

The International Fibrodysplasia Ossificans Progressiva Association

Marilyn S. Hair, MDiv¹ and Jeannie L. Peeper, BA²

¹Vice President and ²President of The International FOP Association, Inc., Winter Springs, FL

Abstract

The International Fibrodysplasia Ossificans Progressiva (FOP) Association was founded by patient Jeannie Peeper in June of 1988 to educate patients, doctors, and the public about FOP; to raise funds and provide a patient base to support medical research into FOP; and to support patients with FOP and their families by providing a network of communication to help end the isolation that accompanies this rare and severely disabling condition.

Key Words: Fibrodysplasia ossificans progressiva (FOP); patient support group; nonprofit organization; education; Jeannie Peeper.

Introduction

Fibrodysplasia ossificans progressiva (FOP) was first described in 1692 by French physician Guy Patin. He wrote to a colleague, “I saw a woman today who finally became hard as wood all over.” Most likely, that woman never knew the name of her catastrophic condition. Almost certainly, she never met or even heard of anyone else who had it. FOP was poorly diagnosed and little understood in 1692 and for more than 300 yr thereafter.

Jeannie Peeper was diagnosed with FOP in 1962 when she was 4 yr old. Doctors knew little about the condition and gave her family faint hope for her future. Still, Jeannie attended public school and graduated from college in 1985 with a bachelor of arts degree in social work. Soon after college graduation, she fell and injured her hip. In subsequent medical visits, Jeannie learned that a doctor at the National Institutes of Health (NIH) was studying FOP.

Address correspondence to Marilyn S. Hair, MDiv, Vice President, IFOPA, P.O. Box 196217, Winter Springs, FL 32719-6217. E-mail: together@ifopa.org.

The doctor was pediatrician and geneticist Michael Zasloff. He had met his first FOP patient in 1977 in a clinic with Dr. Victor McKusick at The Johns Hopkins University School of Medicine in Baltimore. Dr. McKusick was, at the time, the world expert on FOP. Dr. Zasloff was intrigued, and he asked Dr. McKusick to refer new patients with FOP to him, which Dr. McKusick did. When Jeannie Peeper met Dr. Zasloff in 1985, he knew 20 people who had FOP.

Jeannie was 27 yr old, and it had never occurred to her that anybody else had FOP. To meet a doctor who knew something about her condition, and who knew other people who had FOP, was a life-changing event. Jeannie Peeper asked Dr. Zasloff to help her meet someone else who had FOP. He connected her with Monica Anderson, the patient he met at Johns Hopkins in 1977. Jeannie and Monica talked on the phone for a long time. Jeannie was intrigued to find out about other people who had FOP. Dr. Zasloff put Jeannie in contact with 18 people, all the living patients with FOP known to the NIH.

In 1987, Dr. Zasloff left the NIH and moved to the University of Pennsylvania in Philadelphia.

The research program on FOP at the NIH ended, and patients with FOP were turned away.

The International FOP Association

Jeannie Peeper composed a letter and questionnaire and mailed it to the patients with FOP. Eleven responded. In early 1988, Jeannie and Nancy Whitmore Sando, 1 of the 11, started a newsletter called the *FOP Connection*. In June 1988, in order to begin raising funds for FOP research, the International FOP Association (IFOPA) was incorporated. Jeannie Peeper became president, and Nancy Whitmore Sando became vice president.

About the same time as Jeannie founded the IFOPA, Dr. Zasloff met Dr. Frederick Kaplan at the University of Pennsylvania. An orthopedist, Dr. Kaplan had a few patients with FOP, and the two physicians dedicated a bench in Dr. Zasloff's lab to research the disease. By 1991, Drs. Zasloff and Kaplan, along with Jeff Tabas, a medical student and the first FOP research fellow, had made some important discoveries about FOP, and decided to hold a meeting to discuss their research. This was the First International FOP Symposium, held in September 1991 at The University of Pennsylvania and The Children's Hospital of Philadelphia. The symposium was attended by a dozen doctors and scientists from around the world who knew about FOP, as well as 25 patients with FOP and their families. This was the largest ever gathering of patients with FOP. It was the first time many of them had met someone else with FOP, and the first time some had been examined by doctors who understood FOP. The symposium also gave the attending physicians and scientists an opportunity to meet the FOP community, small as it was at the time. The FOP Research Laboratory at the University of Pennsylvania was established the following year, in 1992.

