HCP EDUCATION

Reducing Diagnostic Harm and Advancing Therapeutic Readiness in FOP: From Foundational Education to Patient-informed Next Steps

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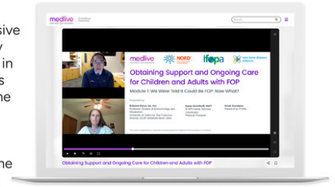
INTRODUCTION



Diagnostic delays, misdiagnoses, and invasive procedures significantly contribute to morbidity in fibrodysplasia ossificans progressiva (FOP). As the therapeutic landscape evolves, improved recognition and management for frontline clinicians become even more critical. We combined outcomes from a foundational, global clinician-education activity with patient-journey insights to inform next-phase clinician education designed to enhance diagnostic and therapeutic readiness in FOP.

METHODOLOGY

Educational Program and Evaluation Details

Education

Clinician education:
- Two 60-minute, online-endured CME activities for the primary care team and for specialists (rheumatologists, orthopedists), respectively
- Video segments of an interview of a person with FOP
- 45-minute "FAQ Spotlight"
- Targeted micro-learning videos via IQVIA and LinkedIn
- Activities released between April and August 2023

Patients / Caregivers :
- Six 30-minute, online-endured modules (diagnostic journey, self-advocacy, and navigation of care pathways)
- Segments of interviews of persons with FOP or caregivers inserted into the content.
- 30-minute "FAQ Spotlight"
- Social media videos via Facebook/Instagram

Data Collection and Statistics

Clinician education:
- Pre- and post-activity survey
- Knowledge (MCQ)[1]
- Self-reported attitudes, barriers, practice changes
- Pre-/post-activity comparisons
- Chi-square test for aggregate pre- vs post-activity comparisons
- Cohort comparisons between learners with FOP experience and those without

Patients / Caregivers :
- Post-activity survey and polling questions
- Patient journey and experience with care
- Correlations between select "tethered" questions across the clinician and patient education related to perceptions of care

[1] NBME Item-Writing Guide. Constructing written test questions for the health sciences. https://info.nbme.org/rs/552-QHC-046/images/NBME_Item-Writing-Guide.pdf

RESULTS

Patient/caregiver education

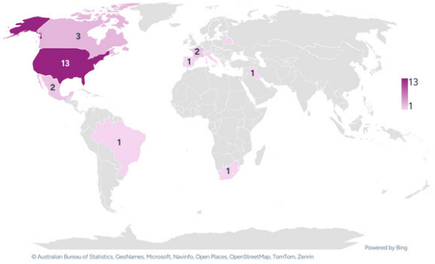
489 long-form views; 45,409 social views (across four posts)

7 were a "person with FOP"

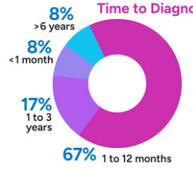
20 were "caregivers of a person with FOP"

Common Misdiagnoses
- Myositis ossificans
- Bunions
- Fibromatosis
- Cancer

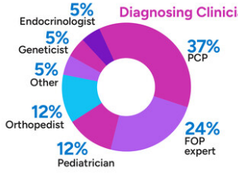
Heat Map of Patient/Caregiver Learners by Country (n = 27)



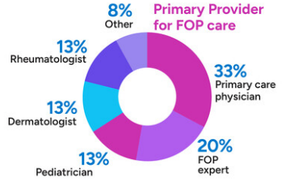
Time to Diagnosis



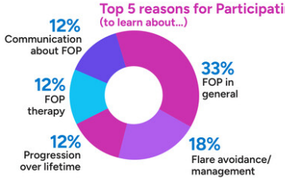
Diagnosing Clinician



Primary Provider for FOP care



Top 5 reasons for Participating (to learn about...)



