



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:

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

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.

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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.

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LCN Participation

To maintain certification, representatives from Certified Centers core team (and multidisciplinary team when appropriate) must participate in the following:

- Two LCN face-to-face meetings a year; Summer and Winter
- LCN Subcommittee and Workgroup conference calls, as needed
- Leukodystrophy Clinical Practice Guidelines development teams

About the Leukodystrophy Care Network (LCN)

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

The medical community will recognize 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 has partnered with affected families and several Leukodystrophy organizations to spearhead the creation of the LCN. These organizations include:

- World Leukodystrophy Alliance
- GLIA
- ALDConnect
- The Myelin Project
- Aidan Jack Seeger Foundation
- The Olivia Kay Foundation
- Bethanys Hope Foundation
- The M.O.R.G.A.N. Project
- The United Leukodystrophy Foundation
- The Jackson Project
- Believing for Bryleigh

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.

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