

Drugs caused woman's death in AIDS study

Special to Sentinel-Voice
Joyce Ann Hafford died without ever holding the son she had tried to save from contracting AIDS by taking an experimental drug regimen administered by government-funded researchers during her pregnancy.

But even before her stunned family could grieve, the 33-year-old's death was reverberating among the government's top scientists in Washington. They quickly realized the drugs the HIV positive woman from Memphis, Tenn., was taking likely caused the liver failure that killed her.

Reports of her declining health were being monitored in late July 2003 at the National Institutes of Health as she lay on a respirator, and the case eventually reached the nation's chief AIDS researcher, according to documents obtained by The Associated Press.

"Ouch! Not much we (we) can do about dumb (dumb) docs," Dr. Edmund Tramont, NIH's AIDS Division chief, responded in an e-mail after his staff reported that doctors continued to administer the drugs nevirapine

and Combivir to Hafford despite signs of liver failure. Nevirapine is an antiretroviral AIDS drug used since the mid-1990s, and the government has warned since at least 2000 that it could cause lethal liver problems or rashes when taken in multiple doses over time.

Hafford's family says they were never told NIH had concluded that the experimental drug regimen likely caused her death until AP gave them copies of NIH's internal case documents this month. They were left to believe Hafford had died from AIDS complications but began pursuing litigation to learn more.

"They tried to make it sound like she was just sick. They never connected it to the drug," said Rubbie King, Hafford's sister.

"If it were the disease, solely the disease, and the complications associated with the disease, that would be more readily acceptable than her being administered medication that came with warnings that the medical community failed to get... to her."

NIH officials acknowledge that experimental drugs,



Rubbie King plays with her nephew, Sterling Hafford, in Memphis, Tenn. On Monday Sterling's mother, Joyce Hafford, 33, of Memphis, Tenn., who had AIDS, died in 2003 while participating in an experimental drug regimen involving nevirapine, an antiretroviral AIDS drug, and administered by government-funded researchers according to documents obtained by the Associated Press service.

most likely nevirapine, caused her death, and that keeping the family in the dark was inappropriate. But NIH usually leaves disclosures like that to the doctors who treated her.

"We feel horrible that something like this would happen to anyone in any circumstance," said Dr. H. Clifford Lane, NIH's No. 2 infectious disease specialist. "There are risks in research and we try to minimize them."

Jim Kyle, a lawyer representing Regional Medical

Center in Memphis where Hafford died, declined comment because of the family's pending litigation. The doctors there deferred to NIH to comment.

The study during which Hafford died recently led researchers to conclude that nevirapine poses risks when taken over time by certain pregnant women. "Continuous nevirapine may be associated with increased toxicity among HIV-1 infected pregnant women" with certain liver cell counts, the study

concluded. Lane said Hafford should have signed a 15-page, NIH-approved consent form at the start of the experiment specifically warning her of the risks of liver failure. The family says Hafford seemed unaware of the liver risks. They even kept the bottle of nevirapine showing it had no safety warnings.

"My daughter didn't know any of the warning signs," said Rubbie Malone, Hafford's mother and now caretaker of Hafford's new baby and older son. "She never got to hold her baby."

Lane confirmed the nevirapine bottle Hafford received likely wouldn't have had safety warnings because the experiment's rules called for the patient to be unaware of the exact drug effects to avoid the placebo effect, or patient influence, on the test results. That means the consent form would have been her lone warning about potential liver problems, he said.

And that 15-page, single-spaced consent form is chock full of complex medical terms like "hypersensitivity reactions" and "pharmacokinetic test." The warning about po-

tential liver problems shows up on the 6th page, where it said liver inflammation was possible and that it "rarely may lead to severe and life threatening liver damage and death."

Hafford, who was HIV-positive but otherwise healthy, agreed to participate in the NIH-funded research project that provided her multiple doses of nevirapine, also known as Viramune, to protect her soon-to-be-born son, Sterling, from getting HIV at birth.

The project was an outgrowth of earlier research in Africa that concluded the drug could be taken in single doses safely to protect newborns half the time.

"She didn't want her baby to be born with HIV infection if it could be prevented at any cost," said King, her sister.

Hafford died Aug. 1, 2003, less than 72 hours after giving birth. Sterling was delivered prematurely by Caesarean section as his mother was dying. Though premature, he was spared from HIV and is healthy.

NIH's documents suggest Hafford's life might also have (See HIV, Page 16)

Powell honors envoys for sharing culture, passion

Special to Sentinel-Voice
WASHINGTON — Secretary of State Colin Powell honored athletes, musicians and artists Monday for sharing America's culture with young people throughout the world.

Dancer Debbie Allen, actress Doris Roberts and author Frank McCourt were among the dozen people to accept awards for their work as ambassadors with the State Department's Culture Connect program.

The program, which began after the terrorist attacks of Sept. 11, 2001, sends participants, such as musicians Yo-Yo Ma and Wynton Marsalis, worldwide to hold workshops and visit schools.

"Reaching out to the world's youth is absolutely essential. They will be called on in our world to lead," Powell said.

Powell said he has talked — and even sung — Calypso music to a teenage girl in Korea and summed up James Bond to a Bulgarian boy, all in the name of understanding.

Mary Wilson, of the



Debbie Allen, right, is honored during a ceremony recognizing the efforts of the Cultural Ambassadors, on Tuesday, in Washington. Allen is an accomplished dancer, choreographer, television producer and director. Alma Powell reacts with chuckles in the center.

Supremes, promoted HIV testing in Botswana by offering a free concert ticket with proof of testing. McCourt, author of "Angela's Ashes," encouraged Israeli and Palestinian students to tell their life stories.

Also on hand was the newest cultural ambassador, Bernie Williams, an outfielder with the New York Yankees who also is a jazz guitarist.


For his project, Joel

Meyerowitz traveled around the world with his exhibit of photographs of the Sept. 11 attacks. People shared their own experiences with disasters and realized that America is no longer the untouchable superpower it once was, he said, adding that's not necessarily a weakness.


"We have real issues and if we share those, if we express them, then the world will have more sympathy for us," Meyerowitz said.

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