Adapted from Pachajoa H, Botero AF. *BMJ Case Rep*. 2015;2015:bcr2015209804.

Adapted from Pignolo RJ et al. *Orphanet J Rare Dis*. 2011;6:80.

Go feet first.

How to recognize fibrodysplasia ossificans progressiva (FOP)

FOP is an ultra-rare, progressive, genetic disorder characterized by progressive heterotopic ossification (HO)[1]

- HO is the abnormal and irreversible formation of bone in muscles, tendons, and ligaments[2]
- As HO accumulates, range of motion is progressively lost, leading to immobility and shortened lifespan[3]
- HO is often triggered by flare-ups, soft tissue swellings that are painful, red, and warm to the touch[4]

LOOK FOR THE HALLMARK CLINICAL SIGNS

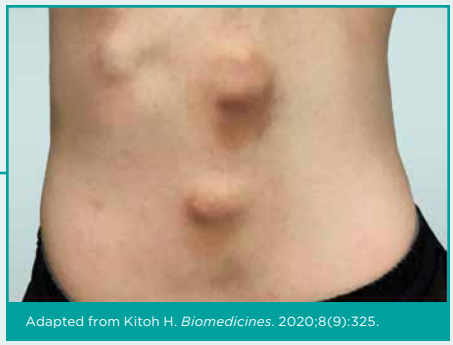
BILATERAL MALFORMATION OF THE GREAT TOES, PRESENT FROM BIRTH[3]

Adapted from Pignolo RJ et al. *Orphanet J Rare Dis*. 2011;6:80.

This congenital great toe malformation is present in almost all patients with FOP, and can vary from a fibular deviation to their complete absence; sometimes, this malformation is misdiagnosed as bunions.[5,6]

Suspect FOP

HISTORY OF SWELLINGS ON THE NECK, BACK, OR HEAD[2,6]



Adapted from Kitoh H. *Biomedicines*. 2020;8(9):325.

Soft tissue swellings (during flare-ups) are commonly mistaken for tumors and often precede HO.

ADDITIONAL SIGNS AND SYMPTOMS[3,6-8]:

- Hearing loss
- Shortened thumbs
- Neck stiffness
- Spinal deformity and fusion
- Locked joints
- Jaw ankylosis

Suspect FOP? Test and confirm.

If FOP is suspected, a genetic test for mutations in the *ACVR1* (Activin A receptor, type I) gene can confirm a diagnosis.

See reverse side for potential ways to prevent iatrogenic harm.

FOCUS ON™ FOP

Learn more at **FocusOnFOP.com**

Avoid invasive measures that might cause injury and lead to irreversible HO

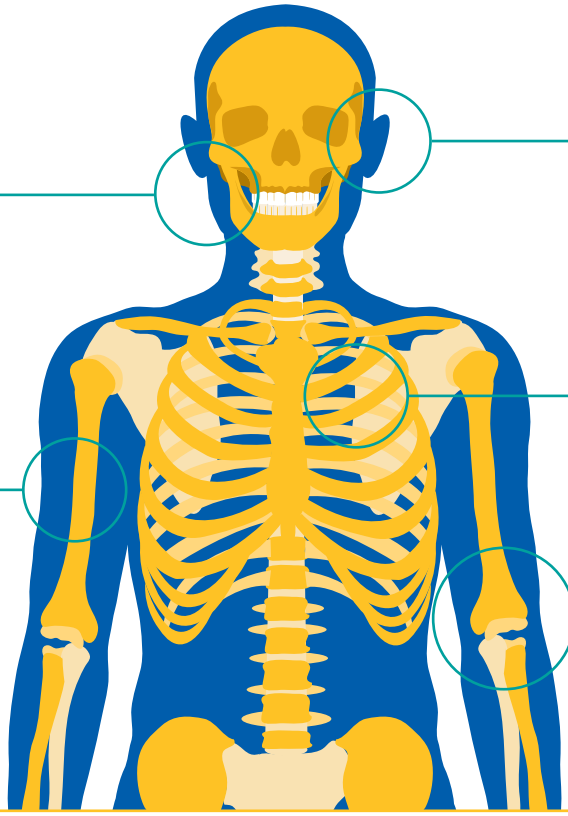
If FOP is suspected, important considerations include avoiding soft tissue trauma, including biopsies, IM injections, and surgical procedures until a definitive diagnosis is made[9]

Avoid mandibular blocks, overstretching of the jaw, and muscle fatigue

Consult FOP dental experts before any procedure[9]

Avoid IM injections[9]

- Consult the ICC FOP Treatment Guidelines for immunization recommendations



50% of patients with FOP have a hearing impairment; refer to an audiologist for screening[8,9]

Do not perform surgery to remove heterotopic and extraskeletal bone[9]

Do not apply passive range of motion[8,9]

ICD-10 Code for FOP: **M61.1 Myositis ossificans progressiva**

All claim forms should include an accurate and appropriately documented diagnosis code. Physicians should select the code that most closely and appropriately represents the diagnosis of the patient.

Help prevent iatrogenic harm.

Understanding and awareness of FOP are essential to proper management.

See reverse side for hallmark clinical signs of FOP.

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Learn more at
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