

ACT FOR ALS ACT

Mr. COONS. Mr. President, I rise today to join with my colleague the Senator from Alaska in celebrating some good news. Every now and then, something really good happens here in the Congress of the United States.

Many of us know the story of ALS, a particularly cruel and brutal disease, a disease that attacks the body but not the mind and whose victims, while they steadily lose their ability to control their muscles and their movement, suffer a sort of living death that, until you have seen it up close, it is hard to appreciate just how cruel this disease is.

Last week, 423 of our House colleagues, Members of the House of Representatives, voted to send the ACT for ALS Act here to this Senate. And last night, we here in the Senate unanimously sent that bill to President Biden's desk for his signature.

I have to start, I want to start by thanking my dear friend and colleague the Senator from Alaska. She has been a tireless, passionate, capable advocate, and without her this would not have happened. For those who question whether bipartisanship can still deliver results that matter, this Senator, this bill, this moment proves that it can and it does.

We are grateful to our lead cosponsors over in the House, Congressman QUIGLEY and Congressman FORTENBERRY.

Frankly, the story behind this moment is the incredible advocacy of the ALS community. They are the reason that the bill got drafted, the bill got introduced, the bill got marked up, the bill passed the House, and that here in the Senate some obstructions were overcome with remarkable force and swiftness. I am just briefly going to mention the tenacity and the strength and the capability of some of the folks who have been my role models in this work, and then I am going to yield to my friend and colleague from Alaska, and she will also speak about it.

I just do also briefly want to say that ACT for ALS is not just some resolution. It is not just some commemorative act. This will deliver \$100 million through a newly authorized FDA rare neurodegenerative disease grant program. It will fund critical research. It will improve coordination between the Federal, academic, and private sector researchers. And more than anything else, it will give people hope.

When I think of this work, Dan Tate is the man who first comes to mind, and Dan, like me, is a graduate of Amherst College and a spirited and capable and soulful person—one of Washington's most skilled lobbyists, someone who worked in the Clinton administration and worked for a Member of the House—and his personal advocacy has meant a huge amount to me, as has the engagement by Brian Wallach and so many others.

And I have a half dozen other folks of whom I want to speak, but, first, I

think simple decency suggests I should yield the floor to my friend and colleague from Alaska.

The PRESIDING OFFICER. The Senator from Alaska.

Ms. MURKOWSKI. Mr. President, as my friend from Connecticut has pointed out, there are—

Mr. COONS. Point of personal clarification: Delaware.

Ms. MURKOWSKI. Oh, my goodness, my soul.

Mr. President, may I strike that erroneous introduction?

Mr. COONS. Born in Connecticut.

Ms. MURKOWSKI. I thank my dear friend from Delaware—always Delaware—but truly a friend; a friend on many different issues, but a man whom I have come to know is motivated not by the politics of what goes on in this body but by the passion and his interest in doing good, doing good policy and doing good things for people.

And what we are speaking to today, recognizing the significant passage of the ACT for ALS Act that happened last evening unanimously, as he has pointed out, that this is not only good for the body, if you will, to say we were able to move good legislation forward, good policy legislation forward, but this is a gift. This is a gift of hope for those who live with ALS, for those families who are part of that journey of those who live with ALS.

ALS, as Senator COONS has noted, is an awful, awful disease. Some would suggest, and I certainly would, that it is probably the worst disease to be afflicted with, when your body literally closes in on you while your mind is still active and vibrant.

I have a very personal connection to ALS. I think many of us have very personal connections to ALS. I wish that we didn't have these personal connections to this hideous disease, but we do, and that connection allows us to learn and understand a little bit more about it.

And I think the most heartbreaking thing that I realized, when my family member was diagnosed with ALS, my cousin's husband, was that there was no treatment. There was no hope. There was no hope.

I am not suggesting that the ACT for ALS is the end-all be-all. I wish that we could stand here and say that. It is not, but what it is, is a glimmer of hope.

I want to read just a couple sentences from an email that I received last evening when I was able to share this good news that this bill was passing unanimously through this body, and my cousin Jen says:

The passage of this bill will bring real, tangible hope to people living with ALS and those to be diagnosed. In this ALS world, right now, there are no effective treatments. All we have is hope. This bill changes everything. It will bring real, tangible hope and treatments to people living with ALS. We have never had that in this disease.

