

## **Public Comment**

### **Reverend Bernard Hillenbrand**

My name is Bernard Hillenbrand and for a quarter of a century I have been tormented by this miserable disease. It started when my athletic daughter Laura, a 3.8 grade point Kenyon College Senior and her now husband while driving one night narrowly missed a deer. Next morning she was into a strange disease which has kept her bedridden to this day. She has described this illness in a classic prize winning story for New Yorker Magazine.

CFS has such an unusual history. It started with ridicule and derision as spoiled white college girls Yippy Flue. It was confused with Aids. Laura had trouble finding a courageous dentist. There is persistent controversy for the correct name for this multi symptom disease. Unlike some diseases there is no evidence in CFS victims of self-inflicted destructive life styles. A federal agency betrayed the victim by diverting the tiny Congressional research appropriation to some other disease. .And finally after all this time we do not have a marker that clearly identifies who has the disease and who does not.

By contrast at about the same time the Aids Epidemic began. As an ordained Minister I was stationed a Walter Reed Hospital where all U.S. Military aids victims were assigned. My first two patients died. Newspapers were filled with obituaries of largely homosexuals. There was a perception that Aids was always fatal. Our worldwide campaign both at prevention and cure has had very promising results. With multiple medications we can extend life and there are periodic hints of the possibility of a cure. .

In another medical field two years ago my oldest daughter Lisa was diagnosed with breast cancer. She is Direct of Global Sales for Proctor and Gamble who had confidence in medical progress and gave her a year's leave of absence for treatment. After three surgeries she is now cancer free and back to work

For 22 years I have shared this long journey with the remarkable Kim Kimberly and our CFS Association, at that time the only national research and advocacy voice for CFS. She leaves the Directorship on a very significant high. She has launched the Research Institute Without Walls dedicated to marry the Research Laborites with the Clinics.

I asked to be heard today because in an already long life I have learned something very important, the VALUE of HOPE. . It started as little boy when I saw the first picture of a young girl in an iron lung and contributed my first ten cents to the March of Dimes. To the one million CFS victims and the millions who suffer with them we must have a fresh MARCH OF HOPE. This should be based upon faith in new technology, confidence in our researchers and clinicians, and a willingness to invest energy and recourses to find a cure.

Thank you for your dedication.