

# The Fibrodysplasia Ossificans Progressiva Patient Journey: What Aligned Education Reveals About Experiences and Future Needs of Patients/Caregivers (P/Cs) and Clinicians (HCPs)

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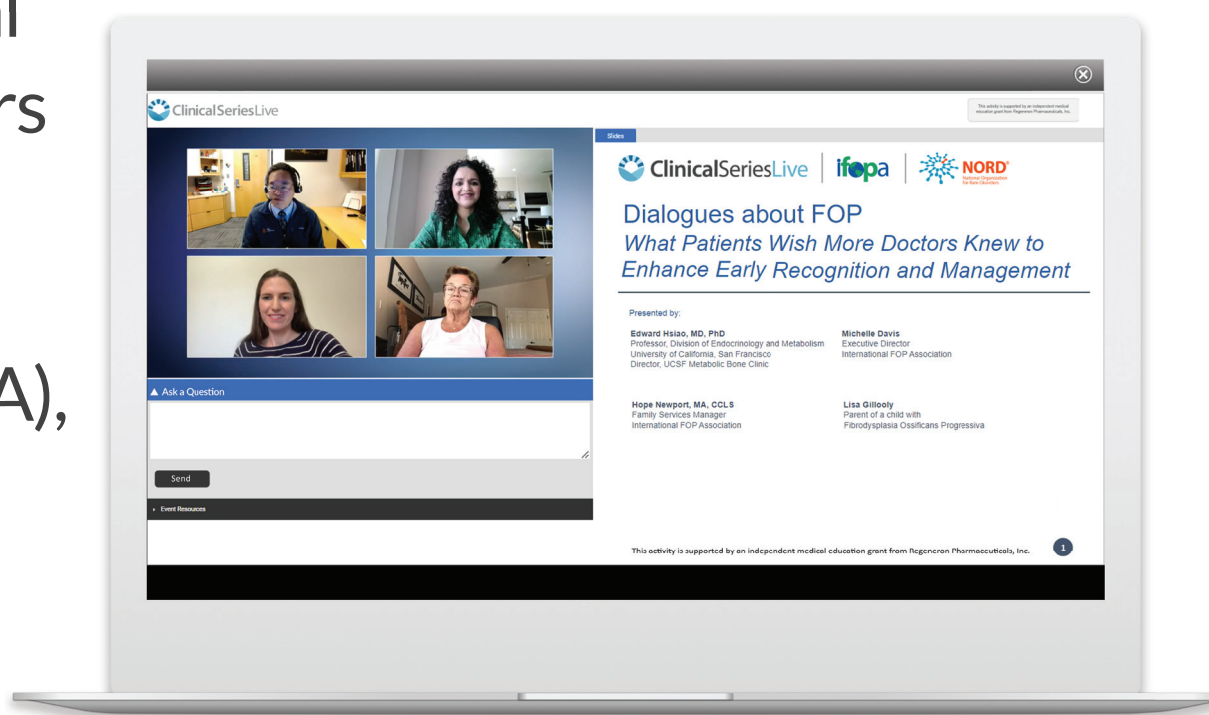


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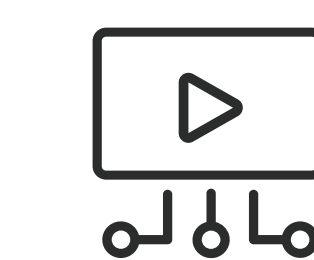
## INTRODUCTION

Beginning in April 2023, PlatformQ Health, the National Organization for Rare Disorders (NORD), the International Fibrodysplasia Ossificans Progressiva Association (IFOPA), and the Rare Bone Disease Alliance (RBDA) launched an online, video-based, CME/CE-certified, tethered educational initiative for HCPs and P/Cs caring for or living with fibrodysplasia ossificans progressiva (FOP). FOP is an ultrarare condition that causes bone formations in muscle and soft tissue, resulting in major disabilities and death.



