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THE "SUPER HOUSE"

Raising two sons
with spina bifida

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"SUPER HOUSE"

Bryce and Allison Lefebvre know real joy raising their three sons, two of whom are extremely medically fragile.

By Karen Davis Barr ■ Photos by Rick D'Elia

SEE THE SIGN FROM THE STREET, before I get out of my car. Before I walk up the sidewalk to the front door. Before my feet crash into the aluminum ramp I don't see, because I am so focused on the sign. Is it some sort of caution?

Hardly.

The words, neatly printed in purple marker, couldn't be more reassuring: "super house." The simple phrase is punctuated by happy, colorful ink-stamped images: flowers, starbursts, puppy prints, hearts.

Slowly, I release my breath. This home, where the edge between life and loss is razor sharp, is not sad or scary. It's strong. It's joyful.

Weston Lefebvre runs to open the door. He's the oldest of Bryce and Allison Lefebvre's three young sons, and the artist behind the "super house" sign. As Weston shyly retreats, I walk into the cozy living room of this modest, north Phoenix home. It is filled to the brim: comfy, overstuffed furniture; a whitewashed upright piano, children's toys. Family photos cover every wall. It's all very typical of a household with children between the ages of 2 and 6.

Some things, however, are not typical. Miles, 4, is in a wheelchair, attached to tubes that feed him and help him breathe. Caleb, 2, scoots around the living room floor with the help of a child-sized walker. And there are two extra adults in the house — caregivers on a team that provides 24/7 medical support and supervision to these two boys, both of whom were born with myelomeningocele, the most serious type of spina bifida, a neural tube defect.

This isn't the kind of life the Lefebvres expected when they fell in love, married and started their family. But it's a life they embrace each day with endless grace and gratitude — despite the wheelchair, the walker, the breathing tubes, the feeding tubes, the closet shelves crammed with medical supplies, the frequent surgeries and hospitalizations, the ever-present nursing support, the difficulty of taking their three children on a family outing, the tough decisions to leave one or two of them at home. And of course, there is the constant threat that one of their boys will suddenly stop breathing,

THE LEFEBVRES lived in Chicago when they got married in 2011. They loved the city, where Allison worked in corporate event planning and Bryce was an associate for the business consulting firm PwC. They were delighted when Allison became pregnant with Weston.

Because Allison has Type I diabetes, her pregnancy was considered high risk. Several doctors urged her to deliver early, by C-section, to prevent complications. She fought for a natural birth; Weston arrived healthy and without incident. The Lefebvres happily began life as a family of three.

They soon felt a pull to return to the Phoenix area. Allison was raised in Washington but graduated from Arizona State University and loved the desert sunshine. Bryce's family traveled a lot as he was growing up — thanks to the pro baseball career of his dad, Jim Lefebvre — but considered Phoenix home base. Bryce played college baseball at the University of California Santa Barbara, then transferred to Grand Canyon University in Phoenix, where he graduated with a degree in accounting.

"We're just West Coast kids," Allison says. "You're drawn to what's familiar."

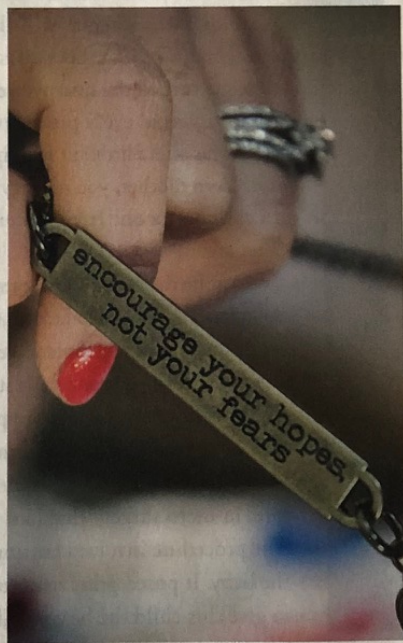
Soon after they moved back to Phoenix, Allison started a small business called AZ Momtourage (like "entourage"), a blogging and social/educational networking group for moms. "I think it's pretty typical for any stay-at-home mommy to want to nurture the business side," she says. Her business took off, fueled by a singular passion: "I could never stand the thought of anyone feeling lonely for

any reason."

Then she became pregnant with her second son, Miles.

Within weeks, an ultrasound confirmed the baby was in trouble. An opening in his back was exposing his spinal cord and neural tissues to damaging amniotic fluid in his mother's womb. The child faced partial paralysis, immobility, bladder and bowel dysfunction, intellectual disabilities and more.