Biggest challenges regarding a child's FOP care:

50% Navigating the school environment for the support they need

50% Helping them maintain as much independence as possible as they grow into adults

63% feel they need to educate their doctors/dentists about FOP care "most" or "all of the time"

50% feel it is "extremely difficult" to find a doctor who is comfortable

40% reported feeling "extremely" or "very" satisfied with how their doctor manages FOP flare-ups

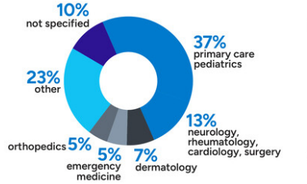
Clinician education

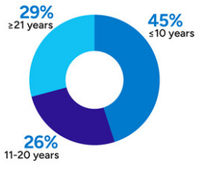
1,670 unique clinicians across 3 CME activities

14% reported current FOP experience (i.e., diagnosed or managed ≥1 patient)

14% participated in more than 1 activity

6,680 micro-learning completions; 4,849 NPI-verified PCPs and 1,831 orthopedist completions





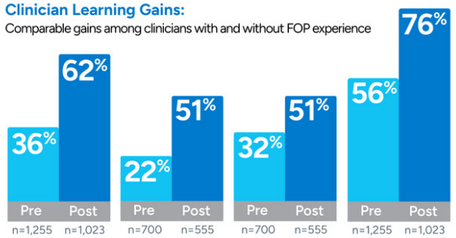
Reason for participation:

Reported Confidence*

*5-point scale (5 = extremely confident, 1 = not at all confident)

Clinician Learning Gains:

Comparable gains among clinicians with and without FOP experience

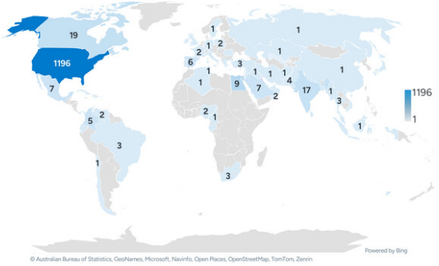


43% of clinician learners intended to implement a change in practice, most related to:
- referral practice
- differential diagnosis
- treatment approach

Additional educational interests (open-ended question):
- Adaptive equipment considered durable medical equipment and covered by insurance
- Daily life experiences living with the disease
- Psychological support; how to prevent social isolation

Reported educational interests:	
Symptoms/diagnosis	36%
Emerging therapies	18%
Managing transition to adult care	14%
Flare prevention/management	12%
Care team members and roles	10%

Heat Map of HCP Learners by Country of Practice (n = 1,670)



Notable quotes from interview with a caregiver:

About FOP diagnosis: "[My son is] going to be 8 years old in a couple of weeks, but he was just diagnosed this past February [2023]. He was getting some swellings early in 2023 around his neck...and [his dentist] started him on some clindamycin because they thought it was just an infection from cavities. But the swellings were getting larger, [they] spread down into his chest. I just took him to urgent care and urgent care immediately said we need to go to the children's ER here in town. And that's where they did a CAT scan and MRI. They did the biopsy."

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. And once it was explained, she was just like, "okay." I also have paperwork documenting how he needs to be treated. And as far as dental goes, I'm so scared because he does still need some dental work. I'm terrified."

About the doctor who gave the diagnosis: "She had to Google it. She had to look it up. Her expertise is in oncology. So, she basically just wrote down the name of it on a sticky note and handed it to me...just said that I need to reach out to the IFOPA and get as much information as I can."

Needed education: "If there's any way to just simplify things and learn how to live a regular life, activities of daily living. Any sort of suggestions for adaptive equipment or how to cope with loss of mobility. I feel like it might be helpful especially for parents of newly diagnosed kids. Know about support groups and everything, maybe even counseling on how to cope."

CONCLUSION

Outcomes data, combined with insights from patients, confirm substantial gaps in knowledge and confidence across clinician groups related to FOP management. Strong learner engagement and reports of interest in FOP demonstrate a clear demand for additional education. Comparable post-activity gains among clinicians with and without FOP experience indicate that exposure does not ensure preparedness. The next step is development of clinician education aligned with real-world patient needs and barriers to accelerate accurate diagnosis, prevent iatrogenic harm, and support timely adoption of emerging therapies.