

# An A-Z of FOP...

**A** is for **ACVRI**: the gene which, when it mutates, causes FOP. It leads to a faulty cell receptor Anti-activin A.

**B** is for **BIG TOES**: Malformed big toes, sometime accompanied by shortened thumbs, and unusual swellings, are key indicators of FOP.

**C** is for **CHROMOSOME**: There are 23 pairs of chromosomes, which each store different genes. The FOP gene is found on chromosome 2q 23-24.

**D** is for **DIAGNOSIS**: FOP is confirmed with a genetic blood test. Sadly, FOP is often still diagnosed too late, causing extra distress for the sufferer.

**E** is for **EPISODIC**: FOP flare-ups occur in bursts, are often unpredictable, and can vary in length and frequency.

**F** is for **FLARE-UP**: the inflammatory and often painful process that precedes new bone formation.

**G** is for **GENE**: a gene is a small part of DNA that stores information. They contain the instructions for our individual characteristics.

**I** is for **ICEBERG**: Researchers think that a drug to treat FOP could treat many other more common illnesses such as rare childhood cancers, osteoporosis, heart disease, burns, and sporting injuries.

**H** is for **HETEROTOPIC**: This means bone occurring in an abnormal position or place.



**J** is for **JOINTS**: When additional bone growth occurs across the joints, a sufferer will permanently lose mobility in that joint.



**K** is for **KIDS**: FOP kids still need to be kids! There are so many ways to allow your child to create memories. Reach out to other FOP parents or older FOPers for support and ideas.

**M** is for **MUTATION**: FOP is usually caused as a result of a random mutation in the DNA at conception. An FOPer has a 50% chance of passing the condition on to their child.

**L** is for **LUMPS**: New FOP bone growth can leave lumps of bone in uncomfortable positions.

**N** is for **NAPROXEN**: This is an anti-inflammatory drug in the NSAID family, similar to ibuprofen, that is used to treat the symptoms of a flare-up.



**O** is for **OSTEOGENESIS**: This is the process by which new bone is formed.

**P** is for **POH**: Progressive Osseous Heteroplasia, or POH, causes extra bone to grow in the skin, and other unwanted areas. The bony lumps can feel like grains of rice under the skin. As in FOP, extra POH bone formation near the joints can lead to pain, stiffness, locking and permanent immobility.

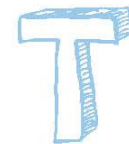


**Q** is for **QUESTIONS**: Whilst we understand more about FOP than ever, there are still many questions the researchers are trying to find answers to.



**R** is for **RECEPTOR**: It is a faulty receptor in the FOP gene that tells cells to produce bone in response to an injury, or to simply make more bone when it's not needed.

**S** is for **SWELLINGS**: FOP patients can suffer from swellings that can look like tumours. These are what sometimes lead to misdiagnoses. The swellings can be red, painful and hot to the touch.



**T** is for **TRIALS**: We now have two active trials, with others potentially on the horizon.

**U** is for **UNDERSTANDING**: Learning to live with a condition such as FOP is no easy task. However, there are lots of support groups available who understand your situation. You don't need to do this alone.



**V** is for **VITAMIN D**: It is extremely important for keeping bones strong and for keeping the immune system healthy.

**W** is for **WELL-BEING**: Self-care and emotional wellbeing are just as important as your physical health. Talk to someone if you feel things are all getting too much.



**X** is for **X-RAYS**: Different types of x-rays and scans can allow doctors to monitor extra bone growth in a patient.

**Y** is for **YES!** Living with FOP isn't easy, but try and find ways to adapt activities that will enable you or your child to join in and find a new 'normal'.



**Z** is for **ZYGOTE**: This is the stage of embryo development when the FOP mutation occurs.