

ALAMO FAMILY LEADS SUPPORT FOR THOSE DIAGNOSED WITH NEPHROTIC SYNDROME

By Fran Miller



The lives of the Callaway family of Alamo changed forever when their son was diagnosed at age six with Nephrotic Syndrome (NS). Mom Andi Callaway will never forget the day when her healthy and eager kindergartener woke up with swollen eyes, a symptom of the rare and serious auto-immune disease that causes the kidneys to shut down.

“The next year brought so many dark days,” says Andi. “There was so much medication, so many appointments, and so many disappointments. Over the next seven years of our journey, and since, we have found a way to manage as any family would; however, our whole family is forever changed by this disease. It has been extremely tough on all of us. Our days are filled with doctor appointments, labs, missed events, missed school, and upwards of 20 pills a day for our son, all which have extreme side effects, both immediate and long term, physical and emotional.”

There is no known cause or cure for NS. Treatments are limited and consist primarily of

transplant and cancer medications, all of which have extreme and often permanent side effects. Many patients are children who spend the majority of their days in and out of the doctor's office and hospital trying to find a treatment that keeps them in remission while trying to manage the side effects. Yet rather than wallowing in the bleak diagnosis, Andi and her husband Tucker took action. After realizing there was no support for those facing a diagnosis of NS, she started the Nephrotic Syndrome Foundation (NSF) in 2017 with the hope that no mother, father, or child should ever have to travel the NS journey alone.

“No one can change the fact that these kids have been diagnosed with this tough disease,” says Andi. “However, together, we CAN change their lives. We can offer support, love, education and community, and we can ensure that neither they, nor their parents or siblings, have to travel this road alone. We have BIG plans to help children diagnosed with this disease.”



NSF offers seven programs in support of families with a child diagnosed with Nephrotic Syndrome including Backpacks of Hope (an assemblage and distribution of medical supplies and comfort items for 100 NS patients), Camp NSF, Direct Patient Grants, Summer Splash Campaign, and more. In addition, NSF is expanding their Finding Health Speaker and Peer Group Series to a virtual platform, allowing them to reach patients all across the United States and internationally in a new

and accessible format. Their first two sessions featured collaboration with Mindful Life Project on the topic of mindfulness. NSF is also launching a Mentor Team program, founded by a group of older patients in the journey who have come together with NSF to offer mentor connections and community programming to younger patients dealing with Nephrotic Syndrome. Additionally, the foundation launched Team NSF, a volunteer effort to support these programs and NSF's growing patient population. Made up of dedicated mothers and daughters, 6th-12th grade, Team NSF hosts monthly meetings, provides unique leadership opportunities for these young women, and fosters a community of compassion and connection to others.

“We are grateful to those who helped us get to this point,” says Andi, who, prior to founding NSF, held a career in finance and public accounting. She also served in 2011 as chairman of another local non-profit, Buena Vista Auxiliary, helping to prepare her for her work in establishing NSF. “Our community has been incredibly supportive, helping us raise more than \$1,000,000 since we started. Because of this, we were able to establish a formal avenue for direct support for those battling NS.”

To learn more about Nephrotic Syndrome, the foundation's various programs such as Summer Splash 2020, the Backpacks of Hope assemblage, or donation in support of these impactful programs, please visit www.nephroticsyndromefoundation.org.

