



# What is FOP?

Fibrodysplasia ossificans progressiva, or FOP, is one of the rarest diseases known to medicine. It affects around 1 in 1.5 million people. It is a painful and debilitating condition. There is no treatment or cure.

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



FOP can significantly shorten the life expectancy of sufferers.



Sufferers appear normal at birth except for the tell-tale turned-in big toes.

These, combined with unexplained swellings across the body, can be a key indicator of FOP.



A knock, bump or fall can trigger a flare-up which can result in new bone growth, and loss of movement.

FOP does not affect a sufferer's intelligence.



There are around 60 known cases in the UK.



When people with FOP lose movement, it can mean they are unable to carry out simple everyday tasks such as washing, feeding, and dressing independently.



FOP causes the body to develop extra bone to form in muscles, ligaments and soft tissue. This creates painful swellings called flare-ups. Where this occurs across joints it progressively restricts the sufferer's movements.

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



It is not possible to remove the extra bone growth as the surgery will prompt further flare-ups.



Tip of the iceberg... Research into FOP has far-reaching benefits and implications for more common illnesses such as osteoporosis, childhood brain cancer, heart disease, heterotopic ossification following military injury, and burns. Research into rare diseases benefits everyone.



Whilst a flare-up can be caused by an impact, they can also occur spontaneously. A child can go to bed one night, then wake up the next morning having lost movement in



an arm. Forever.

Children with FOP can find that they lose movement in their shoulders, neck and arms, at a young age, making playing like their friends very difficult. Children with FOP often don't get the chance to ride a bike or a scooter in case they fall off. Also, children with FOP can't take part in sports such as football as the risk of being injured, thus triggering a flare-up, is simply too great.



**WE HAVE HOPE!** There are three clinical trials for FOP treatments underway, and another one is due to start later this year.

