

# Recent Treatment Advances in Dravet Syndrome: Influence and Continuing Need for HCP and Caregiver Education

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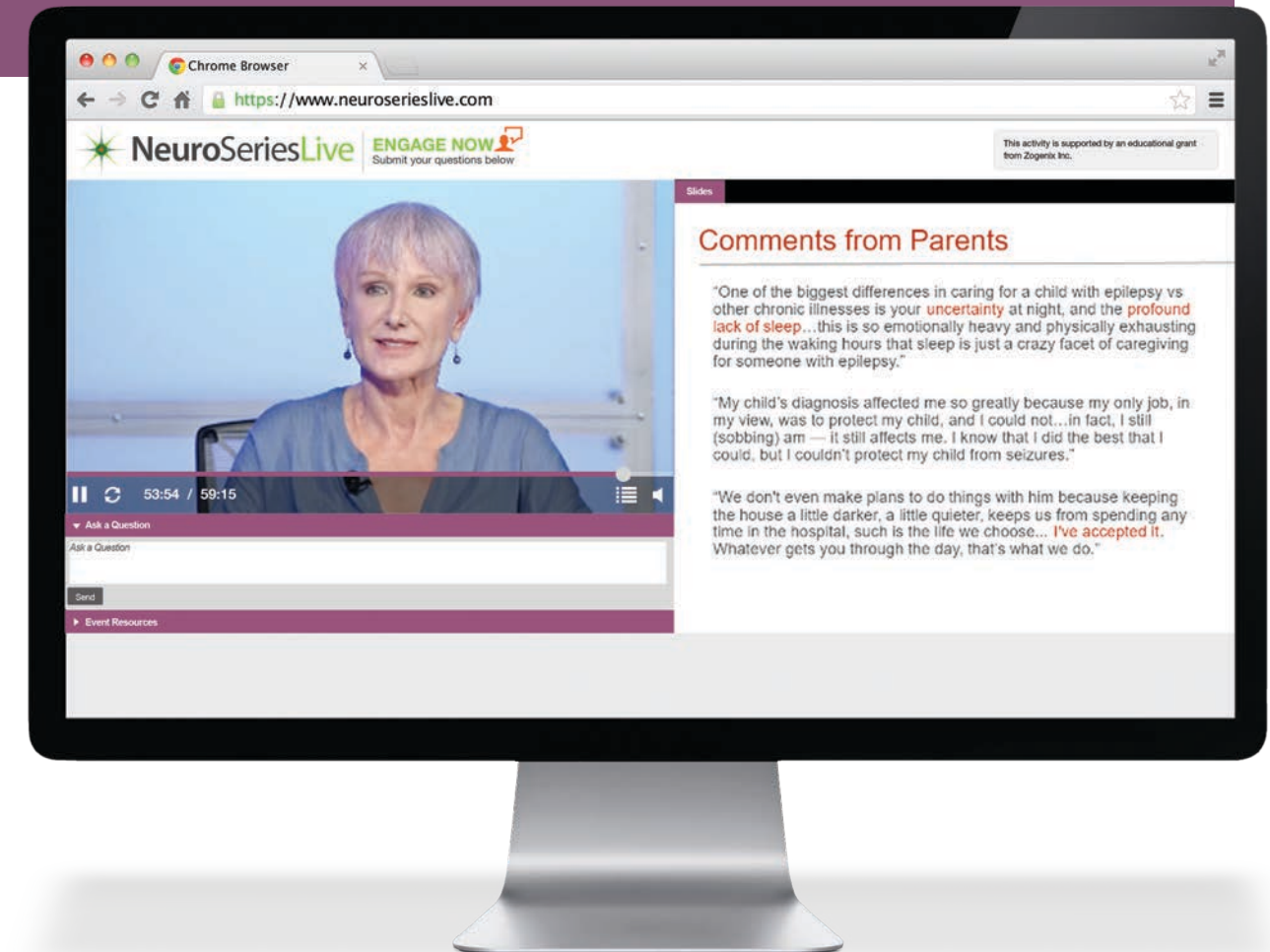
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## INTRODUCTION

The family burden of Dravet Syndrome (DS) is devastating, due to recurrent seizures, intellectual disability, and a greatly increased mortality rate, all of which profoundly affect quality of life (QOL). Additional caregiver burden may also include loss of time from work or unemployment, and other financial hardships. DS is also one rare developmental epileptic encephalopathy where major advances in therapeutic management have taken place in the last 2 years. Clinicians have lacked understanding of the burden of caring with a child with DS, and require education on recent advances in at-home treatment to ameliorate the negative impact of this disease and its comorbidities. Caregivers and families facing this diagnosis have a critical need for education as the drug management of the disease changes.

