



CHRISTOPHER & DANA
REEVE FOUNDATION
TODAY'S CARE. TOMORROW'S CURE.

The inaugural Reeve Summit 2020 in Washington, D.C., allowed those with SCI to connect with their community.

Care & Connection

Christopher Reeve and his wife, Dana, spent years lobbying, funding, hosting benefits and programs for people dealing with life-changing spinal-cord injuries (SCI). The late couple wanted to give people with SCI hope through the Christopher & Dana Reeve Foundation and show them they're not alone.

Like its founders did before, the foundation is looking toward the future, too.

Twenty-five years after Reeve's SCI, the foundation hosted its inaugural Reeve Summit in late-February, which focused on bringing people together to show where they are in finding a cure, what the future could hold and to help the SCI community connect in Washington, D.C.

"Because when the calls first come in, you feel someone's loneliness. You feel their burden. You feel the experience of what people are going

through, and sometimes that feels voiceless or hopeless. And it's hard to reach people during those moments and where they're residing," says Peter Wilderotter, Christopher & Dana Reeve Foundation CEO and president. "But what we see is those families and those living with paralysis, one day something sort of stirs and a light that they thought was extinguished surges and sings anew. And rebirth comes like hero, like Superman, and lifts people up — and that's what we want to do here today, connecting with care, cure and community."

Connecting With Each Other

More than 200 people, including 50 wheelchair users, attended Reeve Summit 2020 Feb. 26–28 at the Marriott Marquis hotel in downtown Washington, D.C.

*by John Groth
photos courtesy
of the Christopher
& Dana Reeve
Foundation*



Christopher & Dana Reeve Foundation CEO and President Peter Wilderotter addresses Reeve Summit 2020 attendees during the Feb. 27 opening day at the Marriott Marquis hotel in downtown Washington, D.C.

and relationships, women living with paralysis, pain management and travel tips.

Paralyzed Veterans of America National Advocacy Director Susan Prokop attended the summit and went to a handful of sessions. She was impressed with guest speaker Julie Hocker’s insights about employment and people with SCI and enjoyed listening to former Sen. Tom Harkin (D-Iowa).

But most of all, Prokop valued the opportunity to learn about the threads, topics and agendas of those who live and deal with SCI on a daily basis.

“This conference enables policy wonks or people who just deal with policy to actually hear the lived experiences of people with SCI, so as to connect that personal experience with the policies that affect their lives,” Prokop says. “I re-learned the absolutely critical importance of connecting those lived experiences with government policies, research agendas, programs and services that are set in motion. How are they actually having a positive impact on the lives of people living with spinal-cord injury?”

Harkin Makes A Statement

Harkin was one of the speakers who made an impact on attendees.

He planned on making a provocative statement during his opening day keynote address. And he did — comparing what’s going on with the housing market today for persons with disabilities to redlining.

“Redlining was what was used to demark certain areas of acuity where persons of color could not buy a house. Rampant all over. Well, a house or a condo built with stairs and narrow doors are as much of a redline against persons using wheelchairs as a redline was against persons of color,” Harkin says. “I believe making housing in the future accessible should be a top agenda item for the next Congress and the next president.”

Harkin proposed changing the current tax law, saying that after a

Attendees ranged from organization founders and directors to registered nurses, recreational therapists, doctors, social workers and government employees. Thirty-seven states and nine countries, including the United States, United Kingdom, Congo, Ghana, Ireland, Israel, Canada, Sweden and Japan, were represented.

The summit focused on five key aspects — advocacy, caregiving, employment, health and wellness and research — and featured sessions on topics such as the future of SCI research, aging with paralysis, navigating employment, intimacy

Former Sen. Tom Harkin (D-Iowa) was one of the keynote speakers during the late-February Reeve Summit 2020 in Washington, D.C.



period of about five years, all new or remodeled housing units that would otherwise qualify for a tax deduction on interest or mortgage payments must be built with American with Disabilities Act (ADA)-compliant accessible features in order for the buyer to take advantage of the deduction.

He thinks it would help make apartments and houses accessible to all, including the elderly, people in wheelchairs and others with disabilities.

Harkin, who introduced the ADA into the Senate, has advocated for disability rights and people with SCI for more than 40 years. It's a personal connection for him. His 65-year-old nephew, Kelly McQuade, served in the Navy and was later in an accident that paralyzed him from



Attendees view a seminar during the late-February Reeve Summit 2020 in Washington, D.C.

the waist down. He watched him grow up before the ADA and after it, and he says it's no comparison.

Harkin also focused on another aspect of the ADA — living with it. Harkin says there are an estimated 18,000 new cases of SCI in the U.S. each year, between 1,500 and 2,000 babies born with spina bifida, plus another 170,000 people living with spina bifida in the U.S. This year is the 30th anniversary of the ADA, and he says advocates have made some ground but not enough.



From left: Maggie Goldberg, Victor Calise, Cody Unser, Bernadette Mauro and Taylor Price share how Christopher Reeve impacted them and what they think the next 25 years will look like for those with spinal-cord injury and disease.



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“But you all know there are four goals of the ADA — full participation, equal opportunity, independent living, economic self-sufficiency. In the 30 years since we’ve passed it and signed it into law, I think we’ve made progress in the first three of those goals. Not complete, for example, independent living. But we’ve made some progress to those first three,” Harkin says. “But we

Others care. There’s a community of people willing to help. Just try to connect.

“The Reeve Foundation has created this summit so you can see that you are not alone, that you’re not by yourself,” Roberts says. “And it’s all about coming together to connect, and I think that is beautiful.”

Roberts was diagnosed with breast cancer in 2007 and struggled about whether to share the diagnosis and how much to tell the television audience. But her mom, the late Lucimarian Tolliver Roberts, gave her some sage advice — she told Roberts that she had health care, a good job and to make her mess her message. And she reminded others to do the same — to talk with others, share their stories on social media or just try to connect.

“If I don’t take the time, I won’t think, ‘Why was this placed in my path? What am I challenged with and what am I supposed to share with others?’” Roberts says. “So, I decided to share with as many people as possible what I was going through.”

Five years later, Roberts was diagnosed with myelodysplastic syndrome, a rare blood disorder affecting bone marrow that is sometimes referred to as pre-leukemia. But she beat that, too, thanks to a transplant from her sister, Sally-Ann Roberts. Roberts’ mom died that year, too.

Roberts was also reminded of a story she worked on about Janne Kouri. In 2006, the then-31-year-old was playing sand volleyball when he jumped into the ocean between games. He hit a hidden sandbar with his head and was paralyzed from the waist down. He started using a wheelchair, and in May 2009, he took his first steps with a walker while Roberts was there.

Three years later, Kouri told her about how he’d stood for the first time on his own, without a walker, and later she and her producer helped Kouri surprise his wife, Susan Moffat, with the dance she never got at their wedding.

“Dreams we have for ourselves may not quite look like what we think they will,” Roberts says. ■



As a cancer survivor, Robin Roberts, host of ABC’s *Good Morning America*, wanted to remind people with spinal-cord injuries that they don’t have to go through their circumstances alone.

have barely have moved the needle on the last one of employment of persons with disabilities and competitive, integrative employment. The unemployment rate of adults with disabilities is the same as it was 30 years ago. Over 60 percent of adults with disabilities are not in the workforce. This is a blight on our national character.”

Sharing With Others

For people with SCI, accessible housing and employment are just a part of life’s struggles. And life, sometimes, doesn’t go as planned. Robin Roberts understands.

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