

2010 Jeannie Peeper IFOPA Award Winners

President's Lifetime Leadership Award

Marie Peeper

“Dear FOP Community,

As President of the International FOP Association, I am honored to choose the first President’s Lifetime Leadership Award recipient. As I pondered and reviewed a list of very deserving people to receive this award, my heartstrings were tugged to someone I think is the most deserving first recipient of the President’s Lifetime Award, my wonderful mom, Marie Peeper.

She exemplifies making a dream a reality. My dream of starting a non- profit organization to raise funding for FOP research to help find a cure for the children and future generations, quickly became my mom’s dream for me and she was eager and willing to do whatever it would take to make sure that I lived my dream. And now twenty two years later, we continue on this journey together hand in hand. Marie has not necessarily been the "leader" that makes things happen, but rather the crucial, unconditional "support" person, without whom the dream of an organization to end the isolation of those with a rare bone condition would not exist. She has been the unsung mother of the FOP community that has worked countless hours in supporting me, her family, as well as others in the FOP community, which in return has helped to make the organization and community of the International FOP Association what it is today.

It would be difficult to list all of the many things my mom has done for the IFOPA over the past twenty two years. She has worked behind the scenes tirelessly doing whatever I needed her to do to get a job done. From working on the FOP Connection, to assisting me in countless hours of writing thank you notes, assisting in the office, traveling to attending media events and awareness conferences, supporting families, making phone calls and being my right hand whenever a task needed attention.

Many of you know my mom personally and some of you have known her for many years. She is a beautiful, soft spoken woman with a heart of gold. She continues today to be an inspiration and has been an incredible mentor to many parents over the years, ending years of isolation for herself and opening a whole new world to many moms who just wanted to know how they could be the amazing mom that she is to her daughter. I think Marie, as everyone calls her, truly represents and honors all the moms in the FOP Community by receiving this award.

Personally, her dedication and love for me shines brightly like the stars at night. I am so fortunate to have her as my mom. She is my rock, my best friend; she always listens to me intently and gives advice in a loving, gentle way. She always provides me comfort, strength and security when the storm of FOP arises.

I will always cherish my mom’s advice to me growing up as a young girl....To Live my Dream and Always Be True to Myself. There is no love, quite like a Mother’s love.” - Jeannie Peeper, IFOPA Founder & President

Outstanding Community Involvement Award

The Noontime Kiwanis Club of Santa Maria, California

The Kiwanis clubs of the Santa Maria Valley became involved in the fundraising efforts for the IFOPA after learning of local resident, Stephanie Snow's, diagnosis with FOP in 1994. The Snow's began two fundraising events on behalf of Stephanie in 1994, the Find-A-Cure BBQ, and the Find-A-Cure Dinner/Auction/Raffle. The Kiwanis club members were involved in volunteering time and their financial support to these events. In 1998, it was clear that one family could no longer keep up the pace of running two fundraising events. It was at that time that the Noontime Kiwanis club took over the Find-A-Cure Dinner/Auction/Raffle. The Noontime Kiwanis club of Santa Maria has made an annual commitment over the past 12 years to raise funding for the IFOPA; their efforts in hosting this event has raised over \$533,000.00 for the IFOPA.

They have received local media coverage via television and radio each year as a part of advertising for the fundraising event, as well as raising awareness about FOP.

Each year as a part of promoting the Find-A-Cure Dinner/Auction/Raffle, Kiwanian members visit several branches of Kiwanis and other local service organizations to educate and update the community of FOP and FOP research.

We would also like to mention the following Kiwanian members who first became involved by volunteering for the Find-A-Cure Dinner, and later went on to continue service to the IFOPA. Don Brister became an IFOPA board member and later Chairman of the Board. Betty Boyce raised funding for the IFOPA through running the New York marathon at the age of 75 and 76, as well as published a magic book which proceeds benefit the IFOPA. Shell gas station's "Fill'er up to Find-A-Cure" program, which raised over \$200,000.00, came to be from a solicitation letter sent by the Kiwanis club requesting donations on behalf of the Find-A-Cure event.

Outstanding Youth Award

Oliver "Ollie" Collins

Diagnosed with FOP at 18 months, "Ollie" Collins is now a 16-year-old Australian student who uses his physical challenges and exceptional public speaking skills to literally transform public attitudes regarding people with disabilities.

The most outstanding example among many is Ollie's role in demonstrating to his school that his disability is actually their asset in understanding how their institution can be improved for students of all abilities. See Ollie's presentation at a teachers' conference entitled "FOP and Me: The Impact on Schooling".

Frequently asked to speak to both adult and teen audiences, Ollie's central theme is how he deals with his disabilities as a youth with FOP. These events have included addressing a major conference in Sydney on adolescent health, a fundraiser attended by over 500 people for a volunteer organization that caters to teenagers with life-threatening illnesses, and a presentation to 200 special educators with the Department of Education.

Ollie currently serves on the Youth Advisory Committee for construction of a new Queensland Children's Hospital, speaks at fundraisers whenever called upon, serves on a "future problem-solving" team, participates in school debates and sings in a choir. But even so, Ollie lives with pain. Recognizing his ability to overcome even this, a local professional training company enlisted Ollie to help runners "break through their pain barrier" with a motivational speech at 5:30 AM.

Finally, to further add to his awareness contributions, Ollie recently participated in the production of an Australian Broadcasting Corporation program on disability and spirituality and how families cope. The producers interviewed Ollie and his mom regarding FOP, and followed Ollie in his regular activities that include a street program in which Ollie and his friends feed the homeless.

Outstanding International Leadership Award

Dr. Patricia Delai

Since 1999 when she encountered her first FOP patient, Dr. Patricia Delai has been heavily involved in creating FOP awareness in Brazil, promoting awareness of FOP worldwide and serving as personal physician to numerous FOP families – all in addition to her busy medical practice as a dermatologist.

In 2003 Dr. Delai organized the first South American FOP meeting in Sao Paulo at which nine Latin American countries were represented and 24 FOP families attended. This in turn led to her founding the Brazilian FOP Association in 2005 that now serves as a home for 65 Brazilian FOP families. Using her professional expertise, she translated all the major IFOPA documents into Portuguese for posting to the FOP Brazil website (currently offline for redesign), a valuable service for the local medical community and Brazilian FOP families. Her translation of FOP Treatment Guidelines was the first case of the guidelines being translated into another language.

In her early involvement, she contacted numerous Brazilian hospitals and medical schools, and in many cases personally telephoned medical schools to inform pediatricians, orthopedists, oncologists, geneticists, and others about FOP. Reaching beyond the medical community, she contacted TV and radio stations, popular magazines and newspapers, all of which led to TV and radio interviews as well as articles in the popular press. In collaboration with Drs. Glaser and Kaplan, Dr. Delai located a multigenerational FOP family, a critical event that enabled the discovery of the FOP gene. Her many other contributions include serving as the Latin American medical advisor on FOP, founding chairperson of the International President's Council, member of the International Clinical Consortium for FOP, and one of the three medical editors for "What Is FOP? Guidebook for Families"