Spencer Man had an infectious smile. Adults were so taken by his tenacious spirit they named their own children after him. Spencer in his short life of fourteen years left a legacy we can learn from that take most people decades to accomplish.

Spencer was born in Oklahoma City, OK in 1976 into the Man family where he was raised with two older brothers, Chris and Derek Man. At birth it was noted that Spencer had malformed great toes but it didn't prepare the family to what lay ahead. After Spencer received his infant immunizations during his first few years of life he began having mysterious swellings or lesions. Once the diagnosis of FOP was made, his parents, Michael and Carol, travelled to visit Dr. Zasloff at the National Institutes of Health, the predecessor to Dr. Kaplan & PA research team. Dr. Zasloff introduced the Man family to the newly formed IFOPA. They readily jumped on board and became active members by attending events and organizing fundraisers. During these events Spencer grew to admire and cherish his friendship with Dr. Fred (Kaplan). They spent many hours on the phone sharing stories, laughs and genuine affection.

Because Spencer’s physical limitations came at such an early age he forged ahead enjoying life to its fullest. He excelled in most anything he put his mind to. This included swimming and high diving (much to his dad’s surprise!) and other sports that he found rewarding. Some of Spencer’s pastimes included watching TV & movies, particularly the Indiana Jones series starring Harrison Ford. There were many times the Mans would go on fishing trips where Spencer was driven to catch as many fish as possible…not necessarily the biggest but quantity prevailed! Spencer marveled at the super heroes of his time the likes of Hulk Hogan. Relaxing for Spencer meant challenging his granddad to a friendly game of cards or singing a song that he liked. He only needed to hear the song lyrics once or twice before committing it to memory.

Spencer’s life came to an end in 1991. His spirit lives in everyone he touched in his fourteen years. He was rare like the rest of those diagnosed with FOP. What made Spencer rarer was his own belief that achieving success was possible in any situation. He overcame the obstacles in his life with the support of his family, the grace of his God and the enduring love that surrounded him.

A few years after his death, A Spencer Man Foundation (1994-2012) was created to further FOP research and education. His family remains active in contributing time, resources and knowledge so that other families find hope and encouragement, especially those that are new to the organization and new to fundraising for the cause. The IFOPA is grateful to the Man family as they continue to rally until our mission is complete.