We sought to meet these educational gaps through online education, and subsequently assessed the impact of the targeted continuing medical education (CME) and caregiver-patient education through survey-based evaluation.



This activity is supported by an educational grant from Zogenix Inc.

# METHODS: EDUCATIONAL IMPACT MEASUREMENT

## Title

Treatment of DS: Proactively Facing Key Challenges in Diagnosis, Treatment, and Transition of Care

## Format

- 6, 1-hour CME and Caregiver education sessions produced and broadcast live-online on NeuroSeriesLive.com, NeuroCareLive.com, and RareDiseaseLive.com, and immediately on-demand 12 mos.
- Downloadable slides, panel discussions, live polling, pre-program and live Q&A.

## Accredited Provider

Global Education Group

## Caregiver Program Partners

- Dravet Syndrome Foundation
- National Organization for Rare Disorders

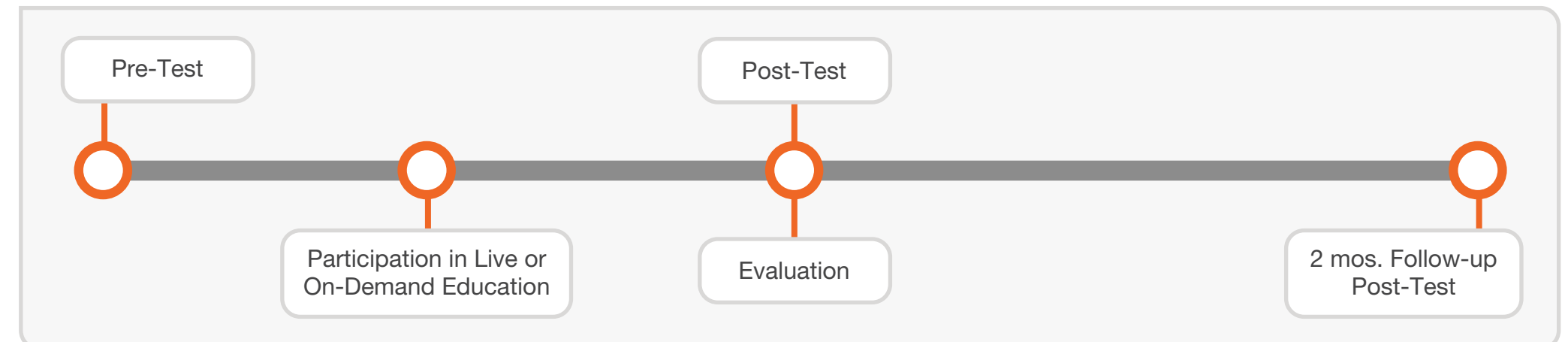
## HCP Learning Objectives

- Recognize the psychosocial challenges and stress-related comorbidities of caregiving for a patient with DS
- Explain why taking a multidisciplinary approach to addressing the needs of parents and siblings of patients with DS, is more meaningful including identification of sources of psychosocial support, caregiver/sibling relief, wellness interventions
- Explain the prevalence, clinical features, and importance of early diagnosis in DS
- Select appropriate treatments with proven efficacy and safety in DS
- Discuss emerging treatment options for DS
- Examine seizure and non-seizure measures to evaluate treatment success with antiepileptic drugs
- Identify strategies to critically appraise clinically meaningful measures in collaboration with families affected by DS

## Caregiver Learning Objectives

- List services and resources that can help address challenges in providing care for children with DS
- Promote awareness of DS, from early childhood throughout on symptoms and burden of disease
- Harness positive coping mechanisms after your child is diagnosed with DS
- Recognize the impact of DS diagnosis with immediate family and relatives
- Evaluate treatment options for DS with your child's health care provider
- Collaborate with health care teams to ensure smooth transition from pediatric to adult health care
- Adopt strategies to address caregiver burden

