



ABN: 23 109 714 310

MSBase Scientific Leadership Group Regulations

February 2021

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

The MSBase Registry (the 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 licensee of the MSBase Registry Platform, the MSBase Foundation Ltd (MSBF). The MSBF is a charitable organisation incorporated as a company limited by guarantee in Australia.

In 2006, the SAB became known as the Scientific Leadership Group (SLG). According to the MSBase Foundation Constitution of 2016, the role of the SLG is to:

- (a) Provide scientific assistance to the Foundation with respect to the use and maintenance of the Foundation's web-based Registry platform;
- (b) Make recommendations to the Foundation with respect to financing of projects that promote the objects of the Foundation;
- (c) Manage the MSBase Registry that is hosted on the Foundation's platform including act as custodians of the data in the database; and
- (d) Become a self-constituting entity, subject to the SLG 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 Registry platform and provide administrative and statistical support staff to fulfil the role of the SLG.

The Foundation's intention is to support the MSBase 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, advises and leads on matters relating to the MSBase Registry and associated research activities. The SLG sets the strategic direction of the Registry and makes recommendations to the MSBF on the use of funding to support Registry 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:

The SLG may be comprised of up to 25 members. A quorum is defined as minimum of ½ of all members.

3. Election and removal of members

- a. The MSBase SLG is self-constituting.
- b. Nominations for new members should be written and addressed to the chair and deputy chair, explaining why the nominee would be a valuable addition to the SLG. Their CV should also accompany this endorsement. Once approval has been granted by the chair and deputy chair, the nominee's CV and nomination from the endorsing SLG member will be circulated to the committee for their consideration and vote.
- c. The MSBase SLG will consider nominations of new SLG members to meet the strategic needs of SLG and MSBase:
 - i. SLG members are expected to actively participate in the development of strategic vision for MSBase, discussion of the SLG matters and voting
 - ii. SLG members represent sites that actively contribute data to the MSBase registry
 - iii. SLG consists of active academics who contribute unique expertise to the SLG
 - iv. SLG members act as local champions for MSBase
 - v. SLG members are actively involved in the work of one or more of the SLG subcommittees
- d. New members can be elected by two thirds majority vote by circular (email) resolution. Any member of the SLG can call for a deferral of the vote and request discussion of the nomination at the next scheduled SLG meeting where a further vote will be called.
- e. All members are required to complete a Conflicts of Interest Disclosure Form annually to be reviewed by the SLG COI 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 shall lead the SLG and chair each meeting.
- ii. In their absence, a meeting shall be chaired by the deputy chair
- iii. 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.
- iv. 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.

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. The role of SLG Research Committee Chair will be filled by the SLG deputy chair. If the SLG deputy chair is unable or unwilling to fill the position of SLG Research Committee chair, the SLG may appoint any other member of the SLG Research Committee as its chair. The process of nomination and voting by the SLG research committee voting members follows the rules specified by section 6a.
- c. Members may 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

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 Registry research activities and supervise the general conduct of the registry.
 - b. Review and approve the membership rules of the Registry.
 - c. Review and approve privacy rules of member information.
 - d. Review and approve the privacy rules for patient data.
 - e. Take all reasonable steps to ensure credibility and integrity of the database, control publication policy for composite data.
 - f. Act as the sole custodian of the actual data contained in the MSBase Registry database.
 - g. Actively facilitate collaboration between centres participating in any study.
 - h. Actively promote and participate in the MSBase Registry.
 - i. Set the three-year strategic plan for the MSBase Registry, seek funding support from the MSBF 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 the MSBF, 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 MSBF.

Article VI - Amendment of Regulations

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