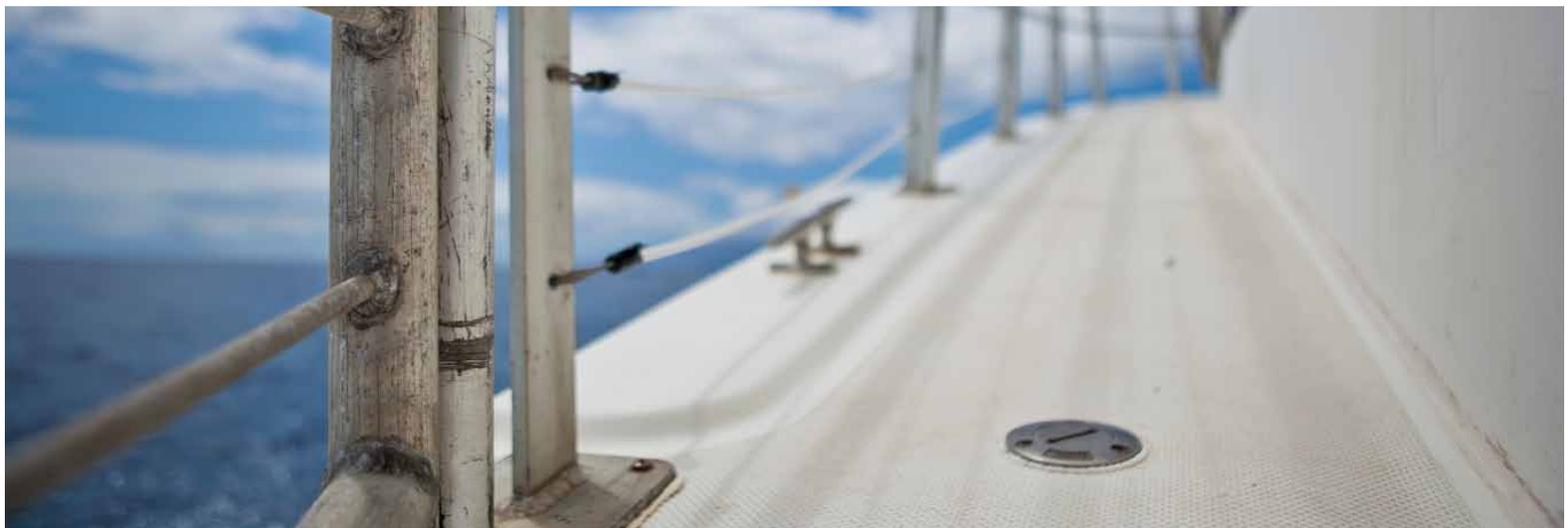


THE LEGACY OF A WARRIOR

Writer Amanda Christmann Larson



Miracles. Gifts are granted to us every day. The air we breathe, the food we have such easy access to, the simple pleasure of being able to move about in the world, unobstructed and able-bodied. It's easy to take these gifts for granted, forgetting them amidst the hustle and bustle throughout the day. That's why sometimes life sends us little reminders: reminders to love each other, care for each other, and to never forget the miracles in our lives.

Sometimes those reminders – angels of sorts, if you will – come in the form of little boys with big brown eyes and a shock of dark brown hair.

Wylder James Laffoon was born May 15, 2009. He was a beautiful, perfect baby boy, and his parents Steven and Shannon were the standard variety doting first-time parents. They were over the moon with happiness, and they held dreams of soccer games and sailing trips.

Their bliss lasted just one month before the first warning sign appeared. Wylder developed terrible reflux. Three months later, tests showed his liver enzymes were elevated, but doctors believed Wylder had a virus. At seven months old, upon his parents' insistence, Wylder's doctors performed a liver biopsy.

"Our doctors thought we were crazy," Steven said. "They kept telling us it was viral, but we wanted to know if it was something more. We felt like, if we could get a diagnosis, we could do something to help before damage was done."

January 7, 2010, Steven and Shannon met their pediatrician, Dr. Gerlach, at a geneticist's office to discuss the findings. When they arrived, both doctors were in suits, and the young couple knew something serious was happening.

It isn't difficult to imagine what it feels like to get the earth-shattering news that your child is going to die.



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Perhaps that's why so many of us avoid hearing stories like the Laffoons'. It's too close to home. It really could happen, and no one wants to entertain that possibility.

Steven, who had documented the entire medical journey up to that point to make sure he had the tools he needed to "fix" it, brought a small recorder that day, not knowing he'd record the pained crack in the doctor's voice when he dealt the initial blow, or the sobs of he and Shannon as their world was turned upside down. In a matter of moments, the diagnosis and prognosis grew more and more grim.

Wylder was born with a very rare genetic abnormality called Niemann-Pick disorder. Worse to hear that fateful January day was that Wylder has the most aggressive form of Niemann-Pick, Type A (NPA).