"Getting the diagnosis was shocking," Allison says. "That was by far the darkest moment of my life. I remember driving home in a daze. I went to pick up Weston, who was 16 months old. It was hot.





THE FACTS

- Spina bifida occurs when a baby's neural tube fails to develop or close properly. The literal meaning of the word is "split spine."
- Spina bifida is the most common, permanently disabling birth defect in the U.S.
- The birth defect typically occurs within the first 28 days of pregnancy, while the neural tube is forming, and often before a woman knows she is pregnant.
- Pregnancy screening tests that can detect or flag concerns about a possible spina bifida diagnosis include the alpha-fetoprotein blood test, an ultrasound and amniocentesis.
- The causes of spina bifida are not fully understood. The possible roles of genetic and environmental influences need further study. Current recommendations to reduce the risk include taking 400 micrograms of folic acid every day during a woman's childbearing years.
- For parents of a child with spina bifida, the likelihood of having a second child with the condition is just 3 percent.

—Sources: Centers for Disease Control, Spina Bifida Association

LOCAL SUPPORT

The Spina Bifida Association of Arizona offers resources, programs and events to support children and adults with spina bifida. 1001 E. Fairmount Ave., Phoenix.

Call 602-274-3323 or email office@sbaaz.org

I stopped to get gas and accidentally locked my keys in the car. I had to call the fire department! I don't know where my head was."

That night, she and Bryce sat in silence for awhile, then went for a walk. Allison had never seen Bryce so low. "All I ever wanted was a normal life," he said.

"Well, you've got an extraordinary one," she replied. It was one time in many yet to come when their emotional dynamic as a couple — rarely are both "down" at the same time — helped them move forward.

The full emotional impact hit Allison soon after. She remembers two weeks of lying in bed, crying into her pillow. "I was walking around like I was a ghost," she says. "I didn't know what was happening around me."

She wanted to cancel a baby shower that was being planned. "I guess I was thinking, I don't get to celebrate this. But wonderful friends said, 'We're having the baby shower.'"

That kind of understanding and support continued after Miles was born. Family, friends and members of their church offered donations, meals, Instagram fundraisers. Though much appreciated, the help wasn't easy to accept, especially for Bryce.

"He is more private than I am, so it's more difficult for him," Allison says. "But people do really want to help."

Somehow they adapted to their new normal: multiple surgeries and hospitalizations for Miles, training in resuscitation and other medical techniques for them, sleepless nights and too many hours away from Weston, who received plenty of loving care from others during each crisis.

As the seemingly impossible became routine, the Lefebvres longed to add to their family.

"I was told the chances [of a second child with spina bifida] are so nominal, I shouldn't worry about it — though I did," says Allison. "I was getting IV folic acid therapy, paying thousands of dollars [for it], eating all the right things. If someone turned the microwave on, I would leave the house." That's how hard she worked to avoid every possible negative environmental influence.

"I was still a little bit feeling like it was my fault [Miles has spina bifida]," she says. "As a mother, you're carrying that child, you have those feelings. I thought if I can control one environmental factor, this birth might have a very different outcome."

Despite the precautions, pregnancy tests showed Caleb, too, would be born with the rarest and most debilitating form of spina bifida.

"I'm sure some people were thinking, 'Why did they have another child? They've already got one with such severe disabilities.' We know what people think," Allison says. "Our support with Caleb ran deep, not wide, but the people that came back the second time were there for us, there for good."

With this pregnancy, however, the couple convinced doctors to undertake a rare, in-utero surgery that had the potential to mitigate the effects of the damage. The procedure involved cutting Allison open and performing neurosurgery on the baby. It posed great risks to both baby and mom, but Allison was determined to give this child the best possible chance for a higher quality of life.

The procedure helped. Caleb hasn't escaped scary complications, brain surgeries, hospitalizations or limitations, but he is much more mobile than his big brother. For now, Caleb doesn't need a tracheostomy, though he has on occasion stopped breathing and required CPR. On optimistic days, his family dreams Caleb may someday be mainstreamed in a typical school classroom.

"I wouldn't trade Caleb for the world," Allison says. "Even if I'd known [before getting pregnant] that he was going to have spina bifida, I would still absolutely have him."

She has a good example for that resolve.