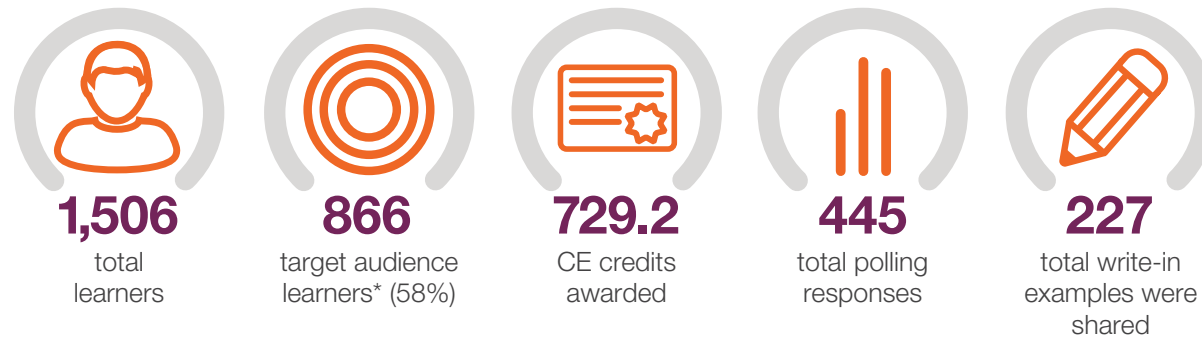
## Educational Impact Measurement



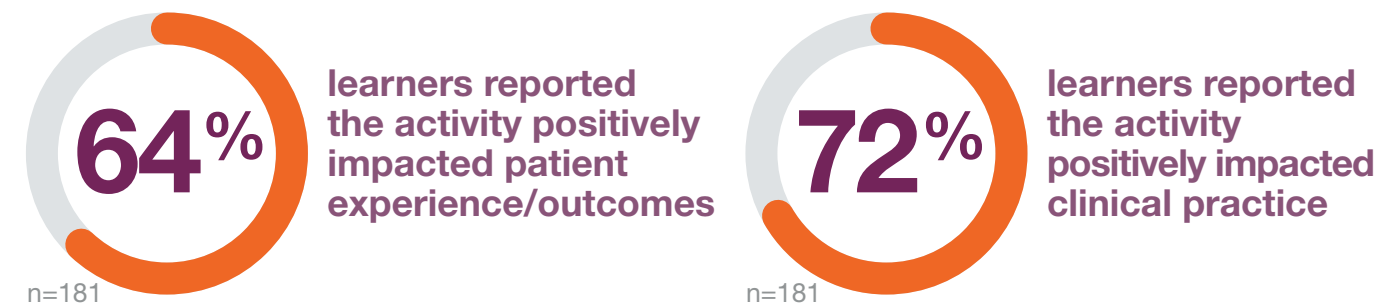
# RESULTS

## HCP Results

### Engagement



### Positive Impact on Patient Outcomes and Clinical Practice



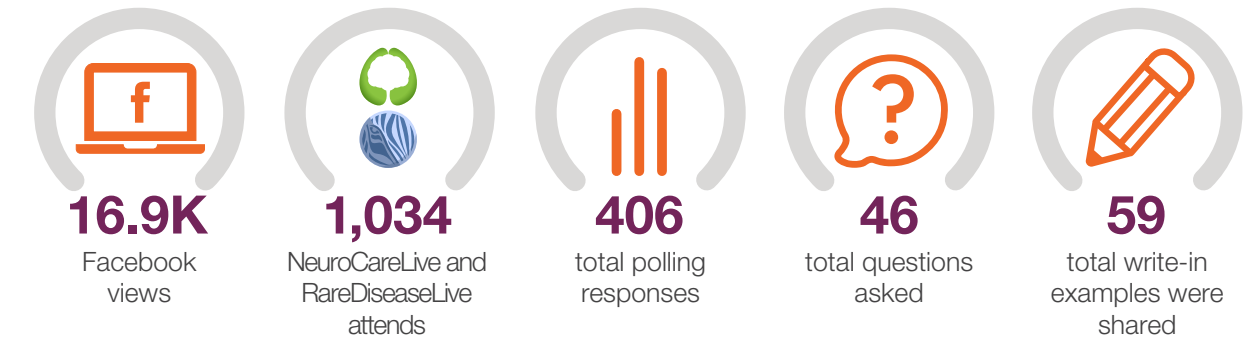
High index of suspicion for Dravet syndrome diagnosis in seizure disorders of infancy. Using genetic studies in reaching early diagnosis. Proper selection of anticonvulsants, stiripentol/clobazam, valproate.

I pay more attention to caregiver support and evaluation of their quality of life.

