

Saturday, February 11, 2012

Written by [Paul Flemming](#)

Florida Capital Bureau

Section: [Local](#)

Publication: Tallahassee Democrat

Erwin Jackson, family raising funds, awareness for dystonia



Caption: Special to the Democrat

Brian Jackson, left, has been treated for dystonia, a neuromuscular disorder. He and his parents, Stefanie and Erwin Jackson, are sponsoring a Valentine's Day dinner and show at the University Club to raise money for the Dystonia Medical Research Foundation.

Erwin Jackson will stand up before a crowd Tuesday night at the University Center Club to make a few remarks.

He'll speak about the importance of the money raised that night for the Dystonia Medical Research Foundation, an organization dear to his family.

On many Tuesday nights Jackson stands before the Tallahassee City Commission, berating and admonishing members during the limited time allotted to speakers not on the agenda.

The program on Valentine's Day will allow him two minutes to speak.

"Two minutes? Even the mayor gives me three minutes," Jackson said Friday with mock indignation.

Brian Jackson, son of the Tallahassee businessman who's the regular critic of Mayor John Marks, has a wonderful story to tell, one that's worth more than a three-minute time limit.

Brian Jackson will graduate in April from Florida State University with a degree in exercise science. He'll walk across the stage to get his diploma.

Six years ago that was anything but a certainty. As a Lincoln High School sophomore, then 15-year-old Brian Jackson played soccer, baseball and football. Suddenly, he was overcome with back pain that eventually contorted his body.

"It was like a light switch, I just started having these horrible back pains," Brian said. "My entire trunk, my chest and back, it was completely shifted. The muscles in my back were contracting 24/7"

Brian's spine was wrenched. His muscles bulged painfully, his left ear was pushed nearly to his left shoulder, bent against his will.

Doctor visits in Tallahassee and Gainesville resulted in misdiagnosis. It wasn't until a visit to Miami Children's Hospital that he was properly diagnosed with dystonia. It's a chronic disorder that causes muscles to contract and spasm involuntarily. The Dystonia Medical Research Foundation says at least 300,000 people in North America suffer its ravages in various forms.

Brian Jackson ended up in a wheelchair, lost his fine-motor skills and had to drop out of school. He couldn't write or feed himself.

Then his parents — Erwin and Stefanie Jackson — found out about the Dystonia Medical Research Foundation. The group put the Jacksons in touch with others who had the disease and pointed them to specialists. They traveled the country looking for hope and help.

"When you're in darkness, any light is helpful," Erwin Jackson said.

The Jacksons ended up at Mount Sinai Medical Center in New York City. A doctor there told them of a procedure to implant electrodes in Brian's brain to combat the disease.

Brian, wracked with pain and his life turned upside down, welcomed the chance at improvement.

"I was in a wheelchair for eight months," Brian Jackson said. "I could walk about 10 feet then I had to sit down."

For 30 days, the Jacksons prepared for surgery, had the procedure to insert the electrodes in Brian's skull and, separately, the batteries to power them were placed in his chest.

Forty-eight hours after the devices were turned on, the Jackson family was in Times Square. Brian said there was tingling in his back, he felt the urge to stretch his legs. He stood up and walked two blocks to lunch.

"Since that day I got up in Times Square, I haven't really sat down much since," Brian Jackson said. He said the procedure has eliminated about 90 percent of his disability.

Now, the Jacksons want to pay back and raise awareness. They've sponsored a few golf tournaments and raised the issue of dystonia in other ways. But Erwin Jackson, the constant critic at City Commission meetings, was looking for a bigger splash.

He met Mark Warple, an adjunct instructor of theater at Tallahassee Community College and executive director of Capital City Playhouse. Erwin Jackson put together a whole plan. The result is a Valentine's Day dinner and production of "The Complete History of America (abridged)," a comedy.

On Feb. 8, Erwin Jackson's usual targets were given a break during his three minutes of commentary at the City Commission meeting.

"Commissioners, I keep nagging you to do the right thing," Jackson said at the meeting. "And I want you to know that Valentine's Day is this Tuesday. I would strongly suggest that you take your spouse out to dinner and a show. It just so happens that my wife and I are sponsoring a dinner and a show to raise awareness and funding for dystonia"

About 250 have already bought tickets. Erwin Jackson is footing the bill to put the whole evening on. When the proceeds are added up to benefit the Chicago-based Dystonia Medical Research Foundation, Erwin Jackson will sweeten the pot with a match, he said. He wants a joyous night of awareness and fund-raising. The non-profit corporation's most-recent tax returns show it made research grants of \$1.4 million in 2010.

For Erwin Jackson, the evening will be a chance to make a difference.

"My mom and dad always say what an adventure it's been," Brian Jackson said.

IF YOU GO

What: Dinner and presentation of "The Complete History of America (abridged)"

Where: University Center Club

When: 6:30 p.m., Tuesday, Valentine's Day

Benefiting: Dystonia Medical Research Foundation

Cost: \$49.95 per person

Contact: Jessica Rossow, 850-645-5693 or jessica.rossow@ourclub.com