

U.S. Sen. Harkin: Statement Regarding the Christopher and Dana Reeve Paralysis Act
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Contact: Jennifer Mullin / Kate Cyrul
(202) 224-3254

Washington, D.C. – U.S. Senator Tom Harkin (D- IA) delivered the following remarks yesterday on the floor of the Senate urging the adoption of S. 1183, the Christopher and Dana Reeve Paralysis Act.

The text of the speech is below.

Mr. HARKIN. Mr. President, I come to the Senate floor with a heavy heart and a clear purpose. Last Thursday would have been the 56th birthday of a great actor, a devoted father and husband, Christopher Reeve. Many Americans got to know Christopher Reeve when he put on that blue and red uniform of Superman and acted in so many Superman roles. He was also on television and stage. So we always think of Christopher Reeve as the first Superman.

Then, in May of 1995, Christopher Reeve was involved in an equestrian accident. He was riding a horse and got pitched off the horse. He suffered injuries to his spinal column, starting in his neck, which left him paralyzed from the neck down.

In the years following the accident, Christopher Reeve not only put a face on spinal cord injury for so many, but he motivated neuroscientists around the world to conquer the most complex diseases of the brain and the central nervous system.

Even before I met Mr. Reeve in 1998, I was a big admirer. Of course, I liked Superman movies. Then I watched what he did after he had been paralyzed. After the accident, he could afford the very best doctors and nurses, the best caregivers and therapies. He could have just withdrawn into himself, focused on his own well-being which was a full-time job in and of itself.

Christopher Reeve made a different choice that defined him as a great human being. He chose to become the man whom I first met in 1998 when he first testified before the Senate Appropriations Subcommittee on Labor, Health, Human Services, and Education on which I was a ranking member at that time. I had been chairman before and then Senator Specter was ranking. In 1998, Senator Specter was chairman of that subcommittee. Mr. Reeve came on a mission to give hope and help to other people with disabilities and thus became a kind of real-life hero to people around the world.

Later on, I got to know Christopher Reeve as a friend, someone who had an impish sense of humor, a great smile, was warm and personable. He spent all of his waking time, days, thinking about and getting information about spinal cord injuries, research that had been done, how it was being researched here and in other parts of the world, at the same time finding time to direct a movie.

Christopher Reeve began to inform me and others on the committee that the kind of research we were doing into spinal cord paralysis was disjointed; it was not well put together. Then he

went on a mission to think about, with others--with scientists and researchers and those of us in the Senate and the House--how we might accomplish pulling this research together in a more unified structure.

In 2002, I first introduced the Christopher Reeve Paralysis Act with bipartisan cosponsors. The bill has passed the House twice, but we have never succeeded in passing it here.

As I said, it is a bipartisan bill. It addresses the critical need to accelerate the discovery of better treatments and one day a cure for paralysis. As I said, currently paralysis research is carried out across multiple disciplines with no effective means of coordination or collaboration. Time, effort, and valuable research dollars are used inefficiently because of this problem. Families affected by paralysis are often unaware of critical research results, information about clinical trials, and best practices.

This bill will improve the long-term health prospects of people with paralysis and other disabilities by improving access to services, providing information and support to caregivers and their families, developing assistive technology, providing employment assistance, and encouraging wellness among those with paralysis.

In August of last year, the Health, Education, Labor, and Pensions Committee cleared this bill for full Senate consideration. Two months after that, our colleagues in the House passed the bill unanimously by voice vote. Yet for the last 12 months, this bill has languished in the Senate, as I understand it, due to the objections of one Senator, my friend, the junior Senator from Oklahoma. At least that is what I am told. I could be corrected, but that is what I am told.

In the past, I have heard the Senator from Oklahoma question our role in promoting health legislation because he has said sometimes in the past that too often we get caught up in one cause or another pushed by a celebrity and other worthwhile causes get left behind because they don't have someone famous out there pushing for them. I guess once in a while I might agree with that point. But even though this legislation has Christopher and Dana Reeve's names behind it, it was really written for the thousands of ordinary Americans living with paralysis and spinal cord injuries and their families and friends who pushed the cause of improved research and treatment.

