

LSSN Application (2013)

Welcome to the Lynch Syndrome Screening Network (LSSN). LSSN is open to institutions or organizations that are interested in promoting the goal of routine* tumor testing for Lynch syndrome on newly diagnosed colorectal and/or endometrial cancers.

There are two categories of membership: full and affiliate members. Institutions (hospitals, clinics, and academic medical centers) that meet criteria are eligible for membership. Organizations (including but not limited to federal/state agencies, not-for-profit laboratories, patient support/advocacy groups, and professional societies) that meet criteria are eligible to be listed as official partners. Below is a summary of the criteria for membership and official partner status.

*Automatic tumor testing to evaluate for Lynch syndrome at the time of cancer diagnosis/surgery on all or a subset of newly diagnosed colorectal and/or endometrial cancers

Full Membership

- Institutions (hospitals, clinics, and academic medical centers) currently performing routine tumor testing on colorectal cancers and/or endometrial cancers; AND
- Commitment to enter data (outlined by the research guidelines) regularly into the LSSN database for surveillance and/or research purposes; AND
- Institutional review board (IRB) approval (either obtained or in process) to enter data (outlined by the research guidelines) into the LSSN database; AND
- A genetic counselor or other qualified healthcare provider† trained in providing cancer genetic services is required to be at the institution; AND
- A genetic counselor or other qualified healthcare provider† must have access (either through clinical responsibilities and/or IRB approval) to both normal and abnormal routine tumor testing results

Affiliate Membership

- 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

Official 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 (non-profit only) or companies

†The following health care professionals are included (www.facs.org/cancer, Cancer Program Standards 2012: Ensuring Patient-Centered Care):

- 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 board certified in medical genetics
- A Genetics Clinical Nurse or an Advanced Practice Nurse in Genetics, credentialed through the Genetics Nursing Credentialing Commission. Credentialing is obtained through successful completion of a professional portfolio review process.
- An advanced practice oncology nurse who is prepared at the graduate level (master or doctorate) with specialized education in cancer genetics and hereditary cancer predisposition syndromes (Specialized training should be ongoing; educational seminars offered by commercial laboratories about how to perform genetic testing are not considered adequate training for cancer risk assessment and genetic counseling); certification by the Oncology Nursing Certification Corporation is preferred.
- A board-certified physician with experience in cancer genetics (defined as providing cancer risk assessment on a regular basis)

1. Which of the following best describes your 2013 application category?

- Full member
- Affiliate member
- Official partner

2. List the name of the Institution for which this membership/partnership application applies?

Name _____ City _____ State _____

3. Which of the following best describes your institution with respect to Lynch syndrome screening?

- Currently providing routine tumor testing for Lynch syndrome on all or a subset of colon, endometrial, or other cancers.
- Trying to implement routine tumor testing for Lynch syndrome on all or a subset of colon, endometrial, or other cancers.
- Involved in the care of patients at-risk for Lynch syndrome, but currently not planning on implementing routine tumor testing for Lynch syndrome.
- Organizations (federal/state agency, not-for-profit laboratory, patient support/advocacy group, or professional society) with interest in promoting routine tumor testing for Lynch syndrome.

4. Primary contact

Primary contact name _____ Institution _____
Street Address _____
City _____ State _____ Country _____ Zip Code _____
Email _____ Phone Number _____

5. Secondary contact (optional)

Secondary contact name _____ Email _____
Phone Number _____

6. The Evaluation of Genomic Applications in Practice and Prevention (EGAPP) published a recommendation in January 2009 endorsing screening for Lynch syndrome on all newly diagnosed colorectal cancers. Please indicate how this recommendation influenced your institution's protocol regarding universal screening.

Select all that apply:

- Supported/justified existing screening protocols
- Altered existing protocols with regards to type of tumor testing performed
- Altered existing criteria for screening by moving from a subset of CRCs (e.g. < 50) to all CRCs
- Provided basis for initiation a Lynch syndrome screening protocol at our institution
- Is being used to justify developing a Lynch syndrome screening protocol at our institution
- Not applicable
- No impact

If your institution is not currently performing routine tumor testing, please disregard questions 7-13.

7. Please list all hospitals under your routine* tumor testing protocol.

Name _____	City _____	State _____
Name _____	City _____	State _____
Name _____	City _____	State _____
Name _____	City _____	State _____
Name _____	City _____	State _____
Name _____	City _____	State _____
Name _____	City _____	State _____
Name _____	City _____	State _____

8. Date routine tumor testing initiated:

Colorectal: Month _____ Year _____
 Endometrial: Month _____ Year _____
 Other: Cancer type _____ Month _____ Year _____

9. For all hospitals combined, please estimate the number of cancers which were screened for Lynch syndrome in 2012 through your institution's routine tumor testing protocol.

Colorectal _____ Endometrial _____ Other _____

10. For all hospitals combined, please estimate the number of cancers which were screened for Lynch syndrome for all years combined through your institution's routine tumor testing protocol.

Colorectal _____ Endometrial _____ Other _____

11. Genetic counseling involvement:

Level of Involvement	Colon	Endometrial	Other
Genetics reviews all screen results and follows-up on abnormal	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Genetics is advised of all abnormal screens to initiate follow-up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients with abnormal screens are referred to genetics at the discretion of the ordering physician, pathologist or other clinician involved in the patient's care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Only patients with identified MMR mutations are referred for genetic counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Genetic counseling is not routinely involved in our Lynch screening protocol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. Cancers included in routine tumor testing:

Select all that apply

- All colorectal cancers
- Colorectal cancers under age _____
- Colorectal cancers with specified pathological features _____
- Colorectal cancers - other specified criteria _____
- All endometrial cancers
- All endometrial cancers under age _____
- Endometrial cancer with specified pathological features _____
- Endometrial cancers - other specified criteria _____
- Other cancers _____

13. Current tumor testing protocol:

More than one reflex strategy may be selected if applicable

Strategy		Colon	Endometrial	Other
MSI only		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MSI with reflex to:	IHC	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	BRAF	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Hypermethylation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IHC only		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IHC with reflex to:	MSI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	BRAF	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Hypermethylation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MSI and IHC:	No reflex testing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Reflex to BRAF	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Reflex to hypermethylation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>