



By-Laws

Version 1: Reviewed and approved by the board of directors on August 15, 2012.

Version 2: Reviewed and approved by the board of directors on October 13, 2015.

Version 3: Reviewed and approved by the board of directors on April 13, 2018.

Article I. – Name

The name of this organization is the Lynch Syndrome Screening Network (LSSN).

Article II. – Vision & Mission

Section 1. Vision

The vision of the LSSN is to reduce the cancer burden associated with Lynch syndrome.

Section 2. Mission

The mission of the LSSN is to promote universal Lynch syndrome screening on all newly diagnosed colorectal and endometrial cancers; to facilitate the ability of institutions to implement appropriate screening by sharing resources, protocols and data through network collaboration; and to investigate universal screening for other Lynch syndrome related malignancies.

Article III. – Membership & Official Partners

Section 1. Introduction

There are two categories of membership: full and affiliate members. Institutions (hospitals, clinics, and academic medical centers) that meet criteria (as outlined in Article III. Sections 2.1 and 2.2) are eligible for membership. Membership is not open to individuals, although each institution shall designate one or two representatives as primary contacts. Applications and re-applications for membership will be available on the LSSN website (<http://www.lynchscreening.net>) or by emailing the board of directors. An institution shall become a LSSN member upon approval of their application for membership by the board of

directors. The board of directors will also determine the eligibility of each institution for their selected membership category.

Organizations (including but not limited to federal/state agencies, laboratories, patient support/advocacy groups, and professional societies) that meet criteria (as outlined in Article III. Sections 2.3) are eligible to be listed as “partners”. For-profit laboratories and genetic companies are eligible for partner status; however, their representatives cannot serve on the board of directors (see Article III. section 2.3). Applications for partners will be available on the LSSN website (<http://www.lynchscreening.net>) or by emailing the board of directors. LSSN partners have an interest in promoting or performing research related to activities of routine tumor testing to identify individuals with Lynch syndrome. Being designated as a partner of the LSSN does not mean that the LSSN endorses any product or service provided or sold by that partner. Furthermore, the LSSN listserv cannot be used for marketing or advertising of any product or service provided or sold by that partner. Individuals are not eligible as partners, although each organization shall designate one or two representatives as primary contacts. An organization shall become a partner upon approval of their application by the board of directors, and if they agree to the terms of that partnership.

Section 2. Membership Categories and Official Partners

Please note the following definitions that are used in membership criteria:

** Routine testing is defined as automatic tumor testing to evaluate for Lynch Syndrome at the time of cancer diagnosis/surgery.*

***A qualified health care professional (see Cancer Program Standards 2016: Ensuring Patient-Centered Care, Standard 2.3, www.facs.org/cancer;) is defined as:*

2.1 Full Membership

Must meet all of the following:

- Institutions (hospitals, clinics, and academic medical centers) currently performing routine tumor testing* on colorectal cancers and/or endometrial cancers
- Intent to request institutional review board (IRB) approval to enter data into the LSSN database [once the database is active]
- Intent to enter data regularly into the LSSN database for surveillance and/or research purposes [once the database is active]
- A genetic counselor or other qualified healthcare provider** trained in providing cancer genetic services works at the institution
Access via the genetic counselor or other qualified healthcare provider** (either through clinical responsibilities and/or IRB approval) to both normal and abnormal routine tumor testing results

2.2 Affiliate Membership

Must meet one of the following:

- Institutions (hospitals, clinics, and academic medical centers) performing routine testing, but not meeting all criteria for full membership; OR
- Institutions interested in starting routine testing*

2.3 Partners

Organizations interested in promoting routine testing* on all newly diagnosed colorectal and/or endometrial cancers that fall into the following categories:

- Federal/state agencies
 - Professional societies
 - Patient support/advocacy groups
 - Laboratories or companies
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- *An American Board of Genetic Counseling or American Board of Medical Genetics board-certified/board-eligible or (in some states) a licensed genetic counselor.*
 - *An American College of Medical Genetics physician, PhD board-certified/board-eligible in clinical or medical genetics.*
 - *A Genetics Clinical Nurse (GCN) or an Advanced Genetics Nursing-Board Certified (AGN-BC) credentialed through the American Nurses Credential Center (ANCC).*
 - *An advanced practice oncology nurse or Physician Assistant who is prepared at the graduate level (master or doctorate) with specialized education in cancer genetics and hereditary cancer predisposition syndromes; certification by the Oncology Nursing Certification Corporation is preferred.*
 - *A board-certified/board-eligible physician with experience in cancer genetics (defined as providing cancer risk assessment on a regular basis)*

Section 3. Change in Membership Category

An affiliate institution that has demonstrated satisfactory performance as an affiliate may apply for and be granted full membership. The affiliate member must meet all requirements for full membership (Article III. Section 2.1) and submit an updated application. The approval to change the status of an affiliate to full membership shall be made by the board of directors. Application for change in membership type may be made at any time during the year.

Section 4. Dues

There are no membership fees or dues at this time.

Section 5. Terms

Membership will be for one calendar year, beginning on January 1 and ending on December 31. Membership will need to be updated annually. LSSN partnerships will last indefinitely until the organization withdraws their application or they no longer meet criteria as a partner.

Section 6. Withdrawal/Termination

Any member site may withdraw from the LSSN by having their institution's representative(s) submit a request to the board of directors. Withdrawal does not preclude future re-application or membership. Withdrawal of membership does not guarantee removal of an institution's data from the database, unless fraudulent and/or inaccurate data entry occurs. Fraudulent data entry is immediate grounds for termination of membership status. Evidence of extensive and/or consistent inaccuracies of data entry may result in revoking of full membership status. The board of directors will contact an institution's representative(s) if inaccuracies are identified: the board of directors may at its discretion choose to downgrade the member to an affiliate until problems with data entry at the institution are corrected. If advertising or marketing of a product or services by a partner occurs on the LSSN listserv, this is also grounds for termination of partnership status.

