If you know a family you would like to nominate, please email shelly@imagesaz.com.

Meet the Laffoon Family

Writer Amanda Christmann Larson

Writer's Note:

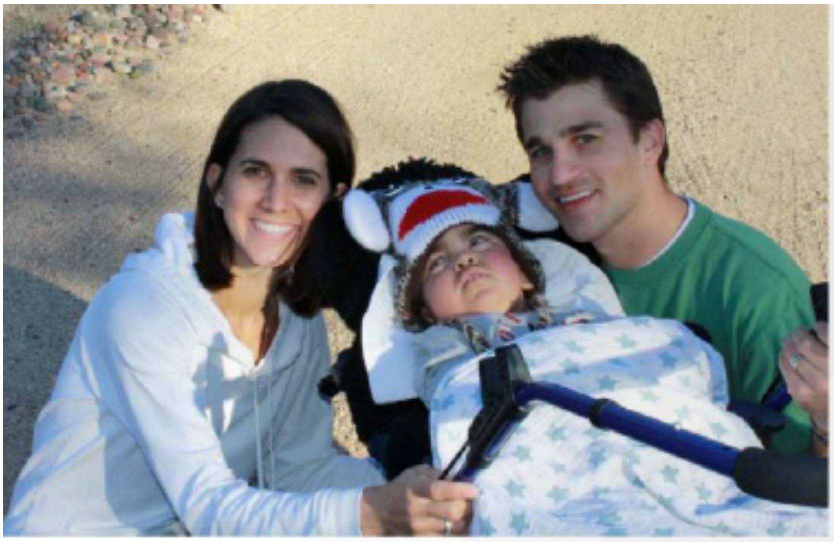
As I drove to the North Scottsdale home of two and a half-year-old Wylder Laffoon and his parents, Steven and Shannon, I had in my mind that I would be writing the kind of story that gives people wider perspective on their own problems – a "you think you've got it bad, check out these other people ..." kind of thing.

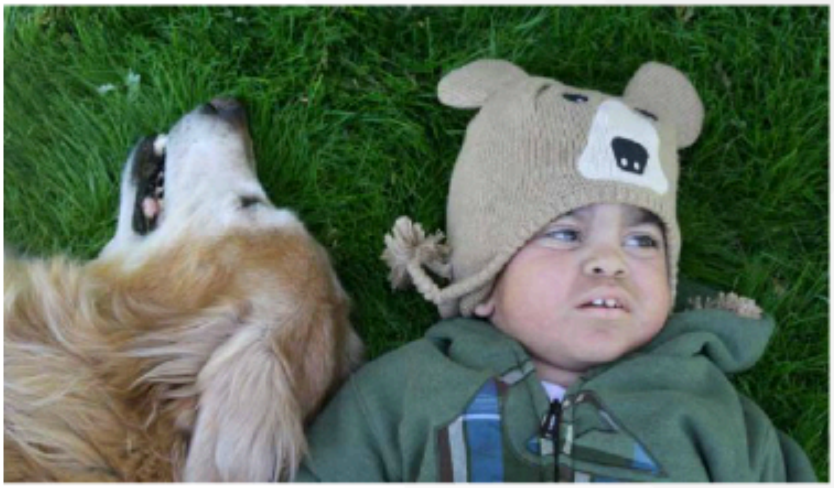
What I didn't expect was to be so inspired by the wisdom of this remarkable family, and touched by their ability to balance fighting for their future and accepting that which cannot be changed. They have taken on these challenges with such dignity and grace that I couldn't help but leave their home a little bit changed.

There is no pity needed for this family, only a mind open to learning more about what it means for each of us to embrace our own journey through life, whatever it may hold.

Parenting is, on the surface, a pretty simple thing. Feed your children the right foods, enroll them in good schools, be consistent with discipline, get them through those tricky teenage years with a few shiny nuggets of wisdom, and let them spread their wings and fly.

These are the rules we live by. We measure success by baseball trophies and spelling bee certificates,





then corner offices and square feet. Good parenting means providing our children with the resources they need to become the people they were meant to be.

What happens, though, when the rules go out the window? What happens when dreams of piling kids and soccer equipment into a minivan turn into daily realities of pain management, aspiration prevention and coming to terms with the fact that your child's life is going to end long before your own?

"It's so unnatural, but at the same time, it's natural," said Steven Laffoon. "There's no way you can prepare for what's going to happen, even though you know what's going to happen."

Steven and his wife Shannon are living out parenthood in ways that many people just can't bear to hear about, but the lessons the rest of us can learn from this young couple and their toddler son, Wylder, are powerful, not for how they've learned to cope, but for how they've learned to embrace the challenges before them with a positive attitude and a fighter mentality.

Three years ago, Steven and Shannon were decorating the nursery in their new home to prepare for their first child. Pictures were framed, bows were tied and teddy bears were waiting to be hugged. Shannon had an ideal pregnancy, and Wylder James was born a healthy, happy baby boy one day before his due date, May 15, 2009.

Early pictures show a sweet baby with wild hair and big, brown eyes framed by his dad's dark brows, held by proud parents. They could have posed as that perfect family that comes in new photo frames.

One month later, 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."

Jan. 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 they knew something serious was happening.

