



INTERNATIONAL FIBRODYSPLASIA OSSIFICANS PROGRESSIVA ASSOCIATION

THE IFOPA EXISTS TO:

- › **Fund research** to discover treatments and, one day, a cure for FOP that will be accessible worldwide.
- › **Raise awareness** of FOP to end misdiagnosis, and ensure people with FOP receive proper medical care without delay.
- › **Advocate** for individuals with FOP who face the challenges of a life-long, debilitating disease.
- › **Educate** those newly diagnosed and their families, and provide access to the best possible FOP resources and services.
- › **Connect and support** the FOP community around the world to end isolation for people living with FOP.



RESEARCH

The IFOPA catalyzes the FOP research and drug development community by funding the highest-quality research, developing research infrastructure, and fostering research collaborations and connections.

- › Provide research funding of more than \$500,000 a year for **The University of Pennsylvania Center for Research in FOP and Related Disorders**
- › Award \$100,000 a year in **Competitive Research Grants** focused on discovery and advancement of drug therapies
- › Run the **FOP Patient Registry**, the largest FOP medical database in the world – a vital tool for researchers, drug developers and regulatory bodies
- › Host the **FOP Drug Development Forum** bringing together researchers, pharmaceutical companies, clinicians and FOP patients to tackle the toughest challenges facing FOP drug development



ADVOCACY AND AWARENESS

The IFOPA serves as a voice for people with FOP and families by building targeted awareness and advocacy. The IFOPA is active in the Rare Bone Disease Alliance and these organizations:



NORD
National Organization for Rare Disorders



FAMILY SERVICES

The IFOPA is a trusted resource for people with FOP and their families by providing support, connections, and information about treatment and research participation.

- › Provide education and support resources through ifopa.org, newsletters, social media channels, a mentoring program, and **Quality of L.I.F.E. Awards**
- › Host **Family Gatherings** to bring together families and clinicians to learn and connect
- › Organize the **International President's Council** – a network of international volunteers – committed to keeping FOP patients and their families informed and engaged in research and providing local support services in Argentina, Australia, Brazil, Canada, China, France, Germany, India, Italy, Malaysia, Poland, Russia, Serbia, South Africa, Spain, Sweden, The Netherlands and the United Kingdom, as well as the United States

FOP FACTS

- › FOP is an ultra-rare genetic disease with only 800 known cases in the world
- › No ethnic, racial or gender patterns
- › FOP is misdiagnosed over 90% of the time
- › Debilitating disease of progressive immobility
- › Once bone has formed, it can't be removed because surgery causes more bone to grow
- › Disease progression is variable and hard to predict
- › FOP does not affect intelligence

ABOUT THE IFOPA

The IFOPA was founded in 1988 by Jeannie Peeper, a young woman with FOP who had never met anyone else with the disease. Feelings of total isolation were typical before the IFOPA was formed, and the goal of Jeannie and the other ten founding members was to bring people with FOP together. Today, the IFOPA is the umbrella organization for people with FOP, researchers and clinicians worldwide.

The IFOPA is funded by the generosity of the community – both through personal donations and community fundraising events.

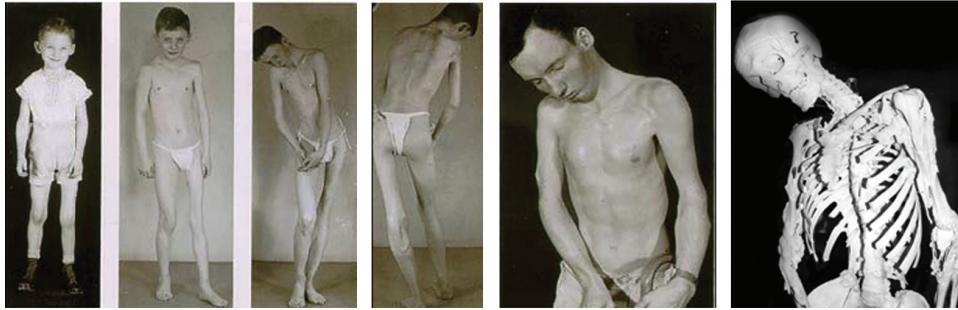
GET INVOLVED

Donate | Fundraise | Volunteer | Advocate | Spread Awareness

Contact us at 407 365 4194 or together@ifopa.org to learn more.

FOP – A Disease of Progressive Immobility

Harry Eastlack, Jr. suffered from FOP and permitted his skeleton to be preserved for scientific research after his death at age 40



Age 6

Age 9

Age 11

Age 13

Age 20

Age 40

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.

Any tissue trauma – knocks and bumps, intramuscular injections, biopsies, dental work and viral illnesses – can trigger new bone formation in those living with FOP. FOP is the only known disease where one normal organ system turns into another – soft tissue into hard bone.

Because FOP is so rare, few doctors encounter it in medical school so FOP is often misdiagnosed and surgery or biopsy usually causes more bone to form.

IS THERE A TREATMENT FOR FOP?

There is currently no treatment to stop the uncontrollable bone growth. The FOP gene was discovered in 2006, which sparked a vibrant research and drug development community. There are now many academic institutions and pharmaceutical companies from around the world researching FOP. FOP patients can contribute to research by participating in the IFOPA's FOP Patient Registry and other clinical studies and trials as they become available and the patient is determined to be eligible for participation.

HOW WOULD UNDERSTANDING FOP HELP OTHER DISEASES?

The information obtained from studying the bone formation in FOP will have far-reaching implications for the treatment of common disorders such as fractures, osteoporosis, hip replacement and other forms of heterotopic ossification that occur in trauma and burn victims and other bone-related disorders.



Malformed big toes are the first sign of FOP

FOP SYMPTOMS

Symptoms are usually first seen in children and teens

- ▶ Big toes that are short, bent and sometimes curved inward (malformation is present at birth)
- ▶ Swellings that look like tumors, typically in the shoulder and back areas and sometimes on the head
- ▶ Instead of crawling, toddlers scoot on their buttocks because joints on the back of the neck have not formed properly or are fused together by extra bone
- ▶ Stiffness, locking of joints and permanent immobility



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FUND RESEARCH, FIND A CURE, SUPPORT FAMILIES ... WORLDWIDE

CONNECT WITH US

ifopa.org

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