

2011 Jeannie Peeper IFOPA Award Winners

President's Lifetime Leadership Award

Amanda Laue Cali

Upon Ian's FOP diagnosis in 1994, Amanda embarked as a mother on a tireless journey to fund FOP research, promote awareness and assist the IFOPA in many facets. Although, it is impossible to describe in this brief summary the magnitude of Amanda's extraordinary contributions, we hope to capture at least some of the essence of the love, compassion and devotion in her vision, commitment and extraordinary leadership.

The Cali family established the Ian Cali FOP Research Fund with its primary focus on supporting collaborative ventures between the FOP Lab and other centers of research excellence. This endowment, providing a reliable and essential stream of critical funding is an extraordinary, central aspect of the research effort at the FOP Lab.

Amanda demonstrated leadership and innovativeness as she created many first time events including the FOP Parent Meeting in Cranford NJ, the Adult FOP Meeting in Parsippany NJ, Planning for Today and the Pathway to the Future IFOPA Organizational Meeting, and the wonderful Mother's Retreats. Amanda was also instrumental in the inception of the LIFE Award Program and her leadership as co-chair of the Third and Fourth International Symposia was phenomenal.

Amanda provided outstanding service as an IFOPA director and as the first Board Chairman after Jeannie's retirement. Among her many initiatives, she provided important guidance and support in establishing the International President's Council. Amanda's promotion of opportunities for families from other countries to have FOP gatherings, events which in turn served to educate foreign-resident physicians, also provided FOP patients with the opportunity for a clinical evaluation by Dr. Fred Kaplan, a tremendous life changing experience. Amanda traveled the world in support of these meetings, provided crucial support and encouragement and gave her personal time by demonstrating tools for everyday independence in the Traveling Resource Center.

Amanda has given many press and media interviews to promote FOP awareness but one of the most memorable one for Jeannie is the South Africa's Carte Blanche interview which brought many to tears.

We are deeply grateful for her quiet and amazing generosity in providing much valued financial and organizational support on so many occasions over the years. Amanda's many initiatives over the years have all been examples of her untiring desire to help families cope, to change lives, and bring awareness about FOP. She is always thinking of and creating new ways to assist the IFOPA in moving forward. Amanda is an inspiration to many and is exemplified by her recent award as "Garden State Woman of the Year in Healthcare". Amanda is a warrior, an inspiration and a dear friend to all of the FOP Community. A sincere thank you from Jeannie and a heartfelt congratulations and appreciation from all in our FOP family.

Outstanding Community Involvement Award

The Weldon Family

In reviewing the Weldon family's many contributions and supportive activities for the IFOPA and the FOP community, we would like to recognize them for the scope and variety of their fundraising and awareness activities. As a start, of course, there is the establishment of the Weldon FOP Research Fund with its focus on the genetic causes of FOP and the development of safe treatment options. Such an endowment, providing a reliable and essential stream of critical funding, is recognized as an extraordinary, central aspect of the research effort at the FOP Lab and especially in support of the search for multigenerational FOP families. In addition, their extraordinary efforts at organizing events such as the annual golf tournaments and luncheons, dinner dances and celebrity boxing bouts, cocktail parties and comedy shows, and Friendraisers and recruiting Boston Marathon runners (to name only some!) are truly impressive. These events in turn also serve to promote FOP awareness as does the green bracelet campaign and the inclusion of information about FOP on the Weldon family business trucks.

Hillary Weldon has spearheaded numerous events such as the Capitol Hill Awareness (at which Whitney also spoke passionately about our cause), and has served as an amazing spokesperson for FOP awareness. It is also important to acknowledge Hillary's valuable leadership and pivotal involvement in the Patient Rare Disease Network for the USBJ Decade. Hillary also graciously co-hosted the First Mother's Retreat, providing an incredible opportunity for FOP moms to bond with each other.

We also wish to recognize Whitney's blossoming into an inspiring young lady with her personal example of courage and determination. Whitney's promotion of FOP awareness through her personal interviews with the press and media are admirable. In particular, Whitney provided a wonderful interview in the Bound by Hope video, and an eloquent presentation at the Sam Adams concert. We also congratulate her on winning the prestigious Steifel Award.

The extraordinary outreach of the Weldon family each year to bring FOP awareness through local media coverage via television and radio is amazing and we are deeply grateful for all that they have done for the FOP Community. They are all extraordinary people with a very special place in our hearts. Thank you!

Emerging Leader Award

Ashley Kurpiel

Ashley has a long list of remarkable list of accomplishments. She is an incredible role model and an amazing spokesperson for the FOP Community and the mission of the IFOPA. Ashley inspires and touches people's heart in a very special way. Her courage and zest for life encourages others to live life to the fullest.

Ashley's many speaking engagements have included traveling the country speaking at various FOP family fundraisers, local rotary clubs and her most recent speech at Starr's Mill High School Baccalaureate. Her presence of "I can do anything" and "life is good" leaves the audiences spellbound, in tears and in awe of how amazing she is.

Over the years, Ashley has been instrumental in promoting FOP awareness by the many press and media outreach she has done including; ABC News 20/20, Mystery Diagnosis, BBC The Skeleton Key, YouTube, Tyra Banks Show and others. Ashley also played an important role in representing FOP as a spokesperson at events, including Capital Hills Awareness Days.

Ashley's active involvement in the FOP Community provides hope, encouragement and comfort to everyone. She has a tremendous gift to inspire others and a warm, loving personality that draws people to her. Ashley has many friends in the FOP Community and her active participation on foonline and facebook is incredibly valuable.

Ashley has been involved with the IFOPA for many years and her list of accomplishments is extraordinary and vast. She provided support in any way possible; assisting with the Teen/Young Adult Meeting, Symposia, hosting fundraising events, including her most recent American 5K Run/Walk event, supporting International IFOPA Awareness Day and many other IFOPA sponsored events.

Ashley, we have seen you grow up from a child to an amazing talented woman. We are very proud of you and want thank you for all that you do for the FOP Community.

Outstanding International Leadership Award

Roger zum Felde

Roger's extraordinary leadership as the FOP e.V. – CEO of FOP Germany, the first international FOP organization, and his guidance as the IFOPA International President's Council representative for Germany exemplifies the amazing community network that we all represent.

His steadfast commitment to promote FOP awareness through personal interviews with the Press and other media such as YouTube videos and presentations at service clubs, such as Rotary and Mercedes-Benz Auto, is a remarkable testimony of his pledge to make a difference. Roger's wonderful personality shines brightly and provides an inspiration to others.

Roger's tremendous support in joining our team effort in fundraising for FOP research and the IFOPA brings us one step closer to our dream of a treatment and a cure for FOP.