Faces of FOP: Patient-centered Storytelling and Digital Education to Strengthen Self-advocacy and Readiness for Emerging Therapies in an Ultra-rare Bone Disease

Carole Drexel, PhD[1] · Eve Wilson, PhD[1] · Melissa Davis, OTR/L[2]

1. Medlive, Needham, MA, USA | 2. International Fibrodysplasia Ossificans Progressiva Association (IFOPA), Kansas City, MO, USA

Introduction

The journey of the person with fibrodysplasia ossificans progressiva (FOP) is a frequently prolonged diagnostic odyssey. Early signs (e.g., great-toe malformation, painful soft-tissue swellings) are commonly misread, and patients face a lifelong fight against flare-ups and mobility loss. But the outlook for patients/caregivers may be changing with the emergence of therapies targeting heterotopic ossification (HO). An educational intervention on FOP and video interviews of people with FOP or their caregivers were designed by Medlive, in collaboration with IFOPA and National Organization for Rare Disorders (NORD), to enhance learners' understanding of the FOP journey and of new treatment options.

Educational Interventions and Data Collected

Multi-component FOP curriculum launched online on February 25, 2026 and is available on-demand for one year:

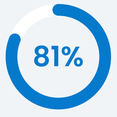
- 30-minute on-demand activity with patient vignettes
- Companion set of micro-videos distributed via Facebook/Instagram
- Patient storytelling gallery, "Faces of FOP," was disseminated through NORD, IFOPA, and Medlive (gallery included 5 persons living with FOP or their caregivers).

Data collection and analysis

- Disease knowledge; confidence in self-management (e.g., flare recognition, safe mobility); awareness of emerging HO-targeted therapies; willingness to consider such therapies; and attitudes about the future (e.g., hopefulness) were measured
- Findings were self-reported or rated on a 5-point scale
- Interviews for patient vignettes and "Faces of FOP" were transcribed and analyzed using artificial intelligence (AI) tools to identify themes

At baseline

somewhat knowledgeable of emerging treatments for FOP



confident in ability to safely manage mobility with FOP

somewhat confident in avoiding an FOP flare-up

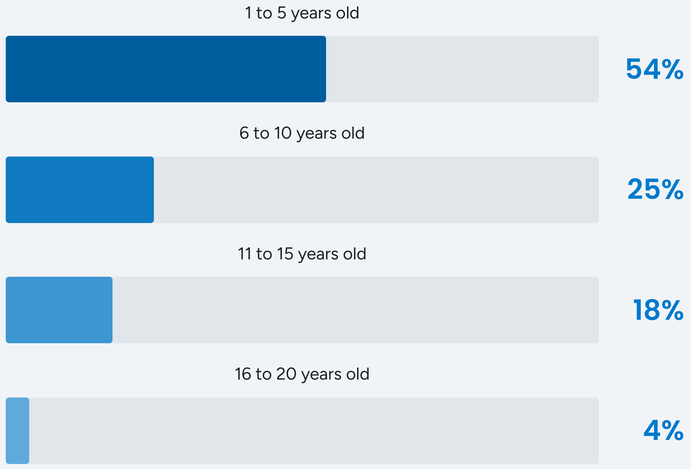
Results as of September 2026

366 views, including **12** people with FOP or their caregivers

21,103 completed views on social media; **82** clicks

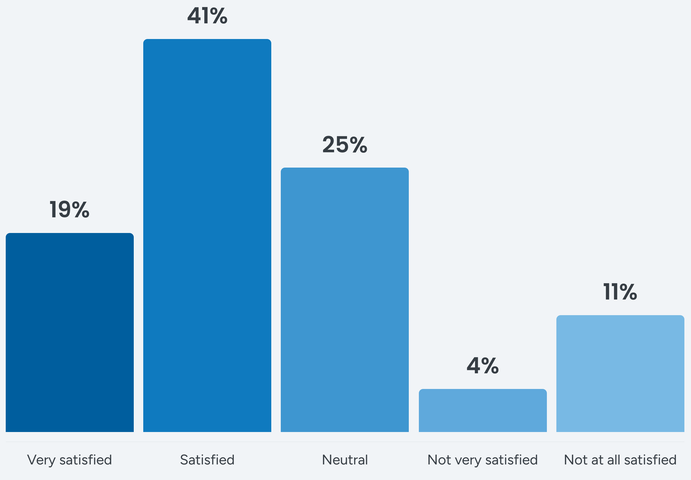
A diagnostic journey that highlights the need for earlier recognition

Age at diagnosis



Living with FOP: flare prevention is a persistent unmet support need

Satisfaction with current strategies for preventing or managing FOP flare-ups



Post-activity

feel the education increased awareness of new and emerging treatments that help prevent extra bone growth, or HO, in FOP

are willing to try a new or emerging medicine to prevent extra bone growth, or HO, if available

feel hopeful about the future for those dealing with FOP after learning about new and emerging treatments

In their own words

1. The Moment Everything Changed

"Initially I was diagnosed with elephantiasis, and then… cancer. They actually did operate on me to remove what they thought was cancerous tumors in my left shoulder that only made the FOP worse…[they] wanted to amputate my entire left arm and shoulder."

Adult living with FOP (age 46; dx ~age 5)

2. Living in a Body that Changes Without Warning

"We may not look like we're in pain all the time, but I can promise that we're in pain all the time…. Some days are lower, some days are higher, but we're always in pain."

Adult living with FOP (dx age 7)

3. Independence, Adaptation, and Creativity

"The world is not adapted to your needs, so you have to bring the adaptations to you…. One thing my mom and I did find was those portable travel, foldable ramps. So, we carry that in the van all the time."

Adult living with FOP (dx ~8 mo; first flares at 10)

4. Identity Beyond the Diagnosis

"When people meet him, he makes an impact on them… he's going to be someone people are always going to remember. And not because he has FOP, but because he's Joe."

Mother of Joe, 18, living with FOP

5. Relationships, Love, and Community

"[It's] moms and parents and siblings who are all going through the same journey, all traveling the same road… without that, this life would be a million times harder."

Parents of Dallas, 5, living with FOP

6. Mental Health, Resilience, and Grief

"It's more of like thinking, 'will I wake up tomorrow or the next day or within the next week with a flare up? And what would that flare up look like and what would it affect?'"

Adult living with FOP (dx ~8 mo; first flares at 10)

7. Hope, Advocacy, and Looking Forward

"Hope looks like a cure to me. It looks like the light at the end of the tunnel. It looks like one day, if not a cure, there will be some way to prevent bone growth."

Adult living with FOP (dx age 7)

Conclusion

By pairing on-demand patient/caregiver-centered education with peer storytelling and broad-reach social micro-content, this initiative successfully engaged an ultra-rare FOP community. It was associated with greater awareness of emerging HO-targeted therapies and future hopes. Patient and caregiver interviews substantiated these findings. However, baseline findings revealed gaps in flare prevention. Data must be interpreted carefully due to very small sample sizes inherent to an ultra-rare disease.

Supporter statement

This activity was supported by an independent educational grant from Regeneron Pharmaceuticals, Inc.