"My mom had me," says Allison, whose older sister has a milder form of spina bifida. (The close connection makes her question common wisdom that the defect is not genetic.) The example her parents always set — "they roll with



Page 16 (clockwise from top): Allison holds Caleb (2) and plays with Weston (6); Bryce and Caleb; Caleb; Miles (4).

Page 18 (left to right): Miles, Allison, Caleb (standing) and Weston.

Page 19: The Lefebvres' primary home nurse, Alma Sanchez, with Miles.

the punches” — would come to serve her well. And her experience as the sibling of a person with disabilities gives her great empathy for Weston’s unique and challenging life experience.

“Weston is forced into very much of a nurturer role,” Allison says. “He is so tenderhearted. It’s a great quality. He’s been asked to be a helper at a very young age, and he does a great job of it. Hopefully the consequence of all of this is he’s going to have a level of moral character ahead of the curve. And I think he already does.”

The Lefebvres enjoy an extraordinary level of home health care that would have been unthinkable until recent years. It wasn’t easy to come by. The couple fought for home-based services, eventually finding support from the Arizona Center for Law in the Public Interest.

“We worked really hard because of Miles’s high acuity,” Allison says. “His baseline status requires one-to-one [care]. Only in the last 10 years have children like him, who are essentially on life support, been able to come home [and have this level of support].”

Because of the damage to Miles’s neurological system, there are times when he simply stops breathing. “And then his heart will stop,” Allison says. “It doesn’t happen as much as it used to, but you can’t leave his side. So either the [home care] nurse is providing one-on-one care or I’m on one-on-one care with him, or my husband.

“We don’t call 9-1-1- very often. Only if ... he’s not coming back.”

That happened once during a Christmas dinner celebration with grandparents. Bryce was grilling ribs; Allison was in the kitchen making salad. When Miles stopped breathing, both parents rushed to his aid, but this time was different — he wasn’t responding. They called 9-1-1. The paramedics stabilized Miles.

Bryce and Allison put the food on the dinner table and tried to bring back the celebratory mood. “It’s Christmas! Let’s celebrate!” Bryce remembers saying. “My dad was like, ‘I’m sorry. I’ve lost my appetite.’”

BRYCE, WHO IS NOW a senior manager for Marriott International, works from home most days, in a separate office he built in the backyard, just steps from the house. “I keep a ‘go bag’ out there in case we need to rush to the hospital,” he says.

Though round-the-clock care means no privacy as a couple or family, Allison and Bryce can’t imagine life without it. They

work very hard to maintain and support these relationships; they know better than anyone how stressful and emotional the work can be.

“It’s very common to have a lot of turnover in home health care,” Allison says, “but Alma Sanchez has been with us for years. Most [care providers] have been with us two to four years. They love Miles, love watching him grow.”

When Miles was born, Allison found solace in writing. She started a blog called An Upward Reckoning (anupwardreckoning.com), where she chronicled her sons’ medical journeys, processed her emotions and shared small victories or hard

lessons learned. As is typical with online posts, her writing drew both support and hurtful criticism. She continues to write, but has switched to a private Facebook group.

She also has started a “passion project” called Something So Worth It (somethingsoworthit.com). The nonprofit will provide “sunshine gift boxes” where “everything is yellow” as a way to connect with parents who face difficult diagnoses during pregnancy, Allison says. “I wanted to be a little ray of sunshine when they’re in a dark spot.” She hopes her charity will evolve to offer community support, resources and roundtables for discussion.

Allison already reaches out to offer one-on-one support to other mothers in situations similar to hers. “I never sugar-coat it too much for them,” she says. “I give them my perspective, [saying] what you’ve been given right now is very difficult. There will be physical and emotional suffering for you and your child, now and forever. It’s not what you were hoping for, but I promise you, you will laugh harder than you ever thought, you will be a better mom, you will not sweat the small stuff. You will see the best in humanity, and it will be so worth it. You will rise to that challenge because you’re a mom.”

“We’ve learned a lot of those lessons now, at a young age,” says Bryce. “Most people don’t figure them out until later in life.”

“That’s why we consider ourselves the lucky ones,” Allison adds. “When I fall into comparison, or think what could have been, Bryce reminds me not to envy people who [appear to] have perfect lives. They don’t know God the way we know God, they don’t know the lessons we know, they don’t love the way we love. We wouldn’t wish for anyone to go through this, but we were lucky to learn those things, because if not, what could we have missed? I’m grateful. Really grateful.”

Karen Davis Barr is the founder and publisher of Raising Arizona Kids.

