

2015 Jeannie Peeper IFOPA Award Winners

President's Lifetime Leadership Award

Jennifer Snow



Jennifer (Jen) is one of the leading pioneers of the IFOPA. She has worked tirelessly for the past twenty one years to help the FOP community and has actively supported the IFOPA's mission. Along with her family, they have held many amazing grassroots fundraising events, including the Find a Cure BBQ. This seventeen year event holds the record for the longest running fundraising event in IFOPA history, raising more than a million dollars for the IFOPA is extraordinary. Since her daughter Stephanie's FOP diagnosis in 1994, Jennifer has shared the FOP story publically in both local and national media and at events. She has served on the board of directors in many capacities over the years, including Vice Chair in 2011. Our Founder and President Emeritus Jeannie notes "Jen, you have played a key role in so many IFOPA projects, wearing many different hats; it's hard for me to name them all." She has lead and served on many IFOPA committees including those that supported past special events such as the 3rd & 4th International Symposiums and more recently helped design the patient panel at the first ever FOP Drug Development Forum. Jen has played a key role in research approaches from the beginning and helped form the current IFOPA research and drug development vision as past Co-Chair of the Research Committee. Jen always advocates for FOP patients everywhere. Her passion for the FOP community and her dedication to the patient voice being heard is reflected in all that she has accomplished. Thank you, Jen for your dedication, love and generosity.

Outstanding Community Involvement Award

Individual – Michael Man



Michael (Mike) has been a pioneer in the IFOPA's fundraising efforts. His commitment to the IFOPA's mission began when his son Spencer was diagnosed with FOP, and Mike's generosity continued long after Spencer's death in 1991 at the age of 16. Prior to Spencer's death and continuing well after, Mike's endeavors in supporting the IFOPA are historic. The IFOPA has been able to expand its research and member services because Michael was consistently committed for so many years. The IFOPA benefited from the Spencer B. Man Memorial Foundation which Mike created in honor of his son in 1994, and our association received funding from the Foundation until its closure in 2012. Michael personally donated to the IFOPA up to a \$4,000 match for each Spencer Mann Memorial Drawing event that the IFOPA held. Mike's fundraising efforts also included his memorable donation of a classic car that the IFOPA auctioned off and IFOPA member, Sharon Fitts and her husband, Henry, won. Mike also provided consulting to the IFOPA on fundraising as the association was growing and he served as a board member from April 2009 through December 2010. Michael Man's dedication and extraordinary passion are remarkable.

Group – Lincoln's Legacy: Doug & Marilyn Wheelock / Mark & Robin Gambaiana



The Lincoln's Legacy events started in 2009, in honor of their grandson Lincoln Wheelock shortly after his diagnosis at age three. Both grandparents and their families immediately became involved in the IFOPA and held a dinner plus silent auction, inviting friends and family to learn about FOP and raise funds for FOP research. They have continued to host biennial dinners and auctions, with each event becoming larger. During the years they don't host the dinner/auction event, Lincoln's Legacy does a very large letter writing campaign to raise FOP awareness and funds to support FOP research. In addition to these larger-scale events, the families have created a variety of other smaller-scale activities including "Leap for Lincoln," a Trike-a-thon, holiday shop, Sioux City Bandit (indoor football team) game volunteers, and Living History Farms "Mud Runs." The "Mud Run" in November 2014, had a total of 29 runners participating in honor of Lincoln and collectively generated \$32,500 for FOP research. Each family has had birthday parties or Boss' Day events, where donations were made to the IFOPA in lieu of presents. To date, Lincoln's Legacy events have raised more than \$500,000 and we are thankful for their continued support to find a cure for FOP.

Inspiring Leadership Award

Patrick Doerr



Patrick (Pat) is an IFOPA member who has FOP. Since he became a member in 1996, Pat has demonstrated exceptional commitment to improving the quality of life of individuals in the FOP community and his personal achievements in the face of adversity are outstanding. He has served on the IFOPA Board of Directors as Secretary and Vice Chair. Presently Pat is actively serving on two IFOPA committees, the IFOPA Website Redesign Committee (co-chair), the IT Committee (co-chair) and he has even given a hand to the Mentoring Committee from time to time. Professionally Pat works as an accountant and his co-workers honor him annually by raising money for the IFOPA. He has encouraged others to donate to the IFOPA through online beauty pageants, local businesses are regular donors and his family orchestrated a bicycle event – Unswerving, The Trans-Wisconsin Bicycle Ride to honor him. Pat is faithful in representing the FOP community and the IFOPA. He has worked with Gary Whyte to further FOP and rare disease efforts in the legislative arena, and has attended annual fundraising events for many years including the Comedy Show and Bingo For A Cure. Pat's support includes attending FOP symposiums, speaking at the Scientific Workshop: Strategies for the Treatment of FOP, participating in the IFOPA's Teen and Adult Meeting and our 25th Anniversary Celebration. Leading by example, living independently with determination, exhibiting a positive attitude and a zest for experiencing life to the fullest, Pat is an inspiring role model to our FOP community.

Outstanding International Leadership Award

Carrie Connell



Carrie Connell lives in London, Ontario, Canada. After her daughter Brooke was diagnosed with FOP in 2007 at age 6, Carrie joined the IFOPA, and was disappointed to learn that there was no national FOP group in Canada. She decided, therefore, to form one herself, and in 2009 she became the founder of the Canadian FOP Network (CFOPN). Carrie has served as president since the group's inception, and has been the driving force behind the organization's activities. Under her leadership, the CFOPN became a not-for-profit corporation and obtained charity status, the latter of which enables Canadians who donate to support FOP research charitable tax receipts, allowing deductions for income tax purposes. Carrie has spearheaded and organized CFOPN family conferences in 2009 and 2013, both of which were deemed a great success by attendees. These events included opportunities for FOP patients to be assessed by FOP medical specialists Drs. Kaplan and Pignolo and by FOP dental experts Drs. Nussbaum and Friedman. Carrie has provided logistical assistance through the CFOPN to families wishing to run charitable fundraising events, including helping organize on-line donation websites. While leading CFOPN, Carrie has also participated in annual conferences run by the Canadian Organization for Rare Diseases (CORD), as well as recently attending the IFOPA's 2015 International Presidents' Council meeting in Rome, hosted by FOP Italia. Her role as the IFOPA's International President's Council Canadian representative is vital to helping us successfully implement our educational, awareness and advocacy programs to support our Canadian FOP members and their families.