

From Awareness To Action: Impact of Patient Education on Clinical Trial Engagement in CIDP and MMN

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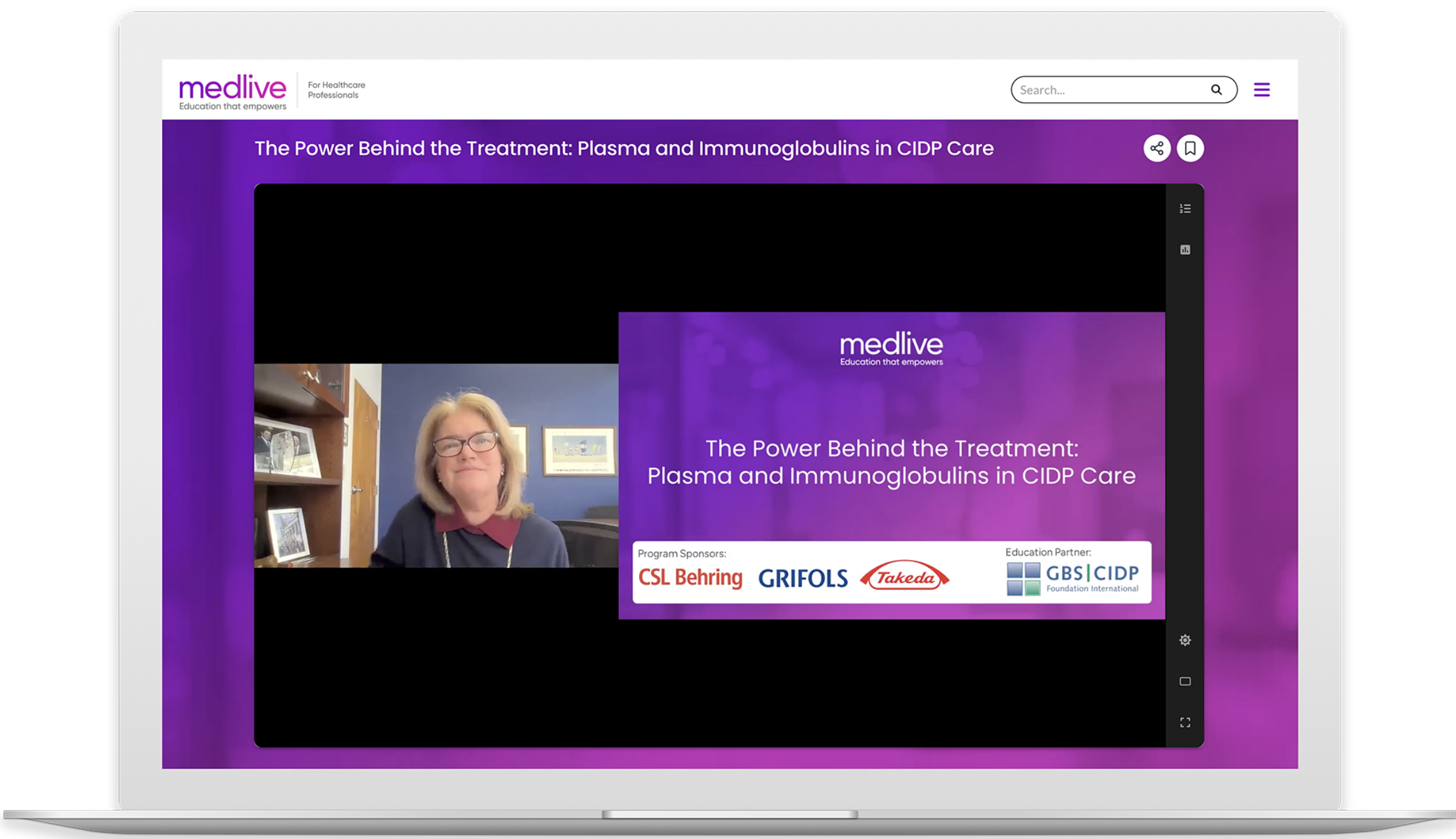


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INTRODUCTION

Recruitment into clinical trials for chronic inflammatory demyelinating polyneuropathy (CIDP) and multifocal motor neuropathy (MMN) remains challenging, due in part to limited patient awareness and uncertainty about clinical research participation. This poster analyzes outcomes from patient-focused education designed to improve understanding of neuromuscular clinical trials and identify barriers influencing willingness to participate.



METHODOLOGY

Educational Program and Evaluation Details

Three 60-minute, on-demand, online programs were conducted, including two focused on CIDP and one focused on MMN. The activities featured neuromuscular clinicians, advocacy leaders, and patient speakers. Sessions included moderated discussions, live polling, and audience question-and-answer segments. Quantitative engagement metrics and polling responses were analyzed alongside qualitative questions submitted by participants.

Objectives were to improve learner understanding of the following topics:

Activity 1: Living With Multifocal Motor Neuropathy? Why Your Participation in Trials Matters!

