

## FOP MILESTONES

The IFOPA and its partners have supported both the FOP community and the FOP research effort worldwide for 15 years. Below are just a few highlights:

■ **FOP Gene Discovery:** Published in the April 23, 2006 issue of *Nature Genetics*, the FOP Research Lab discovered the gene that causes FOP. This groundbreaking discovery will have positive impacts not only on finding a cure for FOP but for many bone related illnesses as well.

■ **FOP Collaborative Research Project:** Established at the University of Pennsylvania by Drs. Frederick S. Kaplan, Michael A. Zasloff, and Eileen M. Shore, this also marked the creation of the FOP Research Lab.

■ **Institutional Grants:** National Institutes of Health grants have been awarded for 12 of the 15 years of FOP research.

■ **Critical Endowments:** Significant endowments established at the University of Pennsylvania anchor the research effort starting with the Isaac and Rose Nassau Professorship of Orthopaedic Molecular Medicine and followed by the Ian L. Cali FOP Research Fund and the Whitney Weldon FOP Research Fund.

■ **International Network:** FOP family organizations have been established in Australia, Brazil, Germany, Italy, Japan, Peru, Scandinavia, The Netherlands, and United States and continue to grow, helping build the network of FOP members and FOP awareness on a global scale.

## FOP FACTS

■ **Diagnosis:** Children with FOP appear normal at birth except for congenital malformation of the great toe. During the first or second decade of life, painful swellings that look like tumors develop over the neck, back and shoulders, and mature into bone.

■ **Progression:** FOP progresses along the trunk and limbs of the body, replacing the healthy muscles with bone. These bridges of bone significantly restrict movement, and attempts to remove them results in explosive new bone formation because trauma, like surgery accelerates the FOP process.

■ **Unique:** FOP is extremely variable and unpredictable. In some, disease progression is rapid, while in others it is gradual. One day a person may be able to bend an arm, and the next day it is frozen forever in a locked position.

■ **Rare:** Worldwide, FOP affects one in two million people. Yet, research into FOP is making discoveries about the basic process of bone formation. As such, it may one day benefit those suffering from more common bone-related conditions and may be a key to a better future for millions.



International  
Fibrodysplasia  
Ossificans  
Progressiva  
Association



Support Families, Fund Research,  
Find A Cure.



## WHAT IS FOP?

Fibrodysplasia Ossificans Progressiva (FOP) is one of the rarest and most disabling genetic conditions known to medicine, causing bone to form in muscles, tendons, ligaments, and other connective tissues. Bridges of extra bone develop across the 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.

### FOP GENE DISCOVERED - A MEDICAL BREAKTHROUGH!

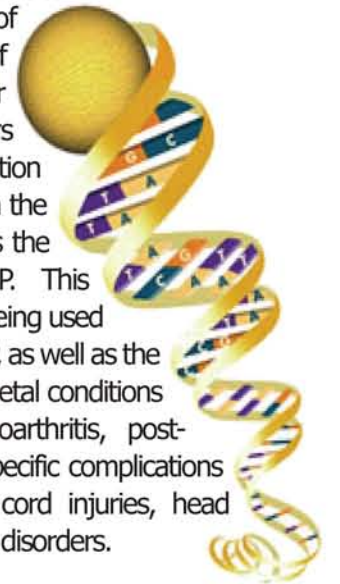
"Cause" and "Cure" have always been guiding principles in FOP research. Our goal has been to discover the exact genetic and molecular cause of FOP and to use that knowledge to develop effective treatments and eventually a cure.

In April 2006, after 15 years of painstaking research, the FOP research

"The discovery of the FOP gene is relevant to every condition that affects the formation of bone and every condition that affects the formation of the skeleton."

**DR. FREDERICK KAPLAN**  
DIRECTOR  
CENTER FOR RESEARCH IN FOP &  
RELATED DISORDERS  
UNIVERSITY OF PENNSYLVANIA  
SCHOOL OF MEDICINE

team at the University of Pennsylvania School of Medicine and their international collaborators pinpointed a single gene mutation - one letter out of six billion in the human genome - that causes the runaway bone growth of FOP. This groundbreaking discovery is being used to unlock the mysteries of FOP, as well as the secrets of many common skeletal conditions such as osteoporosis, osteoarthritis, post-amputation treatment, and specific complications of hip replacements, spinal cord injuries, head injuries and some heart valve disorders.



The FOP gene discovery gives people with FOP great hope for the future. Now that the cause of FOP is known, research efforts can now focus on a treatment and cure. The discovery of the FOP gene provides a highly specific target for future drug development that holds promise for altering not just the symptoms of the disease, but the disease itself.



## WORLD-CLASS RESEARCH: CRITICAL FOR A CURE

The FOP Research Laboratory created in 1992 is located at one of the most prestigious medical and research institutions in the country -- the University of Pennsylvania School of Medicine.

