



Support Families, Fund Research, Find a Cure

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Facts-in-Brief

What is the International FOP Association (IFOPA)?

A 501(c)(3) non-profit organization supporting those afflicted by the rare genetic condition Fibrodysplasia Ossificans Progressive (FOP).

The IFOPA Journey

The IFOPA was founded in 1988 by Jeannie Peeper, a woman with FOP, who established the organization with the goal of bringing people with FOP together. The organization is constantly growing to meet the needs of those with FOP. The IFOPA is now the umbrella organization for those with FOP throughout the globe and is the first place those with FOP reach out to for education and support.

International Council of FOP Organizations

Additional FOP family organizations have been established in Argentina, Australia, Brazil, Canada, Germany, Italy, Japan, Peru, Poland, Scandinavia, Serbia, Spain, and The Netherlands that continue to work together to grow, helping build a network for support, education, and awareness on a global scale.

IFOPA Membership

There are over 700 members worldwide, represented in 57 countries.

Landmarks in IFOPA/FOP History

- Potential medications to prevent and treat heterotopic bone formation in FOP and related conditions
- Connection between the nervous system and the formation of heterotopic bone
- Announcement of the discovery of the FOP gene in *Nature Genetics* in April 2006 by the researchers at the University of Pennsylvania School of Medicine
- Hosted four (4) International FOP Symposiums
- International recognition with Seminal article published in *The New England Journal of Medicine and Science* along with numerous other medical papers, articles, and newsworthy accomplishments
- Held briefings in Washington D.C. to create FOP awareness
- Creation of the FOP Research Lab and the establishment of the FOP Collaborative Research Project at the University of Pennsylvania School of Medicine by Dr. Frederick Kaplan and Dr. Michael Zasloff
- Establishment and awards of significant gifts to fund the University of Pennsylvania School of Medicine

IFOPA Programs and Services

Research

- Funds the Center for Research in FOP and Related Disorders at the University of Pennsylvania School of Medicine with over \$500,000 annually
- Administers instrumental scientific research studies on FOP members facing additional afflictions

Education

- Provides education to the medical community on the early signs of FOP
- Develops, publicizes, and distributes videos, brochures, and information via IFOPA website about FOP and issues surrounding those diagnosed with FOP

Support

- Produces *FOP Connection* (print and electronic newsletter) for those with FOP
- Provides an online member forum for discussion, support, and research news
- Grants L.I.F.E. (Living Independently with Full Equality) Awards to those with FOP - a program that provides funding to enable independent living to those with FOP
- Provides an ongoing mentor program for newly diagnosed members

Advocacy

- Participates as an active member of the Rare Bone Disease Network under the US Bone and Joint Decade to advocate for increased funding for rare and neglected diseases

2010 Expense Breakdown

- Medical Research 53%
- Management & General 14%
- Public Awareness 9%
- Education & Support 16%
- Fundraising 8%



Proud members of:



Our Mission: To eliminate FOP as a health concern through education, advocacy, research, and support.

Our Vision: To instill hope worldwide while searching for a cure.

Facts-in-Brief of FOP

What is Fibrodysplasia Ossificans Progressiva (FOP)?

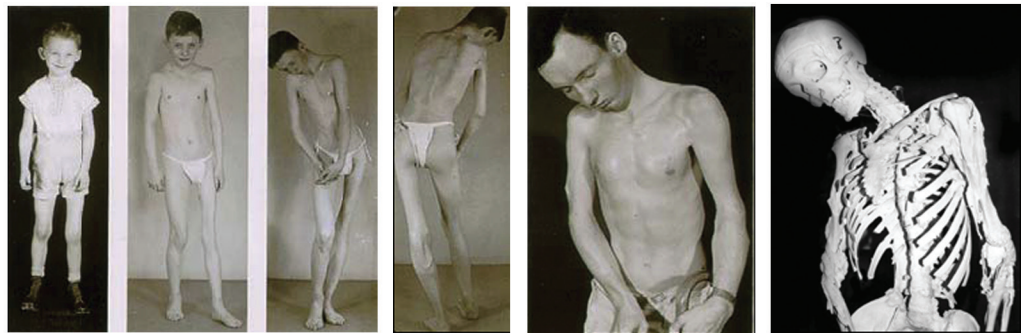
FOP is one of the rarest, most disabling genetic conditions known to medicine; it causes bone to form in muscles, tendons, ligaments, and other connective tissues. Bridges of extra bone develop across joints, progressively restricting movement and forming a second skeleton that imprisons the body in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

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.

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.



Age (years)

6

9

11

13

20

40

Characteristic toe abnormality: 95% of those afflicted by FOP have an abnormally formed great toe which is visible at birth.



Demographics of FOP

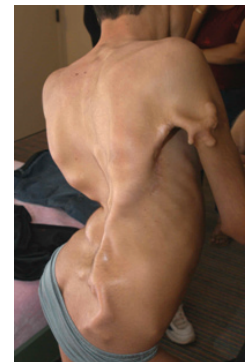
- Genetic disease
- Affects 1 in 2,000,000 people
- No ethnic, racial, or religious patterns
- 700 confirmed cases worldwide
- 285 confirmed cases in the US

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, and viral illnesses
- Misdiagnosed in a majority of cases as cancer
- Surgery makes the condition worse
- No effective treatments or cure

Finding a Cure & Treatment for FOP

- The only laboratory in the US dedicated to FOP research is at the University of Pennsylvania School of Medicine, where the discovery of the FOP gene was made in 2006
- Funds spent on FOP research at the University of Pennsylvania School of Medicine are approximately \$1.5 million per year (IFOPA funds approximately \$500,000 of this). These funds support three principal investigators with 15 postdoctoral fellows, students, scientists, and staff



Penn Medicine