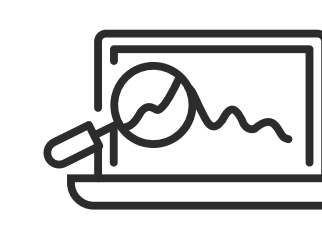
## METHODOLOGY

### Educational Program and Evaluation Details



#### Interventions

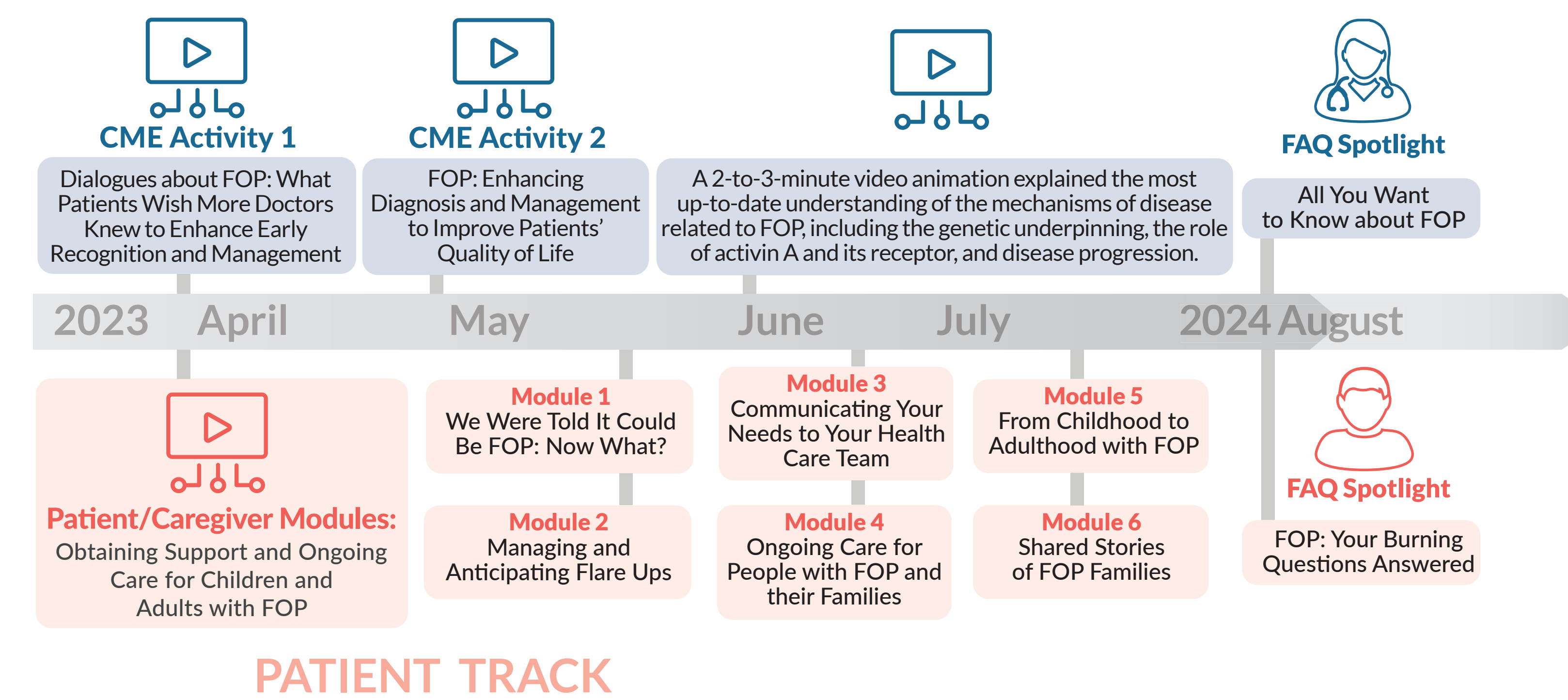
- 1) Series of three CME/CE-certified activities – one for the primary care team, one for specialists, and an “FAQ Spotlight”;
- 2) Six 30-minute educational modules for P/Cs, followed by an “FAQ Spotlight.” Selected segments of the education were distributed through social media (LinkedIn for HCPs and Facebook and Instagram for P/Cs)



#### Data Collected and Analysis

- P/Cs: Engagement, knowledge, attitudes, perceived barriers, and intended behavior changes. P/Cs who viewed the education were invited to participate in a 30-minute interview.
- HCPs: Engagement, changes in knowledge and competence, attitudes and practice behaviors, and self-reported practice changes.
- Statistical tests of significance applied to comparisons of individual questions (pre vs post).

