



Lymphatic Education
& Research Network

Centers of Excellence



Diagnosis and Treatment of Lymphatic Diseases

Program Description and Application

DATES AND DEADLINES

Online Submission of Letter of Intent	Due by June 15, 2019
Invitation to Submit Application	No later than June 30, 2019
Letters of Designation	No later than December 10, 2019

MISSION

LE&RN Centers of Excellence (COE) provide a geographically diverse network of multi-disciplinary clinical care and service centers for individuals and families affected by Lymphatic Diseases (LD).

In addition to clinical and social services, the Centers will provide professional and lay education in the geographic areas they serve, are involved in LD clinical research, and work with LE&RN locally and nationally in its efforts to continually improve the lives of those affected by LD and their families.

OBJECTIVES

- To design an international standard for best practice multi-disciplinary care in the management of LD and providing services for families with LD.
- To select and support institutions that excel with regard to knowledge and experience in LD, education of LD in their local community, establishment of a multidisciplinary care team for LD, and involvement with LD clinical research.
- To directly support LE&RN in accomplishing its mission by developing and maintaining relationships throughout the LE&RN local, regional, and national community, including within the COE network.

CLINICAL AND SUPPORT SERVICES

LE&RN Centers of Excellence provide comprehensive multidisciplinary clinical service for families affected by LD. Services are centered around an organized LD clinic in which an individual's clinical care needs are defined, plans are made to fulfill those needs, and follow-up is provided to continually optimize clinical management. While attending to the individual, needs will be considered in the context of the family unit impacted by LD.

Based on the size and scope of clinics within the LE&RN Centers of Excellence program as determined by the levels of criteria, services may be readily available on campus or provided at off-site facilities at the discretion of the Center. Responsibility for the treatment plan should be retained by the Center so that LD families will benefit from the Center's expertise. Individuals should

be seen annually or semi-annually at the Center of Excellence for LD treatment management, in order to re-evaluate the management, guarantee expert follow-up, and enable access to new knowledge and novel developments in the field; the personnel at a Center of Excellence do not replace the primary care provider (PCP) and are expected to work in concert with the PCP.

In addition, COEs will, when appropriate, refer patients to existing LE&RN chapters/support groups and opportunities to participate in clinical research.

ACCESS TO SERVICES

- Multidisciplinary LD-specific clinic held at least one full day per month, with discussion dependent upon COE category.
- Genetic testing and counseling available when needed.
- Complementary scheduling on campus or in the LD clinic for ancillary services, such as physical therapy, occupational therapy, psychiatry/psychology, and nutritional/dietary counseling. If not available in clinic or on-campus, then services must be referred to therapists with expertise in LD.

EDUCATIONAL MISSION

- Consults/trains/presents/supervises education in LD for area health/science professionals.
- LD advocacy for general public, public officials and agencies, potential donors, etc.
- Educational services in support of LE&RN chapter/regional activities.

- The **Center Director** or **Center delegate** must attend and actively participate in at least two LE&RN-sponsored events annually (with at least one being educational). Center staff is encouraged to participate in a minimum of one event (educational) annually. Attendance at local LE&RN support group meetings is encouraged.

RESEARCH MISSION

Although the primary mission of a LE&RN Center of Excellence is to provide clinical service, Centers are also expected to participate, as much as possible, in research benefiting the LD community.

ADMINISTRATION

Operations Committee: This committee must be comprised of a Center Director and other senior Center professionals. This Committee:

- Selects and supervises employed personnel;
- Manages relationships with collaborating professionals;
- Oversees Center operations; and
- Is responsible for timely and proper reporting.

While it is preferable that the LE&RN Center of Excellence Director be a licensed physician, consideration will be given to a qualified professional who has demonstrated and documented expertise in LD. In those instances where the Director is not a physician, then the co-Director must be a licensed physician. An exception is made for LD Conservative Care Centers of Excellence.

Center Advisory Board: members include representatives from local LE&RN chapter(s)/affiliates and/or community, local business leaders, and the Center director as a non-voting member.

