Fund Research, Find A Cure, Support Families.

IFOPA Programs and Services

RESEARCH

- Funds FOP Research Program at the University of Pennsylvania with over $500,000 annually.
- The IFOPA administers instrumental scientific research studies of FOP members to better understand FOP and secondary conditions that may be related to FOP.

EDUCATION

- Teaches doctors and other medical professionals the early signs of FOP to help the medical community correctly diagnose FOP.
- Provides information via the IFOPA website about FOP, FOP research, fundraising events, and media attention. Videos, brochures, factsheets, annual research reports and journal articles are available at www.ifopa.org.

MEMBER SUPPORT

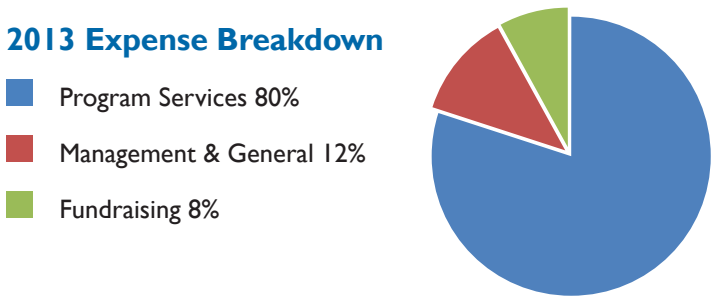
- FOP Connection newsletter is sent to IFOPA members.
- Online member forum for discussion, support, and research news.
- IFOPA Facebook Page offers weekly tips to people with FOP and information for members.
- Connects IFOPA International members with FOP Organizations in their regions of the world.
- Webinars address topics of interest to the FOP community.
- L.I.F.E. (Living Independently with Full Equality) Award for FOP members provides grants to encourage independence.
- Mentor program for newly diagnosed members and their families.
- Medical Binder to help members with FOP keep track of their health.
- Sponsors national and international gatherings of the FOP community.

ADVOCACY

The IFOPA is an active member of:

- The Bone and Joint Initiative USA
- NORD National Organization for Rare Disorders
- The EveryLife Foundation for Rare Diseases
- The Genetic Alliance

2013 Expense Breakdown



Facts-in-Brief

What is the International FOP Association (IFOPA)?

A 501 (c) (3) non-profit organization that provides hope to individuals with FOP and their families through education and support programs while funding research to find a cure for the rare genetic condition Fibrodysplasia Ossificans Progressiva (FOP).

The IFOPA Journey

The IFOPA was founded in 1988 by a young woman with FOP named Jeannie Peeper who had never met anyone else with FOP. This isolation was typical before the IFOPA was formed, and Jeannie's goal was to bring people with FOP together. Today the IFOPA is the umbrella organization for people with FOP all over the world and the place to come for education and support.

International President's Council

The IFOPA's International President's Council (IPC) is a network of volunteers who are committed to helping their national and regional FOP communities by keeping FOP families informed about treatments and research. IPC representatives in Argentina, Australia, Brazil, Canada, China, France, Germany, India, Italy, Malaysia, Poland, Russia, Serbia, South Africa, Spain, Sweden, The Netherlands, United Kingdom and United States of America work together with the IFOPA to provide a global network of support, education, awareness and fundraising for FOP research.

IFOPA Membership

There are 500 members worldwide representing over 50 countries. Over 450 of our members have been diagnosed with FOP and of those 300 are from outside the USA.

Landmarks in IFOPA / FOP History

- Hosted first Drug Development Forum for FOP in 2014.
- In 2014, a phase 2 clinical trial of palovarotene an experimental RAR-gamma agonist, was launched in adults with FOP by Clementia Pharmaceuticals Inc.
- 2013 hosted IFOPA 25th Anniversary Celebration & FOP Family Gathering where FOP Drug Development Tools were launched.
- Genetic Technology Breakthrough - 2011. UPenn researchers developed genetic approach to only block damaged FOP gene copy.
- Scientific Workshop for a Cure: Strategies for the Treatment of FOP. 2011, 27 scientists from various institutions brainstorm FOP treatments.
- Research Breakthrough - 2011: Identified an association between the nervous system and the formation of heterotopic bone.
- The FOP gene discovery was announced in Nature Genetics, April 2006.
- Hosted four International FOP Symposia held in 1991, 1995, 2000 & 2007.
- Hosted FOP family gatherings at Disney World in 1991, 1994, 1997 & 2003.
- Briefings held in Washington D.C. from 2005 - 2010 to make legislators aware of FOP and other rare diseases.
- The FOP Research Laboratory was established at the University of Pennsylvania in 1992.
- The IFOPA's first official fundraiser was held in 1990 – 1st Jud Bogard Golf Tournament for Bone Research.
- The FOP Collaborative Research Project at the UPenn School of Medicine established in 1989 by Drs. Fred Kaplan and Michael Zasloff.

Our Mission: Fund research to find a cure for FOP while supporting individuals and their families through education, public awareness and advocacy
Our Vision: A Cure for FOP

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ifopa

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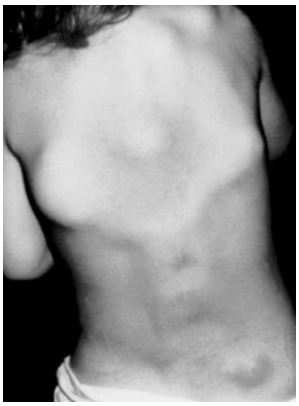
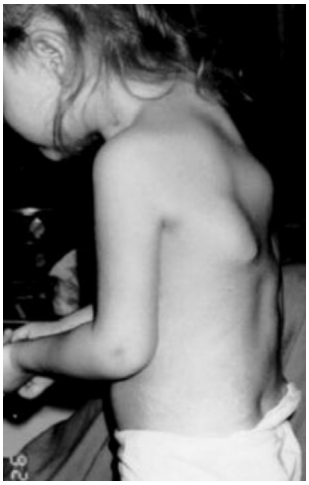
Malformation of the great toes
Patients with classic FOP have abnormally-formed great toes which are visible at birth.



FOP Flare-ups in the back of a young child.



Penn Medicine

Images courtesy of Mutter Museum at the College of Physicians of Philadelphia, Frederick S. Kaplan, MD, and Joanne Deithorn.

FOP Facts-in-Brief

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. (Visit www.ifopa.org for annual research reports.)

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

Finding a Cure & Treatment for FOP

Researchers at the FOP laboratory at the University of Pennsylvania discovered the FOP gene in 2006. The goal of work at the FOP Research Lab is to find effective treatments and a cure for FOP.

The annual budget of the FOP Research Lab is $1.5 million. Over $500,000 of that amount is provided by the IFOPA and is raised by donations and family fundraisers. These funds support 2 principal investigators and 15 scientists, postdoctoral fellows, students and staff. The FOP Research Lab is also supported by the National Institutes of Health, The Center for Research in FOP & Related Disorders, The Cali Family Endowment for FOP Research, The Weldon Family Endowment for FOP Research, The FOPeV (Germany), The Canadian FOP Families & Friends Network and many other organizations and individuals around the world.

Demographics of FOP

- Genetic disease
- Affects ≈ 1 in 2,000,000 people
- No ethnic, racial, or gender patterns
- 800 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, and viral illnesses
- Frequently misdiagnosed as cancer
- Surgery or biopsy makes the condition worse
- No effective treatments or cure to date

An example of the typical progression of FOP

Age (years)	6	9	11	13	20	40

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.