

Strength Despite Disability and Deployment

Family Spotlight: Meet The Work Family



The Works will share their inspirational story at the 2015 Celebration of Special Children Gala.

Twelve years ago, Pat Work walked out of combat and into a neonatal intensive care unit. His wife, Mara, was there caring for their firstborn, six-day-old son, JP. The doctors explained that JP was in critical condition and missing a segment of his 11q chromosome. At the time of his birth, JP was the only child known to have this specific segment deletion. Without a textbook prognosis, the Works waited until JP was finally ready to come home a month later.

JP's chromosome deletion resulted in a series of cognitive and physical disabilities. He can't do things that most people take for granted. He can't chew food thoroughly; he's not potty-trained, and he has no sense of safety. He has ongoing health challenges and one to two surgeries each year. "Nothing is easy for JP," said Mara, "but he's a champion who endures hardship better than most we've seen. He's resilient, tough, loving and gentle."

These traits run in the family. Pat and Mara are committed to each other, to JP and to their ten-year-old daughter, Sally Ann. They do all they can to remain a close-knit family through disability, displacement and deployment. They've moved six times since JP was born in 2002. "That's hard enough with a typical child," said Pat, "but imagine what it's like when you have to change doctors and find good schools and the right supports for a child with special needs, like JP."

In addition to these frequent moves, Pat has been deployed ten times to Afghanistan or Iraq since September 11, 2001. "Sometimes he'll be gone for a few months. Sometimes he's gone more than a year," explained Mara. "This may sound strange, but I try not to make Pat's deployments a big deal for the kids. I want them to feel like it's normal so they won't get upset." Thankfully, Pat's current assignment keeps him grounded in the DC area.

Shortly after moving to Northern Virginia, the Works heard about Jill's House through a parent at JP's school. For over a year now, they've enjoyed the benefits of regular respite. When JP is at Jill's House, his parents have the chance to sleep in, have a date night and spend special time



JP and Mara could not stop smiling at this year's Jill's House Night to Shine Prom.

with their daughter. "We are one very grateful family," said Pat. "Jill's House has really helped all of us. We can slow it down once in a while and truly have that respite that's so necessary to focus on ourselves."

"And it's good for JP too," Mara added. "JP doesn't get invited to sleepovers or birthday parties. He has limited opportunity for summer camps or youth sports. But Jill's House provides a temporary, independent, camp-like experience for him."

When people first meet Pat and Mara and watch them care for JP, they'll say things like, "Wow! You two do a lot." and "How do you manage this or that every day?"

"But then they hang out with JP," said Mara. "They'll see him smile. He'll give them a hug. And then this amazing compassion comes out of that person." JP has that rare ability to pull kindness out of the people around him. "And he's taught Pat and me so many things," Mara continued, "to love more deeply, operate as a team and share parenting responsibilities. And our daughter is mature beyond her years."

The love in this family is evident in the way they care for and speak about one another. We are grateful for the opportunity to support this entire family by caring for JP at Jill's House.

When you sponsor a child's stay at Jill's House on a monthly basis you give a recurring gift of Jill's House to families like the Works, keeping their marriages together, restoring their family and giving them a moment to just breathe.

To learn more, visit jillshouse.org/sponsor or email claire.waldrop@jillshouse.org.