We haven't found the cure, we haven't found the treatment, but what

we are providing today is that first step forward, a tangible step forward to the hope, because every day—every day—those who are living with ALS and their loved ones, who live through this disease with them, have to hope and pray every single day that today is going to be the day. Today is going to be the day that we can slow this, that we can halt this.

There are some extraordinary heroes that have been involved with this fight over the years. They are everyday people. They got into it not because they were paid lobbyists. Most of them got into it because they had lived through ALS. They had lost a loved one to this disease, and rather than to give up and give in and be too tired to carry on, they said: I am going to commit so that no other families have to feel this helplessness.

And so you have got some amazing people. You have got a group out there, the I AM ALS team—extraordinary, extraordinary advocates.

Senator COONS has mentioned Brian Wallach and Dan Tate. The two of them lead I AM ALS. You have got Megan Miller, Deb Paust, Sandy Morris, Christa Thompson, Nicole Cimbura, Becky Mourey, Michael Lecker, Shelly Hoover, Michelle Lorenz, Mayuri and Mayank Saxena—so many, so many more who were part of that effort.

The I AM ALS organization, working with the ALS Association, working with the Muscular Dystrophy Association and so many others were so critical in moving this forward. Think about what happened.

This was introduced over here in the Senate. We looked this up. It was May 25. May 25. And to get over 60 cosponsors in the U.S. Senate on any kind of a measure—I wish that the Senator from Delaware and I could say that we single-handedly got every single one of those cosponsors, but it was these advocates. It was these grassroots individuals. It was everybody that I just named—Dan and Megan and Jenny and Deb and Sandy, who made these calls, who were relentless.

And when the politics did intervene, they were unleashed and passionate in their advocacy. And I think this is a good lesson to us, that when those who are intimately and passionately involved, that you can make a difference, you can move legislation. You can move mountains.

The last thing I want to say before I turn back to my colleague here is that there are a lot of people who are not part of an organization but who have just felt compelled to speak up.

We heard voices from around my State: Marcel from Sitka; Douglas from Anchorage; a gentleman by the name of Mike, also from Anchorage. The calls, the letters, the emails that we got—I know all of our colleagues received the same as well.

So this, again, was an effort that was so personal to so many, but the leadership that I think we saw come together with Brian Wallach, his wife Sandra—

they were the founders there of I AM ALS.

Brian was only 37 years old when he was diagnosed with ALS—37—so super young. And he was told 6 months: You have got 6 months to live.

He is a father to two little girls, and he just said: Got to keep fighting. We have got to keep fighting for a cure—a cure that will allow him to raise his daughters with his wife.

And I think it is fair to say that, 4 years later now, Brian is just as determined, just as tireless an advocate for ALS and the ALS community.

So, again, I think about people like Brian and Dan, my cousin Jenny, who lost Pat to this awful disease in 2013. He lived with ALS for 8 years. Our family lived with ALS for those 8 years.

And so the advocacy continues because of the passion for so many who have lived through a life that is almost difficult for us to imagine.

And as they have come out of losing a loved one to a disease like this, to know that they are willing to carry that flag, that they are willing to commit their time, their resources, and everything that they have so that others don't go through this, we honor them. We honor that commitment.

I am so pleased to be able to work with my partner on this and to know that this was a good success, but we are going to need to be doing more, and I will be doing it with him.

I yield to my friend from Delaware.

Mr. COONS. I want to express my gratitude to my friend and colleague from Alaska.

It is, indeed, a deep well of darkness into which a family is cast when they receive a diagnosis of ALS.

My own awareness of this disease and its dread consequences is rooted in a number of cases that came to me and my extended family now quite a few years ago.

My brother is with us here in the Chamber today, and his dear friend Dan Loftus passed through ALS, and I remember the pain that this caused him and the depth of that loss.

A friend of mine from Delaware, Alex Snyder-Mackler, first shared with me his father Scott's diagnosis with ALS, now 20 years ago. And year after year, as many of us would gather in Newark and run a 5K and do a fundraiser for some sort of research, for some sort of hope, his father Scott slowly slipped away.

I talked to Alex this morning and was reminded of how much this means to those families who have come through this.

