



The Association for  
Frontotemporal Degeneration  
Opening the gateway to help and a cure

## Media Release

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FOR IMMEDIATE RELEASE

*(In response to Thursday evening's segment on frontotemporal degeneration on NBC's Nightly News with Brian Williams, AFTD releases this snapshot of another family dealing with FTD.)*

### When the "Needle Gets Stuck"

Raleigh, NC— In the past six years, Arnette Lester of Raleigh, NC has lost all but a few of her teeth. She can no longer work or drive a car. Arnette has difficulty finding the right words and uses the same word to mean many different things; when she can't come up with any word at all, she'll substitute the word "something" in its place. She eats very quickly, barely chewing her food, and her family worries that she will choke. She wets herself several times a day. This scenario might not seem so odd for an aging dementia patient. However, Arnette Lester is just 60 years old.

Diagnosed in the fall of 2006 with frontotemporal degeneration (FTD), Arnette has no awareness of how this disease affects her or those around her. "In some respects, I consider her lack of insight a blessing," said Paul Lester, Arnette's husband. "She doesn't have a care in the world and she is content for the most part, laughing often."

The Lester family and friends, though, are acutely aware of Arnette's condition. She'll find a phrase and then repeat it for hours on end, such as "I'll be meeting you in the car and putting on my seatbelt." The family refers to it as "Arnette's needle getting stuck," much like a vinyl album with a scratch in it—the needle keeps playing the same line over and over again.

FTD is a neurodegenerative disease that strikes people in their 40s-60s, affecting the parts of the brain used to control language, behavior and movement—the frontal and temporal lobes. Currently, there is no cure or treatment for FTD.

In addition to caring for his wife and two teenagers, Paul makes creating awareness around FTD a priority. For the past five years, Paul sent letters to family and friends about Arnette's condition, asking them to donate to research through The Association for Frontotemporal Degeneration (AFTD). AFTD is a nonprofit organization in Philadelphia that advocates for more funding into the causes and treatments of frontotemporal degeneration, as well as provides caregivers and patients with a dependable source of accurate, reliable information and support. His efforts have raised more than \$50,000 for FTD research.

"I realize that because FTD is a rare disease, contributing to research is the one thing that I can do to change the future for those affected by it," said Paul.

For more information on FTD, please visit [www.theaftd.org](http://www.theaftd.org) or contact Angie Maher at [amaher@theaftd.org](mailto:amaher@theaftd.org) or 267.514.7221.

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