I want to read a couple of stories of Americans today. One story belongs to Marilyn Smith of Hood River, OR. She is one of the many paralysis advocates who volunteer their time through the Unite to Fight Paralysis organization. She took the time recently to share her story with me. I want to read a portion of it for the Record. Here is what Marilyn said:

Paralysis doesn't just happen to an individual, it happens to a family. In December of 2002, our son became a quadriplegic when a careless driver failed to tighten the lug nuts on one of his wheels. It came off and flew into our son's pickup, shattering his cervical vertebra. Our family was thrown into physical, emotional and financial chaos. We have done the best we could after this calamity, but our lives will never be the same. As parents, our greatest wish before we pass on is to see our son's health restored. We have traveled from Oregon to Washington, DC, for 4 straight years to lobby for passage of the Christopher and Dana Reeve Paralysis Act, a well-crafted piece of legislation with bipartisan support that will make a measurable difference in our lives.

I think Marilyn's story underscores the tremendous cost paralysis imposes on families. The

Spinal Cord Injuries and Illness Center at the University of Alabama Birmingham has done a lot of work to quantify that cost. I believe their findings might surprise some of my colleagues.

According to the Spinal Cord Injury and Illness Center, the first-year cost of an injury to the C-1, C-4 vertebrae is upwards of \$683,000, with costs in each subsequent year averaging out at more than \$120,000. Think about that for a moment. That figure represents a cost of personal care attendants, medical treatment and therapy, transportation, and all the necessary modifications made to one's home.

Leo Hallan of Yankton, ND, knows this cost all too well. He has been living with paralysis for the past 32 years. He, too, has a story to tell. I will read a short selection from a letter he sent over the weekend. He said:

I know there is much in life I will never understand, and now near the top of that list are: One, how a single Senator can stop a piece of good legislation; and, two, how some of his colleagues can support those efforts. Failure to act on this legislation is doing great medical harm.

I just have to say, frankly, I am surprised there continues to be an objection to moving this bill. I negotiated this bill with my Republican colleagues before it was marked up in the HELP Committee in July of last year. During the course of those negotiations, we received through Senator Enzi, who is the ranking member of that committee, specific requests to, one, remove authorizations for the titles related to the National Institute for Health Research. In the interest of getting legislation passed, we accepted this change. We removed the NIH reporting provisions in response to concerns that they were duplicative of reporting requirements in the NIH reauthorization legislation. So we took that out.

We responded to all of the feedback from the Department of Health and Human Services and the NIH by incorporating both substantive and technical changes they wanted.

At that point, we were assured there were no more objections, and the bill passed out of our committee with no amendments and no objections. We just passed it out of committee.

So given all of the efforts we made to meet concerns raised by Senators on the other side of the aisle, and given that Senators had an opportunity to file amendments at that time in the committee but chose not to, I had every expectation that the bill would pass the full Senate. Instead, it continues to be held due to one Republican objection. This bill is long overdue for passage.

When I introduced the bill 17 months ago, Dr. Elias Zerhouni, the Director of the NIH, spoke at a rally in support of the bill. They had suggestions on some changes which we did. But he spoke in support of the bill. Here is something Dr. Zerhouni said that day:

So really as the Director of an institution that is committed to making the discoveries that will make a difference in people's lives, I feel proud and I feel pleased. But at the same time, I'm humbled. I'm humbled because in many ways [the Christopher and Dana Reeve Paralysis Act] is the harbinger of what I see as the combination of the public, the leadership in Congress, and the administration and government in our country that is absolutely unique, and humbled because at the same time, I know it contains a lot of expectations from us. And I am at the same time confident that we can deliver on these expectations of NIH, with our sister agencies

throughout the government. But the key thing I would like to provide is an expression of commitment. At the end of the day, if you do not have leaders and champions that look at a problem in its entirety, today in the 21st century, you cannot make progress.

That was Dr. Zerhouni. I wholeheartedly agree with him. You have to look at it in its entirety. Progress is vital in science and biomedical research. It is also important in the legislative process. As Senators, of course, we have a duty to ensure due diligence in considering legislation. That is one of our responsibilities. But to keep this bill from getting an up-or-down vote, despite strong support from both sides of the aisle, and the fact that the House passed it unanimously, I am not certain that is exercising due diligence. I don't know what it is called, but I don't know if that is due diligence.

Brooke Ellison of Stony Brook, NY, is another passionate advocate. She was paralyzed from the neck down when she was 7 years old after she was struck by a car while walking home from the first day of school. She is now 25 years old. In the years since her accident, she has graduated from college--Harvard--with an undergraduate degree and a master's degree, and founded the Brooke Ellison Project for those facing paralysis and adversity, and she asked me to pass along these words.