Max Walton, a dear friend of mine in the bar in Delaware, and his father—just an unbelievable character, a great and funny and creative and capable man who built a family business and then slipped from us through ALS.

ALS was first known to America when Lou Gehrig, an outstanding baseball player, got it. And he is still famous for his "I am the luckiest man in the world" speech, when he announced his retirement from baseball.

But 80 years later—80 years later—it is still a mystery to science and a death sentence to those who get this dread diagnosis who are often told they have just a few short years to live. This bill in their name and honor confronts this stark reality and makes progress.

I cannot close without thanking two other people—Meghan Taira, who is tireless here on the floor in helping move and prioritize things working for Leader SCHUMER, who lost her own mother, Ellen Taira, to ALS, and last, if I could, for someone whom I am not worthy of.

I have a legislative director, Brian Winseck, who is a spectacular human being, whose skill and persistence and diligence and dedication for my side of this kept us at it every day. His father Joseph was a high school civics teacher, and the loss of his life through ALS is something from which Brian has made so much good for others through his role in helping shepherd this through my office.

What Senator MURKOWSKI and I are showing for a moment here today is an answer to a question so many families, so many people living with ALS, so many who have lost a loved one to ALS wonder in the dark moments: Does anyone care? Does anyone see this? Does anyone know what is happening? Is anyone going to do something about this?

The families and those who are living today with ALS and those who have lost someone to ALS need to know that your advocacy is heard, that it moved a mountain here in the Congress, and it will begin moving resources and energy and dedication.

We are at the beginning of the next step of this journey, but, as my dear friend, under whom I served many, many years ago in a very dark time in the history of South Africa, said: Hope. Hope is being able to see that despite all the darkness, there is still light.

Bishop Desmond Tutu spoke that to the people of South Africa struggling in a very dark time and place.

To the families, the survivors, and those who are living with ALS, my dear friend from Alaska and I and the folks in our families and on our staff and in the many countless teams of advocates around this country hope that this holiday season, that this Christmas, that this year, we have brought you some glimmer of the light that you have brought to us.

With that, 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.

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

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

TRIBUTE TO LIEUTENANT COLONEL RANDI LUDINGTON

Ms. MURKOWSKI. Mr. President, I think here in the Senate, so many of us

have the privilege to occasionally host military fellows, congressional military fellows, and I would like to take just a minute here to recognize the great work of a former member of my staff, Air Force Lt. Col. Randi Ludington. She spent the last year working in my personal office as part of the U.S. Air Force congressional fellowship program. She just concluded that fellowship program just last week and has moved on to her next assignment, but I think it is important to be able to publicly express my appreciation for the work she did over the last year and really for her service to the Nation overall.

For 17 years now, Randi has served in the U.S. Air Force. She was first an enlisted financial technician before she earned her commission and worked her way up to the rank of lieutenant colonel. She had a level of exposure before coming to my office certainly. These experiences of being in different places around the world, leading airmen, advising commanders, really proved invaluable when she came to provide her expertise in my office.

Not only has she spearheaded efforts legislatively and prepped me for meetings and hearings, she really became a key member of our team, working with Alaskans, working with counterparts back here, but really serving them just as she would serve her own troops.

When we were faced with a very chaotic withdrawal from Afghanistan, Randi was one of those who was really burning the midnight oil. She was putting in long days and long nights, answering calls from constituents and veterans who were seeking help. She was doing just that. She was there around the clock, sometimes just listening, offering words of support; other times just really helping to synchronize the efforts between people on the ground in Kabul, lining them up with Departments and Agencies here in Washington, doing everything she could to try to help facilitate the needs of so many who were so desperate to get out.

In the end, Randi was honored by an Alaska Native Corporation, the Goldbelt Corporation. They had been engaged in an airlift, a significant airlift, and she was recognized by Goldbelt for her dedicated efforts assisting them throughout that whole ordeal. So it was nice to know that she had received not only the recognition and thanks from those here, fellows back in Alaska, but also the broader international recognition.

So I take this moment to just express my thanks to Randi. It was a pleasure having her in my office. She has a fabulous family. It was a great pleasure to be able to get to meet her husband Brad, an Air Force veteran himself. They have three super-great little kids: Charlee, Ryan, and Graham.

I wish Randi and her family nothing but the best as she moves forward with her military career.

I feel very fortunate that we get some of our Nation's best, who are able