

The IFOPA proudly presents to you a Legacy Member . . .
Louis (Lou) Cantwell – Founding Legacy Member
by Victoria Mandracken



Louis in front with his siblings from left to right:
Alisa, Fred and Lynn



Louis Cantwell standing
behind his mother
Jacqueline in 1985

“I’ve always kept that letter. I know right where it is.”

Yes, 25 years later, Jacqueline Cantwell, mother of Louis Cantwell remembers the day that Jeannie Peeper’s pen pal letter arrived in their mailbox in Sidney Mines, Nova Scotia, Canada.

Louis was 23 years old the day that letter arrived in 1988. Jacqueline and Louis felt a special bond to this stranger who reached out to them, and have always been grateful to Jeannie for doing so.

Louis was born on November 2nd in 1965. At birth he had the usual crooked toes that all FOP’ers have. It wasn’t until he was five years old that he developed a bump on his head. Jacqueline drove the four hours over to Halifax, Nova Scotia, where a friend of hers, a Pathologist, accurately gave the diagnosis as FOP. Unfortunately the next four to five years were not quite so smooth. Jacqueline recalls traveling the difficult road of going from specialist to specialist. They travelled many miles, far from their remote town in the upper part of Nova Scotia. Luckily, a local Orthopaedic doctor referred them to Johns Hopkins in Baltimore, Maryland, USA. At this medical facility in 1975, Louis was examined by Dr. Victor McKusick and Dr. Michael Zasloff. Louis was 10 years old at that time when his diagnosis was definitely confirmed. If it hadn’t been for that meeting with the doctors, Jeannie would not have received information about Louis from Dr. Zasloff.



Louis - 1970 at the
age of five

Louis is a middle child, born to Jacqueline and Louis Cantwell. He has an older brother, Fred who lives in the same town, and an older sister Alisa who lives nearby in Sydney, Nova Scotia. His younger sister Lynn lives in Hamilton, Ontario. Louis’ father died of cancer, at the age of 56, the same year that Jeannie’s letter arrived at the Cantwell home. It is fortunate that Louis’ mom had a medical career as an operating room Registered Nurse for 35 years, for it served her well since she was his main caregiver up until last year. Presently, Louis has a team of aides that come and help him with his care.

Jacqueline wanted Louis to have as normal a childhood as possible and he was very active. Louis did just about everything, and was quite mobile and able to walk. As a young boy, Louis loved playing hockey. He was so happy to get his driver’s license at the age 16! Louis loved driving his car and it wasn’t until a rear end collision that his FOP flared to the point that he could no longer drive.



Louis strolling in the park

Today, Louis enjoys visits from his friends and listening to a range of music from Rock to Country. He also loves playing games on his computer.