Identify Partner for Continuing Medical Education

Request for Proposals No. 2018-07

National Organization for Rare Disorders

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# **ABOUT NORD**The National Organization for Rare Disorders (NORD) is the leading not-for-profit organization dedicated to improving the lives of patients and families impacted by rare disease and supporting the organizations that serve them. NORD, along with its 280 disease-specific members, are committed to the identification, treatment and cure of rare diseases through programs of advocacy, education, research and patient assistance services.

# Rare diseases are defined as affecting fewer than 200,000 people in the United States. There are approximately **7,000 known rare diseases** that impact the lives of **30 million Americans**; more than half are children. Many of these conditions are life-threatening, chronic, multi-system and complex. A majority of them (80%) are genetic and only 5% of the 7,000 have an FDA-approved treatment.

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# NORD was founded in 1983 by patients, caregivers and advocates who wanted to strengthen and unite the voices of the rare disease community and collaborate on advancing policies, regulations, research and education on behalf of all patients, including those without a disease-specific organization championing their cause. This year is the organization’s 35th anniversary.

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# **ABOUT NORD’S EDUCATION INITIATIVES**

# For 35 years, NORD has been a trusted source for providing critical educational resources to the rare disease community. NORD’s educational initiatives provide resources and programs to empower patients and their families, inform students of all ages, and support the vitally important work of physicians and other healthcare professionals. These include videos, webinars, rare disease reports, a student chapter program and more.

**ABOUT MEDICAL EDUCATION AT NORD**

For many years, NORD’s primary means of educating medical professionals were its rare disease reports, physician guides and other publications, including medical textbooks. The most recent of these, *The NORD Guide to Rare Disorders,* was published in 2003 and received excellent reviews from *The Lancet, The British Medical Journal* and other publications. The purpose of NORD’s medical professional outreach has been to provide a resource for clinicians to facilitate the timely diagnosis and treatment of rare disease patients.

In 2017, NORD decided to expand its medical education programming and developed a pilot CME program. This was a live event offered in Washington DC that attracted about 40 medical professionals and received positive reviews from those who participated. It focused on the need for physician awareness of rare diseases and resources available to them to promote earlier diagnosis for patients.

Now NORD is seeking a partner to help us build upon this initial success and develop additional CME resources to reach a broad national or even international audience with a combination of live events and online resources. Our hope is to address universal issues related to rare diseases, such as delayed diagnosis, as well as topics related to specific rare diseases or groups of diseases.

The interest exhibited by medical professionals in our initial CME program, and numerous requests from those outside of the Washington DC area for resources that would be accessible to them, give us conviction that there is a need for NORD to expand its involvement in CME and that this would be consistent with our mission of improving the lives of rare disease patients.

**PROJECT OVERVIEW AND GOALS**
The findings from the analysis made it clear to NORD that a strong partnership with an experienced CME provider is needed to carry out a successful CME program. NORD is fully invested in having a thriving CME program as it sees educating medical professionals as a critical part of its mission. Because of this, NORD would like to identify a full-scale partner with CME accreditation and experience in meeting CME requirements, marketing CME to medical professionals, and attracting CME funding.

NORD would like to implement a multi-format CME program that is designed to reach or exceed the following goals:

1. OUTCOMES - Each CME resource should achieve one or more of the following outcomes:
	1. Reduce time to diagnosis
	2. Provide better treatment
	3. Improve support for rare disease patients
	4. Improve understanding of the patient family experience
	5. Promote awareness of NORD
2. FEEDBACK - In the follow-up survey for each event, at least 90% of participants should respond that they intend to change their behavior.
3. REVENUE - The CME program should achieve the following net revenue targets in 2019 and 2020:
	1. 2019 - $75,000+
	2. 2020 - $100,000+
4. OUTPUT - Launch the following number of resources:
	1. 2019 - at least 1 live event and 2 text-based or online (including webinars, on-demand webcasts, etc.) resources
	2. 2020 - at least 1 live event and 3 text-based or online (including webinars, on-demand webcasts, etc.) resources
5. REACH - The CME program should reach the following number of medical professionals:
	1. 2019 – 300+ medical professionals
	2. 2020 – 450+ medical professionals
6. AUDIENCE SEGMENTS - Resources must be developed for the following types of medical professionals:
	1. One resource must be designed specifically for non-MD medical professionals. This could include:
		1. Nurses
		2. Physician Assistants
		3. Pharmacists
	2. Other should be designed for MDs or DOs

**SCOPE OF NEEDED SERVICES**NORD is seeking a CME partner that can provide the following services:

* CME accreditation
* Marketing services to appropriate audience
* Content development support (Content to be primarily driven by NORD)
* Online content delivery services
* Pre- and post-CME activity support
* Experience in grant procurement and/or revenue generation

**REQUIREMENTS FOR PROPOSAL**
Please include the following in your proposal response:

* Letter of Intent
* Overview of your organization and typical client (industry, size, need, lifecycle)
* Describe your company’s experience in the rare disease space
* Areas of expertise and list of services you provide
* Details about the team that would be working on the project
* Overview of how your company will meet our goals for CME
* Proposed timeline for all CME formats (include timelines for all CME formats i.e. live events, text-based CME, webinar/webcast CME, etc. from concept to delivery)
* Names and overview for any sub-contractors
* 3 recent CME projects with associated metrics (similar scope/type of client preferred but not required)
* 3 client references (within the last 5 years)
* Proof of CME accreditation
* Pricing with identification of in-scope and out-of-scope (optional) activities
* Terms and conditions

**ANTICIPATED SELECTION SCHEDULE**NORD would like to have a signed memorandum of understanding with a CME partner by December 7, 2018. To ensure that this deadline is met, NORD is proposing the following timeline:

**RFP Published:** October 3, 2018

**Deadline for Bidders to Submit Questions:** October 17, 2018
**NORD Responds to Bidder Questions:** October 26, 2018

**Proposals Due:** November 16, 2018

**Final Decision Made:** November 23, 2018

**MOU Draft and Review:** November 26-December 4, 2018
**Final MOU signed:** by December 7, 2018

**TIME AND PLACE OF SUBMISSION OF PROPOSALS**

Letters of Intent and final submissions should be sent to the attention of:

Mary Dunkle

National Organization for Rare Disorders (NORD)

Email: mdunkle@rarediseases.org

Office: 55 Kenosia Avenue, Danbury, CT 06810

NORD welcomes web presentations of proposals

**BUDGET**

While we favor a partner that has a built-in revenue generation model, the determination will largely be based on the company’s capability and understanding of the project, expertise and experience executing upon similar scopes of work, and creative solutions.