A rare disease diagnosis is a significant life event for patients and has the potential to alter patients’ sense of security and elicits feelings of vulnerability and isolation (Haylock, 2010). Rare disease communities have formed around the world to support patients, healthcare providers, and researchers (Colledge & Solly, 2012). Patients seek participation in a rare disease community for many reasons, including increased knowledge, quality of life, holistic wellness, connection, and collaboration with other patients, as well as expert healthcare providers. Researchers and healthcare providers seek participation in rare disease communities because of the limited number of researchers dedicated to working with rare diseases (Aymé, Kole, & Graft, 2008; Budych, Helms, & Schultz, 2012; Colledge & Solly, 2012; Grever & Lozanski, 2011; Holzman, 2009; Huyard, 2009; Patsos, 2001; Schieppati, Henter, Daina, & Aperia, 2008; Walker, 2013). Key members of the rare disease community include the National Organization of Rare Disorders (NORD), established in the United States, and the European Union Committee of Experts on Rare Diseases. The primary mission of NORD includes promoting translational research and advocacy, and funding the search for cures for rare disease. NORD (2013) defines rare disease in the United States as affecting less than 200,000 individuals within the total population. The European Union Committee of Experts on Rare Diseases is committed to identifying rare disease centers of expertise, as well as establishing a collaborative network for information sharing (Aymé & Rodwell, 2014; Humphreys, 2012).

Patients with a rare disease face challenges in terms of treatment. Hairy cell leukemia (HCL) is a rare adult B-cell lymphocytic