

**Testimony of Marcquille Johnson
to the Appropriations Committee
Regarding the Department of Social Services budget for Fiscal Years 2012-2013
March 4, 2011**

Senator Harp, Representative Walker, members of the Appropriations Committee, thank you for the opportunity to speak with you today. My name is Marcquille Johnson. I was born with Sickle Cell Disease. Sickle Cell Disease is a chronic disease, in which there is currently no cure. It affects the oxygen in my Red Blood Cells, which causes them to take on the shape or form of an ice sickle or banana. When too many of the sickle cells get trapped in my veins, I have what is considered a pain crisis. Some pain crisis can be treated at home; however, most times I have to become an inpatient. When I am hospitalized, the medicine and treatment I receive, does not treat the pain, it helps me deal with the pain until it subsides.

Another way to explain my pain is to look at a traffic analogy. Rush hour traffic-High pain days. Normal traffic-every day pain. No traffic-no pain, but these days are extremely rare. I have been in and out of Connecticut Children Medical Center since I was about 3 months old (all of my stays have been related to pain or other problems associated with having Sickle Cell Disease). My hospital stays can range anywhere from an emergency (5-10 hours) visit (s), or inpatient stays (1-2 days to 1-2 weeks). The thing about sickle cell pain is that you never know when it will come or how long it will stay.

I have to take a lot of medicine (narcotics, prevention medicine) to help deal with sickle cell pain and other health issues associated with sickle cell. I have to take pain medicine almost every day, but I don't let me being sick or taking medicine stop me from being a normal 17 year old teenager.

However, I have the best health care team possible. Connecticut Children's has provided me with some of the best health care a child can receive. My Hematologist, Dr. Nathan Hagstrom, has treated me since birth. I see him more than I see my friends (sometimes). I consider him part of my family. My mom tells him everything...even the teenager stuff that I do. I also have a great Social Worker, Nancy Caperino; who has always helped my mom and me with advocating, but she also helps me with completing camp applications, getting proper transportation for school, and attending education meetings at school about my disease. When I am in the hospital the doctors, nurses, cleaning staff, volunteers, even the food service staff is always willing to help. The medical staff answers any questions we have.

It is really important that you continue to provide funding to Connecticut Children's because it is the only hospital in Connecticut that is solely designated to carrying for kids, especially children with complex health issues like me. More than half of the kids who need inpatient care at Connecticut Children's rely on the State's HUSKY Plan for their coverage. Since HUSKY does

not pay what it costs Connecticut Children's to provide that care, it could affect the ability of all kids to get the care they need when they need it. The hospital is located in a central location, where parents can easily access health care. The people that work there take real good care of children and make us feel really special.

Thanks for all of the support you provide to Connecticut Children's.