

approvals of safe and effective Duchenne therapies, but we would like more therapies to be approved in the future.

Duchenne muscular dystrophy is the most common fatal genetic disorder diagnosed in childhood, affecting approximately 1 in every 3,500 male children. The disease results in the gradual loss of muscle strength, usually beginning before age 5. The progressive muscle weakness leads to serious medical problems, particularly issues related to the hearts and lungs. By age 14, over 80 percent of these boys are using wheelchairs.

My work on Duchenne muscular dystrophy began when I was elected to the Senate. It was an issue my dear friend and former Minnesota Senator, Paul Wellstone, championed. Paul was instrumental in getting the Muscular Dystrophy Community Assistance Research and Education Act—or as it is known, the MD-CARE Act—signed into law back in 2001.

The bill dramatically increased investment at the National Institutes of Health for muscular dystrophy research and included funding for the creation of six centers of excellence. In recognition of his work, all of the centers share Senator Paul Wellstone's name. The bill also supported public health policies designed to improve quality of life and boost life expectancy of children and adults diagnosed with muscular dystrophy.

Since passage of the MD-CARE Act, \$500 million has been leveraged for muscular dystrophy research and education programs, half of which is Duchenne-specific. I then led the reauthorization of the MD-CARE Act in 2008, and it passed the Senate by unanimous consent. In 2014, Senator ROGER WICKER and I led the MD-CARE Amendments of 2014, which built upon the progress by ensuring that efforts are focused on the most critical needs of doctors, patients, and researchers. These are important accomplishments, but more needs to be done.

The Food and Drug Administration Safety and Innovation Act of 2012 gave the FDA increased flexibility to grant accelerated approval for rare disease treatments that have proven to be beneficial. The bill also directed the FDA to use patient-focused drug development tools during the drug approval process. The idea is simple: Patient experience should be a factor when the FDA considers a drug for approval. This gives the FDA the opportunity to hear directly from patients, their families, and caregivers about the symptoms that matter most to them, the impact the disease has on patients' daily lives, and their experiences with treatments.

To build upon that progress, Senator WICKER and I introduced the Patient-Focused Impact Assessment Act. The bill would help advocates understand how the FDA uses patient-focused drug development tools and how it engages patients, including those with rare dis-

eases, such as Duchenne, as it reviews drugs and therapies. Last month this bipartisan bill unanimously passed the Senate Health, Education, Labor, and Pensions Committee, bringing us one step closer to ensuring strong patient engagement throughout the FDA review process.

At an FDA meeting on Monday, there was one example of patient involvement in the drug approval process. It was a meeting that broke records. According to advocates, it was the largest gathering of Duchenne families in history. More than 900 members of their community were there. In fact, turnout was so large the FDA changed the meeting location to accommodate everyone.

Many stories were shared during the daylong meeting—stories of hope, stories of progress. Even seemingly small improvements—such as the ability to open a bottle of water on their own or lift their arm a little higher—make a huge difference in the quality of these boys' lives. These small victories have a ripple effect across a lifetime.

Monday's historic event shows the strength of the Duchenne community, the passion of the families, and the hope that treatments are on the horizon. This particular treatment was not approved that day, but we continue to hold hope that change will be on the horizon.

The fight against muscular dystrophy will not be won overnight, but we have already seen incredible progress in the last few years. I am confident that by working together—by bringing families to the table with policymakers and health care experts—we can accomplish some truly remarkable things.

One of the reasons Senator WICKER and I fought so hard to have the FDA officials listen directly to the families is that when you know your child has a disease that is 100 percent fatal, you might take different risks. You might see different improvements in a different way than a medical professional who does not have this experience. We hope going forward this kind of experience and testimony and information will make for better decisions by the FDA.

We need to continue to ensure the FDA has the tools and flexibility it needs to increase the number of safe, effective, and affordable treatments that are available for people with rare diseases. I also thank Senator HATCH, who has done a lot of work with me on the rare disease issue, and we will continue to push for cures for people who have so little hope.

I thank the Chair, and I yield the floor.

I suggest the absence of a quorum.

The PRESIDING OFFICER. The clerk will call the roll.

The senior assistant legislative clerk proceeded to call the roll.

Mr. ISAKSON. Mr. President, I ask unanimous consent that the order for the quorum call be rescinded.

The PRESIDING OFFICER. Without objection, it is so ordered.

#### MORNING BUSINESS

Mr. ISAKSON. Mr. President, I ask unanimous consent that the Senate be in a period of morning business, with Senators permitted to speak therein for up to 10 minutes each.

The PRESIDING OFFICER. Without objection, it is so ordered.

#### VETERANS FIRST ACT

Mr. ISAKSON. Mr. President, this morning at 11 a.m., a big event happened in Washington, DC, on the third floor of this building when all members of the Veterans' Affairs Committee, Republican and Democrat alike, introduced what we call the Veterans First Act—a comprehensive overhaul of the Veterans' Administration to bring about accountability in services to our veterans by the Veterans' Administration. Every member of the committee, Republican and Democrat alike, came to that press conference.

I want to start by thanking Senator RICHARD BLUMENTHAL of Connecticut, who is my ranking member on the committee, for his efforts and his work over the last 10 months to help make this a reality, and each and every member of the committee for the work they did. In the end, we adopted 148 provisions of the Senate to amend, reconstruct, and hold accountable the Veterans' Administration.

I don't know about the Presiding Officer, but every morning when I wake up in Washington, DC, and turn on the TV, whether it is CNN, FOX, or a local station, one of the lead stories is about a tragedy in the Veterans' Administration. This morning, in preparing for this press conference I didn't turn on the TV until after I read my notes. After I read my notes, I turned on the TV, and what, to my dismay, did I see? In Chicago, IL, at the Veterans' Administration hospital, they found cockroaches in the food of our veterans. What kind of accountability is that in the Veterans' Administration? For our veterans to be fed food with vermin in it is ridiculous and crazy.

We all know what happened in Arizona a few years ago when appointments were manipulated, so veterans missed their appointments, and three veterans died. We know what happened in Atlanta, where we had an outbreak of suicide by people who couldn't get to mental health services in time. We know what happened when cost overruns went awry in Denver, CO. When the costs of the hospital got out of line, the Veterans' Administration didn't know how to control it.

Every time we turn around, there is no accountability in the Veterans' Administration, so our committee decided it is our job to see to it that our veterans get what they deserve and what they fought for for us; that is, a Veterans' Administration that delivers on