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The Aids Epidemic Book: Influencing National Healthcare Policy

Situation

As we were writing the book, Dr. Slaff became particularly concerned about a national trend that was being conducted at a clinical level and reflected in the media coverage of the AIDS epidemic. The issue may seem very technical in nature as I explain it, but here is what it was. The American Red Cross had made it national policy to screen every pint of donated blood to see if was infected with the virus that caused AIDS. In order to get a true result, it was necessary to do a three-step testing procedure. The first of these three steps involved the identification of what was known as “false positives” – that is pints of blood which the first test indicated might be infected, but when the three step process was completed it was learned that they were not infected.

Some individuals took this “false positive” to cast aspersions on the validity of the testing – and in some cases were arguing that because of the ambiguity individuals whose blood was found to have been infected with the “AIDS Virus” should not be told definitively that they were infected, but to use more ambiguous language – such as they “may have been infected” or “may have been exposed”. Dr. Slaff was especially concerned about this because unless infected individuals were told honestly of their medical condition, they might not take all necessary precautions to protect their own health status – and also take precautions in terms of possibly transmitting the virus to others.

Our opportunity was that the National Institutes of Health had scheduled a long and detailed national press conference on the AIDS epidemic, that would be covered by national and international media. Our challenge and goal was to be able to ask a question at that conference. There would be an initial presentation of the latest research – and a panel of experts who would then take questions.

Task

We viewed our task as threefold:

- Formulate the right question – with enough detail, but using the fewest words possible.
- Be able to ask it at the press conference – to the best individual on the panel
- Put the answer on the record – hopefully influencing national understanding of this rather nuanced point, and perhaps changing national policy on “donor notification”

Action

I arrived at the event early – and quickly figured out where the line was for people asking questions. I was the third person on that line, and waited there for several hours. I asked the question – which had been carefully crafted – to Dr. Gerald Sandler – Chief Medical Officer of the American Red Cross, in full view of all the cameras and recording devices.

Results

Dr. Sandler admitted that the donors were NOT being notified that they had been infected with the AIDS virus, but rather that they “may have been infected” or “may have been exposed.” I was able to follow-up and ask that, since the science was clear, shouldn’t there be a consideration of a change in policy – for sound public health reasons. Dr. Sandler said that he would take it under consideration. This is a great example of the evolution of the disease and understanding about it – it was happening at a very fast pace. I was praised by several doctors for my courage and for such a great question. One of them was Dr. Alvin Friedman-Kien of NYU Medical School, a man who had personally treated many hundreds of AIDS patients.

In the end, Dr. Sandler changed policy of the American Red Cross. Donors worldwide were informed that as a result of the test that they should “consider themselves infected, and presume themselves to be permanently infected and also potentially infectious to others, on the basis of an exchange of body fluids”. When our book came out, we sent one of the first copies to Dr. Sandler. He formally endorsed the book, and had the American Red Cross buy it in bulk – and distribute it worldwide to people who were involved in blood collection or otherwise effected by the AIDS Epidemic crisis. Dr. Friedman-Kien wrote a wonderful, glowing letter praising us for the book – which was helpful to us in our publicity and credibility.