- Provides feedback on whether the needs of the local LD community are being met;
- Meets at least once per year to assess programs and services delivered by the Center of Excellence prior to submission of a simple, streamlined annual Progress Report or application for designation;
- Provides a letter of support at annual renewal.

Collaboration with local LE&RN Community:

There are many ways in which Centers of Excellence and LE&RN chapters, affiliates and regions can support each other. Consistent with the LE&RN mission, close relations between Centers and LE&RN chapters/

affiliates are highly desired. Some ways that Centers and chapters/affiliates may assist each other include:

- Educational programs for people with LD and their families;
- Public dissemination of information about LD and LE&RN; and
- Involvement/connection to LE&RN support groups.

ELIGIBILITY CRITERIA FOR A LE&RN CENTER OF EXCELLENCE

There are several COE designation classifications under the *LE&RN Center of Excellence* designation. (See Table 1 on page 6.)



Comprehensive Center of Excellence



Network of Excellence



Referral Network of Excellence



LD Surgery Center of Excellence



LD Conservative Care Center of Excellence

Applicant institutions/clinics must complete and submit to LE&RN the COE application form—including attached documents—by the deadlines indicated on page 2, for evaluation.

TERMS AND CONDITIONS

1. Confidentiality

LE&RN and prospective Centers may each provide the other party with financial and other information that is relevant to the application. All such information (whether written or oral) provided by either party or any of its affiliated entities or representatives shall be considered “Confidential Information,” unless such information is publicly available prior to such disclosure. In consideration of the application process, each of the prospective Centers and LE&RN hereby agrees to keep the Confidential Information confidential and use it solely for the purpose of evaluating the application to become a Center of Excellence and acceptance of such designation, and each party will not disclose any Confidential Information of the other party without the prior written consent of such other party, unless otherwise required by applicable law.

2. Non-Disparagement

Each of the prospective Centers and LE&RN (including their respective directors, employees and other representatives) agree not to make any negative comments or otherwise disparage the other party or any of its directors, employees, or other representatives, except with respect to any truthful statements made in response to legal proceedings.

3. Agreement to Terms and Process

Each prospective Center shall be deemed to have agreed to the confidentiality and nondisparagement terms and provisions set forth above automatically in connection with its submission of an application to be designated as a LE&RN Center of Excellence. Each prospective Center agrees that LE&RN and its directors, advisors and representatives (i) reserve the right, in their sole discretion, to approve or reject any applications; and (ii) shall be free to conduct the application and evaluation process, as they in their sole discretion shall determine. Except with respect to a violation of the mutual confidentiality and nondisparagement provisions set forth above, each prospective Center agrees that it shall have no claims whatsoever against LE&RN or any of its directors, advisors or representatives arising out of or relating to the application and evaluation process.

4. Right to Revoke Status

In addition to all other remedies available at law or equity, LE&RN hereby expressly reserves the right to revoke the status of a LE&RN Center of Excellence, as determined by LE&RN in its sole discretion, in connection with any violation of the confidentiality and nondisparagement provisions set forth above, or in connection with any fraud.

The *Terms and Conditions* document must be signed by an official authorized to sign on behalf of the institution. The prospective Center of Excellence director or co-director are not acceptable signers. Please submit the Terms and Conditions document to your institution upon receipt of the Application Package so there is adequate time to process and return it to LE&RN prior to the deadline for submission of your application.

PROGRESS REPORTS

Designation as a LE&RN Center of Excellence is valid for three years. Therefore, institutions/clinics do not have to re-apply each year unless changes occur in their partnership or if they desire to be considered for a different classification of COE. To maintain designation,

current COEs must complete and submit an annual progress report to LE&RN by December 1st each year. In year 3, a more extensive annual review will be required of COEs, including a letter of interest in a new three-year award. Progress report templates will be provided to each COE.

In any year in which an unsatisfactory *Progress Report* is submitted or upon failure to deliver the services or adhere to the terms and conditions delineated in the letter of award, LE&RN reserves the right to suspend the Center of Excellence designation until such time as identified deficiencies have been satisfactorily addressed. Said deficiencies must be resolved within 90 days of suspension, or the LE&RN Center of Excellence designation will be revoked.

