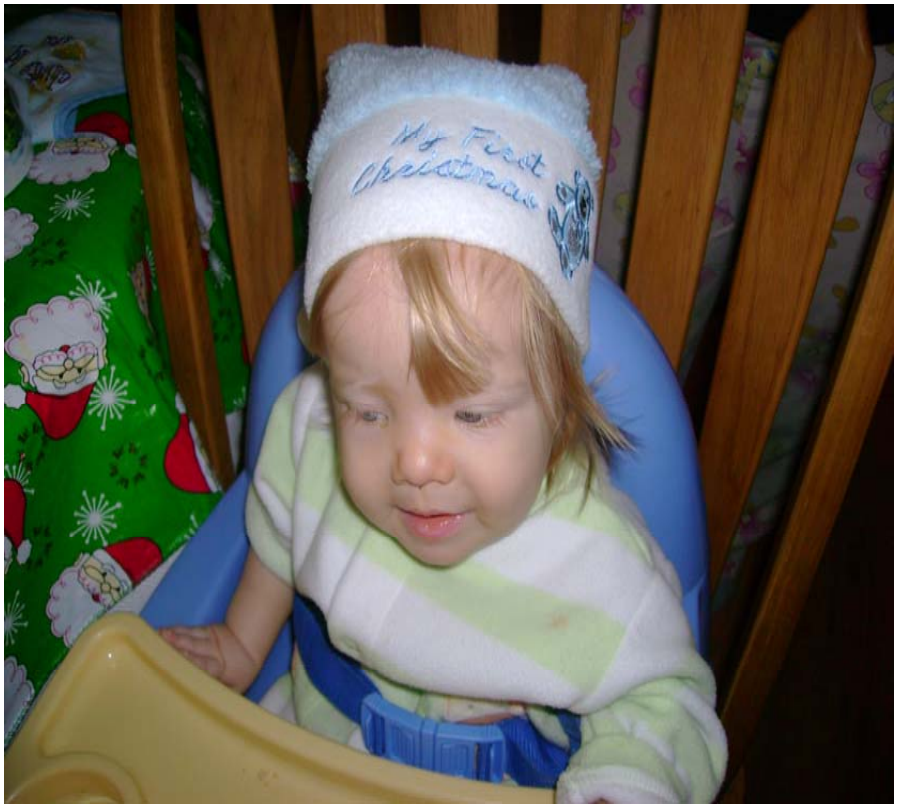
Damien Giammarco

Damien Giammarco was born on May 19th 2009, with a rare genetic disorder called Distal Arthrogryposis and Freeman Sheldon Syndrome. He has bilateral clubfeet and very low muscle tone in his upper Body. Throughout our sons short life he has been through 11 different Specialists, 3 different therapists and more procedures and test then his age. When Damien was born the Doctors told us he wasn't gaining weight or growing the way normal children should be. He was labeled as failure to thrive and referred to a gastroenterologist. From there we were sent to a feeding specialist where we found out Damien could not suck and needed special bottles.

Distal Arthrogryposis and Freeman Sheldon Syndrome.

We almost lost Damien 3 times in his short life. The first was when Damien was 4 months old. He went in for a routine biopsy to rule out a condition. He went through the biopsy with flying colors and was sent home. 4 hours later he was rushed back to the hospital and admitted due to blood loss. He was given two units of blood and released two days later. The second was 3 days after he got home he was once again rushed back to the hospital. This time he was admitted for 5 days.



After being home for about a month Damien went for an MRI of his spine and had to be put under anesthesia. He came through fine until an hour after we got home when he spiked a fever of 104 and had labored breathing. Once again he was back in the hospital. Thankfully his fever came down and he was sent home.

Recently Damien saw a hematologist that determined he has a platelet aggregation dysfunction and Von Wille Brands disease. Both these factors now make any further procedures, tests or any kind of trauma cause serious problems or death. Our son may seem like a happy baby, but his problems are below the surface and not even our friends and family know the extent of his disorder.

Despite his problems we are thankful the milestones he has achieved and the joy he brings to our lives every day