A cure for FOP, accessible worldwide
To **fund research** to find a cure for FOP while **supporting, connecting and advocating** for individuals with FOP and their families, and **raising awareness worldwide**.
ifopa.org is a Resource for Everyone!
1. Fund innovative FOP research to advance treatments

2. Establish and grow FOP Patient Registry - fopconnection.org

3. Enable FOP Research Community *(coming in 2018)*
   - Open Access R206H FOP Mouse Model* and Biomaterial Repository

4. Host FOP Drug Development Forum

5. Educate FOP community about their role in clinical studies and trials

* Through grant from La Jolla Pharmaceuticals and generous in-kind support from Vanderbilt University
Access Clinical Studies & Trials at ifopa.org

Quick Links

FAQs

Clinical Studies & Trials

Coming Soon: Patient Directory

Find International Organizations
List and Status of All Trials

FOP Clinical Trials

The most up-to-date place to find information on clinical studies and trials that are active in the page lists all active clinical trials for individuals living with FOP.

**Active, Not Yet Recruiting**

**A Study to Examine the Safety, Tolerability and Effects on Abnormal Bone Formation of REGN24 Ossificans Progressiva**
Condition: FOP
Interventions: Drug: REGN2477; Drug: Matching placebo

**Active, Recruiting**

**The Fibrodysplasia Ossificans Progressiva (FOP) Connection Registry**
Condition: FOP
Intervention: N/A

**Active, Not Recruiting**

**An Efficacy and Safety Study of Palovarotene to Treat Preosseous Flare-ups in FOP Subjects**
Condition: FOP
Intervention: Drug: Palovarotene; Drug: Placebo
Provide Education and Support – FOP’ers and Families and Along the Continuum of the Disease
Initial Education about FOP
Resources for FOP Families

Awards to Live Independently With Full Equality

For those diagnosed with Fibrodysplasia ossificans progressiva (FOP), we are here to provide support, and the disease better and improve your quality of life. Explore the pages below to learn stories of courage and strength.

Resources for individuals and families living with FOP.
Where Are We Going/Future Direction

- Family Services Committee with program task forces
- Expanded Mentoring Program
1. **Guidebooks**
   - Easily accessible sections based on topics
   - Housed on website
   - Can be easily translated and printed if desired

2. **Medical Binder and Emergency Tools**
   - *Medical Treatment Guidelines* currently being reviewed by International Clinical Council
   - Quick access through Pinterest and on website
Connect

1. Patient Directory
2. Virtual Support Groups
   • Email
   • Social Media

Founded in 1988 by Jeannie Peeper, a woman with FOP, the IFOPA was originally established because Ms. Peeper wanted to bring people with FOP together. Today, the organization has grown to include members across the globe.

The IFOPA also supports FOP research at the University of Pennsylvania School of Medicine at a rate of more than $500,000 annually and is a source of invaluable support and comfort to those who suffer from FOP.

Our mission is to fund research to find a cure for FOP while supporting, connecting and advocating for individuals with FOP and their families, and raising awareness worldwide.

Our vision is a cure for FOP, accessible worldwide.

The International FOP Association is a 501c3 non-profit organization supporting medical research, education and communication for those afflicted by the rare genetic condition Fibrodysplasia ossificans progressiva (FOP).
3. Mentoring program – FOP’ers, Parents & Siblings to come, Who Else?

4. Family Gatherings

5. Patient panels and advisory boards
   - Drug Development Forum
   - Pharmaceutical companies
1. FOP Awareness Day – April 23

Thank you for participating!

2. Rare Disease Day – Feb. 28 (or 29)

3. FOP Online Store

4. Targeted Physician Awareness

Raise Awareness
Stay Connected to the IFOPA

1. Become a member!
2. Connect on Facebook and other social media
3. Complete IFOPA surveys/polls

They can be translated!
International FOP Association

Adam Sherman

Research

Anitha Devadason

Family Services

Mentoring (ongoing)

Transition (project-based)

Quality of L.I.F.E. Awards