NORD’s Rare Disease Centers of Excellence

Application Requirements

The NORD Rare Disease Centers of Excellence program (NORD CoE) is new, launched in Spring 2021. Individual centers or groups of centers may apply to receive the Center of Excellence designation at either the national or regional level. Application and designation criteria are described below.

All NORD CoEs will together form a Network to support effective patient care, promote generation and documentation of patient experience data, and to facilitate the development, dissemination, and implementation of best practices and novel treatment protocols.

Completing the Application

Please complete the online application form found at nordcoeapp.rarediseases.org. Responses are required for every question.

- A letter of support is required from your institution or Center’s senior leadership and must be uploaded at the time of submission.
  - For group applications, all participating institutions will need to provide letters of support.

Information About Your Rare Disease Program and Institution

- Contact information for Institution/Center, Center Director, and location.
  - For group applications, the name and contact information for each institution and their Director are required.

- Institution Description (750-word max).
  - For group applications, include descriptions for each institution joining this group application and the role each participant will play (750-word max for each)

Medical Services and Care

Question 1: With a focus on clinical care and services, tell us about your institution's experience and commitment to treating rare disease patients. Please include areas of rare disease expertise and qualifications (patient volume, clinical research programs, recognitions) (750 words)
Question 2: Does the institution hold any rare disease-specific designations or accreditations? (Example: Cystic Fibrosis Foundation Care Center)

Question 3: Describe any ACGME certified clinical training programs at your institution that have a focus on rare disease. Include the number of program slots and fill rates for the last 3 years. (500 words)

Question 4: Describe any clinically oriented teaching programs that have a focus on rare disease topics. (500 words)

Question 5: Describe the teaching and informatics programs that your institution provides for patients at the local and broader level. (500 words)

Question 6: Describe how your program manages the transition of pediatric patients into adult care. (500 words)

Question 7: Describe any rare disease research programs at your institution. (750 words)

Question 8: Describe any other collaborations or commitments that are worth noting relating to your institution’s engagement in rare diseases. (500 words)

**Patient Satisfaction Data**

Question 1: Where/how do you capture patient satisfaction information? (Press Ganey or other)

Question 2: How frequently does your institution conduct patient satisfaction surveys?

Question 3: What critical feedback did the institution receive during its last survey? How did the institution respond to this input?

**Programs & Resources**

Applicant will need to state which of the resources listed below your program has available to rare disease patients and whether they are made available on site, locally accessible, or unavailable.

- Quality improvement
- Telemedicine services for rare disease patients
- Inpatient dialysis/hemofiltration team
- Pediatric emergency room (level 3 or greater)
- Adult emergency room (level 3 or greater)
- Pediatric intensive care (level 1)
- Neonatal intensive care (level 3 or greater)
- Pediatric cardiac surgery
Physical Facilities and Services

Applicants will need to describe the facilities and services (see list below) present and readily available for patients at their institution. For joint applicants, there must be easy cross-institution access. It is understood that some facilities may be spread across the institution and that naming conventions may vary.

- General chemistry and hematology laboratory
- Phlebotomy with pediatric trained personnel
- Biochemical laboratory (amino acids, organic acids, acylcarnitine)
- Lysosomal enzyme laboratory
- Cell culture facility for clinical testing
- Molecular genetics laboratory with cytogenetic capacity
- Molecular genetics laboratory with single gene and DNA testing capacity
- Molecular genetics laboratory with whole exome capacity
- Molecular genetics laboratory with whole genome capacity
- Pathology clinical service (with pathologist)
- X-ray facility with pediatric radiology
- MRI/CT facility with neuroradiology
- MRI spectroscopy capacity
- PET scan capacity
- Ultrasound diagnostic facility
- Electroencephalography service
- Electrocardiography service
- DEXA (bone density)
- Inpatient pharmacy
- Outpatient pharmacy
- Research pharmacy
- Muscle biopsy capacity

Patient Services

These are patient care services that are present at the institution(s) and readily available for patients. For joint applicants, there must be easy cross-institution access. It is understood that some facilities may be spread across the institution and that naming conventions may vary.
Pediatric ophthalmology clinic with special needs experience  
Rare disease program dedicated case manager/coordinator  
Pediatric dental clinic with special needs experience  
Hearing and speech evaluation  
Home infusion service  
Child psychology  
Pediatric physical/occupational therapy  
Formal child psychology/neuropsychology testing program  
Home health coordination or case manager for complex patients  
Family counseling and/or adult psychology services  
Infusion center for biologics and drugs  
Newborn screening follow-up program  
Social work program  
Patient Care Navigator

**Adult and Pediatric Medical Specialties**

Applicants will need to state whether they have adult and pediatric staff and services across a range of medical specialties, listed below. Applicants will also have to state whether the staff and services are available on-site, locally accessible, or unavailable.

<table>
<thead>
<tr>
<th>Adult and Pediatric</th>
<th>Other Specialties</th>
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<tbody>
<tr>
<td>Dermatology</td>
<td>Adult cardiology</td>
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<tr>
<td>Ear Nose and Throat surgery</td>
<td>Biochemical nutritionist</td>
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<td>Endocrinology</td>
<td>Board Certified/eligible genetic counselor</td>
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<td>Gastroenterology</td>
<td>Board Certified/eligible geneticist</td>
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<td>General surgery</td>
<td>Board Certified/eligible medical biochemical geneticist</td>
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<td>Hematology</td>
<td>Board certified/eligible molecular geneticist</td>
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<td>Hepatology</td>
<td>Fetal medicine specialist</td>
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<td>Immunology/allergy</td>
<td>Pediatric behavior and development</td>
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<td>Intensivist</td>
<td>Pediatric cardiothoracic surgery</td>
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<td>Neurology</td>
<td>Pediatric epileptology</td>
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<td>Neurosurgery</td>
<td>Pediatric infectious disease</td>
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<td>Oncology</td>
<td>Pediatric orthopedics experienced in skeletal dysplasia</td>
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<td>Urology</td>
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Clinical Full Time Equivalents for Critical Specialties

Additionally, applicants must include the total FTE assignment to clinical service for all providers in these fields as of the date of this application (fractional allowed).

- Board Certified/Eligible Genetic Counselors
- Board Certified/Eligible Clinical Geneticist
- Board Certified/Eligible Biochemical Geneticists
- Board Certified/Eligible Molecular Geneticists
- Board Certified/Eligible Biochemical Nutritionists
- Board Certified/Eligible Pediatric Neurology
- Board Certified/Eligible Pediatric Endocrinology