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CMT is not life threatening, although it can be disabling and painful at times, he says. "They lead a normal life span and can do most everything everybody else does."

"It is a progressive disease but it is self-limited in that it doesn't go beyond the hands and the feet," he adds. "At this time, we cannot control the progression of the disease."

Surgery is usually not recommended, except in severe cases, such as Lupski's. He underwent 11 operations as an adolescent to correct mobility problems. Normally, leg braces are used to remedy gait imperfections that result when the foot drops flat due to useless muscles.

If a person has CMT, there is a 50 percent chance that offspring will inherit the condition. Even so, this does not usually deter those who are affected from having children, says Garcia.

Lupski is convinced that CMT is more widespread than originally thought and that many undiagnosed people have it. "I think the disease is a lot more common than what's being reported," he says. "There's a lot more people that have the disease."

The first symptoms include foot deformities and gait problems, often followed by cramping and numbness. "It can be painful," he says, but adds, "Longevity is not affected and it doesn't affect the central nervous system." He urges anyone who thinks they may have the disease to

"Some members of the same family are very mildly affected and some are very bad."
—Dr. Carlos Garcia

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be tested at the MD clinic at Lourdes.

Lupski stresses how very important the Cajuns’ role is in eradicating the disease. “You can’t do these kinds of studies without the patients being cooperative,” he says. “We need to get the most people we can from the families. Investigators are good, but families are most important.”

Those who provide blood samples and family histories are doing their part to solve the jigsaw puzzle that Lupski and Garcia collaborate on. “We give our blood, sweat and tears, but they truly have to give their blood,” says Lupski.