My name is Allegra, but everyone calls me Allie. I recently moved to Texas, and I am married to my high school sweetheart. Together we have three amazing children and up until recently I've been a stay-at-home mom since my youngest was born in 2018 (prior to that I worked in 911 communications).

Histiocytosis became a part of my life in July of 2019 when my youngest child, Hudson, was diagnosed with Rosai Dorfman disease (RDD) at only eight months old after having surgery to remove an enlarged lymph in his groin that had been enlarged for a couple months with no answers as to what was causing it to enlarge. What we thought would be a routine removal surgery was complicated due to the first node being very close to impacting his femoral artery. We were fortunate to have an amazing surgeon who worked very cautiously to remove the node without hitting the artery or causing any nerve damage. Several more, smaller enlarged nodes were found during the first surgery but since the pathologist was unable to determine what they were, the surgeon did not remove any more at that time.

Eight long days after Hudson's surgery we received his Histio diagnosis and Hudson was referred to the local pediatric oncology office. Unfortunately, the doctors in the office were not familiar with RDD and we hit several roadblocks along the way in terms of his oncologist listening to our concerns and their unwillingness to work with Texas Children's Hospital Histio unit to make sure Hudson was receiving the best care. After a struggle with Hudson's oncology office to have more testing done when he presented with more enlarged, painful lymph nodes in his groin (which led to Hudson needing another surgery at 13 months old), my husband and decided we no longer trusted this office with Hudson's care and decided it was time to consider relocating to Texas so that Hudson could be under the care of doctors that had experience with his disease.

It took us almost two years, but we made our move to Texas in November of 2021 and are so glad we did! Hudson is currently under that care of two different specialists in the oncology and hematology department, but I am happy to report that he has not needed any other surgeries and his RDD has not progressed!

When we received Hudson's rare disease diagnosis, I knew immediately that our lives would never be the same. I instantly felt compelled to fight for a better future for my son and the only way I knew how was by helping to raise awareness for Histiocytosis and to participate in fundraisers that would aid in the fight against Histiocytosis.

Hudson's diagnosis came just two months before Histiocytosis Awareness month so with no time to spare, I got to work immediately, making awareness shirts, registering for events to help raise money in the fight against Histio, and sharing all I could about Histio and why it was such an important cause to contribute towards.

Through my fundraising and awareness efforts, I became more involved with the Histiocytosis Association and began organizing my own fundraisers because I wanted to continue to help make a difference in the Histio community. Then, in early 2022, I was given a chance to take my involvement a step further when I was presented with an opportunity to become an ambassador for the Histiocytosis Association (which I gladly accepted.)

Over the last three years since Hudson was diagnosed, my focus in life has been about making sure Histio warriors have a better and brighter tomorrow. Hudson's Histiocytosis diagnosis changed my

entire world in the blink of an eye because the moment I heard those terrifying words, I knew I would do whatever it took to make sure my son had the best care and treatments available, no matter what. In this mission, I quickly realized that I would not only be fighting for my son, but for all those affected by Histiocytosis since it is so rare and there is so much more awareness, education, and research that needs to be done and we can't do it alone.

When Hudson was diagnosed, I felt very scared and alone but then I found the Histiocytosis Association and for the first time I felt a sense of hope. Although I hate that my son's reality is that he is a rare disease warrior, I am so grateful that the Histio community is such a strong one and I am happy to be part of such a passionate team that continues to fight for a cure for Histiocytosis.

In my new role with Histiocytosis Association, I hope to help expand our reach, not only within the Histio community, but to communities across the nation. I am excited to be able to use my personal experience and firsthand knowledge with Histio to lend a helping hand for others that are interested in fundraising and raising awareness so that one day, we might find a cure for Histiocytosis.