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## **Support for the Connecticut Home Care Program for the Disabled**

March 4, 2011

Dear Senator Harp, Representative Walker and Distinguished Members of the Appropriations Committee,

My name is Doug Jones and I am from Manchester. My wife, Karen, is 60 years old and has been living with progressive multiple sclerosis for nearly 30 years. The progression of her disease has left Karen completely immobile – she can't move her arms or legs. Karen spends her days in one of two positions – in bed or in a power chair, precisely stationed in front of the television by me as I leave for work in the morning, and later, by her personal care assistant before she leaves for the day.

Karen was a stay at home mom, and later unable to join the workforce due to her rapidly developing disability. As a result of this she doesn't qualify for financial benefits through Social Security Disability Insurance. I work full-time and our health coverage is through my employment.

**Karen is enrolled in the groundbreaking state-funded Connecticut Home Care Program for Disabled Adults.** Through this program, Karen receives eight hours of personal care assistance five days a week.

The eight hours of personal care assistance five days a week is a huge support and helps both of us feel that Karen is safer in our home. Nonetheless, the assistance we receive does not sufficiently cover the eleven hours a day that I am away from home at work. When Karen's personal care assistant leaves for the day she cannot move, she cannot eat, she cannot even take a drink of water.

During this time, her safety lies in the hands of a voice-activated phone that the National MS Society was able to purchase for our family and a Lifeline alert system, which I carefully pin to her clothing each morning, my hands shaking from the agonizing thought of leaving her alone.

Please see reverse side...

Due to mounting medical bills we were forced to declare bankruptcy to protect our home. We are living paycheck to paycheck with no savings, desperately trying to keep our heads above water.

I wish I could say that our story is unique, but I've met so many others with multiple sclerosis or similar degenerative neurological diseases who live in this tenuous position. Collectively, we face nearly insurmountable financial pressures and our families are forced to make gut wrenching decisions – like leaving our loved ones at home alone while we work – nearly every day.

Karen is very susceptible to complications and problems from her severe disability. Medically, her need varies from week to week, she may be hospitalized and become very weak or she can have good periods where she is stronger. We need the flexibility that the CT Home Care Program for the Disabled can provide through its care coordination/care management.

Karen was hospitalized early last year and it was recommended that she do breathing exercises to help increase her lung capacity. The care staff is working with Karen on these exercises. Karen is getting stronger and can talk better, and now she keeps the helpers laughing!

Now more than ever, we need the Connecticut Home Care Program for the Disabled. Please preserve this vital program. It is the only option available for younger individuals under age 65 who need ongoing care coordination and home care supports. The program saves the state money by helping to keep individuals at home; where home care is less expensive.

**We hope that we can count on you for your support to maintain the Connecticut Home Care Program for the Disabled.**

Thank you!  
Sincerely,

A handwritten signature in black ink, appearing to be 'A. Jones', written in a cursive style.

On behalf of the Jones Family