

2012 Jeannie Peeper IFOPA Award Winners

President's Lifetime Leadership Award

Nick Bogard

Nick Bogard is the father of FOP Member, Jud Bogard. Nick is a true pioneer of the IFOPA, as he quickly became involved in 1989 after Jud's diagnoses. His commitment to the growth and development of the organization was paramount. In 1990, Nick established the very first IFOPA fundraising event for FOP Research, the Jud Bogard Golf Invitational, which still stands as a benchmark for our grassroots family fundraising efforts. This fundraiser was the miracle for the IFOPA, as it allowed us to give funding to Dr. Frederick Kaplan and Dr. Michael Zasloff for the very first FOP Symposium at the University of Pennsylvania. This one event spearheaded the enthusiasm and the FOP Research initiative.

Nick has also graciously volunteered many hours, serving on the IFOPA Board of Directors for eighteen years. (1989-2007). He is the longest serving Board Member to date. During this time he also chaired and continues to serve on the Finance and Audit Committee. His dedication to our mission is a testimony that encourages all of the families that continue to carry the fundraising torch.

Outstanding Community Involvement Award

Christine Flexer

Christine Flexer is the aunt of Joshua Scoble, a little boy diagnosed with FOP a few years ago when he was a baby. After her nephew's diagnosis, Christine sprang into action. In short order, she organized the "Bingo for a Cure", which raised many thousands of dollars. Under Christine's leadership, the Bingo for a Cure has become an annual event in Pennsylvania, and has continued to raise very significant funds for FOP research and awareness. However, Christine's efforts didn't stop there - she was a driving force behind the establishment of a new FOP charity, Joshua's Future of Promises, which puts on the Bingo for a Cure, as well as a number of other fundraising events throughout the year. Christine's efforts for FOP appear to be the equivalent of full-time employment, and yet are done on a completely volunteer basis.

Emerging Leader Award

Stephanie Snow

Stephanie has been involved in raising awareness for FOP since her diagnosis in 1995 at the age of three. She spreads awareness of her condition by being a "poster girl" for a variety of IFOPA fundraising events including the "Find-A-Cure" BBQ, "Find A Cure" Dinner/Auction/Drawing and "Fill'er up to Find A Cure" (donations per gallon of gas sold), just to name a few. Stephanie also regularly attends two annual community FOP fundraisers in which her family is involved with a smile on her face and an attitude of "let's have some fun!" Stephanie has been interviewed numerous times by the media to help increase awareness about FOP, most notably when she was "the face of FOP" during the exciting times of the discovery of the FOP gene. Stephanie shows leadership in her life with her involvement in local non-profit groups. Currently she is the leader of the rabbit group at her local 4-H, and she donates her time to the animal shelter as well as a veterinary office. Recently, she has been raising funds and awareness for the George Mark House (a pediatric palliative/hospice care facility). As Stephanie continues to study for her degree in Psychology, she also has become a fish breeder,

supplying fish for the local pet store. She hopes with this new "pet project" to work on a new way to help the IFOPA through a new idea called "Fish for FOP".

Outstanding International Leadership Award

Marie Hallbert

Marie's son Hugo Fahlberg, who is now a young teenager, was diagnosed with FOP at age 2. When Hugo was diagnosed, Marie noted that there were no resources about FOP in their home country of Sweden, and certainly no Swedish language information. Marie set about to change that. She is the founder of "FOP Sverige", a group which provides support and information to Swedish and other Scandinavian people with FOP and their families. Through FOP Sverige, Marie has organized 3 FOP conferences in Sweden over the years, and she has worked to ensure that important information about FOP is available in Swedish - including parts of the FOP Treatment Guidelines. Marie has also been interviewed about FOP numerous times by Swedish news media, and has given speeches about FOP in Swedish to medical professionals. More recently, Marie organized the FOP "Collection Project" in which cans for donations by the public are placed in stores and other public places. Marie has also designed and organized FOP Sverige's new website, and has been writing a regular Swedish language blog on the site about her family's life with FOP and important news concerning FOP. Throughout this time, Marie has been a source of help, strength and support for families dealing with FOP, especially in cases of new diagnoses (both in Scandinavia and elsewhere). One mother of a recently diagnosed child in Sweden calls Marie the "FOP Angel".