may nominate a proxy to attend the meeting on their behalf.
- c. Members (or their proxy) are expected to attend a minimum of 2/3 of the scheduled meetings.
- d. Meetings may be attended by invited non-voting experts.

8. Voting

- a. Each member of the SLG has one vote
- b. Voting may be conducted during meetings or via email.
- c. With the exception of the election and removal of members, all decisions shall be made by a majority of the votes cast,. If requested by a member, the vote will be secret.
- d. All decisions of an SLG sub-committee shall be made by a majority of the votes cast,. If requested by a member, the vote will be secret.

9. Composition

At March 2014 the SLG comprised:

- R. Alroughani, MD, FRCPC, Kuwait
- C. Boz, MD, Turkey
- H. Butzkueven MBBS PhD, Melbourne, Australia
- J. Chapman MD, Tel Aviv, Israel
- E. Cristiano MD, Buenos Aires, Argentina
- F. Grand'Maison MD, Montreal, Canada
- O. Gray, MD, Belfast, United Kingdom
- G. Izquierdo MD, Sevilla, Spain
- J. Haartsen, Masters in Nursing, Melbourne, Australia
- J. Herbert, MD, New York, USA
- D. Horakova, MD, Prague, Czech Republic
- L. Kappos MD, Basel, Switzerland
- T. Leist MD, Philadelphia, USA
- T. Petersen, MD, Denmark
- D. Pöhlau MD, Asbach, Germany
- M. Trojano, MD, Bari, Italy
- F. Verheul MD, Gouda, Netherlands.

An up to date list of SLG members can be found on the MSBase website www.msbase.org.

Article III - Responsibilities of the MSBase SLG

1. The responsibilities of the SLG are set out in detail in the MSBase Observational Plan. In principle, the SLG will perform the following functions.

- a. Closely monitor all MSBase research activities and supervise the general conduct of the registry.
- b. Take all reasonable steps to ensure credibility and integrity of the database, control publication of composite data and maintain confidentiality.
- c. Act as the sole custodian of the actual data contained in the MSBase database.
- d. Actively facilitate collaboration between centres participating in any study.
- e. Actively promote and participate in the MSBase registry.
- f. Set the three year strategic plan for MSBase and review progress annually.

Article IV - Reimbursement

The MSBase Foundation will aim to reimburse the SLG for all reasonable costs for travel and accommodation if approved in advance. Members of the SLG may also receive an honorarium from the Foundation or its appointed agents for specific projects, the amount of which will be fixed in advance of each meeting. The above reimbursements are subject to the availability of sufficient Foundation or agent funds and must be included in the budget for the relevant year.

Article V - Relations with other research institutes

In order to enhance the functionality or fulfil the mission of MSBase, the SLG is entitled to seek long-term relationships with other research institutes or other groups. The establishment of such collaborations is subject to the approval of the Foundation.

Article VI - Amendment of Regulations

These regulations may be amended by the SLG but must comply with the Constitution of the MSBase Foundation.