



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.

## 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



### 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



### 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

## 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.



### 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:



## GET INVOLVED

Donate | Fundraise | Volunteer | Advocate | Spread Awareness

Contact us at 407 365 4194 or [together@ifopa.org](mailto:together@ifopa.org) to learn more.