

iConquerMS™ and the Multiple Sclerosis Patient-Powered Research Network
Revised iConquerMS™ Governing Board Charter
January 12th, 2016

1. iConquerMS™ and the Multiple Sclerosis Patient-Powered Research Network (MS-PPRN),

The iConquerMS™ initiative is a unique resource that enables clinical research on multiple sclerosis to be conducted rapidly and efficiently on topics that matter to people with MS by engaging them in every aspect of the research from conception to impact on healthcare.

As of October 2015, the iConquerMS™ initiative's MS-PPRN is one of 33 health data networks established with funding from the Patient-Centered Outcomes Research Institute (PCORI, pcori.org) to form PCORnet (pcornet.org), the National Patient-Centered Clinical Research Network. PCORnet is transforming clinical research by engaging people with medical conditions, care providers, researchers and health systems in collaborative research partnerships to improve healthcare and advance medical knowledge. Access to the large amount of diverse, nationally representative health information contributed by participants and made available through PCORnet will reduce the time and resources needed to launch new studies and focus research on questions and outcomes that matter most to people with medical conditions and those who care for them.

iConquerMS™ is an pioneering initiative and patient-powered research network of the Accelerated Cure Project for MS (ACP) developed in collaboration with the Complex Adaptive Systems Initiative (CASI) at Arizona State University and Feinstein Kean Healthcare (FKH), collectively known as the “iConquerMS™ Founding Partners”.

The iConquerMS™ initiative emphasizes governance by people with MS and is supported by an integrated information technology (IT) and communications platform featuring a participant-driven online portal, iConquerMS.org, through which people with MS and researchers are able to participate in and drive MS research. Registered participants are able to:

- Share personal health and medical information in a secure and de-identified way;
- Help to set the research agenda for studies performed using network data or infrastructure;
- Participate in research studies conducted via the network;
- Review reports on the studies supported by iConquerMS™;
- Access educational content about MS research;
- Connect and share experiences with other people in the MS community; and,
- Play a leading role in the translation of research findings to impact healthcare.

2. The iConquerMS™ Governing Board

The iConquerMS™_Governing Board (the “Board”) is a key component of the governance structure of the iConquerMS™ initiative which also includes a Research Committee and an Engagement Committee. The Board oversees all activities of the initiative.

3. Board Responsibilities

The Board is responsible for:

- Approving the mission of the iConquerMS™ initiative (as presented in 1., above);
- Electing the Board Chair and the Board Members;
- Approving the Charters of the Board and Research and Engagement Committees;
- Approving policies, procedures and codes of conduct that govern the initiative's operations;
- Providing guidance and feedback to the initiative's management team in its efforts to achieve the mission of the iConquerMS™ initiative;
- Approving nominations for new members of the Research and Engagement committees;
- Approving the recommendations of the Research and Engagement Committees;
- Overseeing the MS-PPRN's involvement in PCORnet activities;
- Overseeing financial matters for the initiative; and,
- Approving plans to achieve sustainable operation of the initiative for the foreseeable future.

4. Board Operations

The number of members of the Board ("Board Members") will be 9 or 11 people as approved by a vote of the members of the Board. The majority of Board Members will be people with MS.

Meetings of the Board will be held bi-monthly, or as close as practical to a bi-monthly schedule.. A meeting of the Board will be deemed official if at least a majority of Board Members participate in the meeting.

The initial Chair of the Board was appointed by ACP for a period of 6 months and the initial Board Members were appointed by ACP for an initial 3-year period.

The Board Chair is elected annually, or as necessitated by a vacancy occurring, by a majority vote of the Board members (excluding the candidate). Nominations of existing Board Members as candidates for Board Chair will normally be sought, for a period of one month, beginning 6 weeks prior to the date of the expiration of the term of the Board Chair. In the case of a vacancy occurring before the expiration of the term of the Board Chair, nominations of existing Board Members as candidates for Board Chair will be sought as soon as practical after the occurrence of such vacancy and the election of the new Board Chair will take place at the earliest convenient Board meeting. A Board Chair may serve for up to 2 one-year terms.

Board Members are elected, as necessitated by a vacancy occurring or by expiration of the term of a member, by a majority vote of the Board Members (excluding the candidate, if already a Board Member) at the earliest convenient Board meeting. Nominations for new Board Member candidates will be sought as soon as practical after the occurrence of a vacancy. The re-election of an existing Board Member will take place at the Board meeting prior to, or coincident with, the expiration of the term of that Board Member. Each Board Member's service on the Board will initially be for a 3-year term and can be renewed by majority votes of the Board for one subsequent 3-year term. By majority vote of Board Members, the term of any Board member's service may be extended for a period of up to 12 months in order to avoid the simultaneous

expiration of the terms of service of more than one-third of the Board Members.

If a Board Member is unable to participate in Board activities for a period encompassing 3 Board meetings, the Board will have the right to declare a vacancy and elect a replacement member.

Members of the Board will be *ex officio* members of all committees and have the right, but not the obligation, to attend but not vote at committee meetings.

Board Members shall attend, via conference calls, web-based services or in person, the bi-monthly Board meetings that will be scheduled at times convenient for the majority of participants. A Board Member unable to attend any Board meeting shall communicate her/his apologies to the Board Chair. Board Members may be required to communicate between meetings, review materials in preparation of meetings, and complete other activities as requested from time to time by the Board Chair. *Ad hoc* Board meetings may be scheduled as necessary to discuss time-sensitive topics.

The Board Chair will be responsible for working closely with the initiative's principal investigator(s), program manager and management team to create an agenda for each Board meeting, make sure that Board Members receive appropriate materials prior to meetings, keep Board Members informed of the activities of the initiative, and deliver Board decisions and recommendations to the initiative's management team.

Resolutions of the Board will be approved by a simple majority vote, although the Board will strive for consensus on all resolutions. Resolutions may be approved by votes held at meetings of the Board, by mail or by e-mail.

Members of the Board are expected to devote the amount of time necessary, and to make reasonable efforts, to satisfy their commitment to the iConquerMS™ initiative. The Board's successful execution of its responsibilities is vital to the overall success of the initiative and the MS-PPRN and to the sustainability of the initiative.

RESOLVED

That the Board hereby approves this Revised iConquerMS™ Governing Board Charter.

Signed on behalf of the Board following approval of the resolution.



Laura Kolaczowski, Board Chair

Date: January 15, 2016