

## The Difficult Life They Would Not Trade

### Family Spotlight: Meet the Larson Family



*Take a moment to experience the Larson's world and better understand why Jill's House is so important to them.*

hospital. It's the year your life falls apart as you search tirelessly for the reason your child can't lift his head or roll over.

After Bridger's diagnosis year, his mom, Cindy, received a call from his geneticist. He told her that Bridger's condition would result in physical and mental disabilities, that he'd never walk, talk, eat on his own or take care of himself. "I had no words when he finished talking," said Cindy. "I just stood there in our den with the phone in my hand. My world was spinning, and I was totally stunned." After the geneticist hung up, Cindy called her husband, Alan, and delivered the life-changing news.



*Alan and Cindy share the weight of parenting so their kids know only joy on their journey together.*

A hard-working dad, a PTA-soccer mom, three kids and a baby in tow, the Larsons thrived in the thick of family life and parenthood. They were a typical, busy, northern Virginia family. Fun was an essential ingredient in their day-to-day lives, and they looked forward to all they hoped the future held. All this changed when their four-month-old son, Bridger, missed several developmental milestones.

Special families call it the "diagnosis year". It's a year of doctor appointments, testing, therapy and endless hours in the



*The love Bridger's siblings have for him is anything but typical.*

Bridger has an extremely rare condition called congenital disorder of glycosylation type 1A. It's so rare that it's difficult for doctors to describe what Bridger will be like as he grows up. "That's been one of the hardest parts of this diagnosis," shared Cindy. "Every person holds some idea of what their future life might be like. But Bridger's diagnosis forced us to give that up. We can't anticipate the future, so we try to live one day at a time--a practice that's been helpful on this journey together."

Now nine years old, Bridger lives with a host of symptoms of his condition. He has seizures, poor vision, behavioral issues, an irregular sleep pattern and a quick gag-reflex. He's not non-verbal as his doctors predicted, but his ability to communicate with words is very limited. He has autistic tendencies and struggles with sensory integration. He uses a wheelchair, eats through a feeding tube and needs constant supervision. "Bridger gives us empathy for all children and families with special needs," said Cindy. "From physical to intellectual disability, we understand the challenges."

Cindy first heard about Jill's House at a committee meeting for moms raising children with special needs. At the meeting, Dana Hecht, Jill's House director of Family

*"He's taught us what's worth caring about and what's not, what's worth our energy and what's not, and what true love really is."*

*-Cindy Larson*

Relations, explained the Jill's House model of respite, and Cindy immediately scheduled Bridger's first weekend stay. "I barely slept at all that first night Bridger was at Jill's House," said Cindy. "All night I had one eye on my phone, waiting for the text that something had gone wrong, but it never came."

"Cindy was a ball of nerves that first weekend," said Alan. "The second weekend was better, and by the third she was totally on board."

When Bridger is at Jill's House, Cindy and Alan and their four other children can spend the entire weekend together. "Alan and I can take all four kids to the park and we can both give our full attention to our five-year-old as she climbs the monkey bars," said Cindy. "We can go to a restaurant together--eat an appetizer and a dessert--and all still be sitting at the table when the check comes." She explained they typically can't do this with Bridger because he's often uncomfortable in restaurants. He fusses until one parent takes him outside, leaving the rest of the family to wait for the check.

And Bridger loves Jill's House. He enjoys swimming and bowling, but his favorite part is the one-on-one attention he receives from staff. Bridger loves people--a skill he learned from the family who loves him so well. "Bridger is our breath, love and joy," shared Cindy. "He's taught us what's worth caring about and what's not, what's worth our energy and what's not, and what true love really is. Life with Bridger is the most difficult life I can imagine living, but I wouldn't trade it for anything."