

The FSH Society honors the memory of **Stephen J. Jacobsen, Karen L. Johnsen and William T. “Billy” Michael**, three dear friends of the Society and many of its members. They lived fully with FSHD, helped countless others understand, accept and cope with FSHD, and were devoted to solving its mystery. They lived with grace, wisdom, kindness and courage, and used their experience of having FSHD to help others, both by specific contributions and by personal example.

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Stephen J. Jacobsen co-founded the FSH Society in 1991, serving as its Chairman of the Board from its inception until his death. A pioneer of FSHD research, Steve methodically, creatively and patiently researched his own disease. At a time when few others shared his belief, Steve was convinced that the puzzle of FSHD could be solved and FSHD eventually treated and cured. Steve was an optimist who never wavered in this conviction and an advocate who believed that FSHD is unique and merits specialized research. FSHD research and the FSH Society wouldn't be where they are today without him. He earned a Ph.D. in biochemistry and virology from Brigham Young University and did post-doctorate work at Harvard University's Massachusetts General Hospital. Steve died on January 21, 2006 in San Diego and was survived by his wife, Jan; sons Jared and Nathan; daughters Laurel and Natasha; and son-in-law Kevin.

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Karen L. Johnsen was a founding member of the FSH Society and served as a Board member from the Society's inception until her death. Karen was director of Beltsville Agriculture Day Care, Miss Wheelchair Maryland two years in a row, and an effective disability rights advocate who was present at the signing of the Americans with Disabilities Act. She testified before Congress many times advocating disability rights and funding for muscular dystrophy research. Together with her husband Dean, she formed one of the first support groups for people with FSHD. Through the support group, phone and email, Karen touched the lives of hundreds of people with FSHD in the United States and abroad, giving them hope, love and counsel. Karen died on December 14, 2004 in Maryland and was survived by her husband, Dean; son, Jeremy; and mother, Doris Olds Eck. Mrs. Olds Eck has established the “Karen's Dream for a Cure” research fund at the FSH Society.

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William T. “Billy” Michael attended the initial meetings that led to the formation of the FSH Society. Billy was diagnosed with infantile FSHD at age four, after having had weakness for several years, and, although he was able to participate in Little League as a young boy, he needed to use a wheelchair by age 10. The severity of his FSHD tested Billy's courage, faith, ability to love, maturity, resourcefulness and wisdom early in life and in a way that few people ever are tested. He loved life and loved his family, who were devoted to him and ensured that he continued to live with them instead of an institution. Billy was strong, selfless, uncomplaining, compassionate and brave. He was accomplished in computers, an avid collector of sports and other memorabilia, and interested in current events. Billy's father, Bill, is Treasurer and a Board member of the FSH Society, serving in both roles since the Society's inception. Billy died at age 35 on December 7, 2004 in West Bridgewater, Massachusetts, and was survived by his father, Bill; mother, Ginny; sister, Beth; both grandmothers and a very loving supportive extended family.