

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.
- Additional brochures or information sheets about your Institution or Center are optional and should be uploaded at the time of submission.

Required Institution Information

- 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: Please tell us about your institution and its experience treating rare disease patients (750-word max).
 - **For group applications**, include descriptions for each institution joining this group application; whether this is a new collaboration or building upon existing relationships; and what the overall architecture of the proposed program will be. You can upload the descriptions into one combined document or separate file uploads for each. (750-word max for each)

Useful Definitions and Clarification

Question 1:

What is the makeup of rare disease medicine at your institution(s)? *The focus of this should be on clinical care and services.* What service(s) are the main focus for these patients? *List particular strengths and areas of rare disease expertise.* What concrete commitments has the institution made to rare diseases (facilities, services etc.)?

750-word max

Question 2:

Describe any clinical training programs at your institution(s) (ACGME certified) that have a focus on rare disease. Include number of slots in the program and fill rates for the last 3 years. Do not include general medical specialties (i.e. Pediatrics, Internal Medicine, Surgery, OB-Gyn, Family Medicine).

500-word max

Question 3:

Describe the clinically oriented teaching programs at your institution(s) that focus on rare disease topics. *Focus on any programs that cover any clinical aspects of treating rare diseases, even if they are not ACGME accredited.*

500-word max

Question 4:

Describe teaching/informatics programs that your institution(s) provides for patients at the local and broader level.

500-word max

Question 5:

Describe how your program manages the transition of care from pediatrics to adulthood for rare disease patients.

500-word max

Institution Programs

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
- Pediatric heart transplant program
- Adult heart transplant program
- Pediatric kidney transplant program
- Adult kidney transplant program
- Pediatric liver transplant program
- Adult liver transplant program

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

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.

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

Adult and Pediatric

Dermatology
Ear Nose and Throat surgery
Endocrinology
Gastroenterology
General surgery
Hematology
Hepatology
Immunology/allergy
Intensivist
Nephrology
Neurology
Neurosurgery
Oncology
Ophthalmology
Orthopedics
Plastic surgery
Psychiatry
Pulmonology
Urology

Other Specialties

Adult cardiology
Biochemical nutritionist
Board Certified/eligible genetic counselor
Board Certified/eligible geneticist
Board Certified/eligible medical biochemical geneticist
Board certified/eligible molecular geneticist
Fetal medicine specialist
Pediatric behavior and development
Pediatric cardiothoracic surgery
Pediatric ENT
Pediatric epileptologist
Pediatric infectious disease
Pediatric orthopedics experienced in skeletal dysplasia
Pediatric pathology
Pediatric psychology
Pediatric radiology
Perinatal Medicine