ifopa

Support Families, Fund Research, Find A Cure.

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.

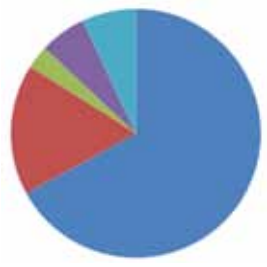
ADVOCACY

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

2011 Expense Breakdown

- Medical Research 67%
- Management & General 17%
- Public Awareness 3%
- Education & Support 6%
- Fundraising 7%



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, France, Germany, India, Italy, Malaysia, the Netherlands, Poland, Serbia, South Africa, Spain, Sweden, and the United Kingdom 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

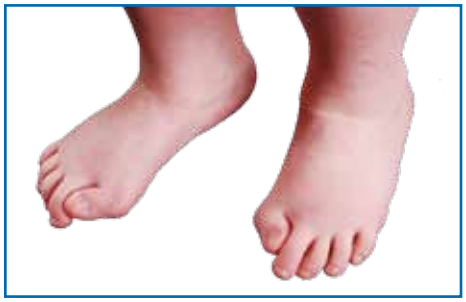
- Genetic Technology Breakthrough October 2011. Dr. Fred Kaplan, Dr. Josef Kaplan and Dr. Eileen Shore have developed a new genetic approach to specifically block the damaged copy of the FOP gene in patient cells while leaving the normal copy untouched.
- Scientific Workshop for a Cure: Strategies for the Treatment of FOP. August 2011. Bolstered by recent advances in FOP research, 27 scientists from various institutions met to brainstorm possible treatments for FOP.
- Research Breakthrough - July 2011: Identified an association between the nervous system and the formation of heterotopic bone.
- Researchers at the University of Pennsylvania FOP Collaborative Research Project identified the gene mutation that causes FOP. 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 & 2004.
- 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 University of Pennsylvania School of Medicine was established in 1989 by Dr. Frederick Kaplan and Dr. Michael Zasloff.

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.

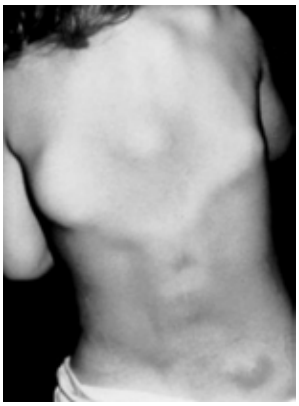
IFOPA • P.O. Box 196217, Winter Springs, FL 32719 • 407-365-4194 • www.ifopa.org

ifopa

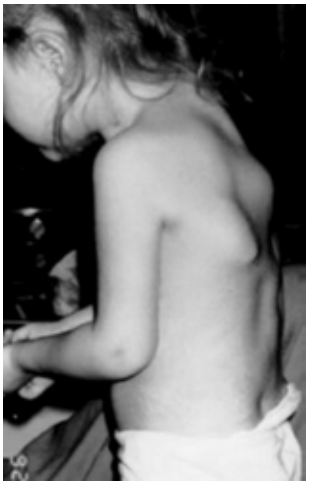
Support Families, Fund Research, Find A Cure.



Characteristic Toe Abnormality
95% of those afflicted with FOP have an abnormally-formed great toe which is 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.

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 focus 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
- 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, 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.