

The IFOPA proudly presents to you a Legacy Member . . .
Shay Williams – Founding Legacy Member
Interview by Gretchen Emmerich



Front Shay Williams, Back Kish Castillo,
Mackinzie Castillo, photo taken after
Mackinzie's High School Graduation

When did you join the IFOPA? January 1, 1988

How did you find out about the IFOPA? My mom, Susan Williams, told me about it.



Shay Williams on his 19th Birthday

What do you remember about the IFOPA when it started? When I was 14 we went to NIH and met Dr. Zasloff. So at that point I knew there were others with the condition. Five years later the IFOPA was formed. It was nice to know there was an organization out there supporting this very rare condition.

Please share your experiences since then...including any hobbies, pets, favorite foods, etc. Well since joining the IFOPA I graduated from UC Berkeley with a B.S. in Business Administration and graduated from California State East Bay with a Masters in Public Administration. I have been living on my own all that time. I have personal care attendants that help with daily tasks. I work for the Educational Testing Service scoring the California High School Exit Exam (CAHSEE), Early Assessment Program (EAP), and English Placement Test (EPT). The scoring is done all online. I watch a lot of sports on television and play video games. I have attended Cal football home games for 27

years. I went to a lot of concerts when I was younger. Now I seem to go to a lot of comedy shows.

Please share a bit of your childhood memories and any information about when you were diagnosed. I had heart surgery when I was three and half years old to fix what was called a coarctation of the aorta. They were going to wait until I was older but a doctor heard a heart murmur and decided it needed to be done sooner than later. After the surgery my back, shoulders, and neck froze shortly thereafter and I had bumps on my head that they thought were neurofibromatosis so they cut them off. Luckily they never grew back. Eventually they figured out because of my big toes that it was myositis ossificans progressiva which later became known as FOP. I was diagnosed in 1973. When I was young I did just about everything other kids did. Yes, I had limitations, but I still was able to ride bikes, run around, and play sports with my friends. I would fall down and get back up. As my FOP progressed more and more of my body was affected- but I would do things until I couldn't do them anymore. I am glad I got to experience being a kid that way I didn't feel like I missed out. Sure my mom was scared every time I went out to play but she realized that

being a kid was an important part of life. The condition keeps progressing but I had a great childhood and experienced many things including climbing the steps of a waterfall in Yosemite.



Photo above taken after Mackinzie's Middle School Graduation, left to right: Mackinzie Castillo, Susan Williams, and Shay Williams.

advocating for me. She helped set up the LIFE committee. Unfortunately she died a few years ago. I have a girlfriend, Kish Castillo, who has a son, Mackinzie. I have helped raise him and Mackinzie is presently in college.

What is your hope for the IFOPA's future? My hope for the IFOPA is that they continue to do research but also focus some on the people that are living with it (FOP) and the difficulties involved. Research is important because a cure would be great. Part of the funding should be put towards helping people and families live with the everyday difficulties of FOP.

Where have you lived since becoming part of the IFOPA Family? I have lived in Berkeley since joining the IFOPA. I moved here for school and decided I liked the city because it is very accessible. I have lived in Berkeley ever since.

What do you want us to know about your family? My mom, Susan Williams, was a big part of my life and was involved in the IFOPA. She was a board member and helped many within the FOP community with her knowledge of all the things she learned advocating for me. Unfortunately she died a few years ago. I have a girlfriend, Kish Castillo, who has a son, Mackinzie. I have helped raise him and Mackinzie is presently in college.