

Title: A qualitative investigation of the daily experience of children and adolescents with Fibrodysplasia ossificans progressiva (FOP)

Authors

Jessica T. Markowitz¹, PhD; Diana Rofail^{2,6}, PhD; Gerrit Vandenberg¹; Jessica Baldasaro¹; Robert Sanchez², PhD; Robert Pignolo³, MD; Richard Keen⁴, MD; Michelle Davis⁵; Patrick Marquis¹, MD

¹Modus Outcomes, a Division of Thread, Cambridge, MA, US

²Regeneron Pharmaceuticals, Tarrytown, NY, US

³Mayo Clinic, Rochester, MN, US

⁴Royal National Orthopaedic Hospital, Northfield, Birmingham, UK

⁵International Fibrodysplasia Ossificans Progressiva Association, North Kansas City, MO, US

⁶Corresponding author, diana.rofial@regeneron.com

Appendix A. FOP symptoms and illustrative quotes

Symptom	Illustrative quote
Pain	“The pain in my back, always something’s just happening back there. If I lean on – if I sleep wrong or something, and my back’s not on the bed right or something, it’s going to hurt more. It kind of always bothers me. Even if it’s not pain, it’s hurting, just sore.” (17 years old)
Swelling	“A flareup means pain, it means swelling, it means being uncomfortable, and I think that affects their life hugely.” - (Parent of a 9-year-old)
Redness	“Pain – a lot of pain. And then it turns red. Usually the area’s red or hot, and it starts swelling.” (17 years old)
Warmth	“Pain – a lot of pain. And then it turns red. Usually the area’s red or hot, and it starts swelling. I also become quite moody when I’m having a flare.” (17 years old)
Stiffness	“We just notice stiffness. He’ll say my leg hurts or my foot hurts or whatever, and that’s indication for us that something’s not quite right.” (Parent of a 5-year-old)
Feels sick/fever/flu-like symptoms	“Sometimes I can feel sick like a cold or something.” (15 years old)
Tired	“The ones she’s had so far, she has done the same activities and sort of suffered through, but she’s been more tired and more uncomfortable.” (Parent of a 10-year-old)
Tingly	“Remember when you first started having it, it would tingle first, or itch, or tickle? You would tell me it’s a tingly sensation first, and then I looked at the area and I could see little red blood spots or something sprouting.” (Parent of a 10-year-old)
Itchy	“I noticed there was a red part on one of my back places, and it hurts when I put some – like it itches.” (5 years old)
Strong smelling urine	“I will also say this – the smell of his urine is something else, and I don’t know if you guys have that, but it’s so strong during a flare.” (Parent of a 9-year-old)
Twitching in eyes	“We had migraines, and then we had a twitching issue that was happening, and they felt that that was happening because there’s no place for the inflammation to go, so it was going to his brain and causing the migraines and causing an issue with his eyes.” (Parent of a 9-year-old)
Migraine	“We had migraines, and then we had a twitching issue that was happening, and they felt that that was happening because there’s no place for the inflammation to go, so it

	was going to his brain and causing the migraines and causing an issue with his eyes.” (Parent of a 9-year-old)
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Appendix B. FOP functional impacts and illustrative quotes

Impact	Illustrative quote
Accommodations	“I have an electric wheelchair that I take if I want to go distances or if I go to school.” (17 years old)
Mobility	“The place where I got the flare-up like changed and I lose mobility” (15 years old)
ADLs	
Bathing	“I need help with showering because I can’t reach parts of my body.” (17 years old)
Brush teeth	“He can’t brush his teeth on his own.” (Parent of a 9-year-old)
Brush/comb hair	“I need help to comb my hair. But I do have adaptive comb” (17 years old)
Dressing	“Sometimes getting dressed, it’s kind of hard to do it on my own” (16 years old)
Eating	“Or when he has lunch, he kind of has to stand up or kneel in his chair to be able to eat his food because of his mobility.” (Parent of a 6-year-old)
Toileting	“I do also have to help her with her toiletry like in the restroom to make sure her hygiene is good, because she cannot reach behind her back or reach down” (Parent of a 5-year-old)
Daily activities	
Arts and crafts	“Q: And what types of things – are there any activities that you feel like you can't do because of your FOP? A: Like cooking, arts and crafts – yeah, I think that’s it.” (15 years old)
Cooking	“Q: And what types of things – are there any activities that you feel like you can't do because of your FOP? A: Like cooking, arts and crafts – yeah, I think that’s it.” (15 years old)