### HCP TRACK

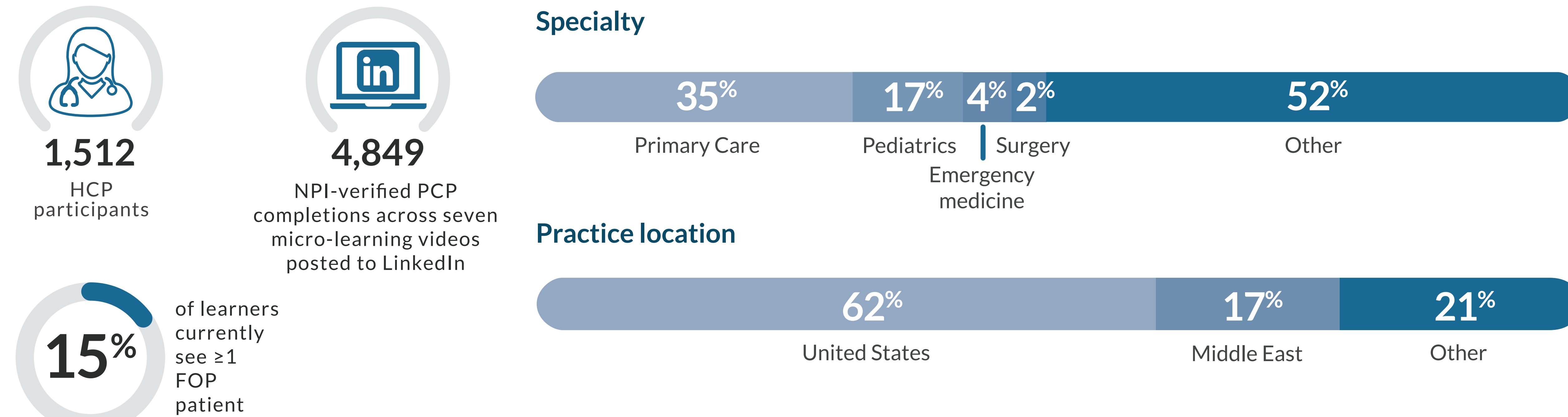


### Faculty

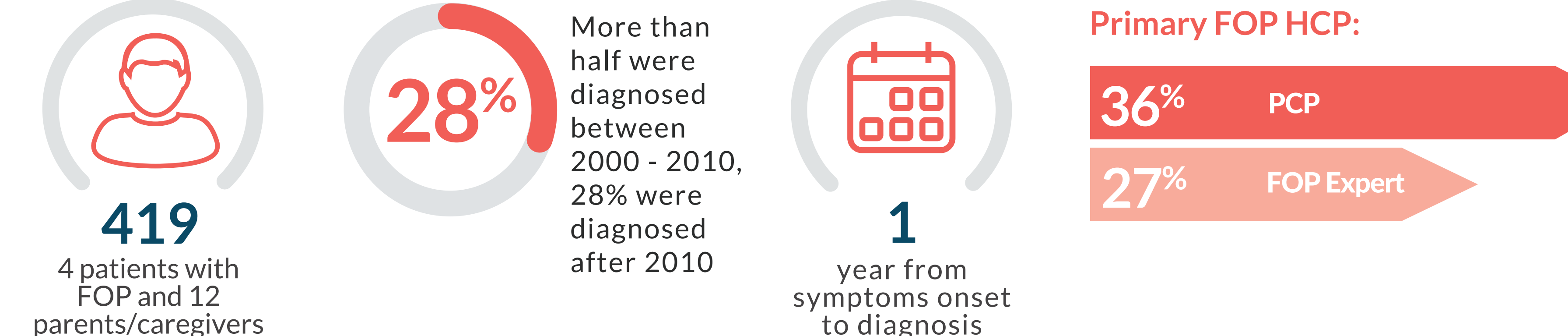
	<b>Edward Hsiao, MD, PhD</b> Professor, Division of Endocrinology and Metabolism University of California, San Francisco Director, UCSF Metabolic Bone Clinic		<b>Michelle Davis</b> Executive Director International FOP Association
	<b>Hope Newport, MA, CCLS</b> Family Services Manager International FOP Association		<b>Karen Kirchhoff, MSPT</b> IFOPA Family Services Coordinator Physical Therapist

