



One Man's Journey.

Jerry discusses what it was like to be treated for hemophilia in the 1960s in Nevada and how much treatment options have improved for those with inherited bleeding disorders.

Jerry, diagnosed with hemophilia at about 6 months of age, is shown here during a trip to Hawaii. (above photo)

The knowledge and treatment of Hemophilia has changed dramatically in the last fifty years ... thankfully, for the better.

When Jerry was diagnosed with Hemophilia in 1967, he had to travel to Palo Alto, California where medical experts were capable of making that determination. Once diagnosed, he could get treatment in Las Vegas. He is the only person in his entire family with Hemophilia.

When he was five years old, treating a bleed required a trip to the hospital. His mother had to call ahead to the hospital and let them know they had to start thawing out the Cryo, (Cryoprecipitate) used to treat his bleed.

A couple years later, Jerry's mother learned how to infuse Jerry herself at home.

"This still took time, not six hours like with Cryo, but at least an hour. It had to be mixed very slowly and was infused using a drip bag that we hung from our chandelier over the dining room table."

Jerry had to lay on a foam bed on the dining room table in order to be infused with this home treatment. As the years went on, the medicine (also called factor) improved immensely and now Jerry can mix and infuse on his own, "and be done in five minutes."

Growing up, Jerry wasn't allowed to ride a bike until he was eight years old, wasn't allowed to participate in any sports except swimming and often had to sit out for P.E. class in school. He also wasn't allowed to take shop class or work with tools because his family feared he would receive an injury. Many of these things made him feel "like the odd man out." The only activity he was allowed to be in was music class.



This photo shows Jerry soon after he learned to self-infuse at home. Over the years, the process of self-infusion has become simpler and quicker.

"I was allowed to be in band, marching band, as well as jazz band."

As he got older and started working, he was challenged in making sure he had medical insurance to help pay for infusion treatments.

"I lost three jobs due to my Hemophilia. I was on a group plan and when the rates went up and they looked at the reasons why, it was discovered that I alone was responsible for a million dollars of claims a year, so they came up with a bogus reason and they let me go."

Much more is known about Hemophilia today than when Jerry was diagnosed. At the age of eight, Jerry had to undergo his first surgery, a synovectomy, which is the removal of the synovial membrane of a joint in his knee, and had to travel from Las Vegas to Los Angeles to have the surgery done. When he was older, he also had to have an ankle fusion, both his elbow joints replaced, and his knee joint replaced. Jerry believes that "the medication today and treatment plans given to the new generation of young Hemophilia kids means they will not likely ever have to have any of this. As long as they follow their



treatment plan, joint replacements and joint fusions could be a thing of the past for these kids.”

Even with these challenges in his life, Jerry remains positive and educates people along the way about Hemophilia. “I’ve never been shy about letting people know about my Hemophilia. Most don’t know anything or very little about Hemophilia, so I was always educating as I went along.” He wants people to know that, “We are not contagious. We don’t die if we get cut. We are very aware of our condition and act accordingly so you don’t have to walk around us with kid gloves on.”

The Nevada Chapter of the National Hemophilia Foundation offers a number of support groups, including groups for families of newly diagnosed children. For additional information on support groups or any other services and benefits provided by NHF Nevada, please call (702) 564-4368 or email Anne at amcguire@hemophilia.org