

Greg Benton

The Myelin Project



Greg's brother is affected by adrenomyeloneuropathy (AMN).

His uncle Richard was diagnosed with AMN in 1994 at which point his mother tested positive as a carrier. Consequently, he and his brothers were tested and unfortunately his eldest brother Mike was diagnosed with Adrenoleukodystrophy (ALD), later developing the adult form, AMN. Richard passed away in 2000. His brother Mike is currently in a wheelchair and the disease is continuing to

progress.

In 2010, Greg became involved in The Myelin Project helping with administration, development, and marketing for the organization. In 2014, they had one of our biggest successes when California Governor Jerry Brown signed a bill into law requiring all newborns in CA to be screened for ALD, to be enacted once the U.S. Secretary of Health adds ALD to the Recommended Uniform Screening Panel.

Greg attended the first in-person LCN meeting in May 2015 and was able to take part in its vision and goals. The LCN concept is something he believes to be an incredible idea that he and the organization would love to support completely.

Greg says he would love to see Leukodystrophy Care Centers in major hospitals throughout the U.S. that can serve as a "one-stop shop" for comprehensive leukodystrophy care.

Greg has a Bachelor's from the University of San Francisco and his professional experience is in Development, Administration, and Marketing. He currently resides in San Francisco, California.