Let's talk FOP

Fibrodysplasia Ossificans Progressiva

It is important to understand FOP and get a confirmed diagnosis, in order to receive appropriate care.

FOP affects only 1 or 2 people in every million.[1] This rarity makes it unlikely that your regular healthcare provider will have seen a person with FOP before, meaning they may be unaware of the signs or the potential complications. If you or your loved one has been diagnosed with FOP, or you think it could be FOP, this guide can help you have meaningful conversations with your doctor.

Conversation starters

Below are some questions you could use to initiate a discussion about FOP with your healthcare provider.

Q

Can you help me understand how rare conditions like FOP are typically diagnosed and managed?

Can we consult with a geneticist to explore possible diagnostic tests?

Can we explore options for obtaining a second opinion from a specialist experienced in rare diseases?

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 these symptoms could be due to FOP?

Q

Can you order any tests that could help diagnose FOP?

How can we work together to make informed decisions?

Could you give me a referral to a specialist who diagnoses and treats FOP?

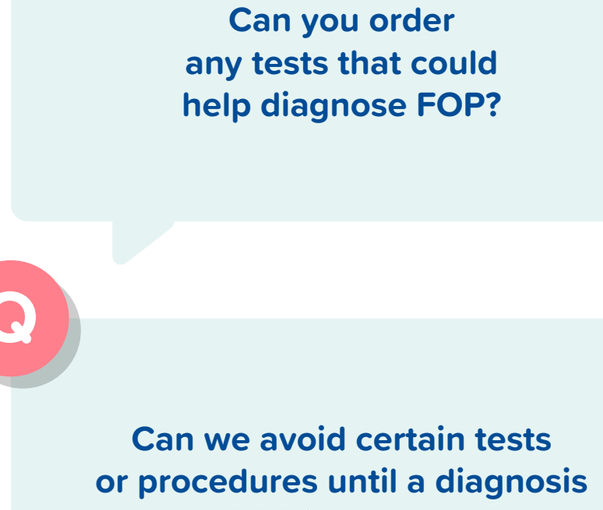
Q

Can we avoid certain tests or procedures until a diagnosis of FOP is ruled out?

In this situation, could we use the FOP Medical Management Guidelines (also known as the FOP Treatment Guidelines) from the International Clinical Council on FOP?

Did you know that painful swellings that are warm to the touch/ shortened and turned in big toes could be a symptom of FOP?

Signs of FOP



Shortened turned-in big toes, which may be mistaken for bunions (hallux valgus)

Image from Pignolo RJ et al. *Orphanet J Rare Dis* 2011;6:80[2]*

Swellings or lumps that appear and disappear, move or change shape

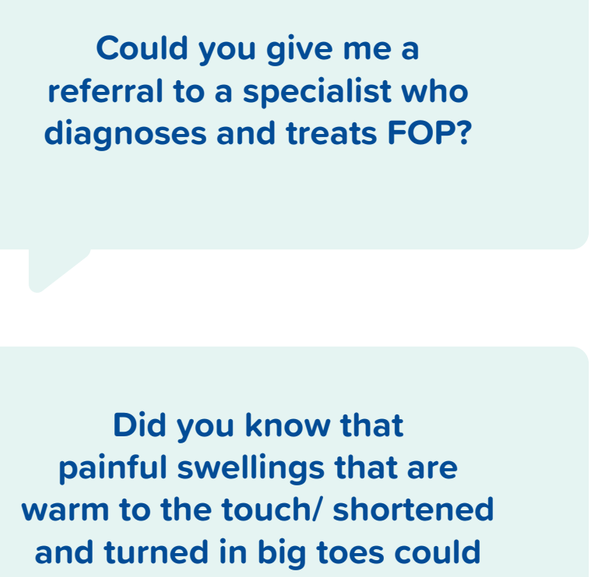


Image from Pignolo RJ et al. *Orphanet J Rare Dis* 2011;6:80[2]*

Minimizing risk in FOP

Some activities may worsen FOP by triggering new bone formation. If FOP is suspected or known, the following situations should be avoided or carefully discussed with an FOP expert.[3,4] More advice can be found from the International Clinical Council on FOP (ICC).

Intramuscular injections

Injections into the muscle can cause an FOP flare-up.[3,4] Ask the healthcare provider if an alternative method is available

Biopsy

Biopsies should be avoided if possible. If biopsy is necessary, it should only be conducted under expert advice from an FOP specialist[3,4]

Surgery

Surgery should be avoided, where possible, if FOP is suspected or confirmed. If surgery is necessary, FOP experts should be consulted[3,4]

Dentist

Certain dental procedures can cause harm to people with FOP.[3,4] Ask the healthcare provider if the procedure can be delayed until a diagnosis has been made, or consult with a dentist experienced in FOP

Physiotherapy

Passive manipulation and range of motion must be avoided unless FOP has been ruled out[3]

Anesthesia

If general anesthesia is needed, an anesthetist experienced in FOP should be consulted[4]

Further information on FOP

International Fibrodysplasia Ossificans Progressiva Association (IFOPA)

IFOPA is a not-for-profit organization that provides education and resources to help people living with FOP and their families. The IFOPA website also provides information for healthcare professionals, including a list of emergency medical contacts and treatment guidelines.

Visit the IFOPA website

FOP Medical Management Guidelines (FOP Treatment Guidelines)

The FOP Medical Management Guidelines (also known as the FOP Treatment Guidelines), published by the ICC, provide a summary of how to manage FOP. The guidelines are written by an independent group of internationally-recognized physicians, selected for their knowledge and experience in FOP, and are updated regularly. The Guidelines are freely available via the IFOPA website.

View the guidelines

References:

1. Baujat G et al. *Orphanet J Rare Dis* 2017:12:123.
2. Pignolo RJ et al. *Orphanet J Rare Dis* 2011;6:80.
3. Di Rocco M et al. *Orphanet J Rare Dis* 2017;12:110.
4. Kaplan FS et al. *Proc Intl Clin Council* FOP 2022;1:2–127.

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