Strip away the feeding tubes, hospital visits, surgeries, and everything else that has come with Wylder's diagnosis, and what is left is profound, unconditional love and a deep understanding of what it means to be human.

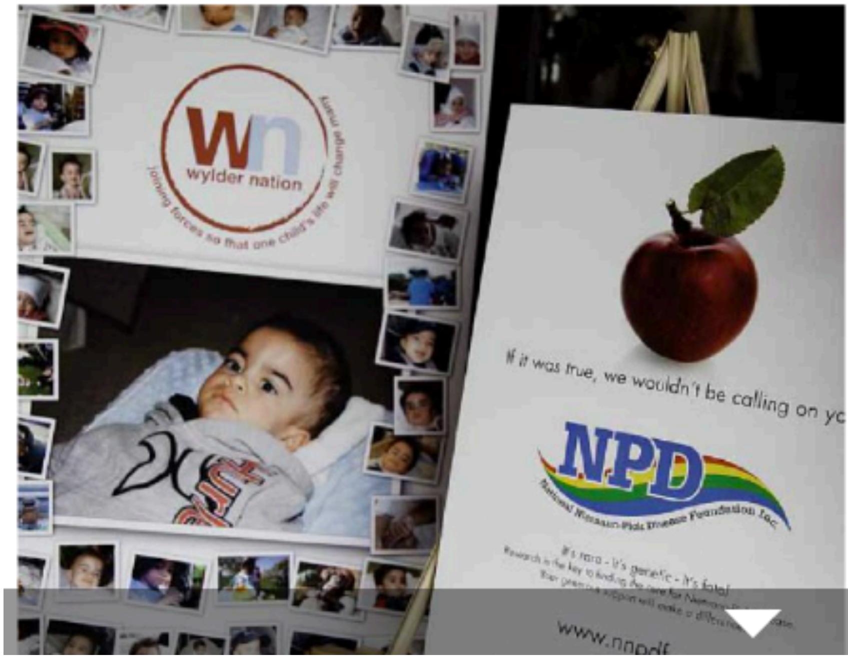
It isn't difficult to imagine what it feels like to get the earth-shattering news that your child is going to die. Perhaps that's why so many of us avoid hearing stories like the Laffoons'. It's too close to home. It really could happen, and no one wants to entertain that possibility.

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 disorder called Niemann-Pick (NP) disorder. Worse to hear that fateful January day was that Wylder has the most aggressive form of NP, Type A (NPA).

NPA affects Wylder's body's ability to metabolize a fat, called sphyngomyelin, produced by every cell in the body. Wylder does not make the enzyme that is needed to break that fat down into energy, so it accumulates in his cells, eventually killing them. Unlike other types of Niemann-Pick, Type A affects his brain, and had caused severe brain damage by the time he was a year old.

It is so rare that there are only five children alive in the U.S. with this disorder, and about as many doctors who understand what it does, although no one knows how to treat or cure it.



Over the last two years, as much as he has fought his disease, Wylder has deteriorated. It is impossible to ignore that fact. It is also impossible to ignore the changes in Shannon and Steven's lives. They have become 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 have to offer. They've flown around the country, speaking to scientists, foundations, drug companies, and the FDA. They have done everything they can to find a cure or a treatment, but time is not on their side.

They know a cure will not come soon enough for Wylder, their little warrior, but still, they will not give up. Their push has become selfless, searching for a cure not to help their son, but to bring meaning to his suffering.

"There's no doubt in my mind that whatever treatment will help kids with this disease in the future will come out of this house," said Shannon. She should know; she has lived with Steven's bulldog tenacity and drive for knowledge, and knows he will never take "no" for an answer. She has seen him buried in a pile of books and research, looking for clues. "No parent should have to hear there is no hope, no treatment. There are so many kids out there like Wylder with really rare diseases, and there is always hope."

"I want to fix it," added Steven. "I think there is a way to fix it. I think they've made extreme progress in the last eight to 10 years. I don't think it will be within Wylder's lifetime, but I'm confident there will be a treatment in my lifetime."

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Shannon still counts fingers and toes, and Steven still makes growling noises to make Wylder's eyes smile. Even though Wylder doesn't speak a word, the three are connected in a bond so strong that, NPA be damned, nothing can tear it apart.

And with that has come the biggest lesson. It's not about learning to cope, so much as it is about accepting that there is something much bigger at work than just a disease slowly killing their little boy.

Steven and Shannon have come to realize that they are doing exactly what they were meant to do, and that

Wylder is their son for a reason. Thirty pounds of love has made them strong in ways they could never have dreamed, and what comes from that strength has the potential to be something spectacular.

They have learned that their journey is different than that of other people, but they don't assign labels like "worse" or "harder," "easier" or "insignificant." It simply is, because each of us has a journey of our own to teach us compassion, kindness, and make us wise. Wylder has taught them that there is only today, and making the most of it is the best we can all do.

The patience and appreciation they've learned, the pathways they've taken, have beckoned them forward and made them better people. And in the process, as they prepare to say goodbye, they have never lost hope that there is purpose to every life, no matter how long it stays, as long as there is love.

"Inevitably, there is going to be a time to mourn," Steven said, Shannon running her fingers through Wylder's dark hair as he rests comfortably beside them. "Now is not that time."

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