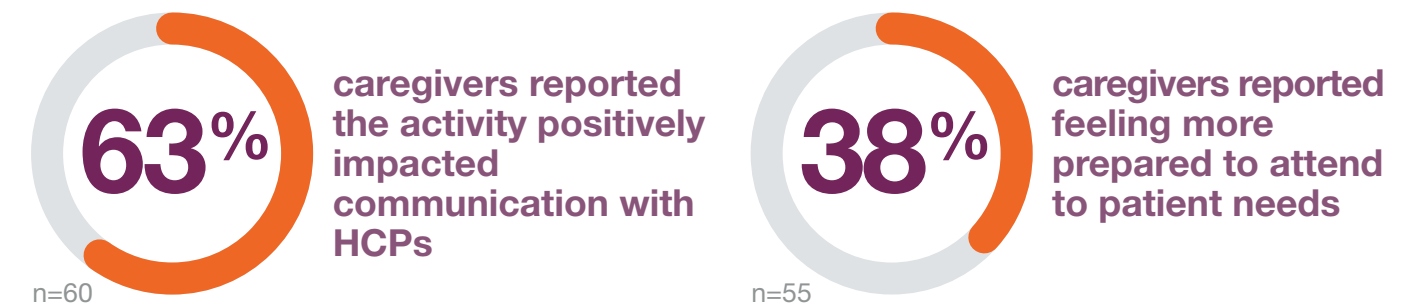
\*Target Audience: Neurology, Pediatrics, Pediatric Neurologists, Primary Care, Internal Medicine

## Caregiver Results

### Engagement



### Positive Impact on Communication and Preparedness



I feel as prepared now as I always have. However, since viewing the program I feel a greater sense of connectedness to other parents/caregivers who are in similar situations. It is a difficult thing indeed to feel prepared to face the challenges we face. But when there is solidarity, there is a greater sense of preparedness in facing what we must.

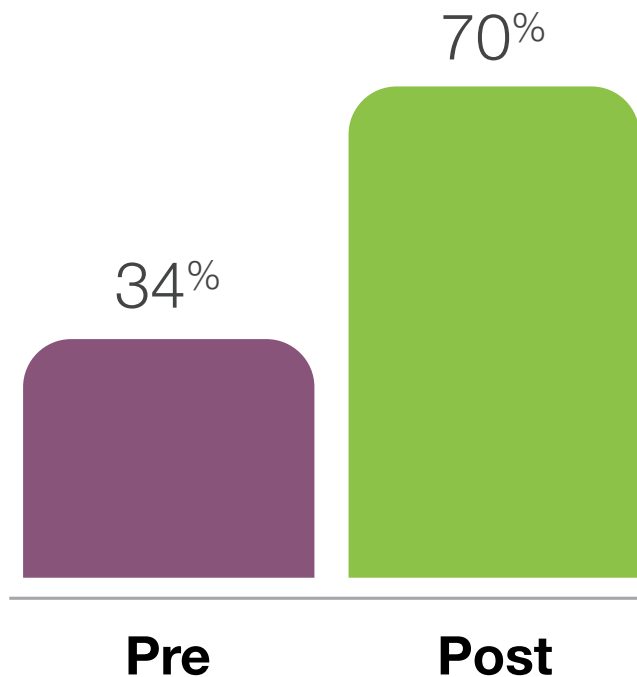
I'm more open about my personal ability to care for my daughter and ask for ways that I can be more effective and request more information when I don't understand something so that I can be a better caregiver.

# RESULTS: CHANGES IN KNOWLEDGE/COMPETENCE

## HCP Results

**36% & 23% increase over pre-test**

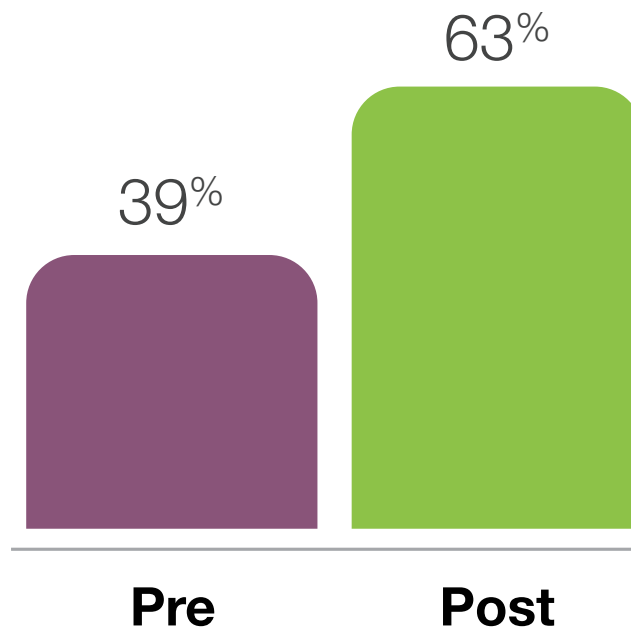
in competence concerning therapeutic approaches for seizure control



