AIDS: An Eerie Calm

Donald Chambers, M.D.
Vice President and Chief Medical Director
Lincoln National Life Insurance Company
Fort Wayne, IN

Dr. Chambers gave this speech to the ACLI Spring Conference in Chicago, on May 18, 1989.

In 1985, 1986 and even 1987, those speaking on the subject of AIDS nearly always had the luxury of being able to refer to some sort of AIDS article on the front page of that day's local and national newspaper. And we grew weary of these stories.

Things then changed. AIDS articles moved to back pages and finally disappeared altogether. The media itself had grown tired of this disease.

While overkill was a problem, there is an even greater problem with the media dropping this issue, which is that this tends to send a message that the AIDS scare was a hoax. That AIDS is not the problem it was made out to be by public health officials and others. That AIDS is burning itself out within the confines of small, well defined risk groups, and that, like a meteor falling through the atmosphere, most of us will never feel the affects of this disease.

Some of this same sort of what one might call "wishful thinking" is happening among insurers. There have always been doubters and deniers. But there seems to be more such people today than there were a year or two ago. We too are influenced by news—or lack thereof.

One of the major problems that we have with AIDS—perhaps the most important problem of all—is that it is virtually impossible to predict what will happen in the next 5 to 10 years and beyond. The variables that will shape destiny are many and mutually dependent. To illustrate the complexity of this issue, let me review a number of important but difficult if not impossible questions that cry out for answers.

How many people are already infected with HIV? This is such a fundamentally important question, and it's truly sad to say that we just don't know.

Do we really know which subgroups of our society are now—at greatest risk for HIV disease? What are the behavior characteristics of these groups? How large are these groups?

To what extent can we expect that experience in one part of our country can be extrapolated to or repeated in other areas of our country?

How can we effectively inform and educate these people who are at greatest risk? Who is responsible for such education?

To what extent will such knowledge translate into behavioral change? To what degree can modified behavior be sustained over time?

The longer we study this disease, the longer the estimated average incubation period becomes. The higher that number, the worse the epidemic. When will we have the final answer on this matter?

What preventive and therapeutic miracles might lie ahead? Short of miracles, what drugs or combination of drugs like AZT will be discovered that prolong the life of the person with AIDS? Can we hope for significant life extention? And what effect might extended survival have in regard to our ability as a society to care for these patients; on health care costs and the very structure of our health care system; on the person with AIDS' growing resistance to various antiviral drugs that we now read about; and on the virulence of mutant strains of HIV-1 and the person with AIDS' relative infectiousness over the course of his disease?

Another question that is being asked more and more is this: What happens when scientists find convincing evidence that AZT or some other drug arrests the progression of this disease for the asymptomatic carrier? There seems to be a good chance that this will occur. Would this force us to consider "infection" with HIV as equivalent to "disease?" If so, will private insurers and employers then have to pick up a good chunk of the enormous costs for preventive therapy of "asymptomatic HIV disease," both for the drugs themselves as well as the monitoring of immunologic and hematologic status and the treatment of the side effects of such medications?

Does AZT (and will subsequent anti-retroviral drugs) lower the infectivity of those who are infected with HIV? If so, would this suggest an additional public health incentive to identify as many infected people as possible and encourage them to initiate therapy? Powerful anti-discrimination laws would surely be passed at the federal level prior to any sort of mass testing. To what extent would such laws infringe on the insurer's right and/or ability to test?

It's interesting to note that after four long years, the PHS and certain AIDS organizations have just recently advocated that everyone in high risk groups be tested. The reasons cited for this dramatic change of position are that there are now good ways to predict who will soon be experiencing serious clinical complications and there are medicines and other things that such people can do to help themselves. And they
add that “by the way, if people know they are infected, this may help to slow down the spread of this virus.” The caveat that they make is that if widescale testing is to be done, then tough confidentiality and anti-discrimination laws must be passed at the federal level.

We read that HIV-2 has hit Brazil, and it seems reasonable to suppose that it’s just a matter of time until this second AIDS virus reaches North America. Will this add to our problems? When will we have to start testing for HIV-2? And how about the increasing incidence of HTLV-1? Is this of any consequence?

We continue to hear stories about HIV infected people who are seronegative. Who are not detected by routine screening tests. How common is delayed seroconversion? Or no seroconversion? Or seroretroconversion, i.e., where people lose the antibody that they once had? Just how insensitive is the ELISA test that we now depend upon for screening? Will second or third generation tests offer significantly greater protection than those we use today? Should we be using recombinant tests for screening like many of the European countries are now doing?

Will additional HIV viruses be found? If so, how might they different from HIV-1 and HIV-2? Will they have similar virulence and mode of transmission? Or not?

Sooner or later, home test kits will be approved by the FDA and consequently significantly more people will learn that they are infected. From a public health standpoint, will it help to have a markedly higher percentage of people know that they are infected? To what extent will this increase antiselection and force insurers to lower their testing limits still further?

More and more, the AIDS epidemic is becoming closely linked to IV drug abuse. Can our society lick the drug abuse problem? If not, how can we hope to stop the spread of HIV? Is significant heterosexual spread within our inner cities inevitable? We’ve all read what is happening in NYC, Newark, and certain other large metropolitan areas of the U.S.A. Will minorities and the economically disadvantaged become so hard hit by HIV disease that the very fabric of our society will be threatened? And if our inner cities become ravaged by this virus—and some say this is already happening—is it reasonable to think that heterosexual suburbania will remain untouched? We’ve been told for years now that AIDS is not just a gay or IV drug abuser epidemic. This has been hard to accept. But are we now seeing early evidence that this is in fact so?