Led by Frederick Kaplan, MD, and Eileen Shore, PhD, the FOP Research Laboratory's dedicated research team includes four principal investigators with many post-doctoral fellows, scientists, students and staff. This core team collaborates with physicians and scientists worldwide to develop treatments and someday a cure for FOP.

The FOP Research Lab's seminal work has been highlighted in many prestigious medical publications including the *New England Journal of Medicine*, *Nature Genetics*, *The Journal of Bone and Joint Surgery*, *Clinical Orthopaedics*, and *The Journal of Bone and Mineral Research*.

## RESEARCH FUNDING: ENDOWMENTS, GRANTS AND GRASSROOTS

Seventy-five percent of the funding required to support the FOP Research Laboratory comes from FOP family fundraising, endowments, and donations. The balance comes from the National Institute of Health and other institutional grants. With the bulk of funding coming from the FOP community, the IFOPA is focused on developing new fundraising opportunities.



## SUPPORT FAMILIES, FUND RESEARCH, FIND A CURE

### EDUCATION

Due to the rarity of FOP, misinformation is common. Even today, few doctors know about the disease. Almost 90% of patients are misdiagnosed, with correct diagnosis taking an average of four years. To help educate families, physicians and the general public about this condition, the IFOPA does the following:

- **FOP Information Center:** The Betty Ann Laue FOP Library is a central repository for FOP information including: awareness materials, informational videos and CD's, special interest articles and copies of medical publications.
- **Comprehensive Online Resource:** [www.ifopa.org](http://www.ifopa.org) provides up-to-date information on FOP research, fundraising and awareness.
- **FOP Guidebooks:** "What is FOP? A Guidebook for Families" and "What is FOP? Questions and Answers for the Children" are valuable resources written specifically for families dealing with FOP.
- **Newsletters:** Two newsletters provide insightful information about FOP, community activities and fundraisers being held across the world.
- **Member & Board Participation:** The IFOPA promotes awareness for FOP through member and board participation in numerous activities.
- **International Outreach:** The IFOPA is continuing to build an international network of family and medical ambassadors throughout the world while also supporting other international FOP organizations.

### HOPE & SUPPORT

Having the opportunity to talk to someone who understands the unique challenges of FOP is extremely important. By providing access and enabling communication within the FOP community, the IFOPA has helped to end the isolation of the past. The IFOPA networks FOP families with each other by:

- **Community:** Connecting families and providing membership resources to bring those afflicted with FOP closer together providing support.
- **FOPonline Newsgroup:** Encouraging FOP members and their families to join the FOPonline newsgroup where they can share thoughts, concerns and questions among the FOP community.
- **LIFE Committee:** Helping members live satisfying and independent lives by providing information and assistance about advocacy, entitlements, adaptive equipment, special education, and more.
- **International Symposia:** Building international awareness and support across the globe, international symposia enables families, scientists, and medical specialists to come together to share knowledge, exchange ideas, and experiences while fostering inspiration.

## WHAT IS THE IFOPA?

Established in 1988 by Jeannie Peeper, a woman with FOP, the IFOPA is a non-profit organization focused on instilling hope through research, education and support while searching for a cure for FOP.

To date, the organization has donated more than \$5 million in support of a treatment and cure. Currently, the IFOPA contributes approximately \$500,000 annually in support of funding this important research.

## MEDICAL & SCIENTIFIC ADVISORY BOARD

### Frederick S. Kaplan, M.D.

Isaac & Rose Nassau Professor of Orthopaedic Molecular Medicine  
Director, Center for Research in FOP & Related Disorders  
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### Eileen M. Shore, Ph.D.

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## YES!...

*I Want To Participate in a Miracle*

I would like to become a  
**MEMBER** of the IFOPA  
(includes *FOP Connection* subscription).

I am a:  
\_\_\_\_ Person with FOP                      \_\_\_\_ Caregiver  
\_\_\_\_ Healthcare Professional        \_\_\_\_ Family  
\_\_\_\_ Other \_\_\_\_\_

I have enclosed \$25 for annual dues.  
In addition to my membership dues, I  
have also enclosed a contribution of  
\$ \_\_\_\_\_.

I would like to be a Friend of the IFOPA  
(includes *Milestones* subscription).  
Enclosed is my gift:

\$25    \$50    \$100    \$ \_\_\_\_\_

In memory/honor of (please circle one).

\_\_\_\_\_

The IFOPA will send an  
acknowledgment of your gift to  
the person you listed below:

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Address \_\_\_\_\_

Your Name \_\_\_\_\_

Address \_\_\_\_\_

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Mail to:  
IFOPA, P.O. Box 196217  
Winter Springs, FL 32719

Thank you for your contribution.  
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