

Committee Members;

I am Dr. Dana Kuhn. I am one of the first consumers to serve at the inaugural meeting of this committee in 1997 and served on this committee until September of 2001. I am a 27 year survivor of HIV/AIDS after receiving one dose of contaminated factor eight concentrate on March 26, 1983. My wife died of AIDS in 1987 because I unknowingly infected her through sexual intimacy before I was tested. I became the sole parent of our 3 and 5 year old children. I compiled the "Trail of AIDS in the Hemophilia Community" a collection of documents evidencing the contamination of the blood supply leading to 10,000 hemophilia HIV infections and ultimately their deaths due to "failure of leadership of the U.S. Public Health Service agencies and private-sector organizations, and inadequate institutional decisionmaking processes"¹. This document was the ground work and basis of the 1995 IOM published report, "HIV and the Blood Supply: An Analysis of Crisis Decisionmaking". On a weekly basis, I spent hours explaining the sequence of events with Lauren Leveton and Michael Stoto. I was a leader in enacting the Ricky Ray Hemophilia Relief Fund Act whereby the United States Government due to "failure of leadership and inadequate institutional decisionmaking processes" paid out approximately \$750 million dollars to these 10,000 families because decisionmakers underestimated the threat of AIDS for blood recipients. I believe given my professional and personal experience, as well as advocacy status, I can provide some respectful insights and concerns to this topic.

First of all, this committee is charged with being the last defense to protect the nation's blood supply by assessing current and potential future threats to the blood supply. Your decisions become life or death outcomes to citizens while you balance risk-benefit ratios.

Second, we need to know if the risks of the transmission of AIDS or other blood borne pathogens/viruses collected from diverse populations have changed since 1983. What are the comparative risk studies? Where is the science?

Third, this is not a discriminatory issue; it is a safety issue founded upon 10,000 dead, and \$750 million paid out in a semblance of acknowledging "inadequate institutional decisionmaking".

Fourth, I am not respectful of how many representatives or senators sign on to bicameral letters unless they are intelligently willing to embrace the science, risk-benefit ratios, and take responsibility for the outcome of their decision.

1 Leventon, L., Sox, H., Stoto, M., *HIV and the Blood Supply: An Analysis of Crisis Decisionmaking*, Institute of Medicine, National Academy Press, Washington, DC 1995 pg. 9-10 "Conclusion"

Fifth, I believe this issue opens the door for a possible trade off. Recommendation #3 of the IOM report encourages the federal government to establish a no-fault compensation system for individuals who suffer adverse consequences from the use of blood and blood products similar to the past Vaccine Injury Act. If there is confidence that the risk is minimal in lifting this ban, then back that confidence with the establishment of a no-fault blood injury act.

Lastly, I am not opposed to change except when change is accompanied by the lack of convincing science, lack of respect for historical lessons, lack of evaluating risk/benefit ratios, and the lack of backing actions with preparation for consequences. This is what a business does to remain successful; this is what the government needs to do to remain vigilant in this business of blood.

Respectfully submitted,
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