Criteria for LCN Center Certification

The Leukodystrophy Care Network (LCN) certifies Centers with the same philosophy and core values as the LCN and meet the criteria below.

Multi-Disciplinary Care Team
The following required care team members must regularly attend outpatient clinics and be available for inpatient consultation or coordination of care with inpatient staff.

The Core Team is composed of at least the following:
1. Program Director (Neurologist or another MD determined by the LCN)
2. Associate Program Director
3. Clinical Care Coordinator (NP or RN)

The following Extended Multi-Disciplinary Team must be available and designated as members of the Multi-Disciplinary Care Team:
1. Allergist/Immunologist
2. Anesthesiologist
3. Cardiologist
4. Dentist
5. Dermatologist
6. Dietician
7. Durable Medical Equipment
8. Ear, Nose & Throat Specialist
9. Endocrinologist
10. Gastroenterologist
11. Geneticist/Genetic Counselor
12. Infectious Disease Specialist
13. Internist
14. Neonatologist
15. Neurodevelopmentalist
16. Occupational Therapist
17. Ophthalmologist
18. Orthopedist
19. Pain Management Specialist
20. Pharmacist
21. Physical Therapist
22. Psychiatrist and/or Psychologist
23. Pulmonologist
24. Radiologist
25. Respiratory Therapist
26. Speech Therapist
27. Surgeon

Infrastructure and Services
LCN Certified Care Centers must have the following characteristics and services.
1. Hospital for inpatient care must be Joint Commission on Accreditation of Health Organization (JCAHO) approved
2. A formal plan must be in place to ensure that any and all Leukodystrophy patients, no matter how they enter your institution, are immediately referred to your Leukodystrophy Care Center.
3. Referral plans must be in place for procedures and services such as stem cell transplantation.
4. A formal plan must be in place for the transfer of patients from pediatric to adult care with regular meetings of the Pediatric and Adult Program care teams.
5. Electronic patient records to allow for a seamless transfer of information between the LCN Center Core Team, Extended Multi-Disciplinary Teams and patient’s hometown care providers, for easy access to the patient’s full medical records.
6. Ability to participate in IRB-approved clinical research and data registries involving Leukodystrophy patients.
7. Easy and secure communication between the patient and healthcare providers for questions, scheduling, prescription refills and referrals.
8. All outpatient clinic reports and discharge summaries should be sent to referring physician as appropriate.
9. Telemedicine utilized for education, training and support of patients and their local medical teams.
10. 24-hour on-call coverage by a center physician must be available.
11. Core Team meetings are to occur on a monthly basis, at a minimum.

Ongoing Certification
Ongoing certification requires the following:
1. Adherence to the LCN Center Certification Agreement
2. Annual submission of the LCN Center Grant Application
3. Adherence to the LCN Center Grant Agreement awarded by the Hunter’s Hope Foundation
4. Demonstrated adherence to the LCN Clinical Practice Guidelines
5. Entry of patient registry data as required and determined by the LCN when available
6. LCN Center Status Report when required for requisite site visits to occur every 1-3 years by the dates specified by the LCN

Education and Training
Ongoing education of Leukodystrophy care providers is critical to the continued development of their expertise in the care of individuals with Leukodystrophies. At a minimum, all LCN Certified Centers must conduct or participate in educational activities such as:

1. Allied health personnel teaching and training in Leukodystrophy care as it relates to their discipline.
2. Leukodystrophy-related support groups and community/lay group activities.
3. Leukodystrophy-related presentations at area hospitals, medical meetings and national conferences.
4. Peer and non-peer reviewed, Leukodystrophy-related articles and book chapters, and development of special educational materials, e.g., webinars, booklets, videotapes, etc.
5. Integration of Leukodystrophy into the core curriculum of your medical school and opportunities for medical students to be involved in Leukodystrophy patient care.
6. Well-defined program for involvement of clinical fellows in Leukodystrophy care and the LCN Center program.
7. Other educational resources that could be applied to Leukodystrophy patients.

The LCN is a program of Hunter’s Hope Foundation.
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