

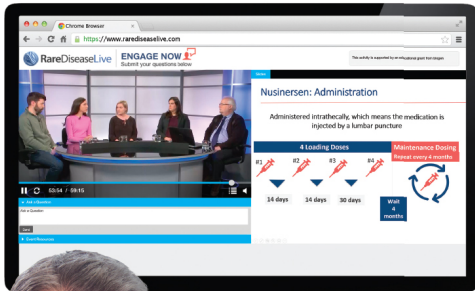
# Educational Outcomes of Aligned Caregiver and HCP Online Education on Spinal Muscular Atrophy

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## INTRODUCTION

**Educational Need:** Novel therapeutic strategies and updated consensus recommendations have led to changes in the treatment landscape of spinal muscular atrophy (SMA).

Health care professionals (HCPs) benefit from online education to stay up to date with these advances, as well as developments in genetic diagnosis and disease course monitoring. Families affected by SMA similarly benefit from online educational programming that include strong contributions from patient advocacy organizations such as NORD and CureSMA. They are able to utilize increased knowledge and confidence to better ensure quality care for children with SMA. These distinct needs for ongoing education led to the development of an online educational initiative that targeted both HCPs and caregivers/families.



## Program Details of Aligned Education for HCPs and Caregivers:

**Program Title**  
Improving Outcomes in Spinal Muscular Atrophy: Best Practices for Clinicians and Families

**Live-Virtual program launched** 12/12/19

**On demand through** 12/12/20

**Program location**  
RareDiseaseLive.com  
NeuroCareLive.com  
NeuroSeriesLive.com

### Learning Objectives HCP

- Summarize clinical practice/consensus guidelines for the comprehensive management of SMA
- Determine strategies to incorporate new disease-modifying therapies for SMA into daily clinical practice

### Parents/caregivers

- Summarize key clinical features of SMA, its genetic basis, tests done throughout the course of disease, and what their results mean
- Outline treatment options for SMA and interventions aimed at treating the disease, as well as addressing disease-related complications

### Target Audience HCP

Pediatric neurologists, neurologists, pediatricians, primary care physicians, internal medicine physicians, nurse practitioners, physician assistants, physical therapists, occupational therapists, and other HCPs interested and/or involved with the management of patients with SMA.

### Parents/caregivers

Parents, caregivers, and families of patients affected by SMA.

## METHODS

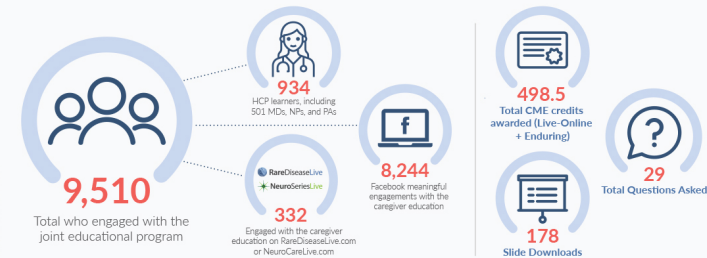
### Test Questions

For both HCPs and caregivers who took part in the education, test questions were administered at 3 time points (pre-activity, immediate post-activity, and 2 months [follow-up] post), in addition to practice/behavioral and communication-focused questions asked at the follow up point. 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.



## ENGAGEMENT RESULTS

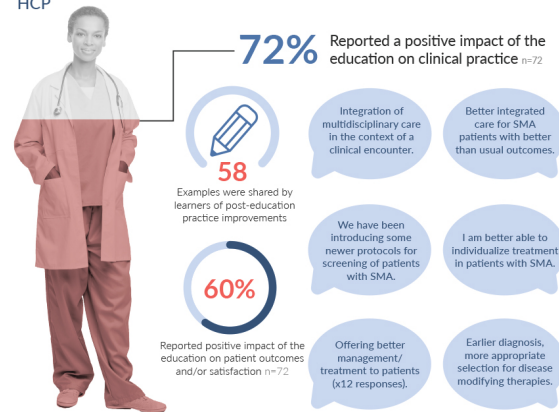
### Final Metrics



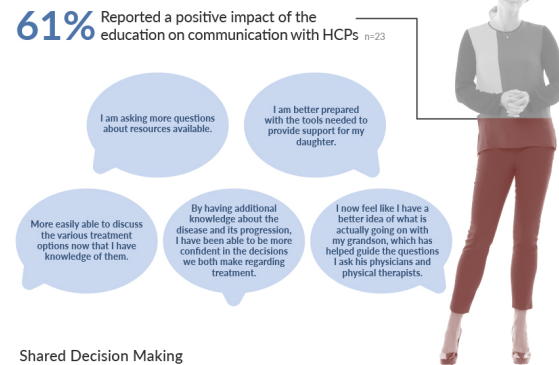
## IMPACT

### Positive Impact on HCP Practice, Patient Empowerment and Communication

#### HCP



#### Caregiver



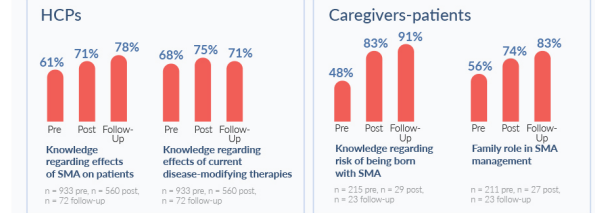
#### Shared Decision Making

Caregivers held strong support for models of shared decision making, with a slight post-education improvement

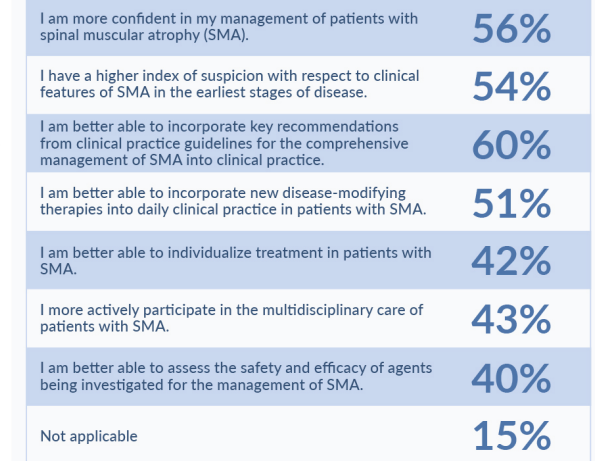


### Changes in Knowledge

All 7 knowledge and competence questions yielded improvements for HCPs and Caregivers



### HCPs: What changes have you made to your clinical practice as a result of participating in this activity?



Source: follow-up survey, n = 72

## CONCLUSION

Evaluation results support existing evidence of the effectiveness of online CME and 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 promoted the program to the audience most in need of the education.

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 Albert Einstein College of Medicine-Montefiore-Medical Center, Center for Continuing Medical Education, served as the accredited provider for the CME program.