Classified as a lysosomal storage disease, NPA affected Wylder's body's ability to metabolize a fat, called sphingomyelin, produced by every cell in the body. Wylder did not make the enzyme needed to break that fat down into energy, so it accumulated in his cells, eventually killing them. The disease had caused severe brain damage by the time he was a year old.

When we first met Wylder in early 2012, there were only five children alive in the world with NPA, and about as many doctors and researchers who understood the disease. At any given time, as children pass and new babies are diagnosed, five seems to be the average number of young NPA patients. Niemann Pick Type A is one of more than 50 identified lysosomal storage diseases.

With his parents valiantly fighting for answers, poring over stacks of research, Wylder's condition continued to deteriorate. The pair became over-the-counter neuro-scientists, nurses and advocates, pushing the envelope on research and treatment for Wylder by trying all that Western and Eastern medicine had to offer. They flew around the country, speaking to scientists, foundations, drug companies and the FDA. They did everything they could to find a cure or a treatment, but time was not on their side.

As their network grew and glimmers of optimism were on the horizon, they realized that the time would come when their fight would no longer be for Wylder, but for others.

On July 20, 2012 at 5:15 a.m., three-year-old Wylder's time here on earth came to an end. He left peacefully, snuggled in bed with his parents, in his own way, winning his battle with Niemann Pick A, the disease that stole his body, but couldn't take away the lessons or the love he exemplified.

In a private ceremony just off the coast of Maui, under the brilliant blue sky, Wylder's ashes were released into the crystal sea among 5,000 flowers tossed in beautiful memory. A friend gently strummed "Twinkle, Twinkle," and as the current reclaimed Wylder's body, his spirit was finally freed.

In his short lifetime, Wylder the Warrior inspired thousands of people to live like a warrior, embracing each day as an opportunity to make a difference for others, and to recognize that each moment in life is precious.

Their story could have ended there. Many parents stop their fight with the death of a child, and the Laffoons certainly had reason to be exhausted. But Shannon and Steven believed Wylder's life was not an accident, that it was a miracle. They believed he came with a purpose, and that his was a legacy of love for the 48 children born each and every day with a lysosomal storage disease. Together, they dried their tears and strengthened their already iron-clad resolve. They started the Wylder Nation Foundation to help other families like themselves who were short on answers and long on hope.

Roughly one in 7,000 children is born with a lysosomal storage disorder. Most do not live to celebrate their fifth birthday. There are no cures for these genetic diseases, and only six of the 50 recognized versions have FDA-approved treatments.

The Wylder Nation Foundation, a 501(c)(3) non-profit organization, is continuing the warrior fight to advance research, provide funding for medical

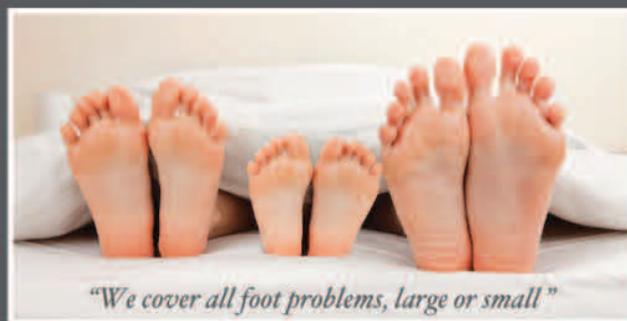
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trials, encourage dialogue among experts from different fields and encourage the families who are often silently feeling the pain of helplessly watching a child suffer the effects of a lysosomal storage disease.

Wylder Nation Foundation is a warrior community of families, scientists and doctors who are passionate about connecting with each other and sharing hope with those affected by childhood lysosomal storage disorders.

“Our thinking is that, although each lysosomal storage disorder is different, many share common hurdles to overcome,” Steven said. “For example, crossing the blood/brain barrier has been a tremendous challenge in creating potential therapies. We strongly believe that, by focusing on the common obstacles, the answers for one lysosomal storage disease may be the key to others as well.”

And so their fight continues.

For those of us fortunate enough to bear witness to this remarkable family and their journey, Wylder constantly reminds us of the miracles: the miracle of life, of love, and of hope. The strength and the beauty that one little boy inspired in the world is humbling. The Laffoons took a situation that brought them to their knees and turned it around to help others. They embraced their pain, held on to each other, and accepted the gifts in their grief.

Today, they are also welcoming a second chance at parenthood. A new little life will be entering the world, this time without the pain and limitations of a lysosomal storage disease. Their second son, whose name is yet to be determined, will arrive sometime around February 28 – which is National Rare Diseases Day, not by coincidence the Laffoons believe. It’s also not a stretch to think that, from somewhere above, his older brother will be smiling.

Because miracles really do happen all the time. It is not Wylder’s death that touched those who knew him, rather it was the way he lived the life he was given. He spent his short time here on earth as a teacher, and his lessons, and his spirit, live on.

www.wyldernation.org

