

# The Boston Globe

## South

### For a special boy, love has made all the difference

By Bella English | GLOBE STAFF FEBRUARY 09, 2014

It was a perfect full-term pregnancy, and April and Shawn Wilmar, who live in Dedham, were thrilled with the impending arrival of their first baby.

April, a lawyer for a Boston firm, had worked practically up until the day she delivered at the Brigham and Women's Hospital. All of the baby's tests were normal, as was the delivery.

They were shocked and terrified when their baby boy was born not breathing. In fact, his face had turned blue.

What had gone wrong?

The long answer to that would take up half of this column space. The short answer: Toriello Carey syndrome, a genetic disorder so rare that only 45 children worldwide have been diagnosed with it. One of them is John Thomas Wilmar, now 9, a winsome little boy whose progress in the face of long odds is a testament to the power of parental love and perseverance.

The newborn wasn't breathing because his cleft palate caused his tongue to obstruct his airway. His intestines were rotated and he was rushed into surgery.

He also had hip dysplasia, and his hands were tightly locked in a clench. He couldn't extend his feet, either. He couldn't see or hear well. He would have numerous developmental delays.

"We sat there and massaged his hands for hours," says April, who is 37. John spent 2½ months in the neonatal intensive care unit at Boston Children's Hospital.

It takes at least a village to raise a special-needs child. The Wilmars were connected to MassHealth, which covers medical care for the disabled.



Shawn and April Wilmar with their sons, John, 9, (left) and Ryan, 6. John has a rare genetic disease but, thanks to his parents' perseverance enjoys an active, full life.

And then they were connected to Community Case Management, a partnership between University of Massachusetts Medical School and MassHealth, which helps families with complex medical needs.

The idea is to make it easier to keep such children in their homes, an approach that is both humane and cost effective, instead of institutionalizing them.

Under the program, a medical assessment is done annually to gauge how much nursing and personal care John will get each week under MassHealth.

His case manager, a nurse, coordinates the care and insurance issues, and can buy whatever medical equipment he needs.

Each case manager cuts through the horrific red tape to lift

that burden, too, from parents who have their hands full with a sick child.

“Whatever these kids need, they will get: physical therapy, occupational therapy, dieticians, specialized wheelchairs, feeding tubes,” says Joyce Murphy, executive vice chancellor at UMass Medical School. “Without the service, these kids would be forced to live in institutions.” The program currently serves 672 families.

The Wilmars vowed from the start to include John in every activity possible. On a recent morning in their home, the tow-headed boy wearing jeans and glasses plays with an action figure while snuggling, variously, with his mother, his father, and nurse Julia Moszka, who has been with the family for five years.

“When I first started working here, John was in his own little world,” says Moszka, who lives in Methuen. She is an independent contractor, not connected to MassHealth like John’s other caregivers. “But through the process of inclusion, John kind of woke up.”

That’s an understatement. John is so active — and so prone to possible accidents — that he must be watched every second. But that doesn’t stop him from doing stuff that other 9-year-olds do.

Though he walks only short distances, and with what his parents call “a drunken sailor’s gait,” he plays soccer, with someone holding on to him up and down the field. He ice skates with his mom. He rides horseback. At school, he swims and bowls. All of this is modified for his special needs.

In the early years, his father stayed home with him, taking him to doctors’ appointments several times a week, and blending all his foods into purée. John has had a feeding tube since he was 4 weeks old.

“We started feeding therapy with him when he was 9 months old,” says Shawn Wilmar, who works with special-needs kids at Needham High School.

John could not keep food down and would vomit more than a dozen times a day. His parents, taking shifts, stayed up all night as he slept, to make sure he didn’t aspirate his food.

When Community Case Management brought in nurses and personal care attendants, things improved. With a therapist, John learned how to eat. “He really hated it at first, but I knew that once we gave up, he would absolutely never learn to eat or drink, so we continued with feeding therapy services,” says April.

As a toddler, John went to the Perkins School for the Blind in Watertown, where he thrived. But his third year there, he began to regress and was diagnosed with autism.

His parents searched for a school and found the LABBB Collaborative in Belmont, which teaches children with special needs, including those on the autism spectrum. Now, his parents and nurses are working on toilet training with him.

John doesn’t speak but, as his little brother Ryan says, “he can sing.” That is, he emits sounds now and then. The family uses picture cards to communicate with him.

It was a tough decision to have a second child. John’s needs were so extensive and worse, there was a 25 percent chance that the couple’s next child would also have Toriello Carey syndrome.

But Ryan, now 6, is the little brother every kid should have. He keeps an eye out on John, includes him whenever friends are over, and doesn’t treat him like a handicapped kid.

Wherever the family goes, John goes. This has included swimming with the dolphins on a Disney cruise, and zip-lining. “Inclusion, inclusion, inclusion,” says Shawn. “Everything you do, your [special needs] child should do with you.” He adds, with a chuckle: “But do apologize to the restaurant for the clean-up.”

In 2009, the Wilmars founded the nonprofit John Thomas and Special Friends Fund to help other kids, and the hospitals and schools that work with them.

They hold two fund-raisers a year. The next is Casino Night on May 31 at the Dedham Holiday Inn. The fund has supported research at Children’s Hospital, and given to both of John’s schools, Perkins and LABBB.

They’ve helped build a handicapped-accessible playground and donated more than 30 iPads to special-education programs.

The Wilmars, who have relied on a village to help raise their son, have become part of a village to help others raise their special children, too.

Bella English can be reached at [english@globe.com](mailto:english@globe.com).

<http://www.bostonglobe.com/metro/regionals/south/2014/02/09/special-needs-dedham-boy-shows-power-parental-love/MZQ27x5FsyXo4O1hm8HUip/story.html>