I have seen up close and in person how very quickly any one of our lives can change and we find ourselves facing challenges unlike anything we may have expected. Eighteen years ago, I learned this lesson in a personal and profound way. Yet each day, an increasing number of people find themselves in similar circumstances, and we need to do all we can to alleviate their suffering. Christopher Reeve lived his life as a testament to helping to reduce the challenges people suffering from paralysis face. The Christopher and Dana Reeve Paralysis Act is critical to changing the fate, and sometimes even dire conditions, that millions of people face. And the events in my life have shown me all too clearly how essential it is to be passed.

I wish to be clear; by putting this bill on hold, we are also putting Brooke Ellison and Leo Hallan and other people living in paralysis on hold. It tells the more than 400 Iraq war veterans who have returned with spinal cord injuries that they are on hold. It puts the needs of Bethany Winkler from Yukon on hold. She has been paralyzed for 7 years, since falling in an accident. She has taken the time to come to Washington to lobby for this legislation. I met Bethany in the past, and I can testify to what a passionate and effective advocate she is for the cause of paralysis research and care.

Although we often find ourselves on different sides of the table, I wish to say publicly I respect the fact that Senator Coburn believes strongly this legislation inappropriately grows the size of the Federal Government. I have heard that stated. I see my friend is on the floor, and he can state it if he wants. But if that is the case, I wish to say I disagree with that assessment. I am on the Appropriations Committee, sure, but I am on an authorizing committee as well, and this legislation appropriates no money for paralysis research. It doesn't appropriate any money for care or quality-of-life programs. It simply says we authorize funding for programs. So they still have to be funded through the regular appropriations process.

So I come down to the floor with renewed hope. This past week, the Senate passed several bills by unanimous consent with new authorization for Federal spending. Two of those bills, the Drug Endangered Children Act and the Emmett Till Unsolved Civil Rights Crime Act, which were also being held up, and again were authorizations for appropriations, received unanimous consent and were passed. So I have come to the floor today, and as soon as I finish, in another

page or two, I will ask unanimous consent that the Christopher and Dana Reeve Paralysis Act pass.

But I am going to give two more cases. One is from Donna Sullivan, another of the many concerned advocates for paralysis research and care. Donna is fighting not for herself but for her son, and here is what she said:

Three years ago, my son was the lone survivor of an airplane crash. His injuries were extensive, and my heart literally felt as if it was broken. After numerous operations and procedures, under the care of well-trained doctors in three States, he has overcome all of his injuries except for one, it is his spinal cord injury, which waits for science to move forward and allow him further recovery.

Together, we have attended research symposiums and visited our legislators in Washington, DC, to share our story and the promise that research holds. It is our hope that the Senate will join others who understand the potential and release this bill. When you understand the potential paralysis research holds, it is difficult to ignore, and it is difficult for me to accept that some do.

Christopher Reeve spoke up passionately for people such as Donna Sullivan and her son. Christopher Reeve's untimely death in 2004 robbed the paralysis community of its most passionate and effective advocate. As we know, his widow, wife Dana, continued her husband's quest until her untimely death in 2006 of lung cancer. Across the country, thousands of ordinary Americans, whose lives have been touched by paralysis, have taken up Christopher and Dana Reeve's advocacy work at great cost to their health and wealth.

Well, I have one last story I have to share with you. It has to do with a young man--a big kid; strong. His dad had been in the Navy in World War II and imbued that in each of his kids. Each kid went in the military--different branches. But this one kid, Kelly--big Irish kid--he went in the Navy. He went in the Navy. He went to work on an aircraft carrier. He was one of the launch people, an enlisted guy on the deck of an aircraft carrier.

They were cruising off the coast of Vietnam. Unbeknownst to Kelly, on one of the planes--it was an A-6 Intruder--the pilot had run up his engine. The intakes on an A-6 are on the bottom. They are big intakes. He was not supposed to have run up his engine, but he ran up his engine to 100 percent of power. Kelly, doing his job, got too close to the intake and got sucked into the intake. He had a hard hat on--his Mickey Mouse ears and his hard hat on--and evidently the pilot, through later investigations, saw something going wrong with his engine, heard a thud in his plane, and pulled the power back. Someone saw Kelly's feet sticking out of the intake, and they got people up there and rushed him down to the infirmary on the ship and then put him in some kind of traction thing, got him off the ship, and got him back to the States.

I will never forget the day my sister called me about Kelly. It was my nephew. When my sister called me, I was a Member of the House of Representatives, and she called me up to see what I could do to help. She was extremely distraught, as you can imagine. Kelly was 20 years old and had his life ahead of him. So I went to work, as any Congressman would, for my family, and I got him in at the VA hospital out in California, near Stanford, and that is the first time I flew out to see him. He was quadriplegic at the time. He couldn't move anything.

