

'Curtains' production raises funds, awareness for disease

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Written by Karl Etters, Democrat staff writer



Brian Jackson was diagnosed with dystonia in 2006, which left him confined to a wheelchair. In May, he walked across the stage and received his degree from Florida State University in exercise science. / Provided by Erwin Jackson/Special to the Democrat

An often misdiagnosed, not widely known disease will get some attention next week from an off-Broadway play, the Florida State University College of Medicine and the Tallahassee Memorial Hospital Foundation.

Tallahassee resident Brian Jackson will be honored Thursday and Friday at the second annual Curtains for a Cause. Jackson was diagnosed with dystonia when he was a 16-year-old high school student at Lincoln High, leaving him confined to a wheelchair.

The disease affects about 300,000 people in the U.S. according to the Dystonia Medical Research Foundation and renders people unable to control their movements and leaves muscles contracted involuntarily.

Last May, Jackson received a degree in exercise science from FSU, where he walked across the stage to receive his diploma. But the road to that moment was anything but easy.

Jackson's father Erwin said the disease affected his son, who once played football, soccer and baseball, unexpectedly.

“When your son looks at you and you’re supposed to fix and protect and know and teach — it was the most frightening day of my life.”

Erwin said the eight or nine months of traveling the state looking for help eventually led doctors to correctly diagnose his son with dystonia.

They found additional help, and a temporary solution, in New York from a doctor who specialized in neurological disorders nearly a year after symptoms of the disease began.

Doctors used existing skin cells to create stem cells, which were then grown into brain cells, which were used to test possible remedies for dystonia. Erwin said, all controversy aside about the use of stem cells, he was amazed at the advancement in technology and medicine.

Brian is able to live without the symptoms of dystonia thanks to a set of batteries implanted in his body that regulate electronic signals sent from his brain, known as deep brain stimulation therapy.

“It was the most phenomenal change,” he said of his son’s condition only a day after the surgery. “He’s walking, climbing stairs and picked up a fork for the first time in months.”

If you go:

Feb. 14 and 15, FSU University Center Club. Dinner starts at 7 p.m. and the show starts at 8 p.m.

Off-Broadway Musical performance of “I Love You, You’re Perfect, Now Change”

Tickets are \$100 and can be ordered online at curtainsforacause.com or by calling Mark Marple at (850) 431-4080

Proceeds will go toward the Brian Jackson Dystonia Research and Discovery Program and the FSU College of Medicine.

Dr. Pradeep Bhide, director of the FSU Center for Brain Repair said “in terms of treatment,” DBS is “the only form of treatment that shows dramatic changes in the symptoms. It doesn’t cure it though.”

Bhide said dystonia is the third most common form of neurological, muscle tremor diseases behind essential tremor and Parkinson’s disease. He added that it is also the most debilitating.

In its second year, Curtains for a Cause will not only donate funds to the FSU College of Medicine, but increases awareness about neurological diseases like dystonia and Parkinson’s disease.

Bhide said he was excited about the increase in funding from the event. “This is a big thing for FSU as well as dystonia research,” he said.

The Center for Brain Repair received funding from the Department of Defense in January to study the neurological and biological connection between dopamine receptors, feel-good nerves and diseases like dystonia. Bhide said the funding would provide more room for high risk, but productive research in the future. He explained that normally funding is based on nearly completed research or research plans.

Not the case with the funding received in January.

TMH major gifts project director Mark Marple said the response from last year’s event was “unbelievably positive.”

He said of the available 700 seats for both nights this year, about 350 have been sold. Proceeds from the two-night event will go toward funding research at FSU's College of Medicine and the Brian Jackson Dystonia Research and Discovery Program.

Marple said "this is the opportunity that it goes not to a national organization, but benefits locally," something he was proud of.

Now, Brian works for the company that makes his electronic gatekeeper, Medtronic. He talks to doctors and works with patients who are going through the same thing that he did.

"He's in a position to explain to people," Erwin said. "This is what happens, this is how it works. And I've had it done and this is how it impacted me."