

What is Fibrodysplasia Ossificans Progressiva (FOP)? A musculoskeletal condition where, after birth and progressively through life, muscle is transformed into bone, creating a second 'skeleton' of extra bone, rendering movement impossible. The cause of bone formation in FOP is unknown.



Age(years) 6 9 11 13 20 40

An example of the typical progression of FOP: Photos of an individual through his lifetime. Spontaneous flare-ups of the disease arise in defined temporal and spatial patterns, resulting in ribbons and sheets of bone that fuse the joints of the axial and appendicular skeleton, entombing a patient in a skeleton of heterotopic bone.

How would understanding the cause of bone formation in FOP help others? The information obtained from studying this disease will have far reaching implications for the treatment of common disorders such as fractures, osteoporosis, hip replacement surgery, and other forms of heterotopic ossification that occur in trauma and burn victims.

Demographics of FOP:

- Genetic disease affecting 1 in 2 million people
- No ethnic, racial, or religious patterns
- 500 confirmed cases across the globe
- 230 known cases in the United States

Clinical Characteristics of FOP:

- Characteristic malformations of the great toe
- Flare-ups occur spontaneously or following bodily trauma such as: childhood immunizations, falls while playing, viral illnesses
- Misdiagnosed in a majority of cases as cancer
- Surgery makes the condition worse
- There are no effective treatments

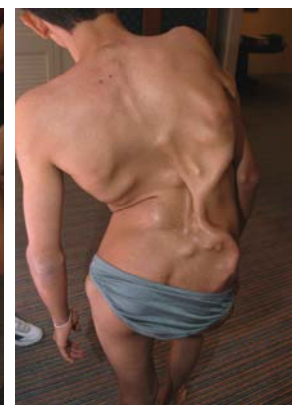
Finding a Cure for FOP:

The Center for Research in FOP and Related Disorders at the University of Pennsylvania

- The only laboratory in the US dedicated to FOP research
- 10,000 sq. ft. of shared research space in the Department of Orthopaedic Surgery
- 4 principle investigators with 18 post-doctoral fellows, students, scientists, and staff
- Funds spent on research – Approx. \$1.8 million/year
 - 77% from FOP fundraising and donations
 - 23% from institutional support (NIH/NIAMS, Orthopaedic Research and Education Foundation)



Characteristic Toe Abnormality: 95% of children afflicted by FOP have an abnormally formed great toe.



Characteristic bone formation: Note the ribbon of bone extending from the right hip, up the back, and into his right arm.