



## **NORD Launches Digital Education Initiative with PlatformQ Health**

*New program by the trusted voice and leader in the rare disease community aims to increase clinician preparedness and improve the care of patients living with rare diseases*

**BOSTON, MA and WASHINGTON, DC, June 18, 2019** – The National Organization for Rare Disorders (NORD)®, the leading independent nonprofit organization representing the 25 to 30 million Americans living with rare diseases, is proud to announce it has joined forces with PlatformQ Health, a leading provider of digital education for clinicians and patients, to create accredited online education about rare diseases. Recognizing the need for accessible, engaging and effective digital education on rare diseases, NORD seeks to equip healthcare professionals with the information they need to improve patient outcomes.

"Unfortunately, it can take several years for a person who has a rare disease to receive a diagnosis. Those years of unanswered questions are extremely difficult on families, and delaying treatment that long often has serious implications on a person's health," explained Sika Dunyoh, NORD's Director of Education Programs. "Creating awareness of rare possibilities through education can shorten the diagnostic odyssey and improve the quality and timeliness of treatment."

The continuing medical education released under the new collaboration is designed to be convenient, trustworthy, engaging – and perhaps most importantly – measurably effective and will include:

- Live and on-demand, video-based programs accessible from any internet-connected device
- Content created with additional leading patient organizations that will explore both disease-specific topics and cross-cutting issues
- Expert panelists featured alongside speakers from affected families, so clinicians can gain a better understanding of the patient journey
- The ability for learners to ask questions in real-time, respond to polls and download slides and resources prepared by the panelists
- The sharing of programs with specialists and general practitioners across NORD's network and via PlatformQ Health
- An integrated learning management system that will measure gains in knowledge and changes to clinical practice after learners attend a program

Through this initiative, NORD will have opportunities to collaborate with its member organizations, over 280 disease-specific partners, to educate clinicians and patients in their respective disease areas.

"Doctors are trained to look for the most common explanation of symptoms, and with the numerous time constraints and other pressures physicians face, it can be easy to miss or misidentify a rare condition when it shows up in daily practice," PlatformQ Health CEO Robert Rosenbloom remarked. "No doctor wants to feel unprepared, and for the families who are facing a rare disease, the status quo isn't enough," he continued. "With NORD's understanding of and connections to the rare disease



world, and our technology and experience in continuing medical education, we hope to empower clinicians so they can guide patients to the best possible results.”

Those interested in learning more about this new partnership are invited to contact NORD and PlatformQ Health [here](#).

### **About the National Organization for Rare Disorders (NORD)**

[The National Organization for Rare Disorders \(NORD\)](#) is the leading independent advocacy organization representing all patients and families affected by rare diseases. NORD is committed to the identification, treatment and cure of the more than 7,000 rare diseases, of which approximately 90 percent are still without an FDA-approved treatment or therapy. Rare diseases affect 25-30 million Americans. More than half of those affected are children.

NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. For more than 35 years, NORD has led the way in voicing the needs of the rare disease community, driving supportive policies and education, advancing medical research and providing patient and family services for those who need them most. NORD is made strong together with over 280 disease-specific member organizations and their communities and collaborates with many other organizations on specific causes of importance to the rare disease patient community.

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### **About PlatformQ Health**

[PlatformQ Health](#) is the leading provider of interactive digital medical education for clinicians, patients and caregivers. To improve patient care, PlatformQ Health creates video-first educational modules with premier partners, so learners can better understand conditions, available treatment options, and the latest research. The company’s proprietary platform allows participants to engage in real-time discussion with scientific, research and patient care experts – and the integrated learning solution enables advocates, administrators, health systems and plans, foundations, societies, member organizations and associations to measure the impact of their education.

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