<p>Fidgety until comfortable</p>	<p>“But he might be fidgety. When he sits on the sofa, he fidgets, fidgets, fidgets until he finds a comfortable spot.” (Parent of a 5-year-old)</p>
<p>Get a snack</p>	<p>“A: It’s sometimes hard to do what we want to do. Q: You want to do? Can you give me an example of one of those things? A: Getting a snack” (9 years old)</p>
<p>Hard to focus on anything else</p>	<p>“It’s really hard, both me and my body, because it really hurts a certain area and it makes it hard, really, to focus on doing anything else because it’s always there.” (17 years old)</p>
<p>Have to be more careful</p>	<p>“Yeah, I mean, it – we just have to be a lot more careful all the time. Like the things you – most people wouldn’t think about.” (Parent of a 10-year-old)</p>
<p>Independence</p>	<p>“I try to force him to be a little more independent, so pulling up his pants, pulling up his underwear, and I will refuse to do it until he sighs and tries, and he'll say I can't. I can't reach behind. It's too difficult.” (Parent of a 5-year-old)</p>
<p>Sitting</p>	<p>“Other things that have become limited are most of the growth for him is in his back, so sitting at a 90-degree angle is not possible anymore.” (Parent of a 17-year-old)</p>
<p>Sleeping</p>	<p>“Sleeping is really difficult for him.” (Parent of a 17-year-old)</p>
<p>Sports</p>	<p>“I used to do sports before I got FOP, but I don’t really do much sports anymore, and I do any, I try to keep it to a minimum and just make sure not to overexert myself.” (17 years old)</p>
<p>Trampoline</p>	<p>“Well, I can't really jump on a trampoline. Well, I can, but my mom doesn't want me to.” (11 years old)</p>
<p>Social activities Bounce house with others</p>	<p>“Q: Is there anything that you can't do because you have FOP? A: Bounce houses with other people or trampolines with other people.” (6 years old)</p>

<p>Can't play rough with other kids</p>	<p>"We need to make sure kids aren't pulling on him and roughhousing with him at school. So just things like that that he's not allowed to do, I think has been the biggest impact." (Parent of a 5-year-old)</p>
<p>Doing things with friends</p>	<p>"Well, I can be active, but just sometimes it's harder for me to do stuff that like my friends or something are doing, because I don't want to get hurt or something." (17 years old)</p>
<p>Feels left out socially</p>	<p>"There's been times when he has felt left out because he couldn't – he wasn't allowed to do things for safety reasons, like bounce houses at birthday parties and those kinds of things." (Parent of a 5-year-old)</p>
<p>Involvement with other kids</p>	<p>"And we do have to limit her involvement with other kids, as well as just being in a structured environment to play. And even just go to the playground." (Parent)</p>
<p>Play on the playground</p>	<p>"I think it's frustrating to him that he can't play sports or run and be on the playground like the other kids." (Parent of a 5-year-old)</p>
<p>Social life</p>	<p>"I've seen two of her friends just walking around the local shop together and that ain't something XXXX can do, so social life, no. And that's only going to get worse as she gets older, I think." (Parent of a 10-year-old)</p>
<p>School</p>	<p>"Again, he's had a really good year, but previously there have been times where he's missed a lot of school due to pain, and that was really difficult for him, too, just socially – anything at school that he had to do differently, like not participating in gym or doing it differently or special equipment in the classroom, stuff like that." (Parent of an 11-year-old)</p>
<p>Mental health</p> <p>Anxiety</p> <p>Depression</p>	<p>"Her anxiety usually tends to be a lot of – a lot worse than her age." (Parent of a 9-year-old)</p> <p>"I feel the FOP doesn't only affect her physically, but it affects her emotionally on a high level. We've – I've had her</p>

<p>Discouraged</p> <p>Frustration</p>	<p>in counseling just because she'll hit these ultimate lows of depression." (Parent of a 9-year-old)</p> <p>"Well, he's not able to do what the rest of his siblings do, so at first, he used to get kind of discouraged." (Parent of a 6-year-old)</p> <p>"And then I would say a bad day is when he's in pain and he's frustrated and he's angry at FOP, and it just leads him to some crying and some being angry and frustration. I would say it affects everybody." (Parent of a 9-year-old)</p>
<p>Medical</p> <p>Bone growth</p> <p>Hearing loss</p> <p>Scoliosis</p>	<p>"Well, I can most certainly see and feel that this is not normal and that there's a bone growth up here." (17 years old)</p> <p>"He has hearing aids due to the hearing loss." (Parent of a 9-year-old)</p> <p>"So she's now got severe scoliosis as well. Yeah. Bent sideways." (Parent of a 6-year-old)</p>