



LCN Care Coordinator

The LCN is committed to providing patient-centered, multidisciplinary, expert care to all individuals affected by Leukodystrophies. The Care Coordinator is crucial to implementing these standards at each Leukodystrophy Care Center (LCC). This role includes the oversight of the implementation of the following:

1. Coordinator must be a Nurse Practitioner or Registered Nurse, or another medical professional approved in advance to hold this position.
2. Assists with triage of urgent patient medical issues to the correct provider within the LCC.
3. Serves as the point of contact for patients and referring physicians in their interactions with the LCC.
4. Assists in coordinating communication/collaboration between LCN providers and patient's local providers.
5. Oversees the coordination of outpatient/in-home services such as physical and occupational therapy, nursing, etc.
6. Coordinates the referral for medical equipment and supplies, as well as appropriate parent training, as needed.
7. Ensures that all medical records are accessible to LCC team and all other medical providers as needed for multidisciplinary coordinated care.
8. Coordinates the various appointments with team members, laboratories, imaging studies, etc. for patient clinic visits.
9. Ensures timely communication of test results to family and all physicians as needed.
10. Attends all meetings/conference calls related to the medical care of the patient.
11. When patients are hospitalized at LCC, the care coordinator visits them regularly to make sure their needs are being met in accordance with the LCN Criteria. When hospitalized outside LCC, the coordinator is the liaison between local and LCC teams.
12. Keeps LCC team members informed of patient's medical developments between clinic visits.

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

PO Box 643, Orchard Park, NY 14127, 716-667-1200, www.huntershope.org



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13. Oversees the provision of letters of medical necessity, insurance authorization, prescription refills, and proper documentation for school, work, travel, etc.
14. Links families to LCN educational materials, website, and family advocates.
15. Implements Care Coordinator processes and procedures established by LCN Care Coordinator Subcommittee.
16. Coordinates the implementation of the LCN Clinical Practice Guidelines at the LCC.

All Coordinators participate on the LCN Care Coordinator Subcommittee. This entails the two in-person LCN meetings each year (winter and summer) and monthly conference calls to share best practices, learn from members, provide input for the Clinical Care Guidelines, etc.