



# Bright Light Foundation

## Ben Sargent

2011 BLF Recipient



“There are only two ways to live your life. One is as though nothing is a miracle. The other is as though everything is a miracle.” -Albert Einstein

Ben Sargent is a smart and talkative 6-year-old boy who is the light and joy of our family. He started fighting for his life before he got a chance to take his first breath.

With no explanation, Ben’s mother experienced contractions months before little Ben was ready to join the world. When Ben was finally old enough to join our family, the joy of his arrival was

quickly replaced with the thought that his time with us would be tragically short. Ben, though, proved them all wrong.

Ben was born with an unrecognized condition thought to be fatal within four months. Doctors took blood samples, tissue samples and finally a muscle biopsy, all in the first two months of life. He left the hospital with oxygen, and doctors recommended we move from Colorado to a city at sea level. After a move to Houston to stay in the oil and natural gas industry, we celebrated each day with Ben – not knowing how many we’d get.

Finally, Ben was diagnosed with Central Cord Disease, a muscular myopathy disease that causes problems with the tone and contraction of skeletal muscles. It’s commonly caused by defects in a gene that carries instructions for a molecular “gate” that releases calcium from inside muscle cells. Its onset is congenital, and is described by poor muscle tone and persistent muscle weakness in infants, late development of motor skills, skeletal deformities including joint dislocations and scoliosis and susceptibility to malignant hyperthermia, a dangerous adverse reaction to anesthesia. The disease has slow or no progression.

Ben faces a life of muscular problems as he grows. If we don’t help Ben surgically, his lack of muscle tone will continue to cause his own weight to put pressure on his lungs and heart – potentially leading to life-threatening complications. Every nine months, these surgeries add rods and stretch them afterward to somewhat correct the scoliosis to support his growth. Also, corrective orthopedic surgery will help his feet contractures to allow him to use a stander.

Ben is a beautiful, loving little boy with curly dark hair and a great spirit who will always depend on us for his day-to-day living. Ben takes his nutrition through a feeding tube. He does not stand, crawl, roll over