

BERLIN MOTHER AND DAUGHTER TESTIFY

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WASHINGTON, D.C.—U.S. Congressman John B. Larson (CT-01) yesterday introduced Kathleen Anderson and her daughter Kathryn of Berlin, Connecticut to the House Appropriations Subcommittee on Labor, Health, Human Services, and Education, where they testified on Reflex Sympathetic Dystrophy (RSD) disorder. In 1998, Kathryn Anderson, who was then 14, was involved in a serious car accident in which she suffered injuries that led to the development of RSD, which is a painful, chronic, neurological disorder. The condition is characterized by severe burning pain, pathological changes in bone and skin, excessive sweating, tissue swelling, and extreme sensitivity to touch.

While nearly 7 million people suffer from the disorder in the United States alone, it remains poorly understood, and is often misdiagnosed.

After bringing the Andersons to meet the Subcommittee Chairman, Rep. Ralph Regula (OH-16), Larson gave his introductory comments: "This disorder does not discriminate – it can affect anyone, at any time in their life. There is no known cure and oftentimes doctors will misdiagnose this disorder and perhaps diminish the chance of prompt treatment that could provide the greatest opportunity for recovery. I believe that there should be greater awareness of this disorder and that the National Institute of Neurological Disorders and Stroke should continue their research relevant to RSD and receive continued, if not additional, funding. I am happy and fortunate to have such courageous and strong voices next to me today who are both here to tell their story."

Larson met Kathleen in his Congressional office in June of 2000, and after hearing her story, became a co-sponsor of a House Resolution which would create a National Reflex Sympathetic Dystrophy Month to raise awareness of the disorder and emphasize early diagnosis. The Resolution, H. Con. Res. 61, was re-introduced in the House on March 13, 2001, and Larson is an original co-sponsor. A companion bill was introduced in the Senate by Sen. Joseph Lieberman on the 13th as well.

Kathleen Anderson is now the East Coast Director of the American Society for RSD, as well as being the organizations National Children's Advocate. She also serves as the Director of the Connecticut Chapter of the group. Kathleen offered her testimony to the Subcommittee following Larson's introduction.

"I am sure most of you have either hit your elbow or your shin at one time or another. Perhaps broken a bone or had surgery. Think back to how agonizing the initial onset of pain was. Eventually the pain subsides and you go on with your life. If you develop RSD, the pain never goes away. In fact, without proper diagnosis and early treatment, the pain worsens, the extremity swells, motor function becomes limited and eventually dystrophy or atrophy occurs. Your life as you once knew it, ceases. You lose your job, your home, your friends and in many instances your family," said Anderson.

"When you are injured your sympathetic nervous system turns on and tells your brain you are in pain. With RSD your sympathetic nervous system does not turn off and it continues to send pain signals to the brain. Allonoyida is a common occurrence with RSD. It is pain that is produced by stimuli that does not normally induce pain such as touch, pressure and temperature," said Anderson. "Present treatments include: Drug Therapy, Nerve Blocks, Physical and Occupational Therapy, Sympathectomy, Implantable Devices and Psychological Counseling. These are trial and error treatments. Many patients are told they must learn to live with their pain, and the mental anguish is more than they can bear.

Recently, Kathryn was hospitalized for a condition secondary to her RSD. I was summoned to the nurses' station where I was asked to gather information off the Internet and educate them about RSD. Can you imagine? In the 21st century, in

the United States of America, a parent has to inform medical professionals on how to treat a disorder that has affected so many for so long," said Anderson.

After her mother's testimony, Kathryn Anderson told the Subcommittee that this illness had robbed her youth, and asked Congress to act now to help insure that no one else has to give up their childhood to the painful disorder.

Kathleen Anderson recommended several courses of action that government can take in order to fully combat the disorder. She said that by increasing federal funding for RSD research and recruiting research facilities to distribute the available funding, they can hope to achieve the following:

- Education for medical professionals to assure early diagnosis.
- Development of protocols for treating RSD patients.
- Advancement of treatments by researching the cause and/or causes of RSD.
- Discovering a cure that would allow RSD sufferers the quality of life that they deserve.

The American Society for RSD has a web site at www.americansocietyforrsd-crps.org, or Kathleen Anderson can be contacted by Kathleen3@prodigy.net, or at 1-800-866-687-7246, for more information on the disorder.

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