REVIEW AND SCORING OF APPLICATIONS

Applications will be reviewed by the LE&RN Center Programs & Education Advisory Committee (CPEAC). All applications will be scored, using the following three individual criteria:

1. The quality of the overall application/services
2. Unique offerings or particular characteristics that add to the LD clinic
3. Miscellaneous (e.g., LD community citizenship, research)

More than 50 percent of the emphasis will be placed on the first criterion, which is the overall quality and completeness of the application and LD services provided at the prospective Center. If no research activity is listed in the initial application, and Center of Excellence designation is granted, the Centers will be asked to include in Progress Reports some evidence of research grant application, development of research collaborations with research-conducting institutions, inclusion in multi-site studies, where allowed, or provision of research samples (surveys, blood/DNA, etc.) to studies at other institutions, where allowed. The scoring of applications is part of an internal review process used by CPEAC to determine outcomes. Therefore, scores will not be shared with any site submitting an application for designation as a LE&RN Center of Excellence, regardless of whether the site is given COE designation.

DECISION NOTIFICATION

Applicants will be notified by e-mail after a decision has been made by CPEAC and no later than December 10, 2019.

If a clinic is designated as a LE&RN Center of Excellence, an award letter will be sent to the Center's medical director. Information regarding branding materials and corresponding media package will be included. At that point, a letter indicating institutional support will be required. The clinic director will be responsible for ensuring the services listed are available to patients and families. Considering that responsibility,

the most appropriate representative from the institution can provide the letter. Examples may include department chairperson, Dean, etc.

If a clinic does not receive the LE&RN Center of Excellence designation, a letter detailing areas for improvement in future applications will be sent to the Center's medical director. All awards will be retroactive to January 1, 2020. If you have any questions about the LE&RN Center of Excellence program please direct them to LE&RN at 261 Madison Avenue, 9th Floor, New York, NY 10016 or by calling the LE&RN office at 516-625-9675.

CENTERS OF EXCELLENCE CATEGORIES

There are five categories for Center of Excellence designation. We invite centers around the world to apply for COE designation under one of these categories.



COMPREHENSIVE CENTER OF EXCELLENCE (COE) designation indicates that an institution can provide the listed services on-site, all within the same institution, and can coordinate provision of the services.



NETWORK OF EXCELLENCE designation indicates that an institution and its affiliate institutions (within walking distance) can provide the listed services. For example, University "A" School of Medicine, University "A" Teaching Hospital, University "A" Cancer Center, and University "A" Rehabilitation Facility can provide the listed services, and can coordinate provision of the services.



REFERRAL NETWORK OF EXCELLENCE designation indicates that the institution and/or nearby collaborating institutions can provide the listed services, and that these institutions can coordinate provision of the services. For example, University "A" School of Medicine, University "B" Teaching Hospital, "C" Cancer Center, and Private Practice "D" Rehabilitation Facility can provide the listed services, and can coordinate provision of the services.



LYMPHATIC DISEASE (LD) SURGERY COE designation indicates that an institution (usually, a cancer care center) can provide the listed surgical services.



LD CONSERVATIVE CARE COE designation indicates that an institution can provide the listed conservative care services.

Services and activities that are not required for COE designation, but are encouraged by LE&RN, are listed (without check marks), and may be considered by the selection committee.



