



**STR<sup>NGER</sup> Than SARC<sup>ID</sup>SIS**

**Frank Rivera**

*President*

Frank was diagnosed with **sarcoidosis** in 2011 after being misdiagnosed with lung cancer for 7 years prior. He also lives with IBS, Sjögren's Syndrome, and Parkinson's Disease. He has become disabled as a result of these conditions, and was told in 2018 that his condition was terminal. Still, he remains incredibly active in the Sarcoidosis and Rare Disease communities.

In order to support others living with this disease, Frank founded Sarcoidosis of Long Island in 2012. Since then, he has been an active local, state and federal advocate for Sarcoidosis. Frank strives to raise awareness nationally, specifically focusing on the government sector. He has represented the Rare Disease and Sarcoidosis communities as a speaker at two Congressional briefings, and appeared on NBC Nightly News in 2018 to discuss "Right to Try" legislation. He shares his experience through his personal blog, [My Life As a Rare Disease Patient](#), and is the author of two books, *Walking in Silent Pain* and *I Have Sarcoidosis But It Doesn't Have Me*.

Frank is a National Ambassador for Foundation for Sarcoidosis Research, a Global Genes RARE Foundation Alliance Member & Advocate, and a Working Group Member for EveryLife Foundation. In 2016, Frank partnered with Global Genes to raise awareness about over 7000 rare diseases including sarcoidosis; in recognition of his efforts, Suffolk County and the Town of Brookhaven officially declared October 15 A Day for Rare Diseases. Frank also organized RareNY, to raise awareness about these rare diseases in the State of New York. He was named Rare Undiagnosed Genetic Disease (RUGD) Ambassador for Illumina in October 2017, and "Person of the Year" in Brookhaven Town.

*Frank lives in Long Island, NY with his wife Diana and daughter Savannah. Savannah's beautiful singing voice always calms the sarcoidosis storm, and Diana's love and support keep him going strong.*