I can remember walking in there and seeing this kid--and I don't mean to be overly maudlin

about this, but you see, I was a Navy pilot. I used to fly my plane around a lot of times, and these kids always looked up to their father because he was in the Navy and I was in the Navy. I was a Navy pilot. I still have pictures of my jet and young Kelly as a kid sitting in the cockpit of my jet with my helmet on dreaming that someday he, too, would do something such as that. So I kind of felt a lot of responsibility for this because I had encouraged him to get into the Navy, to go into aviation, to do things with airplanes.

I will never forget the first time I saw him lying in that hospital bed at Stanford--I think that is right, the Stanford VA hospital--and the look on his face. I mean, this kid was scared. He couldn't move anything, and he was wondering what was going to happen to him.

Well, he had good medical care, and the good news is that over some years he actually got the use of his arms back, through sheer will and determination. And through those years he then went back to school. I remember how tough it was for him, using a wheelchair to get around on campus. That was before the Americans with Disabilities Act. That was before we had ramps and widened doorways and things such as that. This was in the 1980s when he was going to school.

I remember his father building him ramps and stuff so he could get in and out of places and learn how to live. Well, that happened 28 years ago--28 years ago. Now, the good news is Kelly is alive and well. He lives by himself, in his own home, and has a van that has all these automatic lifts that put him into the van so he can drive himself around. He can't use the lower half of his body, but he can drive around.

He started a small business and he is very self-sufficient. I saw Kelly--well, whenever the Democratic Convention was--because he lives in Colorado, and so I went to see him. We were talking about this and that, a lot of things, and I can't begin to tell you what a profound effect Christopher Reeve had on my nephew's life. It seemed as though all of a sudden there was someone like him, who was big and strapping and full of life, with a lot of energy, and then one accident and that is it. So I could see Kelly could identify with someone such as a Christopher Reeve, a healthy, strong, vibrant man, and suddenly one accident and that is it. So he followed him. Kelly is on the computer, on the Internet, and he follows research all the time. During this period of time in the late 1990s, he became more and more encouraged by what Christopher Reeve was doing and how he was pulling all this stuff together. He kept asking me about it: What are you guys going to do? Are you going to pass this? Are you going to do something about paralysis research? Kelly follows this today to the nth degree.

Then Christopher Reeve passed away, and then his wife. I saw my nephew Kelly out in Colorado last month. Once again he asked me, he said: Are you going to get that bill passed or not?

I said: I don't know. I will try. I am still trying.

Of course he knows all about this. He knows it passed the House. He follows all this. He just wondered what the problem was.

I said: A person has a hold on it.

Can't you bring it up, do this?

I don't know if we can bring it up or not--go through cloture and debate and all that kind of stuff. I don't know. He reminded me it passed the House. I said: I know that, it passed the House unanimously. It passed out of our committee.

So I told Kelly when I saw him in August: We will come back in September and I will try another go at it and we will see what happens. I hope we get it passed.

Here we have the medical community, in the personage of Dr. Zerhouni, saying this does what we should be doing, bringing everything together, coordinating it. It authorizes appropriations but doesn't appropriate any money.

I can tell you, it is not just because there was a famous person behind it. There are people such as my nephew Kelly all over the United States who are wondering, are we going to pursue this? I don't like to give anyone false hope. My nephew is a realistic person. He has lived with this for 28 years now. But he still believes strongly that we ought to be pushing the frontiers and that we ought to be doing everything we can to promote research, of course--obviously into paralysis, because that is what affects him. If anybody wants to talk about this and what needs to be done, he can talk about it at greater length and in more depth and understanding than can I.

I was not going to do this until my colleague from Oklahoma came to the floor. I see him here. All I say is I hope we can move this bill. I am hopeful, after looking it over and understanding we do not appropriate any money, and looking at what we did with a couple of other bills earlier, we can get this bill through. I will be glad to engage in any colloquies such as that.

UNANIMOUS CONSENT REQUEST--S. 1183

I am constrained to ask unanimous consent the Senate proceed to the immediate consideration of Calendar No. 326, S. 1183, the Christopher and Dana Reeve Paralysis Act, that the committee substitute amendment be agreed to, the bill as amended be read a third time and passed, and the motions to reconsider be laid upon the table, with no intervening action or debate.



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