

2014 Jeannie Peeper IFOPA Award Winners

President's Lifetime Leadership Award

Sharon Kantanie



Jeannie Peeper notes, "I have chosen Sharon Kantanie for this year's award. Sharon has been a member of the IFOPA since 1990 and a pioneer who has spearheaded many projects, especially in the formative years of the organization." Sharon served as a member on the IFOPA Board of Director's from 1991 through 2000 in which she held executive director leadership positions including Treasurer and Vice President. She was instrumental in editing the FOP Connection newsletter; producing a number of IFOPA brochures; hosting, along with her family, an FOP family meeting in Nashville, TN; establishing the first FOP Resource Center Library; co-organizing the 1995 FOP symposium; implementing the "Flat Stanley" project at the 2000 FOP symposium; helping design the first IFOPA website; and initiating and moderating the FOP Online private e-mail chat group. In addition to the above, Sharon committed many hours to editing and writing multiple editions of "What is FOP? Fibrodysplasia Ossificans Progressiva: A Guidebook for Families." Sharon continues at present to promote FOP awareness – she was recently featured in an article about FOP research carried out by Vanderbilt University's Dr. Charles Hong. Sharon's contributions to the FOP community truly are extensive and exceptionally valuable.

Outstanding Community Involvement Award

Individual – Gary Whyte



Gary Whyte is an individual who, though he has no family members with FOP, has made it his mission to promote awareness of FOP and raise funds for research. Gary is perhaps best known for performing in his very successful annual comedy show fundraiser and in 2014 he hosted the 13th Annual Comedy Show. Over the years he has generously raised funds for FOP research. Gary's commitment to finding a cure for FOP has not stopped there; he has tirelessly devoted many hours to raising awareness, including making presentations about FOP to numerous clubs and organizations, even to mayors, congressmen, senators, state assembly members and others. Recently, we learned Gary has successfully convinced 390 mayors of towns and cities out of the 566 in New Jersey, to issue proclamations to raise awareness of FOP. This was a family affair for Gary, involving his three sons in helping with presentations and other events. Gary is an extraordinary friend to the FOP community and dedicated supporter of our IFOPA mission.

Group – Hayden's Hope



Hayden's Hope was inspired by its namesake, Hayden Pheif, an adorable young boy who is now an amazing teen with FOP. Hayden's Hope was started by Hayden's mother and father, who led fundraising efforts in Northern California with the help of many relatives and friends. Year after year, Hayden's Hope provided significant revenue, which is now close to one million dollars in total donations. These donations propelled the IFOPA mission forward. All their efforts have helped bring FOP awareness to the forefront and these funds have significantly advanced FOP research. Today, Hayden's Hope continues its efforts on-line with a website and blog, while still raising awareness and funds for research and other IFOPA programs. Photo is Megan Pheif the mother of Hayden Pheif

Emerging Leader Award

Ian Cali



Ian Cali is an adult with FOP. Over the past twenty years, he has taken part in numerous fundraising campaigns for the IFOPA and for the Ian Cali FOP Research Fund at the University of Pennsylvania (UPenn). Ian was a participant in the announcement of the FOP discovery in 2006, and for a number of years he put on presentations about FOP at UPenn for second-year medical students. In his teen years, Ian and Newark Academy started fundraising for FOP research together. Celebrating their tenth year, fundraising efforts at Newark Academy have continued even though Ian has since graduated. As a young adult he even participated in Capitol Hill Days to raise FOP Awareness among the United States political leaders. Ian has also been a guest speaker about FOP at scientific workshops and conferences, and has been featured in film documentaries about FOP that give insight into living with a rare disease. Ian organized “Fist Pump To Beat FOP,” a fundraising concert series at the University of Delaware and in Philadelphia. These experiences led him to develop Contagious Atmosphere LLC, a company which supports building FOP awareness and funding research.

Outstanding International Leadership Award

Enrico Cristoforetti



Enrico Cristoforetti lives in Italy, and is the founder and president of FOP Italia. He established FOP Italia in 2006 after his young daughter was diagnosed with FOP. Over the years, FOP Italia has organized and held annual conferences which have been attended by respected FOP researchers and many individuals with FOP and their families. Attendees have traveled from many countries outside of Italy including Holland, Austria, Russia, South Africa, Australia, Sweden, the UK, France and Argentina. With the driving force of Enrico’s leadership efforts behind it, the Italian FOP organization has been active in raising funds for FOP research, and successfully obtaining tax funds available for non-governmental organizations in Italy. Incredibly, FOP Italia has even established and presently fund a small FOP research group at Genova, Italy. Enrico’s extraordinary leadership skills bring together a global effort for FOP awareness and funding for research to find a treatment and cure for FOP.