WICKER and COLIN PETERSON, for introducing motions aimed at managing the symptoms, not support has resulted in minimal treatment options or a cure since this initial discovery has been minimal. Of the few million dollars are invested in medical research devoted to potential treatment options or a cure since 1987, federal research devoted to Duchenne muscular dystrophy, coordinate that research across federal agencies, and translate discoveries in the lab into improved patient care.

I have seen the human face of Duchenne muscular dystrophy. For decades, the only drug treatment known to extend life, typically by boosting research funding and raising public awareness. Less than 1/2000 of the children born with Duchenne will lose the ability to walk. The deterioration process continues until it ultimately takes the boy’s life, typically by the late teens or early twenties.

Although the gene that causes DMD was successfully identified and isolated by medical researchers in 1987, federal research devoted to potential treatment options or a cure since this initial discovery has been minimal. Of the $20.3 billion allocated for the National Institutes of Health (NIH) during FY 2001, only a few million dollars are invested in medical research specific to DMD. This limited federal support has resulted in minimal treatment options aimed at managing the symptoms, not treating the disease.

I want to commend my colleagues, ROGER WICKER and COLIN PETERSON, for introducing H.R. 717, the CARE Act. This legislation will increase the funding available for researching DMD, direct NIH’s attention to solving this problem, and better educate the public on this tragic disease.

Further, I want to thank the leadership of the Energy and Commerce Committee and its Subcommittee on Health for expediting this matter to ensure that the federal government acts quickly as possible to combat DMD. Finally, I want to thank the leadership of the House and Senate for their strong support of H.R. 717, the Duchenne muscular dystrophy Community Assistance, Research, and Education Act.

Representative WICKER and I introduced H.R. 717, after being inspired by testimonies from our constituents. I am inspired by an extraordinary 9-year-old boy, Jacob, who has Duchenne Muscular Dystrophy.

For those of you who don’t know about Duchenne muscular dystrophy: Duchenne is typically diagnosed in boys between the ages of 3 and 5 years; the disease is characterized by progressive weakness, with a gradual deterioration of muscle capacity, first in the legs, then in the arms, back, lungs, and heart; and children affected by Duchenne typically do not live to see their 20’s.

Currently, Jacob uses a motorized scooter to get around, but soon he will need a ventilator to breathe. There is no treatment for Duchenne muscular dystrophy. The life expectancy of a child with Duchenne has not changed since 1859 when it was first identified. It is time for us to focus our efforts and target funds to Muscular Dystrophy research at NIH and CDC.

I urge you to support H.R. 717.