Let’s talk FOP

Fibrodysplasia Ossificans Progressiva

Understanding FOP and getting a confirmed diagnosis is important to making sure that you or your loved one gets the right care.

Below are some example questions you could use to start a conversation with your doctor or other healthcare provider about FOP if you suspect that you or a loved one might be affected by the condition. As FOP is an ultra-rare genetic disorder,[1] your family physician or other primary health providers might not have heard about it.

Conversation starters

Q

Have you heard of FOP – Fibrodysplasia Ossificans Progressiva?

Did you know that short and turned-in big toes could be a sign of FOP?

Could you help me find out more about FOP?

Q

Did you know that FOP causes bone to grow where it should not?

Have you ever seen a patient with FOP?

Do you think my/my loved one’s symptoms could be due to FOP?

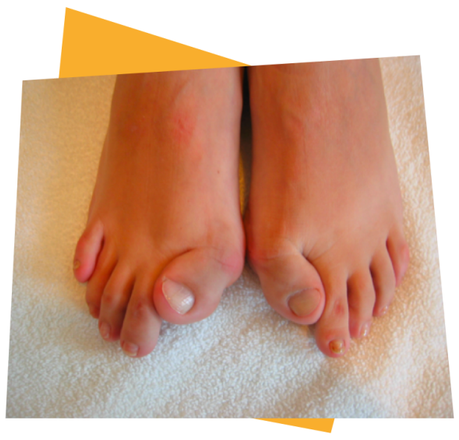
Q

Is genetic testing for FOP available?

What should I do to help a loved one with FOP?

Could you help me find a specialist that manage people with FOP?

Signs of FOP



Shortened and turned-in big toes are a hallmark sign of FOP[1]

Sudden swellings that are red and warm to the touch may be a sign of a FOP flare-up[2]

In young children and infants, FOP flare-ups may show up as lumps on the head, neck, back, chest or abdomen[2]

Babies scooting on their bottoms rather than crawling could be due to a stiff neck from FOP[3,4]

Five FOP facts

1. **FOP is an ultra-rare genetic disorder that affects only around one or two people per million.[1]**

2. **FOP causes bone to grow where it should not – in the muscles, tendons and ligaments – by a process known as heterotopic ossification (HO). Over time bone can grow over the joints, causing stiffness and joints may lock in place.[1,2]**

3. **Nearly all people living with FOP were born with a deformity of their big toes that may look like bunions: both big toes may be shortened and turn inwards towards the rest of the foot.[1,3,5]**

4. **FOP can also show up as spontaneous swellings on the upper body (head, neck, back, chest, abdomen) or locked joints. It can be confused with other conditions at first, including cancer and lead to unnecessary biopsies and surgery that can make FOP worse.[2,3,5]**

5. **As there is currently no cure, management focusses on avoiding unnecessary procedures that may cause HO and managing symptoms such as locked joints.[4,6,7]**

Minimising risk in FOP

If FOP is suspected or known, the following situations should be avoided or discussed carefully with an FOP expert before going ahead. This is because they can make FOP worse by triggering extra bone formation.[6,7]

Intramuscular injections

Can cause a FOP flare-up and should be avoided unless FOP has been ruled out.[6,7] Is there a subcutaneous injection available or other alternative?

Biopsy

Should be avoided if possible, and if necessary perfomed only under expert advice from a FOP specialist.[6]

Surgery

Should be avoided unless FOP has been ruled out.[6,7] If surgery is necessary then a FOP expert should be consulted.

Dentistry

Can the work be delayed until we know whether it is FOP or not?

Physiotherapy

Passive manipulation and range of motion must be avoided unless FOP has been ruled out.[6]

Anaesthesia

Does the anaesthetist know about FOP?

Further information on FOP

International Fibrodysplasia Ossificans Progressiva Association (IFOPA)

IFOPA is an international not-for-profit organisation that provides education and resources to help people worldwide living with FOP and their families. The IFOPA website (**https://www.ifopa.org/**) also provides information for healthcare professionals, including a list of emergency medical contacts and treatment guidelines.

FOP Medical Management Guidelines (FOP Treatment Guidelines)

The FOP Medical Management Guidelines (also known as the FOP Treatment Guidelines) provide a summary of how to manage FOP. The Guidelines were written by an international group of specialists who were selected for their knowledge of FOP and for their clinical experience in treating people living with FOP. The Guidelines are freely available via the IFOPA website (**https://www.ifopa.org/**).

References:

1. Baujat G, et al. Orphanet J Rare Dis. 2017:12(1):123.
2. Pignolo RJ, et al. J Bone Miner Res. 2016:31(3):650–6.
3. Pignolo RJ, et al. Pediatr Endocrinol Rev. 2013;10(0 2):437–48.
4. IFOPA website. FOP Symptoms. Available at https://www.ifopa.org/symptoms. Accessed November 2020.
5. Kaplan FS, et al. In: J Bilezikian et al., editors. Primer on the Metabolic Bone Diseases and Disorders of Mineral Metabolism. 9th ed. Washington, DC: American Society for Bone and Mineral Research, 2019:865–70.
6. Di Rocco M, et al. Orphanet J Rare Dis. 2017
7. Kaplan FS, et al. Proc Intl Clin Council FOP. 2019;1:1–111.

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Focus on FOP aims to serve as a useful guide for those who are starting their journey with FOP and those who are continuing their journey as part of the wider FOP community.

The website is provided by Ipsen and has been developed with the aid of people living with FOP.