Table 1

	 Comprehensive Center of Excellence	 Network of Excellence	 Referral Network of Excellence	 LD Surgery Center of Excellence	 LD Conservative Care Center of Excellence
DIAGNOSIS					
Cancer-related or non-cancer related LE	✓	✓ or affiliate referral	✓ or local referral		
Lipedema	✓	✓ or affiliate referral	✓ or local referral		
Congenital vascular anomalies including lymphatic malformations, discernment between vascular, lymphatic, and combined disorders	✓	✓ or affiliate referral	✓ or local referral		
Systemic lymphatic disorders (pleural effusions, pulmonary, chylothorax, protein-losing enteropathy, lymphangiectasias, genital)	✓	✓ or affiliate referral	✓ or local referral		
Protein-losing enteropathy	✓	✓ or affiliate referral	✓ or local referral		
Lymphangiectasias	✓	✓ or affiliate referral	✓ or local referral		
Lymphaticovenous disease	✓	✓ or affiliate referral	✓ or local referral		
Pediatric lymphatics expertise	✓	✓ or affiliate referral	✓ or local referral		
Filariasis, podoconiosis	✓	✓ or affiliate referral	✓ or local referral		
Gorham's disease, lymphangiomatosis	✓	✓ or affiliate referral	✓ or local referral		
Collaboration with practitioner(s) or facility capable of accurate LD diagnosis				✓	✓
IMAGING					
Radionuclide lymphoscintigraphy	✓	✓ or affiliate referral	✓ or local referral		
Near-infrared fluorescence lymphography	✓	✓ or affiliate referral	✓ or local referral	✓	
Direct contrast lymphography (for cisterna chyli and thoracic duct visualization)	✓	✓ or affiliate referral	✓ or local referral		
Venography	✓	✓ or affiliate referral	✓ or local referral		
Venous and lymphatic ultrasonography	✓	✓ or affiliate referral	✓ or local referral		
MRI imaging	✓	✓ or affiliate referral	✓ or local referral		
MR lymphography	✓	✓ or affiliate referral	✓ or local referral		
CONSERVATIVE MANAGEMENT SERVICES					
LE risk reduction and surveillance for high risk, or collaboration with practitioner(s) who do so	✓	✓ or affiliate referral	✓ or local referral	✓	✓
Complete lymphatic decongestive therapy (intensive treatment—5X/week, 60-minute sessions), LANA-certified or equivalent practitioner(s), short stretch bandaging expertise	✓	✓ or affiliate referral	✓ or local referral		✓
Maintenance treatment including garment fitting, dispensation of medical bandages, garments, pneumatic compression, other medical goods	✓	✓ or affiliate referral	✓ or local referral		✓
Management and surveillance of head/neck LE	✓	✓ or affiliate referral	✓ or local referral		✓

Table 1 (Cont.)

	 Comprehensive Center of Excellence	 Network of Excellence	 Referral Network of Excellence	 LD Surgery Center of Excellence	 LD Conservative Care Center of Excellence
Management of vascular and other complex malformations, for overlapping vascular/lymphatic conditions	✓	✓ or affiliate referral	✓ or local referral		
Management of protein-losing enteropathies, chylothorax, chyloperitoneum, management of mTOR inhibitors/other pharmacotherapies for lymphatic malformations and complex vascular lesions	✓	✓ or affiliate referral	✓ or local referral		
ASSESSMENT TOOLS					
Perometer, bioimpedance, truncated cone/tape measurement, or other serial measurement modality expertise	✓	✓ or affiliate referral	✓ or local referral		✓
Risk assessment using perometry or bio-impedance spectroscopy	✓	✓ or affiliate referral	✓ or local referral		
INTERVENTIONAL THERAPIES					
Venoplasty and stenting for venous lesions presenting as LE (including ovarian vein ablation)	✓	✓ or affiliate referral	✓ or local referral		
Venous and lymphatic sclerotherapy	✓	✓ or affiliate referral	✓ or local referral		
Thoracic duct embolization for plastic bronchitis, chylothorax, and chyloperitoneum	✓	✓ or affiliate referral	✓ or local referral		
Sclerotherapy for macrocystic lymphatic malformations	✓	✓ or affiliate referral	✓ or local referral		
SURGICAL					
Suction-assisted lipectomy (including surgical follow-up)	✓	✓ or affiliate referral	✓ or local referral	✓	
Tumescent liposuction for lipedema	✓	✓ or affiliate referral	✓ or local referral	✓	
Lymphaticovenous anastomosis	✓	✓ or affiliate referral	✓ or local referral	✓	
Vascularized lymph node transfer	✓	✓ or affiliate referral	✓ or local referral	✓	
Pleurodesis and shunts for chronic effusive disorders	✓	✓ or affiliate referral	✓ or local referral	✓	
Collaboration with a facility or practitioner meeting Conservative Care COE criteria				✓	
GENETICS					
Screening for known genes and mutations	✓	✓ or affiliate referral	✓ or local referral		
Genetic counseling to patients and families	✓	✓ or affiliate referral	✓ or local referral		
CONSULTATIVE					
Psychiatric/psychological services for depression	✓	✓ or affiliate referral	✓ or local referral		
Pulmonary medicine	✓	✓ or affiliate referral	✓ or local referral		
Gastroenterology	✓	✓ or affiliate referral	✓ or local referral		
Gynecology	✓	✓ or affiliate referral	✓ or local referral		

Table 1 (Cont.)

