

PlatformQ Health Education, NORD and CureSMA to Co-Present on the Impact of Digital Education on Clinicians and Caregivers at NORD's Rare Disease and Orphan Products Breakthrough Summit

Partners present findings from an outcome-centric joint educational initiative that showcases the impact rare disease education can have on improving health outcome.

PlatformQ Health's partnership with the National Organization for Rare Disorders (NORD) and CureSMA cultivated a successful educational program that led to the poster presentation, "Educational Impact of Digital Education: Spinal Muscular Atrophy Education for Clinicians and Caregivers," that will be presented at NORD's 2020 Rare Disease and Orphan Products Breakthrough Summit on October 8th and 9th. The PQHE team is excited to be able to contribute to this virtual event that promotes innovation, collaboration, and meaningful rare disease education to improve patient care and health outcomes.

About the Poster

The poster presents evaluation results from the joint CME and caregiver program, Improving Outcomes in Spinal Muscular Atrophy: Best Practices for Clinicians and Families. This live virtual program launched on RareDiseaseLive, NeuroCareLive and NeuroSeriesLive in December of 2019 and remained on-demand for 12 months. The joint format allowed poster creators to identify unique areas of disconnect between clinicians and patients related to awareness of treatment options, treatment expectations, and practice of shared decision making.

"NORD's unwavering commitment and connection to the rare disease community paired with PlatformQ Health's proprietary learning management platform and therapeutically-aligned learning channels, empowers a partnership that can drive meaningful results and positive outcomes, which is highlighted in this poster presentation. Virtual education designed for patients, caregivers and clinicians is proven to be instrumental in helping clinicians better identify, diagnose, treat and prescribe these conditions while also empowering patients to become advocates for their care," shared Robert Rosenbloom, CEO of PlatformQ Health.

The Educational Need

The joint educational program was designed in response to the rapidly changing treatment landscape for spinal muscular atrophy. There has been recent development of novel therapeutic strategies and updated consensus recommendations on diagnosis and management. Clinicians are challenged to keep abreast of these advances, as well as developments in genetic diagnosis and disease course monitoring. Parents, caregivers, and families also require significant knowledge and support to aid in providing the best care for children with SMA.

For both HCP and caregivers who took part in the education, test questions were administered at 3 time points, including a 2-month follow-up post-test. that also included practice/behavioral and communication-focused questions. Data from these questions, live polling responses, and learner-submitted questions for Q&A were analyzed to determine engagement, lessons learned and continuing HCP and caregiver education gaps.

At-A-Glance Engagement Statistics

- 4,277 total engagements with the joint educational program
- 542 hcp learners including 299 MDs, NPs, and PAs

- 230 engaged with the caregiver education on NeuroCareLive
- 30:19 average time in session (70-minute session)
- 29 total questions asked
- 108 slide downloads

Making an Impact on HCP Practice, Patient Empowerment, Communication & Knowledge Retention

This educational program was outcomes-driven, and measured impact and improvements in a number of facets, including knowledge, communication, behavior, shared decision making, activation, and more.

Some key data highlight from this program include:

- 72% of HCPs reported a positive impact of the education on clinical practice
- 60% of HCPs reported positive impact of the education on patient outcomes and or satisfaction
- 61% of caregivers reported a positive impact of the education on communication with HCPs
- 100% of caregivers strongly supported models of shared decision making

Based on the outcomes testing, HCPs showed knowledge improvements and increased retention regarding effects of SMA on patients along with improvements about the effects of current disease modifying therapies. Similarly, caregivers showed knowledge improvement about disease modifying therapy impact along with risk of being born with SMA.

Data Determines the Next Wave of SMA Education

Evaluation results support existing evidence of the effectiveness of online CME and caregiver/patient education, while specifically showing support for online education on SMA as a positive influence on caregivers, patients, and clinicians. The strong impact of the program also highlights the value of collaboration among the initiative partners, NORD and CureSMA, who helped develop relevant educational content and promote the program to the audience most in need of the education.

Support for this online education was provided via an educational grant from Biogen.

Have any questions or interested in chatting with us? Email us at digital@platformq.com today!