It is crucial for patients with FOP to obtain a correct diagnosis in order to receive appropriate treatment and to be spared harmful procedures, such as biopsies, operations, and chemotherapy. The 1991 symposium brought attention to FOP. Drs. Zasloff, Kaplan, and Eileen Shore (a geneticist and senior research scientist who had joined the team in 1991), along with other FOP researchers at the University of Pennsylvania, published many articles on FOP for doctors who might see undiagnosed patients.

Referrals of patients with FOP to the University of Pennsylvania multiplied. Dr. Kaplan told his new patients about the IFOPA, and the organization's membership grew rapidly. The advancement of FOP research and the growth of the FOP community have developed in tandem.

The Second International FOP Symposium was held in Philadelphia in 1995. Forty patients and their families and 75 physicians and scientists participated. In 1999, FOP was brought to the public's attention in a 50-min documentary, "The Skeleton Key" on the BBC's *Horizons Science* program. ABC's *20/20* program also publicized FOP in a segment called "The Bone People." The Third International FOP Symposium in 2000 doubled in size, hosting 85 patients with FOP and their families from 12 countries, along with 100 doctors, scientists, and researchers.

IFOPA Goals

The goals of the IFOPA are (1) to educate doctors and the public about FOP, (2) to raise funds and provide a patient base to support medical research into FOP, and (3) to support FOP patients and families.

Education

The Internet has been central to making technical medical information available to the public. Parents can search for their child's symptoms and find information about FOP, sometimes before their doctors find it. The Internet has helped patients with FOP from all over the world find the IFOPA.

The IFOPA website at www.ifopa.org includes *What is FOP? A Guidebook for Families*, medical articles, treatment guidelines, the Annual Reports of the FOP Collaborative Research Project, and *Overcoming Obstacles: A Catalogue of FOP Resources*. The website describes the search for multigenerational FOP families and the need for postmortem FOP tissue and bone marrow donations, reports on IFOPA fundraising and member news, and includes a photo gallery.

Fund and Support FOP Research

The IFOPA provides researchers with a population to study. For example, in 1994, Rocke et al. systematically surveyed 44 individuals with FOP to document the typical sequence of joint involvement and the characteristic pattern of disease progression in FOP (1).

Through donations and many extraordinary FOP family fundraisers in their local communities worldwide, the IFOPA provides funds each year for FOP research at the FOP Laboratory at the University of Pennsylvania.

Support Patients With FOP and Their Families

The *FOP Connection*, first published in 1988, is now a 20-page quarterly magazine. FOP members look forward to reading news and stories about others with FOP, hearing about progress in FOP research, celebrating fundraising successes, and learning how to live well with FOP.

In addition to the resources available on the IFOPA website, the organization sponsors a private online listserv for patients with FOP and their families. E-mail gives instant access to the wisdom and experience of the FOP community.

The IFOPA has sponsored four family gatherings at Disney World in Orlando, FL. FOP families have the opportunity to meet one another, socialize, and learn about the latest FOP research. Dr. Kaplan and his colleagues hold clinics to examine patients and gather data for research.

Through the Living Independently with Full Equality Committee, the IFOPA offers resources and consultations about assistive technology and funding sources. A scholarship program provides small grants to FOP members to help purchase adaptive

equipment and services to help increase independence and quality of life.

FOP patient organizations have been established in Brazil, France, Germany, Great Britain, and Sweden. The first FOP Latin American Family Meeting was held in October, 2003 in São Paulo, Brazil. Forty-seven FOP families from nine South American countries attended.

The IFOPA Today

In early 2005, the IFOPA had 378 members, including 158 in the United States and 220 international members. The membership represents 51 countries. The IFOPA is located in Winter Springs, FL.

The IFOPA has more than met Jeannie Peeper's initial goal of helping people with FOP get connected. The loneliness and isolation that characterized past generations of people with FOP has been transformed into a community. The IFOPA is proud of the role it plays in making life better for people with FOP. We hope and believe that the research described in this publication will unveil the secrets of this complex condition and lead to treatments and, ultimately, a cure for FOP.

Reference

1. Rocke DM, Zasloff M, Peeper J, Cohen RB, Kaplan FS. 1994 Age and joint-specific risk of initial heterotopic ossification in patients who have fibrodysplasia ossificans progressiva. *Clin Orthop* 301:243–248.