(launched October 18, 2023)

- The role of clinical trials for multifocal motor neuropathy (MMN)
- When a clinical trial is a viable option
- The benefits of clinical trials and how the GBS-CIDP Foundation International can help
- Review of ongoing MMN trials

Activity 2: Why Clinical Trials Matter for Patients Living with CIDP

(launched April 20, 2024)

- The role of clinical trials in improving your health and that of your community
- Benefits of participating in a clinical trial for people with CIDP
- The research process and commonly used terminology to describe it
- Tools and resources to keep up to date with ongoing clinical trials and their results

Activity 3: The Power Behind the Treatment: Plasma and Immunoglobulins in CIDP Care

(launched January 8, 2026)

- How IVIg and SCIG work in the body
- Why plasma is essential to CIDP treatment
- What to expect before, during, and after therapy
- Tips to manage side effects and fatigue
- How other patients navigate treatment decisions

RESULTS

Education

Educational campaigns generated substantial reach across social media channels including:



Activity	Social media views	Learners
1	70,979	990
2	84,976	1,288
3	259,354	339

Qualitative analysis of participant questions revealed concerns about eligibility criteria, placebo assignment, interruption of existing therapies, travel burden, and insurance coverage.

Key themes included:

1. Clinical Trial Participation and Concerns:

- Concerns about eligibility, care during the trial, outcomes, and withdrawal from trials
- Questions about differences in clinical trials, locations, care team involvement, and risks associated with trials

2. Treatment Options:

- Comparing different treatments (IVIg, sub-Q, and other newer and emerging therapies) and the benefits of switching treatments
- Concerns about treatment effectiveness, side effects, and future approved treatments

3. Insurance and Approval:

- Frustrations with insurance coverage for treatments like IVIg and the need for more accessible options
- Interest in understanding the process of getting FDA approval for treatments

4. Symptom Management and Outcomes:

- Managing symptoms like neuropathy, muscle wasting, and residual weakness, even when in remission
- Effectiveness of continued treatment for residual symptoms

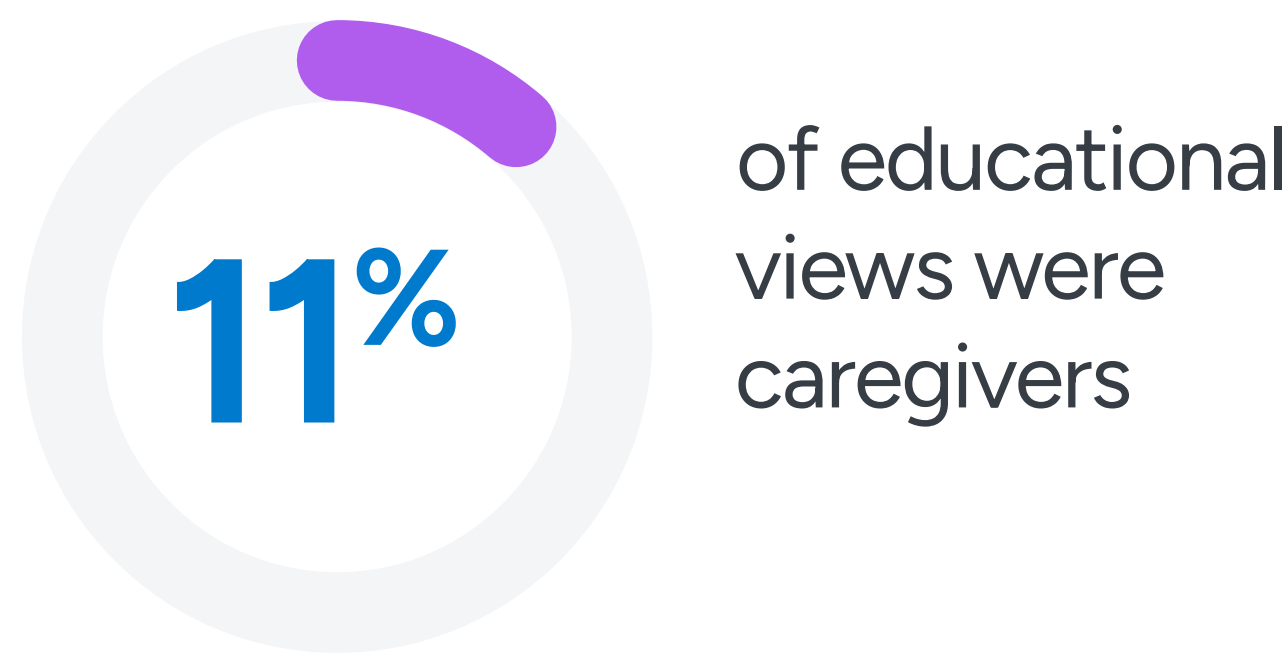
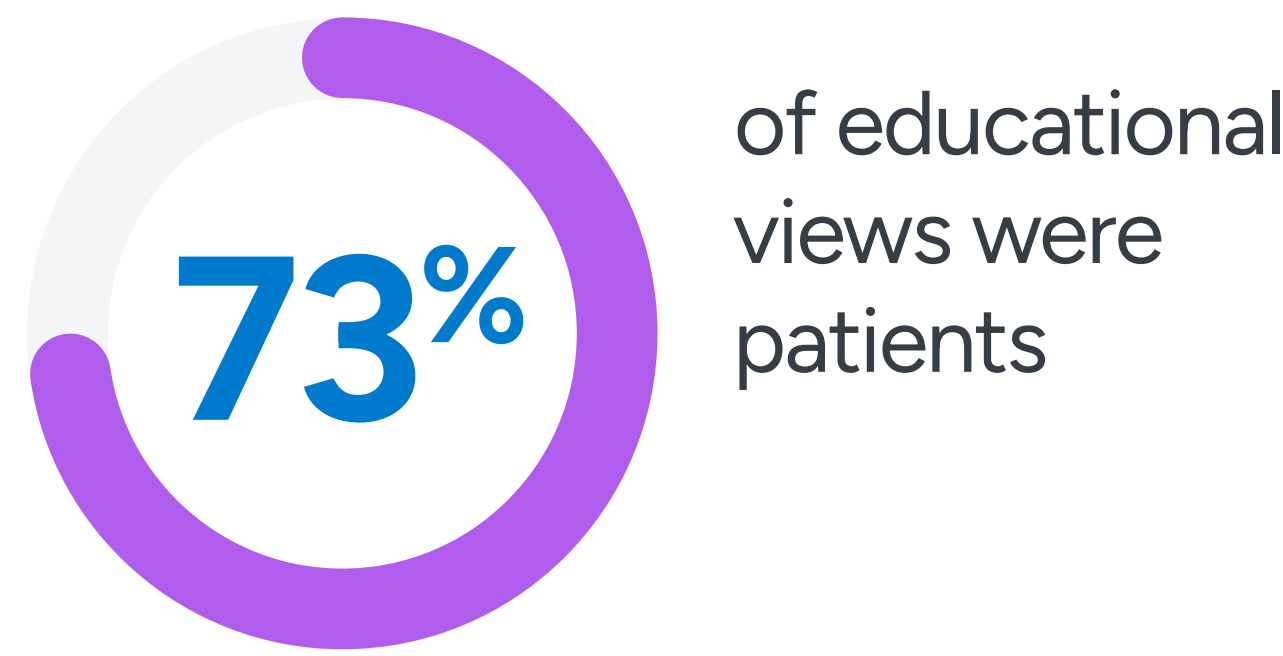
5. Disability and Social Security Benefits:

