

**Testimony of The Neuropathy Association
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Presented by

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Summary

As many as 20 million Americans suffer from peripheral neuropathy, a neurological disorder that causes debilitating pain, weakness in the arms and legs and difficulty walking. For most of its victims, the only recourse is pain medication, physical therapy or prosthetic devices to help maintain strength and improve mobility. In light of the large number of Americans afflicted and the attendant costs to society, the Committee is urged to provide substantially more appropriations for research to find ways to cure, prevent and more effectively treat peripheral neuropathy.

Mr. Chairman and Members of the Subcommittee:

My name is Mother Dolores Hart. I am the Prioress of the Abbey of Regina Laudis, a monastery of contemplative Benedictine women, located in Bethlehem, Connecticut. I am here on behalf of the Neuropathy Association, a nonprofit organization dedicated to helping those afflicted with peripheral neuropathy and to finding a cure for this disorder.

I have undertaken this mission as public spokeswoman for the Neuropathy Association because my community knows from firsthand experience the devastating effects of this disease, and as women of prayer, we could not leave the 20 million Americans who suffer from it, without a voice. My professional background has prepared me to serve as that voice. Before I was a nun, I was an actress, appearing on Broadway and starring in eleven films, during which time I had the chance to work with many gifted artists, among them my first co-star, Elvis Presley. I learned at an early age to love life passionately and to speak out whenever it is at risk.

What is peripheral neuropathy? In simple terms it is a neurological disorder that causes debilitating pain, weakness and poor coordination. It occurs when nerves are damaged or destroyed by disease or injury, and cannot carry messages from the brain and spinal cord to arms, legs, joints, skin and the internal organs of the body. Peripheral neuropathy comes in many forms. One type affects about one-third of all diabetics, or about 5 million people.

Other forms of neuropathy associated with cancer, kidney disease and hepatitis are inherited. Still others are caused by traumatic injuries, poor nutrition or certain medications.

If you have never heard of peripheral neuropathy, you are not alone. Neither had I, until 1997, when I had a root canal from hell. The fact that I was not able to eat after the procedure certainly came as no surprise. What alarmed me was that, two days later, I was not able to walk either! I could not put any weight on my feet when I tried to stand. That was just the beginning.

My pain became so constant that I developed TMJ from clenching my teeth all of the time. At times my feet felt like they were on fire, then they were freezing. I developed chronic pain in my ankles and legs. As time passed the pain spread, with no observable pattern or waning, attacking the hips, back, bladder, and face, and causing an incessant ringing in my ears.

I went from physician to physician with no results. Some offered medications for diseases I didn't have. One suggested a psychiatrist as if the pain is all in my mind. Several mistaken diagnoses led to serious complications with medications that landed me in the emergency room and proved nearly fatal.

Finally, eight months after my symptoms first appeared I was diagnosed with Idiopathic Sensory Peripheral Neuropathy. I have subsequently received invaluable treatments, which, though not curing the disease, allow me to live with its effects.

I am no longer in a wheel chair, but in the almost nine years since my diagnosis, the only thing I know for sure is that idiopathic means "nobody knows why."

- Why is it that peripheral neuropathy strikes some with such ferocity, but not others?
- Why does it afflict some in their childhood, and others not until adulthood?
- What mutant gene is triggered in those who inherit this disorder?

Those are just some of the questions that will have to be answered by scientists—if they are given the chance. The National Institutes of Health is spending only about \$51 million on peripheral neuropathy research—a disorder that affects as many as 20 million Americans. That is the same amount NIH was spending two years ago; and even more troubling, it is the same amount the budget before you proposes for next year. Unless we invest more money in research and discover more effective treatments or find a way to cure peripheral neuropathy, millions more people

will be stricken. We cannot afford to wait any longer. This disorder is not going away. In fact, the numbers climb.

Mr. Chairman, I hope you and your colleagues can find it in your hearts to recommend that more funding be designated immediately for the research necessary to conquer this horrible disorder. Please do not turn your back on this opportunity to affect the lives of millions of Americans, for whom relief from this crippling disease would be nothing short of a miracle.

Thank you for the opportunity to be here today. I would be glad to answer any questions you may have.