Article IV. – Board of Directors

Section 1. General Powers

Unless specified otherwise in these by-laws, the board of directors shall have all of the powers and authority to manage the business and affairs of the LSSN. Decisions by the board of directors will be made by majority vote. In case of a tie, only those votes from directors at institutions that are full members (Article III. Section 2.1) will count. If there is still a tie, the Chair will have the final decision.

Section 2. Number, Terms of Office and Qualifications

The LSSN will have one permanent executive director and five directors consisting of members from different institutions. The five board of director members will have voting privileges; however, the executive director will not. All of the board of directors must be from a current LSSN full or affiliate member organization or partnership organization. None of the board of directors can be a representative from a for-profit laboratory or a genetics company.

- Newly elected directors will serve a term of five (5) years.
- Starting in the year 2016, at least three (3) directors shall be at an institution that has full membership (Article III. Section 2.1). The other remaining directors shall be at

institutions that are full members (Article III. Section 2.1), affiliate members (Article III. Section 2.2) or not for-profit partners (Article III. Section 2.3).

- Starting in year 2016, one board of director member will roll off and one new board of director member will be elected each year.
- In the event that the board composition does not meet the above requirements due to unforeseen circumstances, the board will have the authority to make a determination regarding member replacement.
- Directors are eligible for re-election, they can serve multiple terms with a maximum of two consecutive terms.

The executive director shall convene regularly scheduled board meetings and shall preside or arrange for a proxy to preside at each in-person regular meeting.

Directors may be removed by a majority vote of the remaining directors based on failure to attend (either in person, web conferencing, and/or by phone) at least one half (50%) of all scheduled meetings (unless missed due to personal illness and/or emergency family matters), with a minimum of four (4) meetings scheduled per year. Directors may also be removed by a majority vote of the remaining directors in the event of ethical improprieties or other inappropriate activities or conduct. The executive director can be also be removed and replaced by a majority vote of the board of directors.

Section 3. Regular Board Meetings

Meetings of the board of directors shall be held at least four times per year without other notice than this by-law. These meetings may be held in person, telephone conference call or web conferencing. Reasonable notice of each such meeting shall be given to each director by mail, e-mail, telephone or personally.

Section 4. Special Meetings

Special meetings of the board of directors may be requested by the executive director or one of the board of directors and approved by majority vote of the board of directors. Reasonable notice of each such meeting shall be given to each director by mail, e-mail, telephone, or personally.

Section 5. Vacancies

If a vacancy occurs on the board of directors between elections, the remaining board of directors shall be empowered to appoint a director to complete the unexpired term, by majority vote. A vacancy may also be filled by the remaining board of directors for the unexpired portion of the term, if it is less than one (1) year, at the discretion of the board of directors.

Section 6. Compensation

The board of directors shall not receive any remuneration for their services as directors.

Section 7. Election

Nominations for the board of directors shall be sought from the directors, members, and/or official partners no less than 30 days prior to the end of the calendar year. The final decision regarding nominations for elections will be determined by majority vote of the board of directors. Elections will be held by a ballot that will be sent via email or other communication methods to the primary representative (and secondary representatives when applicable) at full member institutions (voting members). Each full member institution will be allotted one vote. The directors will be determined by majority vote (the nominees with the most votes will be elected each year). Affiliate members and official partners will not have voting rights in elections.

Article V. Committees

Section 1. Appointed Committees

Unless specified otherwise in these by-laws, all standing and special committees shall be appointed by the board of directors. The composition, terms, powers and duties of all committees shall be determined by the board of directors.

Article VI. LSSN Member Meetings & Communication

Section 1. In-person Meetings

In-person regular meetings for the purpose of conducting business as is necessary and appropriate will be held as funding allows. The executive director shall preside or arrange for other director(s) to preside at each in-person regular meeting. In-person meetings will be held at such time and place as shall be determined by the board of directors. Because the LSSN currently has no membership fees or dues, funding for meetings may limit the frequency, location, and attendance at meetings.

If funding is available for in-person meetings, priority will be granted first to the board of directors. Allocation of any remaining funds will be determined by the board of directors. Space may also limit attendance at in-person meetings. Attendance priority will be determined by the board of directors.

Section 2. Notice of In-Person Meetings

A written or printed notice stating the place, date, time, and, with respect to the in-person regular meetings, the purpose of the meeting of the members shall be delivered by email, or other social media to the primary (and when applicable, secondary) contact listed for each full member institution at his or her address as shown by the records of the LSSN.

Section 3. Communication

Communication with members and partners is the responsibility of the executive director and board of directors, and should be timely. The representative(s) of each member institute and

official partner is responsible for providing the board of directors with up to date contact information.

Article VII. Research

Section 1. Research Responsibilities

The board of directors will establish and oversee development of research collaborations and projects. At the discretion of the board of directors, a research committee may be appointed to assist with this process.

Article VIII. Amendments

Section 1. Selection

These by-laws may be altered, amended, repealed or added to by an affirmative vote of not less than two thirds (~66%) of the board of directors. Requests for changes to these by-laws can be made by full and affiliate members and/or official partners by having their representative(s) submit a request to the board of directors.

Section 2. Notice

All members and official partners shall receive notice of any changes to the by-laws within fourteen (14) days of final approval of the amendment.