n = 400 pre; 187 post

**24% & 20% increase over pre-test**

in knowledge regarding DS characteristics

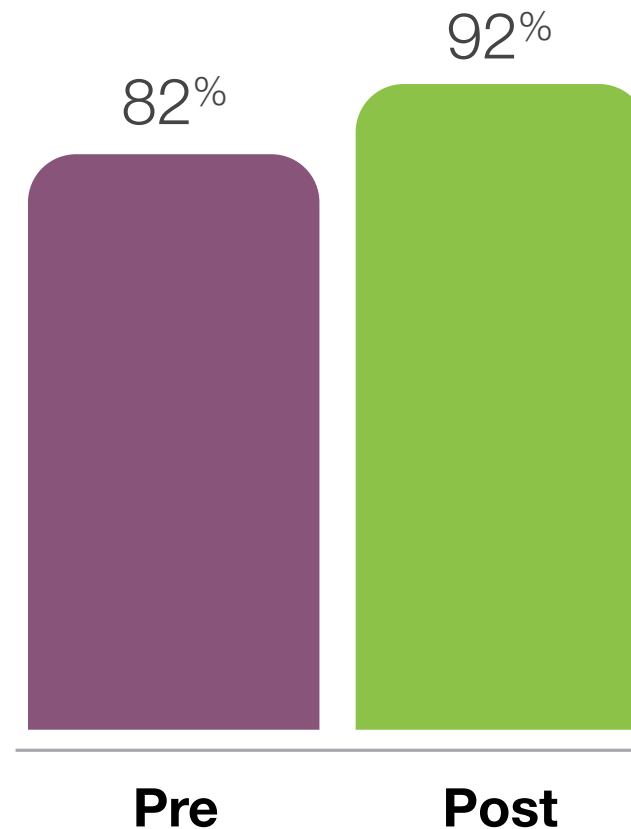


n = 400 pre; 187 post

## Caregiver Results

**10% increase over pre-test**

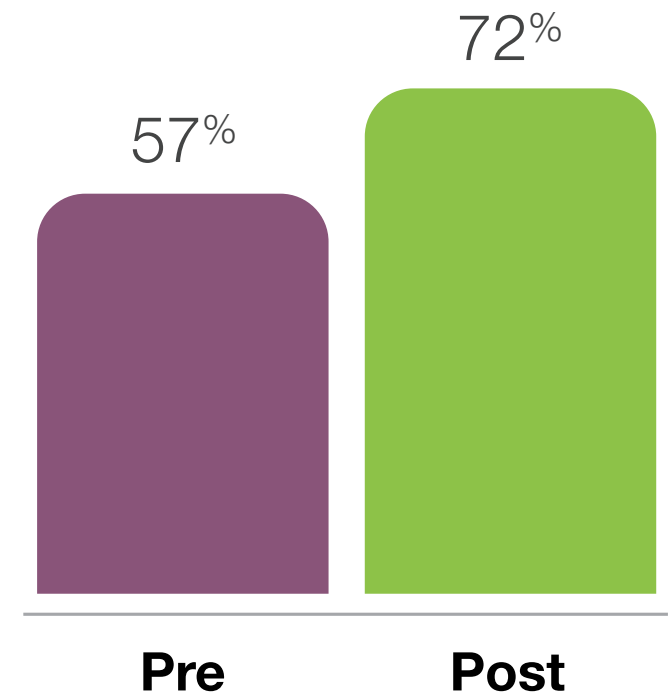
in knowledge regarding approved medications for DS



n = 200 pre; 49 post

**15% increase over pre-test**

in knowledge regarding strategies to alleviate caregiver burden



n = 128 pre; 33 post



# CONCLUSIONS & FUTURE EDUCATIONAL TARGETING

## HCP

Quantitative testing and surveying support the positive impact of CME and caregiver education focused on DS characteristics, treatment options, multidisciplinary care coordination, caregiver burden, and coping mechanisms. Ongoing HCP education is advised on:

### Management of DS:

- Effecting a smooth transition from pediatric to adult care
- Endorsement of multidisciplinary care and shared decision-making in DS – including the caregivers
- Supporting patients/families with DS – over and above medications
- Current, investigational and adjunct therapies for DS
- Balancing optimal seizure control and medication side effects

### DS - the disease:

- Genetic, signs, symptoms, characteristics and disease course of DS
- Transition from pediatric to adult care
- Interpreting EEG results
- Effective communication with case managers
- Resources providing benefits to families dealing with DS
- Developmental benchmarks in older patients

## Caregiver

Ongoing caregiver education is advised on:

### DS Treatment/Management:

- Investigational gene therapies
- Care for low-functioning adults with DS when caregivers age
- Genetic understanding of DS
- Seizure control and cognitive development

### DS General Issues:

- Addressing sibling needs
- Strategies for stress/anxiety relief in caregivers/families
- Utilization of support groups
- Strategies for financial issues

