

FOR THOSE LIVING WITH FOP

Irreversible heterotopic ossification (HO) is episodic, but disability is cumulative^{1,2}

FLARE-UPS OFTEN LEAD TO HO:

Individuals with fibrodysplasia ossificans progressiva (FOP) experience painful swellings called flare-ups that often develop into heterotopic bone³



CAN BE CAUSED BY INJURY, TRAUMA, OR ILLNESS:

Although the onset of HO cannot be readily predicted, it is often induced by connective tissue injury, trauma, or viral illness^{2,4}

NECK AND UPPER BACK AFFECTED FIRST:

HO formation typically first appears in the neck and upper back and, through life, progresses to the trunk, arms, and legs¹

RESULTS IN IMMOBILITY:

Over the patient's lifespan, this extraskeletal bone fuses the skeleton and spans joints, ultimately resulting in substantial loss of mobility¹



Adapted from Rogoveanu O et al. J Med Life. 2013;6(4):454-458.



HAS SEVERE CONSEQUENCES:

HO often results in pain, disability, and can impact activities of daily living^{3,5}

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

Care of patients with FOP is currently focused on symptom management, which can help patients avoid injury and iatrogenic harm.^{2,6}

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.



Learn more at
FocusOnFOP.com

See reverse side for guidelines on preventing iatrogenic harm.

Helping to prevent irreversible HO is critical in FOP management^{2,6}

Selected recommendations from The International Clinical Council on FOP (ICC) Treatment Guidelines²



AVOID REMOVING HO: Surgical removal and/or release of joint contractures are generally unsuccessful and often followed by significant recurrence and expansion of HO^{2,6}



AVOID KNOWN TRIGGERS: Including biopsies, IM injections, all non-emergent surgical procedures, contact sports, soft tissue injuries, blunt muscle trauma, muscle fatigue, muscle stretching, and viral illnesses²



IMMUNIZATION CONSIDERATIONS: IM immunizations and intranasal influenza immunizations with live or attenuated viruses may precipitate flare-ups²

- Whenever possible, immunization by subcutaneous route is recommended by ICC FOP Treatment Guidelines
- According to ICC FOP Treatment Guidelines, avoid immunizations during flare-ups and up to 8 weeks after a flare-up
- Refer to the ICC FOP Treatment Guidelines comprehensive recommendations prior to vaccination administration



HELP PREVENT FALLS: Soft tissue trauma from falls often leads to HO and joint ankylosis, which may impair balance and cause instability, resulting in more falls

- Locked upper limbs may accentuate head and neck trauma from falls²



AVOID PASSIVE RANGE OF MOTION: Activity is encouraged at all ages, but passive range of motion (motion performed by someone other than the patient) must be avoided. Ensure physical therapists understand proper FOP management^{2,4}



TAKE DENTAL PRECAUTIONS: Prophylactic dental approaches are essential. Dental therapy should preclude mandibular blocks and stretching of the jaw. Consult FOP dental experts before any procedure²

The complete ICC FOP Treatment Guidelines are available at iccfop.org.⁷

See reverse side for the impact of HO.



Learn more at
FocusOnFOP.com

References: 1. Pignolo RJ, Shore EM, Kaplan FS. Fibrodysplasia ossificans progressiva: diagnosis, management, and therapeutic horizons. *Pediatr Endocrinol Rev.* 2013;10 Suppl 2(0 2):437-448. 2. Kaplan FS, Al Mukaddam M, Baujat G, et al. The medical management of fibrodysplasia ossificans progressiva: current treatment considerations. The International Clinical Council on FOP (ICC) & Consultants. Published March 2019. Updated June 2019. 3. Pignolo RJ, Bedford-Gay C, Liljeström M, et al. The natural history of flare-ups in fibrodysplasia ossificans progressiva (FOP): a comprehensive global assessment. *J Bone Miner Res.* 2016;31(3):650-656. 4. Di Rocco M, Baujat G, Bertamino M, et al. International physician survey on management of FOP: a modified Delphi study. *Orphanet J Rare Dis.* 2017;12(1):110. 5. Peng K, Cheung K, Lee A, Sieberg C, Borsook D, Upadhyay J. Longitudinal evaluation of pain, flare-up, and emotional health in fibrodysplasia ossificans progressiva: analyses of the International FOP Registry. *JBMR Plus.* 2019;3(8):e10181. 6. Kitterman JA, Kantanie S, Roche DM, Kaplan FS. Iatrogenic harm caused by diagnostic errors in fibrodysplasia ossificans progressiva. *Pediatrics.* 2005;116(5):e654-e661. 7. International Clinical Council on Fibrodysplasia Ossificans Progressiva. International Clinical Council (ICC) on Fibrodysplasia Ossificans Progressiva (FOP). Revised July 17, 2020. Accessed November 15, 2020. www.iccfop.org.