

Lonnie Ali discusses challenges facing Parkinson's Disease caregivers

by Tieast Farr
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Although her husband, three-time world heavyweight boxing champion Muhammad Ali exhibits the characteristic signs of Parkinson's disease – “shuffling walk,” slurred speech and severe tremors- his wife, Lonnie Ali said she chooses to focus on his abilities and not his impairments. The caretaking experience can be a daunting one and that is what brought Ali to Chicago recently, to discuss the challenges patients and caregivers face. She was the keynote speaker at the National Parkinson Foundation Fifth Annual Young-Onset Parkinson Network Conference. She said while the symptoms of the disease vary for each patient, the caretaking experience creates unique obstacles that are difficult to manage. The keynote speech was an extension of her visit to Chicago . She was here too to promote “Fight for MORE.” This is a Parkinson disease educational initiative sponsored by Valeant (cq) Pharmaceuticals. The “Fight for MORE” campaign is an effort to provide Parkinson's disease patients and those that care for them the support, education and resources they need to battle the disease. As the national spokesperson, Ali feels this organization fills a void in the Parkinson's caretaker community. “They came to me and asked me would I be interested in participating in this campaign for caregivers. It was just an epiphany when they said it because it's something you always knew should be out there, but it wasn't,” Ali said, “The opportunity to connect with caregivers and give them support...to give them direction with regards to educational resources and new treatment options; it was just a wonderful opportunity for me, and I really appreciate them even thinking to approach me to be the face of the campaign.” Her first piece of advice to families with a newly diagnosed Parkinson's patient is to learn as much about the condition as possible. “First thing I would say is to learn everything you can about the disease, acquaint yourself about Parkinson's disease as a whole, the second thing I would tell them is keep a positive attitude.” Ali said. “Also, get a good support system in place. The “Fight for MORE” initiative is an easy way to connect with caregivers and the caregiver community, even to form a community where people can share stories of what they are doing and how they are approaching their caregiving role. It offers caregiver tips and educational resources. One of the other things I think is

important is to find a very good Parkinson's specialist. That's critical," Ali said. Instead of staying focused on her husband's limitations, Ali told the Defender she chooses to highlight his abilities, and to support his continuously demanding travel schedule. The former heavyweight champion is dedicated to raising awareness about his condition, and Ali is just as committed to helping him reach his goals. "Muhammad has never allowed the illness to stop him from doing what he wanted to do, to pursue his interests, his hobbies, his passions in life. I feel like anything I can do to help support him in that effort, I'll gladly do," Ali said. "I find it very rewarding. I can only speak from self experience because Muhammad is this unique individual and this world-icon, but just seeing a smile on his face. Just knowing he is appreciative of what I am doing, him giving me a hug and thanking me...to me that's very rewarding." Informing African Americans about Parkinson's disease is paramount for the Ali family. "I appreciate talking to the Defender because in our community people need to know; they don't go to the doctor, they don't take their meds... we are just used to being the caregivers and we neglect ourselves a lot."