## RESULTS

### HCP Demographics



### Patient and Caregiver Insights



### Interview Excerpts

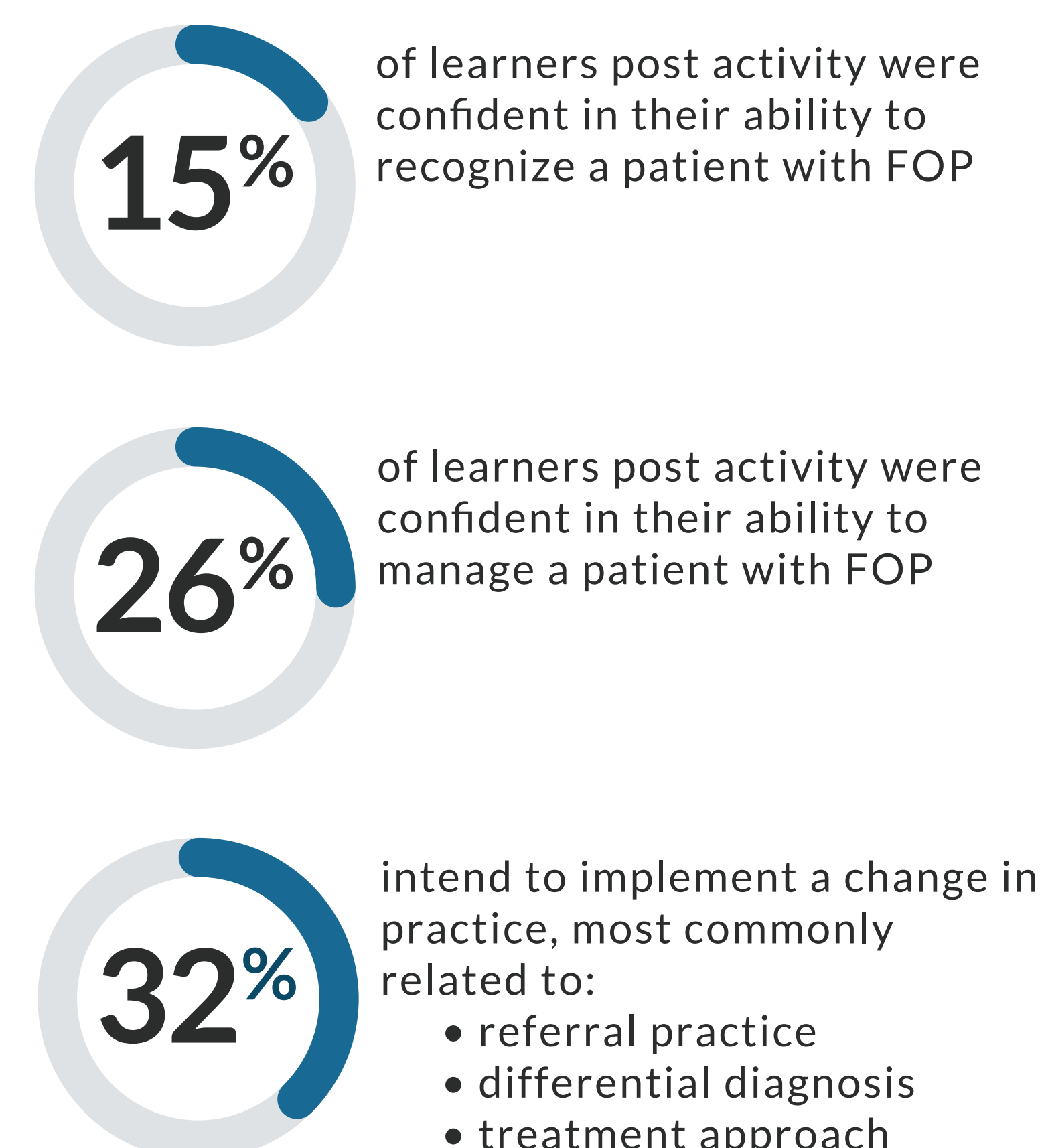
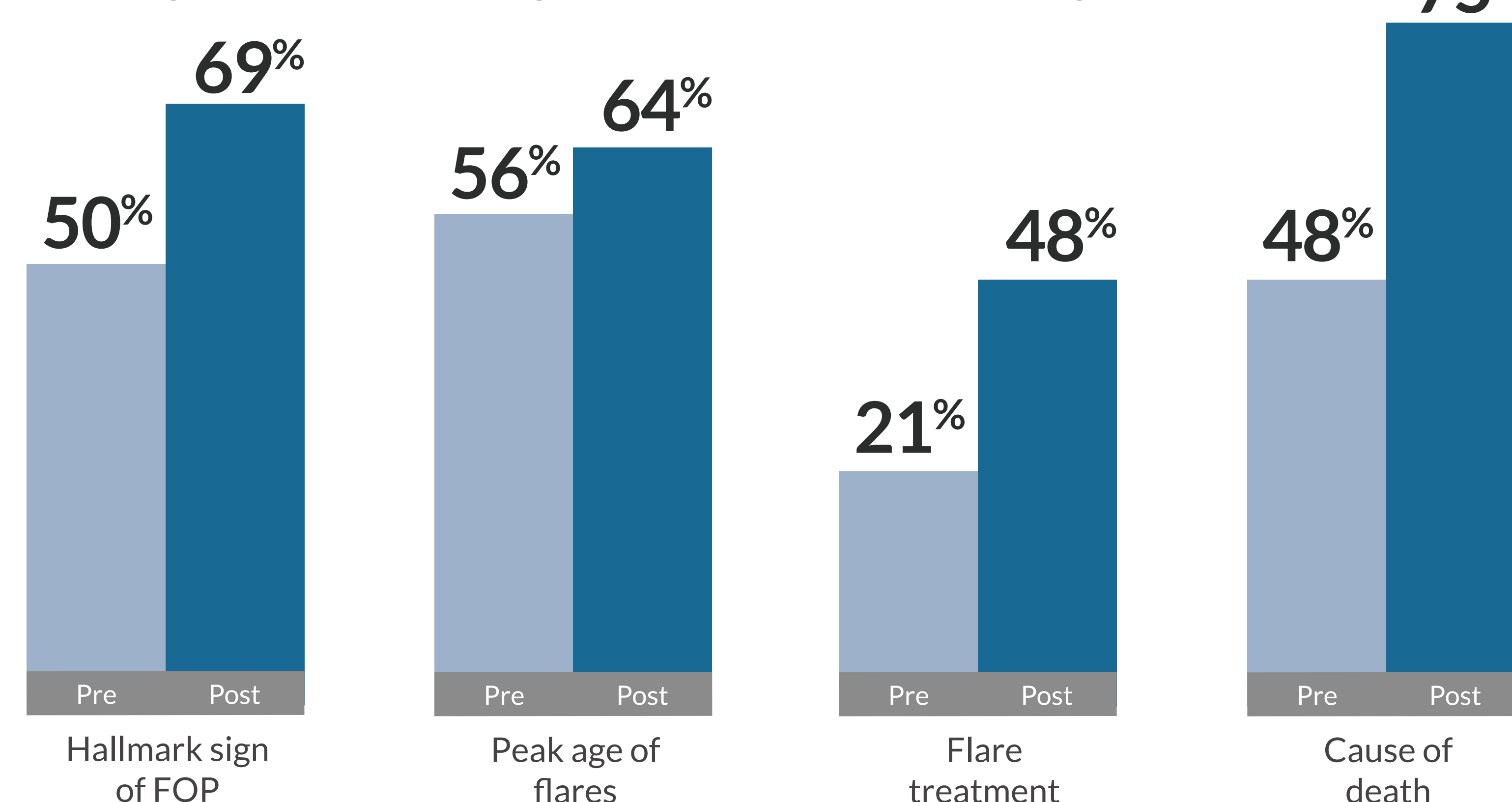
**Educating the care team:** She was totally unaware, I just had some paperwork (to fill out for his wheelchair). I just told her “no blood pressure.” And I just had to explain it to her.

