

“It takes a unique person to come to terms with a terminal illness and then at the same time decide that they want to try to help others and raise awareness of the disease.”

Mark Shreve, CEO of the Coalition for Pulmonary Fibrosis.

# Very little known about Norwood’s fatal disease

## Group: Idiopathic pulmonary fibrosis kills 40,000 a year

*Associated Press*

WASHINGTON — Politics in Georgia might be a lot different today had a little-known disease called idiopathic pulmonary fibrosis not begun scarring Charlie Norwood’s lung tissue almost 10 years ago, sapping his ability to breathe.

Norwood, a seven-term congressman who died Tuesday at his home in Augusta, rose quickly from the backbench after winning election in 1994. For years, he was considered a leading candidate for governor or U.S. Senate.

But he repeatedly passed up the



**Norwood**

chance at promotion, in large part because he knew just how stubborn a disease he faced after receiving the diagnosis in 1998.

IPF, which typically affects patients 50 or older, kills some 40,000 people a year, roughly the same number that die from breast cancer, according to the Chicago-based Pulmonary Fibrosis Foundation. The typical survival rate is

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just a few years, yet public awareness remains relatively low and misdiagnosis is common.

“It wasn’t even its own distinct entity until 1999,” said Mark Shreve, CEO of the California-based Coalition for Pulmonary Fibrosis. “It is a lethal disease, one of the few left on the planet for

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which there is very little understanding.”

The disease — one in a family of about 200 so-called interstitial lung diseases — attacks the lungs, clogging air sacs with scar tissue and restricting the patient’s ability to transfer oxygen into the bloodstream.

While some cases have been linked to external causes such as inhaled pollutants or radiation treatment, it is generally unexplained.

Norwood, who was 65, kept his diagnosis secret for years. But as his condition worsened in 2004, he went public and got onto a waiting list for a lung transplant.

“He was really one of the first national figures to discuss living with pulmonary

fibrosis,” Shreve said. “It takes a unique person to come to terms with a terminal illness and then at the same time decide that they want to try to help others and raise awareness of the disease.”

Norwood introduced the first legislation on IPF, working closely with the Coalition and helping arrange face-to-face meetings with other powerful lawmakers, Shreve said. Norwood’s measure, a resolution that passed the House unanimously in 2005, recognized the need for further research into the disease and called for an IPF “awareness week.”

A slightly different version passed the Senate a year later, and Congress could adopt a final resolution this year.

“Congressman Norwood has given us a voice in

Congress that we simply have never had before,” said Frank Cabral, a Coalition advocate and IPF patient from Fall River, Mass. “His work has given us hope for the future.”

Norwood’s family is holding a public memorial for Norwood today in Augusta. A delegation of lawmakers from Washington is slated to fly in on a military plane for the service.

On Wednesday, dozens of lawmakers recalled Norwood’s passion and determination as the House agreed to a resolution in his honor.

“He only had two gears: neutral and full speed ahead,” said Rep. John Linder, a Republican from Duluth. “The way he would put his teeth in an issue and fight for it without ever backing up was astonishing to me.”