

SYNGAP1 Natural History Study (NHS) Registry Advisory Committee Charter

Role The role of the SYNGAP1 NHS Registry Committee is to manage on behalf of Bridge the Gap – SYNGAP Education and Research Foundation on matters relating to the SYNGAP1 (MRD5) Natural History Study including protocol development; governance structure; patient recruitment and retention; data management, sharing and analysis; and research collaborations.

Responsibilities SYNGAP1 NHS Registry Committee responsibilities include:

- Develops and revises the study protocol
- Develops data elements
- Develops governance issues related to the study protocol
- Develops patient recruitment and engagement
- Develops data management, sharing and analysis
- Develops research collaborations
- Develops strategic direction of study

Bridge the Gap – SYNGAP Education and Research Foundation responsibilities include:

- Approves the development and revisions to the study protocol
- Approves the strategic direction of study

Membership and Voting

Voting members:

- Chair of the Board Monica Weldon
- Director/Co-Lead Dr. Jimmy Holder, MD, PhD
- Director Dr. Connie Smith-Hicks MD, PhD
- Director Dr. Gavin Rumbaugh, MD
- Director Dr. Jacques Michaud, MD
- Director Dr. Michael Parker, MD

Non-Voting-Members at Large:

- Secretary

International Charter Members:

- Director (Your Name Here)
- Director
- Director
- Director

Membership

Section 1: Members will be invited by the of Bridge the Gap – SYNGAP Education Research Foundation Board of Directors to the charter and each charter member must be in good standing with Bridge the Gap – SYNGAP ERF.

Section 2: Membership on the Charter requires individuals to be official voting Board Members of Bridge the Gap – SYNGAP Education Research Foundation, Official Appointed Membership on the organizations scientific advisory board and/or official registered organizations or charities representing the SYNGAP1 International Community.

Section 3: All SYNGAP1 International Organization invited leaders are required to provide a copy of organization incorporated documents showing registration within their country of origin, attend a mandatory training on the registry, compliance and responsibilities before attending any of the formal charter meetings; either in person or through webinar.

Section 4: All Members of the SYNGAP1 (MRD5) Registry and Natural History Study Charter is required to sign the Bridge the Gap – SYNGAP Education and Research Foundation Code of Conduct and Volunteer Handbook.

Section 5: All Members of the SYNGAP1 (MRD5) Registry and Natural History Study Charter is required to sign the Bridge the Gap – SYNGAP Education and Research Foundation Nondisclosure Agreement.

Section 6: Terms. All Charter Board members shall serve 2 year terms, but are eligible for re-election.

Section 7: Voting. All issues to be voted on shall be decided by a simple majority of the board members within a quorum.

Section 8: Notice. An official Board meeting requires that each Board member have written notice 10 business days in advance. The agenda to the meeting will be sent out five business days prior to the meeting.

Section 9: Vacancies. When a vacancy on the Charter exists, nominations for new members may be received from present Board members by the Secretary two weeks in advance of a Board meeting with a qualifying resume. Nominees need to be individuals willing to meet the goals and fulfill the mission of the organization to the best of their ability. These nominations shall be sent out to Charter members with the regular Charter meeting announcement, to be voted upon at the next meeting. These vacancies will be filled only to the end of the particular Charter member's term.

Section 10: Resignation, Termination and Absences. Resignation from the Board must be in writing and received by the Secretary. A Charter member shall be dropped for excess absences from the Board if s/he has (3) three unexcused absences from Charter meetings in a year. A Charter member may be removed for other reasons, such as gross negligence of duties or misconduct. A majority vote of the remaining directors will decide upon removal from the charter. A decision will be made either to remain until the end of their term and placed on a leave of absence, removed immediately or until the decision is reversed by the board because of conflict resolution.

Section 11: Special Meetings. Special meetings of the Board shall be called upon the request of the President or one-third of the Board. Notices of special meetings shall be sent out by the Secretary to each Board member 10 days in advance.

AMENDMENTS

These Charter Bylaws may be amended when necessary by a two-thirds majority of the Board of Directors at the request of the Registry Charter Committee. Proposed amendments must be submitted to the Secretary to be sent out with regular Board announcements.

Chair

President/CEO, Bridge the Gap – SYNGAP Education and Research Foundation

Frequency of Meetings and Manner of Call

Section 1: At least bi-annually at the call of the committee chair in the months of January and June.

Section 2: Notice. An official Board meeting requires that each Board member have written notice 10 business days in advance. The agenda to the meeting will be sent out five business days prior to the meeting.

SYNGAP1 Natural History Study (NHS) Registry Advisory Committee Charter (cont'd)

Quorum	A quorum must be attended by at least 51% percent of the Charter members before business can be transacted or motions made or passed of the committee members entitled to vote
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Resources	Entire Medical Advisory Board
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Reporting	The committee will report to the board of Bridge the Gap – SYNGAP Education and Research Foundation with a summary of the Charter Meetings before 10 working business days by the Chair of the Charter.
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Date of Last Review	May 16, 2016 June 10, 2016 March 22, 2019
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