‘You need hope to keep going’

Family sheds light on living with ALS and its aftermath

By Angelina Berube

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Editor’s note: The Eagle-Tribune interviewed Charles “Chuck” Johnson and Nicole Johnson on April 11 for a story to show how the North Andover family adapted to the life-altering disease of Amyotrophic Lateral Sclerosis ahead of ALS Awareness Month in May. Chuck died April 17 from complications related to ALS. The family asked to move ahead with the story to bring awareness to the progressive disease and to honor Chuck.

NORTH ANDOVER — Eleven-month-old Jenna Johnson was on the verge of walking on a sunny Tuesday afternoon, gripping her mother, Nicole Johnson’s, fingers on a 121-foot ramp set up in her family’s backyard.

“Any day,” family members echoed, predicting the timing of Jenna’s first steps.

It was the same ramp her father, Charles, affectionately called “Chuck,” had used for the duration of her young life after he lost the ability to walk.

Less than two weeks earlier, Chuck, 39, sat in his usual spot at the kitchen table, talking about Jenna’s birth and how the circumstances around it were so different from the couple’s oldest two children.

Chuck was diagnosed with Sporadic Amyotrophic Lateral Sclerosis (ALS) on Valentine’s Day in 2024, a few

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Nicole Johnson sits and holds her children Jenna, 11 months old, Alana, 3, right, and Charlie, 5, on the left with a photo of their father Charles “Chuck” Johnson inside their North Andover home. Chuck was diagnosed with Amyotrophic Lateral Sclerosis (ALS) in February 2024. Chuck died on April 17 after a 14-month battle.

TIM JEAN/ Staff photo

Charlie Johnson, left, sprints next to his father Charles "Chuck" Johnson during a "Make Way For Chucklings" walk in Ipswich in August 2024.

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months before Jenna was born. The progressive neurodegenerative disease affects nerve cells in the brain and spinal cord, causing muscle weakness that leads to the afflicted person's inability to move, eat, speak and breathe over time.

There is no cure for ALS. The typical survival rate is two to five years after diagnosis, according to the ALS Association. About 90% of cases occur without any family history.

Chuck succumbed to his illness April 17, just six days after this interview.

He first experienced shaking in his hands in June 2023, but didn't think much of it. When Nicole was in her first trimester and nauseous herself, Chuck's health issues worsened. He noticed significant weight loss without trying to shed pounds, and also muscle twitches.

There may have been earlier signs, too, but it's too hard to know for sure, Chuck said.

"Looking back, probably there could, like some things could have been related," Chuck said.

After months of testing to rule out other conditions, the soon-to-be father of three received the life-altering news that he had ALS.

"Each day it's like you're losing something," Chuck said on April 11. "You never know the last time you'll be able to do something, like hug anybody, shaking somebody's hand, carry your kids, drive."

A changing family life

At the kitchen table less than two weeks ago, Chuck held on to how his wife, Nicole, didn't want to go on a second date with him nine years ago.

"After the first date, you really didn't even want to go on the second date," Chuck said, smiling at Nicole. "It is what it is. You had a moment of weakness to that date."

Nicole led the conversation about the life they created at their forever home in North Andover, with Chuck chiming in from time to time.

The house is lively with three children: Charlie, 5, Alana, 3, and Jenna, 11 months.

Nicole, 38, and Chuck tried to decipher whose traits their fearless daughter Alana shows more of.

Chuck enjoyed playing card games with Charlie in the sun room, though games of "War" were a bit different in recent months. Charlie dealt both hands, playing his father's turns for him.

"It's just him playing by himself," Chuck said.

"But daddy's watching," Nicole added. "Even though Chuck can't turn over cards, Charlie will play his hand for him and they'll play together. That's really meaningful."

Chuck said, "Sometimes he gets confused which pile is which and he'll pick up 20 of your cards. But he is getting better."

The family found the little joys in the present.

Sundays were the days when things slowed down a bit for the Johnson family. Chuck's "immediate" family of seven extended to his personal caregiver Lola Lebron and family au pair Wendy Llerena.

"It's our most immediate family," Chuck said.

Sometimes Chuck, Nicole and the kids, along with Lebron and Llerna, would hop in their van outfitted for his mobilized wheelchair and drive to Richardson's Ice Cream in Middleton, or spend an afternoon at the library or a farm.

Those were big outings and constants for him and his family as their world changed quickly and drastically around them over the last 14 months.

They were able to enjoy the water and boating, even though it took a little more work to get Chuck on one of their families' boats last summer. Music was important to the couple and they made it out to see Kenny Chesney and the Zac Brown Band at Gillette Stadium by utilizing a wheelchair accessible section of the field.

Their goal was to see Zac Brown Band play again April 27 at Mohegan Sun Arena. It was something the two were planning on attending just two weeks ago.

They lived life as normally as they could.

Chuck left his accounting job to become a stay-athome dad and watched his young family grow as he lost pieces of his own life.

Through it all, the Johnson family adapted to their "new normal," Nicole said. Family members, like Chuck's father, and the personal caregiver attended to him around the clock. Insurance did not cover personal care.

"It's like six figures," Chuck said. "It's crazy."

Nicole said they've always been independent, but the diagnosis forced them to rely on others and turned into "a life lesson for us," Nicole said.

She still worked for Biogen in the neuromuscular field while also becoming one of Chuck's caregivers.

The kids knew about dad's condition, in terms they could understand, but still wondered innocently if things would get better.

"'When dad can walk again, he can play with us in the snow,'" Nicole recalled one of the children telling her last winter.

But Chuck and Nicole were always honest with the youngsters, teaching them about the permanency of his condition.

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Nicole Johnson with Jenna, 11 months old, walk on the ramp outside their North Andover home.

TIM JEAN/ Staff photos

Nicole Johnson, right, and her children Jenna, 11 months old, Alana 3, and Charlie, 5, stand on the 121-foot ramp outside their North Andover home with family members pointing to the back of their shirts that read "Make Way for Chucklings," a movement to raise awareness for Amyotrophic Lateral Sclerosis (ALS). The shirts were made for Charles "Chuck" Johnson, 39, who was diagnosed with ALS on Feb. 14, 2024 and died on April 17.

