

Congressman Dan Burton Receives SBA Congressional Champion Award

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In August, Spina Bifida Association (SBA) Chair Joyce Jones and her daughter Lisa, who has Spina Bifida, presented Congressman Dan Burton (R-IN-5th) with the SBA Congressional Champion Award. Joyce and Lisa, who live in the Congressman's district, represented SBA in this important meeting, during which they delivered the award and thanked Mr. Burton for his support of the Spina Bifida Community. During the award presentation in the Congressman's Indianapolis office, Joyce and Lisa expressed deep appreciation to the Congressman for his long-standing commitment to preventing Spina Bifida and helping to improve the quality of life for the tens of thousands of individuals nationwide who live with this challenging birth defect.

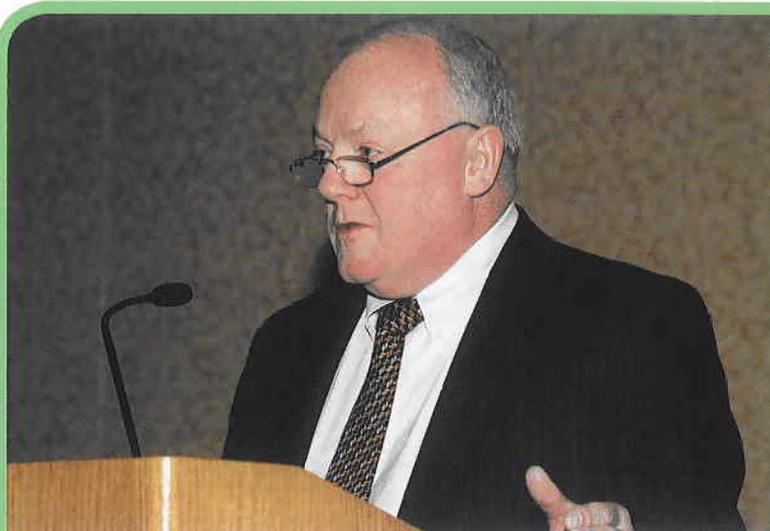
Upon learning that he was to receive the award, Mr. Burton said, "I am most appreciative and honored by this award. Spina Bifida Association and its leaders, such as Joyce and Lisa Jones, do important work to improve the lives of individuals with Spina Bifida, and I am pleased to contribute to their efforts. Unfortunately, Spina Bifida still remains our nation's most common, permanently disabling birth defect which means we still have so much more to do to prevent and reduce suffering from this devastating condition. As long as I am privileged to represent my Hoosier friends and neighbors in the House of Representatives, you have my firm commitment that I will never give up the fight to end Spina Bifida forever and to improve the quality of life for people living with it."

Following the award presentation, Joyce reported that the Congressman was "truly honored to receive the award" and that he and his staff were interested in learning more about the challenges of living with Spina Bifida and hearing about how they can continue to support SBA and its public policy priorities.

Congressman Burton, currently in his 14th term in the U.S. House of Representatives, serves on the House Bipartisan Disabilities Caucus and is an active member of the Congressional Spina Bifida Caucus. Mr. Burton has played an integral leadership role in advocating legislative, regulatory, and programmatic initiatives that seek to improve quality of life for individuals with Spina Bifida. Specifically, the Congressman has helped increase funding for the National Spina Bifida Program and garnered bipartisan support for the creation and funding of the National Spina Bifida Registry, which will improve the quality of care for—and the health and well-being of—people with Spina Bifida. SBA Board Member Donna Jones is a staffer to Congressman Burton and joined Joyce and other SBA leaders in officially thanking Congressman Burton and his staff for their steadfast commitment to improving the lives of individuals with Spina Bifida and other disabilities.

SBA looks forward to continuing to work with Congressman Burton and his colleagues on the Congressional Spina Bifida Caucus to advance policies and programs that will enhance the lives of those with—and affected by—Spina Bifida.

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IN HIS OWN WORDS

Alex Brodrick served two three-year terms as Chair of Spina Bifida Association's Board of Directors. In 1999 along with co-founder Hal Pote, Alex launched the Spina Bifida Foundation (SBF), a supporting organization and partner of SBA, and he currently serves on its Executive Committee. Alex lives in Novi, Mich., where he is President and CEO of Volunteers of America Michigan. He has three children, including a 22-year-old son who has Spina Bifida.

Members of Congress have thousands of constituents vying for their attention, each with a worthy cause. Does meeting with your Senator or Representative really make a difference?

Oh, absolutely! When Hal Pote and I founded SBF, Hal made numerous trips to Capitol Hill. Everyone who knew anyone worked the system, making and maintaining relationships not only with Members of Congress, but with their staffers at home and in Washington, D.C. Because of those relationships, SBF went from an unknown organization with no money to a well-known force for change that each year brings increased government funding for research into the causes of and treatments for Spina Bifida.

Not everyone can make a trip to Washington, D.C. How can people get involved in their hometowns?

As Speaker of the House Tip O'Neill liked to say, "All politics is local." SBA is doing a great job of connecting with Members of Congress in D.C. Cindy (Brownstein, SBA CEO) is brilliant at it. And National SBA will support people who want to visit the Hill by arranging appointments and supporting the meetings in any way it can. But there is much that can be done at home. Visit your local Member of Congress' office and get to know the local staffer that is assigned to you—staffers are often assigned a region or a cause. Check in by phone occasionally to maintain the relationship. Find out when your Member of Congress is in town, usually near holidays, during breaks, or at election time. Go to community forums and town hall meetings. Introduce yourself and ask questions. You can tell a life story in five to 10 minutes.

Once you've made an initial connection, how can the relationship be maintained?

Update the staffer on your life—what new challenges are you facing as your child enters school, or as the economy takes a downturn? When funding for Spina Bifida-related research or other projects are up for a vote, let the staffer know how it will impact your life. And always say thank you, and praise Members of Congress and their staffs for their past support. They don't hear that enough!