



Criteria for LCN Center Certification

The Leukodystrophy Care Network (LCN) will consider applications for certification of centers that have the same philosophy and core values as the LCN Vision 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)
2. Associate Program Director
3. Clinic Coordinator (Nurse Practitioner or RN)
4. Nurse

The following **Extended Multi-Disciplinary Team** must be available:

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 where or how they enter your institution's system, are immediately referred to your Leukodystrophy Care Center and that LCC staff is notified.
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 transition 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 and Extended Multi-Disciplinary Teams, 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, prescriptions, 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, and for patient care as needed/available.
 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 minimum.

Ongoing Certification

Ongoing certification requires the following:

1. Annual review and renewal of the *LCN Center Grant Agreement*.
2. Adherence to the *LCN Center Grant Agreement* awarded by the Hunter's Hope Foundation.
3. Mandatory participation in monthly LCN Care Coordinator meetings. If center's Care Coordinator is unable to attend, must be attended by another member of Core Team.
4. Mandatory participation in Annual in-person meetings by (at minimum) the LCN Center Director and LCN Center Care Coordinator.
5. Demonstrated use of *LCN Clinical Practice Guidelines*.
6. Entry of patient registry data as determined by the LCN as required.

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. Leukodystrophy-related articles and book chapters, and development of special educational materials, e.g., films, 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.



LCN Participation

To be considered for certification, members from the center's core team **must** participate in the following:

- Bi-annual LCN face-to-face/virtual meetings
- The next LCN virtual meeting, is July 18 – 21, 2022
- LCN Subcommittee conference calls as needed
- Leukodystrophy Clinical Practice Guidelines development teams

About the Leukodystrophy Care Network (LCN)

The LCN exists across the United States to provide innovative therapies, treatment options, expert care and information to families affected by these Leukodystrophies.

The medical community recognizes the LCN and its Centers (LCC) as leaders in Leukodystrophies for patients and medical professionals. Centers will be self-sustaining, yet collaborative, networked together to ensure the highest quality groundbreaking care is available for all Leukodystrophy patients today and generations to come. Hunter's Hope Foundation is partnering with affected families and several Leukodystrophy organizations to create the LCN, including:

- World Leukodystrophy Alliance
- GLIA
- ALD Connect
- The Myelin Project
- Aidan Jack Seeger Foundation
- Bethany's Hope Foundation
- The M.O.R.G.A.N. Project
- The United Leukodystrophy Foundation
- The Jackson Project

For more information, visit <https://www.huntershope.org/family-care/leukodystrophy-care-network/>.

About Hunter's Hope Foundation

The Hunter's Hope Foundation was established in 1997 by NFL Hall of Fame Quarterback Jim Kelly and his wife Jill, after their infant son, Hunter (February 14, 1997 – August 5, 2005) was diagnosed with Krabbe Leukodystrophy, an inherited fatal nervous system disease. While Jim and Jill have been blessed with the opportunity to share Hunter's story and the hope of the Foundation named after their son all over the world – their greatest passion is to bring encouragement and hope to families in the midst of suffering.

The Foundation's mission and focus is threefold: to fund research necessary to treat and cure devastating leukodystrophies, increase newborn screening standards across the United States to obtain early detection and treatment for all treatable diseases, and to confront the urgent need for medical, financial and emotional support of those afflicted with Leukodystrophies and their families. For more information, visit www.huntershope.org.