

2013 Jeannie Peeper IFOPA Award Winners

President's Lifetime Leadership Award

Diane Weiss



Diane Nassau Weiss met Dr. Frederick Kaplan, FOP (Fibrodysplasia Ossificans Progressiva) researcher, many years ago, and since then she has been dedicated to supporting his work to find a cure for the rare orphan disease that imprisons children in a second skeleton of bone. Despite having no family members or initially close friends with FOP, Diane has phenomenally supported FOP research.

In 1997, she established an endowment at the University of Pennsylvania – creating the newest Professorship in the USA's oldest school of medicine that year. Dr. Kaplan is the first recipient of this chair named by Diane Weiss in memory of her parents, Isaac and Rose Nassau. Dr. Kaplan in a speech said, "She endowed it with a name and a purpose that continues to link the memory and the history of her own past to a brighter future for children whose lives desperately depend on it." The first endowed FOP chair, Isaac and Rose Nassau Professorship of Orthopaedic Molecular Medicine at the University of Pennsylvania School of Medicine, is used to fund research at the FOP Molecular Biology Laboratory to discover the cause and to develop a cure for two devastating disorders of renegade bone formation in children – FOP and POH (Progressive Osseous Heteroplasia). Today Dr. Kaplan continues to hold this chair and because of the establishment of this important endowment by Diane, Dr. Kaplan has had the freedom to travel to see FOP patients at no cost, and to attend conferences, fundraising events and International Fibrodysplasia Ossificans Progressiva Association (IFOPA) meetings. It is difficult to overstate the incredible value of this contribution to the FOP community.

In addition to her extremely important contribution to FOP research at UPenn, Diane Weiss has also long supported the IFOPA which funds research to find a cure for FOP while supporting individuals and their families through education, public awareness and advocacy. Diane's gifts continue to transcend time and with these gifts she has created hope, the greatest gift of all. Thanks Diane for supporting our vision to find a cure for FOP.

Outstanding Community Involvement Award – Individual

Lori Henrotay



Lori Henrotay is the mother of a young teenage lady, Carli Henrotay, who has FOP (Fibrodysplasia Ossificans Progressiva). Since becoming a member of the International Fibrodysplasia Ossificans Progressiva Association (IFOPA) in 2001, Lori has worked hard for a number of years to raise FOP awareness.

While Lori was on the Marketing Committee of the IFOPA she helped work on the revision of the brochure, web site, and letter head. Lori created the FOP Facts & Insight series video in which she interviewed scientists at the University of Pennsylvania and talked about various issues of importance to the FOP community. You can view these informative videos by clicking on this link: <http://www.youtube.com/user/FOPNews>. Lori was also twice the chair of the Jeannie Peeper Awards committee, and was an IFOPA board member from 2005 through 2008.

As well as her positions within the IFOPA board and committees, Lori has organized a number of fundraising events, including fashion shows, golf tournaments, and in April of 2012, a bocce ball tournament called "Striking Out FOP." Thank you Lori for raising public awareness, providing funds to the IFOPA to find a cure for FOP while supporting families through education and advocacy; we appreciate your efforts to help our FOP community. (photo left to right Carli and Lori)

Outstanding Community Involvement Award – Group

The Dennings Family



The Dennings family is composed of David, Jennifer, Cody (a teenage male with FOP) and Cam –Cody's younger brother. In recent years, the Dennings family has held a number of fundraisers, including "Unmasking the Mystery of FOP," a twice-held FOP dinner mystery that many FOP families enjoyed attending, a barbecue and different awareness/fundraising events within their community of Seabrook, Texas. Cody and Jennifer have also been featured in periodical articles which have raised awareness of FOP in their area of Texas. (Focus on FOP photo: from left to right: Devon Lord, Wesley Lord, Lovie Lord, Eric Visentin, Jen Dennings, Cody Dennings, Dave Dennings, Hunter Haddock, Sheila Haddock, Keith Haddock.)



The spirit of raising FOP Awareness and funds for the International Fibrodysplasia Ossificans Progressiva Association (IFOPA) has been passed from David and Jennifer to their sons! Cody himself established a "Jeans Day" at Seabrook Intermediate School raising FOP awareness and funds when he attended. Cam followed in his brother's footsteps and held the same event successfully on his own. Both brothers have had great success selling Cure FOP bracelets at these events which are usually held in April and Cody has also used the bracelets to befriend some special athletes. (photo to left: Cam #35 posting-up during a basketball game also has the family "gene" to raise FOP Awareness)

Cody is a skateboarding enthusiast and has combined his gift of video production with his love of this sport. He has had the pleasure of meeting some great athletes. Cody has given many skateboarders the CURE FOP bracelets to wear during their competitions to help raise FOP awareness. In 2013, Cody decided to have a very special fundraiser on April 21st – a fantastic skateboarding event named Focus on FOP to benefit the IFOPA. This was not only a great event for teens, spectators, and skateboarders; but the entire community. His family was instrumental in helping Cody make sure everyone who attended enjoyed great food, and prizes plus creative people competed for the Cody Dennings Media Award by submitting their best montage or photo album.

