

The IFOPA proudly presents to you a Legacy Member . . .  
Nancy (Whitmore) Sando - Founding Legacy Member  
by Gretchen Emmerich



Nancy was born on May 29th, 1959 in Detroit, Michigan. A few years later, she and her family moved to Fairfield, Connecticut where her father took a job as an Electrical Engineer. At age 5, Nancy was initially misdiagnosed with cancer when FOP began flaring in her back muscles. Lucky for her, Dr. Pack, the Oncologist from NYC who examined her noticed her toes and correctly diagnosed Nancy with FOP. From that point, Nancy was followed by the Pediatric Child Disability Clinic at Yale where she recalls that she felt like a human guinea pig. At one point, her health care team attempted to “elongate tendons” on her right arm with surgery. Unfortunately for Nancy, this was before the knowledge that trauma would induce FOP flare-ups. In 1976 Nancy’s family moved to Petoskey, Michigan.



Nancy today enjoys Kid’s Ministry at her Church.

Nancy recalls her grade school years (back in the mid 1960’s) how children with disabilities were placed in separate classrooms from the “regular” kids. Nancy’s mother however, would have none of that, and advocated for her to be able to remain in a regular classroom. It worked. Gym classes were off limits for Nancy due to the physical liability yet Nancy was able to do office work during that period, or was chosen to be the score keeper during more rigorous physical activities.

The middle school years were tough for Nancy, but High School was a turning point. Academically, Nancy excelled and one teacher in particular saw Nancy’s potential asking her to be the proprietor of the greenhouse on the school property. Nancy’s self-worth soared with the responsibility given to her, and to this day she still loves plants. At one point, Nancy had over 130 plants in her bedroom! In Nancy’s early life, another self-esteem builder centered on children. She became the “go to” babysitter in her neighborhood throughout her high school years and was usually booked out for several weeks in advance!



Nancy, Aimee (niece), Jay (bro-n-law), Sharon (sister)

**When asked who her greatest support was during times of sickness and flare-ups Nancy quickly responded with this list of special people:**

**Her sister Sharon-** Sharon, who is two years older than Nancy, used to rub her back as a child. The two sisters used to make names for the different lumps and bumps on her back calling one Mt. Rushmore and another Mt. Washington. Nancy laughs that as they studied US geography they used her back as the topography diagram!

**Nancy’s Father, John-** He would always help Nancy find new ways to do the things that were no longer possible for her to do.

**Helen Keller-** Helen made a huge impact on Nancy, especially how Helen overcame different obstacles. Her story inspired Nancy.

**Margaret Jean Jones-** Another key player and support for Nancy was a fellow FOPer named Mary Jean who Nancy met in her 20's. Although they never met face to face, the two women were pen pals. Nancy was always inspired by Margaret Jean's positive outlook on life even though she was bedridden for most of it.

Nancy's faith in God has also sustained her through the tough times. In Nancy's words, she knows that she was given a unique life and chooses to live it according to God's plan not her own. She feels blessed and has always been provided with everything she needs.



Andy and Nancy Sando

Nancy feels privileged to be one of the founding members of the IFOPA. It was while Nancy was in Junior college in 1982, that she and Margaret Jean began writing each other. Shortly after that Nancy was contacted by Jeannie Peeper through the mail. Nancy recalls "It was the greatest thing to know that Jeannie had the vision and desire to contact us. We instantly had a very special bond. It felt like I was coming home. Kind of like how an adopted person must feel when they meet their biological parents."

In 1988 Nancy met Andy Sando who also had FOP. Nancy laughs as she recalled that he was a city boy and she was a country girl. "We fell in love and were married in 1988," says Nancy. It was a match made in heaven. They shared their love of family, their faith, and being positive influences on the world around them. There never seemed to be "no" in their vocabulary. Andy passed away in 2003, and although she misses him terribly, Nancy's memory banks are filled to the brim of 14 joy filled years with Andy.

Nancy is quite well known in Petoskey, Michigan. She walks her 2 dogs every day, and is an avid award winning knitter. Nancy lectures at the North Central Michigan College twice a year, has been featured in numerous newspaper articles, and is very involved in her church serving in children's ministry, publishing the newsletter, maintaining their website, coordinator of the e-prayer chain and leads small groups where she has numerous friends. Nancy employs three full time attendants, Jessica, Elke and Sheryl, and four part time aides, Jennifer, Pat, Kathy & Heather, who are more like family to her than care givers.



Nancy with her family of care givers