One could go on and on. Is AIDS really caused by a retrovirus—a question being asked by Peter Duesberg, a respected molecular biologist from the University of California, Berkeley.

We have learned so much and yet we know so little.

Because important unanswerable questions abound, it is no wonder that we have such difficulty in predicting the future. But regardless of this uncertainty, there is no justification for denial. No justification for thinking that AIDS is not at least a very serious problem for us all.

What is happening to us today—the absence of media attention and the like—can (metaphorically) be compared to being in the eye of a hurricane. As you recall, the storm first struck our industry quickly, unexpectedly and violently in early 1985, triggered by FDA licensure of the AIDS antibody test. Almost immediately thereafter, we were told by states such as California and Wisconsin that we could not use this test. Blood banks and clinicians would test, and many people would discover that they were infected, and many of these would then apply for additional amounts of individual life and health insurance, but we the insurers would not be allowed to defend ourselves from this antiselection.

We spent the next three years or so scurrying to protect our right to use the antibody test. Lobbying. Testifying. Preparing position papers. Educating. Fires ignited spontaneously and unpredictably in many states. Even at the federal level. The same happened in parts of Canada. To cope with this issue, we had to quickly build a model of the state of AIDS within our industry. And we did this very effectively, given the unique challenges of this disease.

Now the winds have subsided. There’s almost an eerie calm. While some in our industry may believe that this reflects a dwindling problem, it is far more likely that we are experiencing a calm before a second coming of the storm.

At present we stand near the bottom of that steeply ascending “S” curve that characterizes most epidemics, including AIDS. Actuaries that have carefully studied AIDS say that AIDS-related individual life claims will rise from their present level of just over 1% to as high as 10% or 15% by the mid 1990’s. They estimate that U.S. insurers will pay out between $10 and $25 billion in individual AIDS-related claims within the next 10 years. And between $50 and $125 billion in total life and health, individual and group combined. It seems almost certain that many, and perhaps the majority of, companies can expect substantial AIDS-related claims within the next few years. Manageable in most cases—so we are told. But substantial none the less.

And AIDS-related claims are but part of the story. But part of the storm to come. We almost certainly face further legislative battles with HIV testing.

The issue of pretest and posttest counseling is but one example. As we move closer and closer to wide-scale testing, there will be ever increasing pressure to do so in conjunction with counseling. Insurers will not be immune to this and will have to find some way to cope with various state or even federal counseling edicts.

Our right to test should not be considered sacrosanct. If, for example, we adopt testing procedures that are even perceived to weaken our ability to maintain confidentiality, we might well be in for another round of proposed state efforts to ban our use of HIV tests. “HIV only” testing and “urine HIV
screening” are but two practices that may be perceived by special interest groups as threats to privacy. There is reason to believe that the issue of confidentiality and the push for additional safeguards against discrimination will intensify.

Allow me to digress from AIDS for a moment and say a few words about another important medical subject, namely genetic testing. All of these political problems that we’ve dealt with, AIDS pales in comparison to what lies ahead in regard to the emerging, closely related, issue of genetic testing. AIDS is but a harbinger of things to come. Even though most genetic testing technology is still on the drawing boards and some will say that it’s therefore unnecessary for us to address this issue at this time, the fact is that social scientists are already speaking out on this issue and claiming that insurers have no right to access and use the results of such tests. As an example, there was an article on genetic testing in the January-February issue of Public Health Reports, a publication of the U.S. Public Health Service. In this article entitled An International Survey of Attitudes of Medical Geneticists Toward Mass Screening and Access to Results, the author said “Nations will need to develop regulations (before mass screening becomes a reality) that will prohibit institutional third parties (insurers) from access to the results, even with (applicant) consent.” “Governments must decide how to prevent discrimination by insurers on the basis of genetic information.” Such statements from a governmental publication stand as a bold warning to insurers of what lies ahead. This audience knows full well what would happen to the underwriting process and to our industry if big brother decides that insurers have no right to inquire about and access the results of genetic tests that have already been performed on someone who applies for individual life or health insurance. The extent to which we might want to defend our right to perform genetic screening tests is yet another matter.

While the issues are quite similar, the size and political strength of those interest groups who are predisposed to oppose our use of genetic tests will be orders of magnitude greater than anything we’ve seen with AIDS.

If correct—if this is the calm before the storm—then we need to prepare, starting immediately. We’ve done pretty well with the AIDS struggle. But our universe is expanding. We now must strengthen our professional capabilities and learn about genetic testing. We must determine what others think about our use of such technology. We must understand their position, anticipate their arguments, comply with reasonable demands that they are certain to make, and last but not least, we must vigorously defend ourselves against fallacious attack. Over and over again, we need to explain the need for and value of underwriting. Somehow, we must convince others that for the sake of past, present and future policyholders—not for our sake as insurers but for the sake of that large portion of society that we serve—the private insurer must be allowed to pursue sound business practices, assess risk and learn as much about the health of an applicant as the applicant himself (or herself) knows. And perhaps most importantly, we must make sure that our own house is in order. Each of us has a responsibility to influence decisions that are made in our own companies that deal with the use of genetic tests and other types of new biotechnology. Such decisions should—must be made in a systematic, reasoned manner, keeping in mind not only marketing and medical-underwriting considerations but political and governmental considerations as well.