- Concerns about accessing Social Security Disability benefits and understanding the support available for patients with CIDP and MMN

Post Education



On average

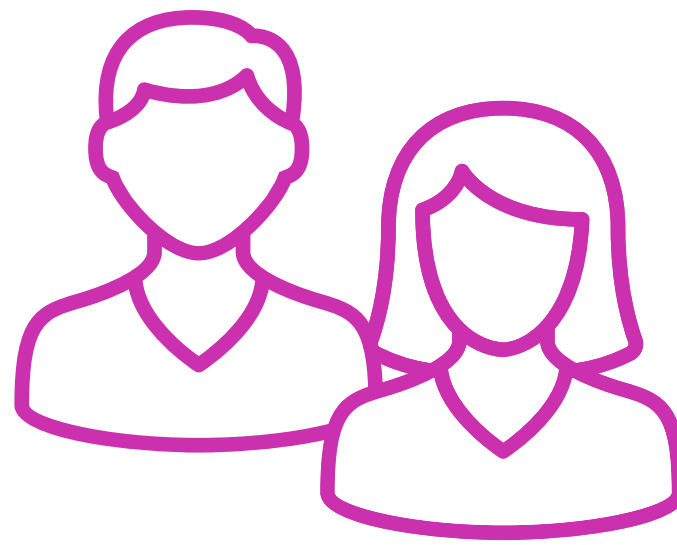


Questions included:

- If I participate in a trial, will I still be under the care of my doctor or will I have a completely new care team?
- If I participate in a trial, is it possible that I will receive a treatment that doesn't work? What happens then?
- If I stop taking IVIg to start a clinical trial and get worse, will I regain what I lost if I go back on IVIg?
- If I don't like the experience of participating in the trial, can I stop at any time?
- What if I get sick during a clinical trial?
- How do I know if I am eligible to participate in a clinical trial?
- Where can I find more resources about ongoing clinical trials in CIDP?

Participation in the education also prompted self-directed exploration of ongoing trials, with

1,586 Learners clicking links to clinical-trial information sites



CONCLUSION

High engagement and viewership numbers demonstrate substantial patient interest in clinical-trial research. Addressing identified barriers through targeted education can enhance recruitment readiness and improve enrollment in neuromuscular clinical trials.