By successfully working with his family, Cody received a great honour from their home city of Seabrook, Texas when the city council decided to recognize April 22, 2013 as "Cody Dennings' Day." This was a great honour for the Dennings' Family, Cody, and our FOP community, since this took place during International FOP Awareness week. Thank you Denning's Family for living the IFOPA mission to find a cure for FOP while supporting individuals and their families through education, public awareness and advocacy.

Emerging Leader Award

Vincent Whelan



After many years of challenging studies, Vincent Whelan a young man with the rare genetic disease FOP (Fibrodysplasia Ossificans Progressiva) graduated from the University of California at Irvine's medical school in June of 2012. Shortly thereafter, the newly-minted Dr. Whelan began work as a resident in pediatric medicine.

Vincent Whelan is the first person with FOP (the rare orphan disease that replaces muscles with a second skeleton of bone) to have become a medical doctor, and he states that his inspirations are Dr. Frederick Kaplan and Dr. Joseph Kitterman. In 1996 Vincent was ten years old and had a life changing experience when he met Dr. Kaplan. Vincent was so amazed by Dr. Kaplan's compassion and dedication to helping people with FOP world-wide, Vincent decided to become a doctor. As soon as Vincent entered high school he started taking as many science courses as possible. During the graduation ceremony on June 2, 2012, Vincent had the honor of receiving his doctorate hood from his mentor Dr. Kitterman (see photo to left) who is well known in our FOP community for his ongoing work in regards to studying the neurologic problems common to people with FOP and the 2012 publication of studies he and his colleagues conducted after collecting data from the neurological survey IFOPA members with FOP completed.

Like his mentors, Dr. Whelan is also very interested in contributing to the dynamic field of FOP research, and as such brings a unique and valuable perspective to this important work. In fact, Vincent has already begun contributing to FOP research in this regard - during his time as a university student, Vincent worked and studied for a period of time in the FOP research lab at University of Pennsylvania School of Medicine, in Pennsylvania, USA. Dr. Vincent Whelan's current hope is to someday work with children affected by rare disorders. The IFOPA commends Dr. Vincent Whelan not only for catching our vision – A Cure for FOP – but also our compassion to help rare disease individuals and families through education, public awareness and advocacy.

Outstanding International Leadership Award

Richard Simcox



Richard Simcox lives in the United Kingdom and although he has no family members with the rare disease FOP (Fibrodysplasia Ossificans Progressiva), he is a great international leader in regards to funding research to find a treatment and cure for FOP. Mr. Simcox first learned about the disease that robs one of mobility, when his wife, Gail, taught a child with FOP at preschool. Since then, he has committed himself to supporting FOP research at both Oxford University in England and Penn Medicine at the University of Pennsylvania in the USA.

For more than a decade, Richard Simcox's company, Roemex, has generously funded FOP research at the core FOP laboratory in Pennsylvania, USA. This funding has advanced the Center for Research in FOP and Related Disorders' understanding of basic FOP disease mechanism at the molecular, genetic, cellular, and tissue levels and has dramatically accelerated the development of in vitro and in vivo models which will be used to test emerging therapies to treat and cure FOP. His efforts not only include the Roemex fund, which contributes 25,000 UK pounds annually to FOP research, but also the annual "Burns Night" balls to raise money. Richard has also guaranteed to underwrite a significant portion of the expense for the three-year research posts at Oxford. As if his financial contributions and fundraising efforts haven't been enough, Mr. Simcox is also the president of FOP ACTION, the United Kingdom's largest FOP advocacy and fundraising group. The chairman of FOP ACTION UK Sheryl Hardley in a recent email wrote, "Richard over the years and to this day continues to give tremendous moral, leadership, and financial support to FOP ACTION UK . . . he will be giving funds to assist with travel and an overnight stay for families, who would not otherwise be able to attend the FOP Symposium Manchester Airport Hotels, in late-Spring 2014." Finally, Richard contributed time and effort to the filming of *The Human Mannequin*, a UK documentary featuring aspiring fashion designer Louise Wedderburn who has FOP.

Thank you Richard Simcox for joining the IFOPA in our mission: Fund research to find a cure for FOP and support individuals and their families through education, public awareness and advocacy.