	 Comprehensive Center of Excellence	 Network of Excellence	 Referral Network of Excellence	 LD Surgery Center of Excellence	 LD Conservative Care Center of Excellence
Oncology	✓	✓ or affiliate referral	✓ or local referral		
Diagnostic and interventional radiology	✓	✓ or affiliate referral	✓ or local referral		
Dermatology	✓	✓ or affiliate referral	✓ or local referral		
Urology	✓	✓ or affiliate referral	✓ or local referral		
Radiation oncology	✓	✓ or affiliate referral	✓ or local referral		
Nutrition (particularly for protein-losing enteropathy and lipedema patients)	✓	✓ or affiliate referral	✓ or local referral		
Neurology	✓	✓ or affiliate referral	✓ or local referral		
Plastic surgery	✓	✓ or affiliate referral	✓ or local referral		
RESEARCH					
Basic/animal lymphatics science, publications	✓ preferred				
Applied/clinical studies or trials, reporting in ClinicalTrials.gov					
Recruitment of patients to the International Lymphatic Disease Registry and Biorepository	✓	✓	✓	✓	✓
Infrastructure to support future research endeavors					
ACCOUNTABILITY					
Participation in patient experience survey network					
Reporting of patient outcomes, at least short-term					
COLLEGIALITY					
Attendance/participation in at least 1 LE&RN-associated event/year	✓	✓	✓	✓	✓
Attendance/participation in other lymphatic/scientific meetings					
Patient education					
Vascular surgeon education					
Physician/therapist education/workshops	✓	✓			
ADMINISTRATION					
Sufficient administrative resources to handle phone calls/emails inquiring of services					
Participation in LE&RN collaborative administration of COEs					
COMMUNITY					
Resources/referrals for need-based financial assistance					
Pro bono services, where appropriate					
Resources/referrals for patient travel assistance					

Letter of Intent to Apply for LE&RN Center of Excellence Designation

Name of Institution/Clinic

Location (City, State, Country)

Physical Address






Mailing Address

Name/Title of Center/Clinic Director

Email Address

Phone #

Category of Center of Excellence (COE) Designation (Please see attached Table 1/Checklist for category requirements and descriptions):

- ☐  **Comprehensive Center of Excellence**
- ☐  **Network of Excellence**
- ☐  **Referral Network of Excellence**
- ☐  **LD Surgery Center of Excellence**
- ☐  **LD Conservative Care Center of Excellence**

Please append a brief letter describing your institution's mission, general patient population demographics, current capabilities, and vision for serving the lymphatic disease (LD) community. The letter should be 1–4 pages in length, and should summarize currently provided and proposed services for diagnosing and treating LD. If your institution does not currently meet all the criteria for the desired COE category, please briefly detail your plan to incorporate needed capabilities into currently provided services. This 1–4 page letter serves as the *Letter of Intent*.

Include in the Letter of Intent a list of team members, with a brief description of roles, and specify whether each team member is in-house, associated with an affiliated institution, or associated with a non-affiliated, neighboring institution (in the latter two cases, please specify geographical distance between team members). For the *Referral Network of Excellence* category, only one institution needs to send a Letter of Intent.

This Letter of Intent serves as the formal request to submit a full application later. Prospective applicants will be notified via email if they are being invited to submit a full proposal. In the event that LE&RN determines the proposed application would not fit with the goals and objectives of the LE&RN COE designations, the applicant will be provided feedback as to why the proposal was not a good fit and what options are available to support future, amended applications.

In addition to recognizing COEs where existing LD patient care is optimal, it is LE&RN's intent to encourage development of multiple LD COEs by guiding evolution of existing patient care facilities into institutions providing excellent care and support for LD patients.