

Spinal Cord Leaders Council

News Release

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Spinal Cord Leaders Council Celebrates Signing of
Christopher and Dana Reeve Paralysis Act; Pledges Continued Support

April 6, 2009 – The signing into law of the Christopher and Dana Reeve Paralysis Act this week is a major landmark for all Americans living with spinal cord injuries or disorders (SCI/D), and for the SCI/D community as a whole. After years in the making, the bill was passed by the U.S. Senate on January 15 and the House of Representatives on March 25 and signed into law by President Obama on March 30.

“We applaud the efforts of the Christopher and Dana Reeve Foundation in leading the effort on this bill, as well as the contributions of a wide range of organizations and individuals in supporting the bill over the past several years,” said Paul J. Tobin, chair of the Spinal Cord Leaders Council (“the Council”) and president/CEO of United Spinal Association.

Enactment by Congress of the Christopher and Dana Reeve Paralysis Act to promote spinal cord paralysis research and to improve SCI/D rehabilitation has been a key component of the Council’s public policy platform.

Tobin said the significance of the Christopher and Dana Reeve Paralysis Act is underscored by the depth and breadth of the support behind it throughout the SCI/D community. He believes that support was key to getting the bill passed, and will be just as important to the appropriations process.

“Authorization of the funding is a real milestone, historic in this case,” said Tobin. “The council will continue its support to ensure that funds are appropriated and that those appropriations are made in way that best promotes collaborative research, rehabilitation and a range of quality of life initiatives for all Americans living with spinal cord injuries and disease.”

The Council intends to continue its staunch support for the bill as it moves into the appropriations process to best ensure that the bill meets its goal of improving the lives of people with spinal cord injuries or disorders.

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The Act's three primary components will enhance paralysis research, rehabilitation and quality of life programs:

Paralysis Research - Expands research on paralysis at the National Institutes of Health (NIH). This will encourage collaborative research by connecting scientists conducting similar work to further enhance understanding and speed discovery of better treatments and cures.

Paralysis Rehabilitation and Care - Builds on research to enhance daily function for people with paralysis, including a Clinical Trials Network to measure effectiveness of certain rehabilitation tactics and encouraging shared findings on paralysis to improve rehabilitation.

Improving Quality of Life for Persons with Paralysis and Other Physical Disabilities - Works with the Centers for Disease Control and Prevention (CDC) to improve the quality of life and long-term health status of persons with paralysis and other physical disabilities.

"This is very exciting news and a huge leap forward for people living with paralysis, the professional community of therapists, doctors and researchers and the Christopher and Dana Reeve Foundation who worked tirelessly pushing this act to become law," said John W. McDonald III, M.D., Ph. director of The International Center for Spinal Cord Injury at Kennedy Krieger, Hugo W. Moser Research Institute. "As one of Chris' doctors, I'm overjoyed to know this bill will fulfill his dream of allowing for the greater dissemination of information and expanding opportunities for research and application that significantly improve the quality of life and long-term health for those living with paralysis. With Christopher's forward vision, drive and extraordinary personal progress we were able to prove that Activity Based Restorative Therapies optimizes the recovery of physical function and recovery across the continuum of life. Christopher was a hero to me and I'm grateful for his work and the continued work and commitment of the Reeve Foundation, the disability community and the medical profession in advancing research that will dramatically change millions of lives."

"The Miami Project to Cure Paralysis and The Buoniconti Fund to Cure Paralysis are delighted to hear the announcement of the passage of the Christopher and Dana Reeve Paralysis Act," said Marc Buoniconti, president. "Passage of this bill truly honors the legacy of both Chris and Dana and their passion to finding a cure for spinal cord injury. This bill will speed up the day that a cure for paralysis will be found and improve the quality of life for all those living with a spinal cord injury."

The Spinal Cord Leaders Council is comprised of leaders from various organizations that advocate for, treat or conduct research on behalf of people with spinal cord injuries and disorders. This non-partisan group promotes legislation, regulations and policies that will have a positive effect on the quality of life of people with SCI/D. For more information regarding the Spinal Cord Leaders Council, please contact Paul J. Tobin, chairman, at 800-404-2898, ext. 203 or email to ptobin@unitedspinal.org, or visit www.spinalcordleaders.org.

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