**Getting the diagnosis:** They asked, is there anything else? And I said, Yeah, you know, he was born with crooked toes... I started taking him to an orthopedic surgeon to figure out what's going on with his toes. They were saying that they were going to eventually perform a surgery.

**About FOP diagnosis:** [My son is] going to be eight years old in a couple of weeks, but he was just diagnosed this past February [2023]. [His dentist] thought it was just an infection from cavities. At this point, now, almost a month has gone by and these swellings have spread into his back... he had a big old hump in his back.

### Pre- vs Post-activity Assessments (all learners)

Percentage of learners providing correct answers on the following topics:



### Patient and Caregiver Disease Journey



### Summary of findings

<p><b>HCP</b></p> <ul style="list-style-type: none"> <li>• Low baseline and low to average post-activity knowledge regarding FOP diagnosis, pathophysiology, and treatment guidelines</li> <li>• Low confidence in ability to diagnose or manage FOP</li> </ul>	<p><b>Patient/Caregiver</b></p> <ul style="list-style-type: none"> <li>• Low to average satisfaction level regarding their FOP care (for those who are not managed by an expert)</li> <li>• Having to educate HCPs (recurring theme)</li> <li>• Confirmed diagnostic delays and undergoing unnecessary traumatic procedures</li> </ul>
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## CONCLUSION

These data confirm published findings regarding the deep involvement of P/Cs in their care, as well as the presence of serious gaps in knowledge and competence among HCPs. Findings also point to the acute need for continuing education for both groups to help shorten diagnostic delays and hasten initiation of appropriate treatments.