

## **FOP FACTS**

### **What is FOP?**

Fibrodysplasia Ossificans Progressiva (FOP) is one of the rarest and most disabling genetic conditions known to medicine, causing bone to form in muscles, tendons, ligaments and other connective tissues. Bridges of extra bone develop across the joints, progressively restricting movement and forming a second skeleton that imprisons the body in bone. There are no other known examples in medicine where one normal organ system turns into another.



### **Diagnosis**

Children with FOP appear normal at birth, except for congenital malformation of the great toe. During the first or second decade of life, painful swellings that look like tumors develop over the neck, back and shoulders and mature into bone.



### **Progression**

FOP progresses along the trunk and limbs of the body, replacing healthy muscles with bone. These bridges of bone significantly restrict movement and attempts to remove them result in explosive new bone formation because trauma, like surgery, accelerates the FOP process.

### **Unique**

FOP is extremely variable and unpredictable. In some, disease progression is rapid, while in others it is gradual. One day a person may be able to bend an arm, and the next day it is frozen forever in a locked position.

### **Rare**

Worldwide, FOP affects one in two million people, 700 people worldwide and only 40 known FOP sufferers in the UK. Yet, research into FOP has led to discoveries about the basic process of bone formation. As such, it may one day benefit those suffering from more common bone-related conditions and may be a key to a better future for millions.

### **Research into FOP at Oxford University**

.Charity No. X7585 .

You can Contact Steven Bowden, Development Officer at Oxford University for more information on donating at- [steven.bowden@devoff.ac.uk](mailto:steven.bowden@devoff.ac.uk) Tel +44(0)186511536

Please help us find a cure for this disabling genetic condition.

Together we can make a difference!

Please look on our Website [www.fopaction.co.uk](http://www.fopaction.co.uk)