Friends with FOP

Supporting those with FOP

We are FOP Friends.

We are the only UK charity which supports people who are living with FOP.

With first-hand experience of the challenges FOP brings, we are able to provide friendship for those living with the diagnosis and connect families with others who truly understand.

We provide information, advocacy, and support, as well as organise events for people living with FOP to come together.

We work to raise awareness of FOP within the medical community to prevent misdiagnosis and to improve the level of care patients receive.

#StrongerTogether

No-one should have to live with the fear, pain, isolation, and loss of independence caused by FOP. Help us to help those living with FOP.

To learn more about FOP or find out ways you can help, visit:

www.fopfriends.com

fop friends®
www.fopfriends.com

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@FOPFriends
/FOPFriends

Registered charity in England and Wales 1147704 and Scotland SC04950

fop friends®
www.fopfriends.com

Let's talk about FOP

We're one in a million!

What is FOP?

FOP is an ultra-rare genetic disorder which turns muscles and soft tissue into bone: it is the only condition known to medicine where one healthy organ system turns into another. Ribbons of new bone develop throughout the body causing stiffness and restricting movement. Over time, a person will become locked inside a second skeleton. Unfortunately, there is no treatment or cure currently available.

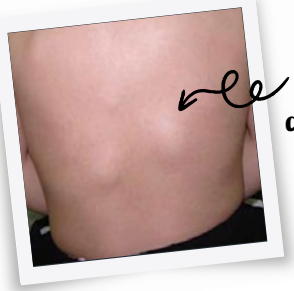
The progressiva nature of FOP means it chooses when and how it will strike. A knock, bump or fall can trigger an FOP flare up, as can fatigue, a virus or stress. However, FOP can also flare-up spontaneously. Some people's FOP progression is rapid and they are affected from birth, for others their FOP is quieter for longer. There is simply no way of knowing. Just as a child begins to take their first steps towards independence, FOP can cruelly steal it away overnight.

Facts about FOP

It is one of the **rarest diseases** known to medicine, affecting around **1 in a million** people.

There are around **70** known people with FOP in the UK, and only **1,000** worldwide.

Most cases of FOP are new. It is caused by a fault in the ACVR1 gene. This gene mutation happens at conception: **an accident of nature.**



Swellings due to the flare-ups are often misdiagnosed as cancer, which can lead to unnecessary and potentially harmful procedures.

FOP doesn't affect a person's intelligence

Around **31%** of people with FOP have partial or full hearing loss.

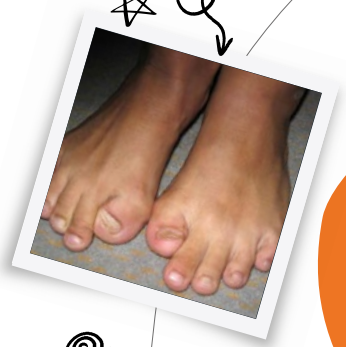
Many people with FOP struggle with their mental well-being, anxiety, and loneliness.

Children with FOP often find that they lose movement in their shoulders, neck and arms at a young age which makes playing with their friends very difficult.

FOP can make the simplest of everyday tasks a challenge – and sometimes impossible.

Could it be FOP?

Turned in toes along with unexplained swellings are a key indicator of FOP.



Over time, random swellings may appear across the body. These may be red or warm to the touch. They are often misdiagnosed as cancer.

People with FOP may also have shortened thumbs.

Babies with FOP appear 'normal' at birth, except for the turned in big toes, which are often misdiagnosed as bunions.

Babies with FOP often don't crawl due to fused vertebrae in their necks.

Research into FOP

However, we have HOPE!
This is an exciting time for us as a community: there are numerous clinical trials in progress and more are on the way. Researchers around the world are racing against the clock to find a treatment for this disease. Although FOP is rare, research into FOP has the potential to help sufferers of more common conditions such as osteoporosis, heart disease and DIPG, a rare, childhood brain cancer.