

## Young Activists Honored At Apollo Theatre

Outstanding leaders lauded for social change

By [LaToya M. Smith](#) - June 06, 2009



Darius Weems was one youth among several honored June 4 at the Apollo Theater in New York for their social activism pursuits.

More than 1,000 supporters gathered at Harlem's Apollo Theater June 4 to honor five outstanding youth at the Do Something Awards "Sweet 16" annual celebration.

The big winners of the evening were [Marvelyn Brown](#), 25, an HIV/AIDS activist; [Eric Glustrom](#), 24, the founder of Educate! which teaches leadership across Uganda; [Maggie Doyne](#), 22, a human-rights activist who assists orphans and displaced children in Nepal; [David Burstein](#), 20, a voting activist; and [Darius Weems](#), 19, an advocate for disability rights and Duchene Muscular Dystrophy funding. Each of the nominees won \$10,000 for their cause. Doyne won the \$100,000 grand prize, which she plans to use toward building a school in Nepal.

"This is something that should be around forever," says Do Something co-founder and former "Melrose Place" actor Andrew Shue. "Young people will always be the inspiration for change in this country so we need to help facilitate that kind of action by giving them the inspiration, tools, and education they need."

BlackEnterprise.com caught up with two of the nominees: Darius Weems, a Duchene Muscular Dystrophy (DMD) advocate who is living with the genetic disorder; and Marvelyn Brown, 25, an HIV positive speaker and activist. Each discussed their goals,

shared why they're motivated to spread awareness, and explained how they plan to spend their grant money.

**BlackEnterprise.com: Why is it important for you to share your story and educate people about DMD?**



**Darius Weems:** This disease is 100% fatal and not that many people know about it. It's hard to raise funds for it when people don't know the disease. People know about AIDS and cancer but they don't know about Duchene Muscular Dystrophy. I want to make it a household-name disease so that people will know about and care about it. It is the most common and

most severe form of muscular dystrophy and is the number one genetic killer of children in the world.

**Did you think your DMD would have such a huge impact on viewers?**

When we decided to go on the trip it was just a way to celebrate my life, but when I was on the road I started getting really getting inspired, and that made me want to do more. I started thinking, 'Wow I can really raise awareness about my disease through this movie.' We had a couple of screenings and people fell in love with the cause. That showed me that I had to keep on pushing.

**Do you feel that this was your intended purpose in life?**

Yes. It's my purpose to change other people's lives. My mother has told me my whole life to never give up. I just appreciate life so much. Life is all I've got so even when it's hard, I'll never give up.

People with DMD will die in their teens or early 20's. I'm working to make the life expectancy better than that, or cure the disease, or even help extend the time that a person can be without a wheelchair.

**Although there is no cure for the disease, have any drugs shown any promise?**

Yes. Darius has invested in five or six experiments that are showing promise. So far he has raised \$2 million that has been donated to research. His project has funded [programs aimed at extending] the life of children with DMD from the time they walk to later in life.

The money he raised helped develop a pill called PTC 120, which hopefully will prevent the muscles from weakening so rapidly. It's currently in a human clinical trial. Unfortunately, only young kids can take the pill. Once you get past a certain age your muscles are too weak. There is no medication Darius takes for this. Although the best DMD specialist in the country sought him out and wanted to treat him, Darius' Medicaid won't allow him to get the best cutting edge treatment.

### **How will you spend your grant money?**

I plan on putting it towards the cause. We'll donate it to the [Charley's Fund](#) and they'll give it to people who know best about distributing the money to scientists. This money is really big for us. The cure is close but hard to find.

### **What's your goal?**

Even if they can't find a cure, I hope that I can help extend the life of a child. We also want to sell a million DVDs by my 20th birthday which is Sept. 8. Since last September we have already sold 25,000. The DVDs cost \$20 and \$17 goes towards the fund and \$3 goes towards traveling and making more DVDs. I know one day that death is going to come, but I'm not worried about that. I just want to make sure that my story lives on and resonates.

### **BlackEnterprise.com: What prompted you to get an HIV test?**



**Marvelyn Brown:** I didn't go voluntarily. I was actually on my deathbed in the hospital for pneumonia and while I was unconscious the doctor performed an HIV test. When I regained consciousness I was told that I had tested positive for HIV. It shocked me. I couldn't believe that I contracted a virus that I felt immune from getting. It was something that I thought could never happen to me.

You contracted it from your partner at the time. Did you confront him?

When I called him he just said he was sorry. The conversation didn't last much longer after that. He hung up. This was the guy that I put before myself. I realize now that when I laid down and had unprotected sex with him I let myself go in that moment. I gave him the power to determine my life and my future.

### **How did your family, friends, and community react?**

[My mother] told me to tell people I had cancer. I felt like a leper in my own home. I had to use plastic plates, utensils, and I had to wash my clothes separately. If I coughed or touched something they sprayed Lysol and would constantly wipe things down. I felt so uncomfortable that I ended up living in my car because that was the place where I felt the most comfort.

My community and friends also turned their backs on me. I was supposed to be my friend's child's godparent, but when I told her I was HIV positive she told me she didn't want anything to do with me. She couldn't see that it could have been her. We both had unprotected sex, but she just got pregnant and I got HIV. Our roles could have easily been switched or we both could have easily gotten both pregnant and HIV. People always

look at someone infected with HIV and say they must be promiscuous. But that's not the way HIV happened; I got the disease from one guy one time.

### **What motivates you to share your story?**

I was alarmed at the HIV statistics of youth. People ages 13-24 make up half of the new HIV infections. That was me. That was my peers. I've made it one of my sole issues to educate. I couldn't really be mad at my community for how they felt about me because we all had the same education. Before being diagnosed, I was just like them — ignorant and uneducated. So I decided to use my story to help break that down.

### **What's your goal?**

In the next five years or maybe before then I hope to get a million and one people tested. So far I have already helped 200,000 people get tested for HIV and have talked to 525,000 people around the world in crowds ranging from 32,000 to five people in a room. I speak opening and honestly from my experience. There's not a cure for AIDS, we haven't even figured out a cure for the common cold, but the cure can start with me spreading the message.

### **How do you plan on spending your grant money?**

I created "The Marvelous Connection Tours." It is going to be a two-month United States tour to visit 20 Colleges and Universities [hardest hit by HIV and AIDS]. I'm traveling to Birmingham, Tennessee, Atlanta, several cities in North and South Carolina, Washington D.C., and New York. HIV/AIDS numbers are high in the big cities, but it's on the rise in the south, and the younger people who are contracting it are coming from the historically black colleges and universities. I just have to go. There's so much work to be done.

The tour is going to spread the importance of HIV testing and education while reducing stigma and dispelling the myths of HIV.

### **Did you ever imagine that after being diagnosed that you would become a nationally recognized spokesperson for HIV/AIDS?**

When I first told my story in the Tennessean [newspaper] I thought it would be a local thing. The response was so overwhelming. I was changing people's perspective and I was encouraging people to get tested. It made me want to do more. To be awarded chokes me up. People said I wouldn't be anything because I have HIV. I proved them wrong.