

## Ice Bucket Challenge held by family of Frenchtown ALS patient

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Bryan Jones is one of a handful of people in Monroe County living with amyotrophic lateral sclerosis (ALS), commonly called Lou Gehrig's Disease, his wife said. When the family became aware of the Ice Bucket Challenge after seeing a video on Facebook, Mrs. Jones said she knew she had to jump on this opportunity to educate people about the struggles her family faces every day.

<http://www.youtube.com/watch?v=HP5AdslSGsU>

FRENCHTOWN TOWNSHIP ? The sun cast a golden glow onto Charlotte Jones' face as she danced in place on a section of cold, wet grass, ice cubes scattered near her feet. ?Okay, I'm ready,? the 9-yearold said, clutching the hand of a friend who stood next to her.

?Wait! Say who you're doing this for,? Janeen Jones, Charlotte's mother, shouted from nearby. ?My dad,? Charlotte said in return. ?ALS Ice Bucket Challenge for Dad.? From under the shade of a tall tree in Frenchtown Kiwanis Park, Bryan Jones smiled as he watched his daughter shriek as a bucket of cold water cascaded over her blond hair. One of the nurses the Jones family employs to care for Mr. Jones stood by his wheelchair, holding the wires of his ventilator and waiting to suction the saliva from his mouth.

Mr. Jones is one of a handful of people in Monroe County living with amyotrophic lateral sclerosis (ALS), commonly called Lou Gehrig's Disease, his wife said. When the family became aware of the Ice Bucket Challenge after seeing a video on Face-book, Mrs. Jones said she knew she had to jump on this opportunity to educate people about the struggles her family faces every day.

"I don't care what anybody does to raise awareness," she said of how the Ice Bucket Challenge has drawn attention to ALS. "They can give \$10, dump a bucket of ice on their heads, giggle and laugh about it all they want. To me, to my family, that \$10 could mean a cure."

The ALS Association has raised more than \$100 million since the challenge became an Internet sensation, according to the association's Web site.

About 150 people came out to Frenchtown Kiwanis Park to take on the Ice Bucket Challenge Wednesday night in honor of Mr. Jones and to donate money to the family's Eagles Fly Foundation, which is dedicated to ALS research.

The crowd consisted of residents from all over Monroe County. There were neighbors like Jodi and Marc Maus' family, who live down the street from the Joneses, and strangers like Catherine McMurrin, who was attending a back-to-school event at her son's school when she drove past, saw a sign for the event outside the park and decided to stop. Even Chad Collum, a Luna Pier resident who was diagnosed with ALS in February and already has lost the movement in his arms and has to be pushed in a wheelchair due to weakness in his legs, was there.

Together, they formed a line and took turns pouring icy water on their heads. More important, they learned a little more about this "monster," in Mr. Jones' words, and how it affects one local family.

Mr. Jones was diagnosed with ALS in 2009. He was 42 and his family was living in Texas, where he was working in the medical field. He started experiencing weakness in his legs, Mrs. Jones said for her husband, while reading a statement Mr. Jones carefully had tapped out on the iPad he uses to communicate.

Slowly, his health declined. He lost the use of his legs altogether and no longer is able to walk or stand. The family relocated to Monroe, where Mrs. Jones grew up. Her parents, Bill and Sharon Buckley, often help care for Mr. Jones and Charlotte.

?Early on, I remember vividly trying to plan my trek from my car to my office,? Mr. Jones told the crowd, his wife reading the prepared statement for him. ?In that planning were mental notes of spots where I could sit down and rest as my body fatigued. I had to think this way because I never knew where or when I would hit the wall and my legs would quit. ?On a few occasions, I fell within 520 feet of my car and literally had to crawl the remaining way,? he said.

Since the diagnosis five years ago, Mr. Jones has lost his ability to talk, swallow and even breathe on his own. He uses a feeding tube, ventilator and power wheelchair. I haven?t tasted food in two years,? he said. ?My daughter, at 9 years old, doesn?t even remember my voice. For now, he has use of his hands, which allow him to communicate by typing words on an iPad, but even that is dwindling.

Everything has changed for Mr

