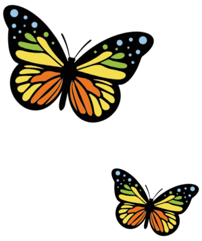
# What is FOP?



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

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.

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.

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 70 known cases in the UK.

When people with FOP lose movement, it can mean they are **unable** to carry out **simple every-day 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 suffer's movements.

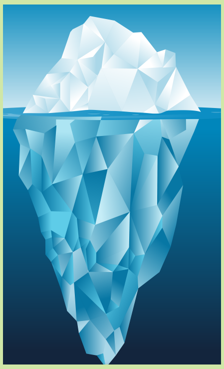
Many people with FOP **struggle** with **mental well-being**, anxiety, and loneliness.

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

friends

www.fopfriends.com

**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 got 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 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's a number of trials underway with more on the horizon. We also have a potential first approved treatment on the way.

**FOP Friends | Finding a treatment and a cure for FOP | Registered charity 1147704 & Scotland SC046950**