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## **FRONTLINE TRACES ONE FAMILY'S ATTEMPT TO CURE LOU GEHRIG'S DISEASE**

**FRONTLINE presents  
*SO MUCH SO FAST*  
Tuesday, April 3, 2007, at 9 P.M. ET on PBS**

**[www.pbs.org/frontline/somuchsofast](http://www.pbs.org/frontline/somuchsofast)**

What would you do if you were 29 years old and found out that you only had a few years to live? Stephen Heywood chose to get married, have a child and rebuild two houses while he was slowly losing control of his body's movement from a crippling disease.

In *So Much So Fast*, airing Tuesday, April 3, 2007, at 9 P.M. ET on PBS (check local listings), Academy Award-nominated directors Steven Ascher and Jeanne Jordan capture the remarkable events set in motion when Stephen Heywood discovers he has amyotrophic lateral sclerosis (ALS), commonly known as Lou Gehrig's disease.

"I started having problems with my right hand when I was working," Stephen recalls. "I went to [Massachusetts General Hospital] for further testing, where unfortunately I did find damage in my other limbs. ... I started figuring out what I wanted to do with the rest of my life."

ALS is a neurodegenerative disease that causes paralysis by killing the nerve cells that control movement. Yet, for the vast majority of people, their minds remain unaffected. Average life expectancy after diagnosis is two to five years. ALS is referred to as an orphan disease, because even though a few hundred thousand people in the world are afflicted with it, most drug companies do not invest the tens of millions of dollars needed to develop a drug to combat the disease. Through it all, Stephen was not alone in his race against time.

"What will people say? Will they say, 'Oh, wasn't that nice of her to marry the ailing man?' or, 'Is that fair for him to marry her?'" recalls Stephen's wife, Wendy. "We thought of those things, and then we said, 'You know, really it doesn't matter what anyone thinks. We don't care.'"

In response, and with no medical background, Stephen's brother Jamie quit his job and created a guerrilla-science research foundation. Finding a drug in time became Jamie's all-consuming obsession. In two years, he built ALS Therapy Development Foundation from three people in a basement to a

multimillion-dollar ALS lab facility.

“What we’re doing here, what I’ve been trying to do, and maybe what my entire family is doing as a rule, is the systematic denial of approaching reality, which we would like to prevent,” Jamie says. “You can’t win if you don’t try.”

Jamie’s first project was a radical but failed attempt at gene therapy, which generated a profile in *The New Yorker* and later a book by Pulitzer Prize-winning writer Jon Weiner. The foundation then established its central mission in discovering new, faster ways to test promising drugs in mice. In the hope of finding a treatment for ALS patients alive today, the foundation shortcut traditional research methods by using FDA-approved drugs and sharing results directly through the Web with patients and researchers. However, their approach is viewed as highly controversial by some in the scientific community. The film captures the tumultuous growth of the foundation, its quest for a drug and its struggles to keep the operation financed. But at the center of the story is a family captured with intimacy and humor.

“*So Much So Fast* is about the tangible bonds between parents and children, husbands and wives, siblings who are also best friends,” says filmmaker Jordan, whose mother died of ALS in 1995.

*So Much So Fast* is a West City Films, Inc., production in association with WGBH/FRONTLINE. The film is produced, directed and written by Steven Ascher and Jeanne Jordan. FRONTLINE is produced by WGBH Boston and is broadcast nationwide on PBS. Funding for FRONTLINE is provided through the support of PBS viewers and by the Park Foundation. Additional funding for *So Much So Fast* is provided by The Michael W. McCarthy Foundation, the Radcliffe Institute for Advanced Study, the LEF Foundation, the Shelby Cullom Davis Foundation, and the Wellspring Foundation. FRONTLINE is a registered trademark of WGBH Educational Foundation. The FRONTLINE executive producer for special projects is Michael Sullivan. The executive producer for FRONTLINE is David Fanning.

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Promotional photography can be downloaded from the PBS pressroom.

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