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Before the House Health and Welfare and Judiciary Committees

Regarding

House Bill 624 and Other Matters Pertaining to

Acquired Immune Deficiency Syndrome

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Good morning. I am Scott Burris, of the American Civil Liberties Union of Pennsylvania. The ACLU is a statewide, not-for-profit organization with over 12,000 members in Pennsylvania. We exist to protect, with advocacy and litigation, the basic rights of Americans enshrined in the Constitution and the Bill of Rights. I thank the committees for providing this forum for discussing one of the most pressing social issues of our time.

You are hearing today about an epidemic has been going on for a decade. You are hearing that painfully, and with almost no support from the state, communities across Pennsylvania have found ways to deal with it. Public health officials, particularly in Philadelphia, have developed successful programs that are a model for the nation. Throughout the state, grassroots organizations have pulled themselves together to provide essential services -- intervention among those at highest risk, case management, education, drug treatment, home and hospital health care. You are hearing that if the General Assembly supports these efforts with money, if it provides protections against discrimination and invasion of medical privacy, it can help stop the disease. But you are also hearing that laws that attack people with the disease will spread the disease.

Finally, you are hearing today about an essentially unprecedented approach to protecting public health, a modern approach grounded in a clear understanding of the ways HIV, the AIDS virus, is actually transmitted, and based on the idea of treating, not punishing, those who carry it. There is no other way: There are more than 2,200 cases of AIDS in Pennsylvania -- 82 in Harrisburg, 1800 in Philadelphia, 400 in Pittsburgh, 56 in Scran-

ton, 70 in Allentown, etc. -- and ten to twenty times that many people who are infected with HIV without showing any obvious symptoms. The only way we can stop the spread of HIV in our society is to get people to make basic changes in sexual behavior and to get them off intravenous drugs. We cannot do this by "outlawing" AIDS. No law has ever stopped drug use. No law has ever stopped people from having sex. No quarantine law, no testing law, no law of any kind has ever stopped the spread of a disease. Modern public health practice in the age of AIDS requires a dedication to reason over fear and real effectiveness over symbolism. In making the right choices, no one can better lead the people of this state than you.

The intersection of law and AIDS is a neighborhood I know about. For several years I studied it from an academic point of view. I have written several articles on AIDS legal issues, and I am the editor of AIDS and the Law: A Guide for the Public, published by Yale University Press, the first and still the only discussion of AIDS law and policy written for policymakers and the general public. I am now directly involved in the legal issues of AIDS as the staff attorney of the American Civil Liberties Union's AIDS and Civil Liberties Project.

AIDS is often said to pose a conflict between individual rights and the general welfare. As a civil libertarian and a professional deeply involved in public health matters, I reject that cliche as legally and medically inaccurate. Long ago, the Supreme Court held that virtually any individual right could be abridged if it was necessary to protect the public health. Ever

since, the real issue in public health law has not been what rights we have, but what is necessary to protect the public health. In the AIDS epidemic, the very things that are necessary to protect public health -- medical and social services, protection of confidentiality, prevention of discrimination -- will enhance individual civil rights; and the same steps that would infringe human rights -- mandatory testing, quarantine, criminalization of HIV infection -- far from being "necessary" to protect public health, would constitute a public health disaster. Most people with HIV want to cooperate with health authorities, and behave responsibly -- they have no problem with necessary health laws.

That leaves as the real conflict the one between a modern approach to fighting epidemic disease and an ancient one, between science and superstition, between reason and fear. In resolving this conflict, the General Assembly has to take a leading role.

This choice is clear. For most of human history, there has been little we could do against epidemic disease. Having no idea what caused disease, humanity relied on mythology, old wives' tales, and rudimentary empiricism. Leaving aside the appeal to the gods for succor, the chief characteristic of the ancient approach to disease was quarantine in a broad sense: the identification and separation of the sick or infected: casting out lepers, boarding up plague victims in their homes, holding newly-arrived ships away from port for "forty days," (from the Italian for which we get the term "quarantine"). This was, at best, what William MacNeil, the great historian of epidemic disease, called "crudely empirical" -- there was a rough association between the

presence of sick people and the spread of disease. But purging the city of non-infectious lepers did not stop leprosy. Locking away people with the plague did not bother the rat-borne fleas that actually spread the disease. Isolating yellow-fever cases did nothing about the mosquitoes which were really to blame. It never worked, not in any of these cases, yet cordoning off the sick from the well gave people the illusion of control.

In fact, drawing a line between the well and the sick felt so good that it was extended beyond the realm of the body to include a kind of mental quarantine: stigmatizing the victim. Leprosy and plague were thought to be punishments from god. Cholera, thriving in the filth of the pre-modern city, was said to be a disease of the poor and immoral. At the turn of this century, physicians diagnosed syphilis and gonorrhea among the poor, prostitutes, and the sexually profligate, and "venereal insontium" -- "innocent venereal disease" -- in their middle class patients. Regular V.D. was spread by sex; innocent V.D. was spread by drinking fountains and doorknobs. Ironically, thinking of disease as divine punishment actually helped give people a sense of control, or, at least, of order: if one is good, one will not get it. If one gets it, it must be because one is bad.

Only when science discovered in the late nineteenth century that diseases were caused by germs -- specific etiologic agents -- did we begin to be able to control epidemic disease. In the last hundred years, medical knowledge has grown enormously; miracles are routine. In the 'seventies, we even managed to

entirely eradicate one of the oldest epidemic diseases, smallpox. In contrast to the ancient approach to public health, which saw disease as a shrouded mystery of uncharted menace, the modern approach understands disease as a collection of specific threats, of known factors, unknown factors, and more or less predictable variables. As happened with AIDS, medical science applies its tools to identify how a disease is transmitted, what causes it, and how it may be treated. Public health decisions are based on this kind of specific information. Uncertainty is dealt with squarely. Without necessarily knowing all the answers to the greatest degree of certainty, without being able to solve every problem, we are able to assemble the information we need to accurately assess major health threats and rationally prioritize our response.

But scientific knowledge is not universally distributed or entirely trusted. Many of us know little more about disease than did our great-grandfathers, and we still react as they did: calls for testing, quarantining, even tattooing people with HIV have been common throughout the epidemic. As a few years ago people with cancer were made to feel unclean, a diagnosis of AIDS often carries with it a sense of shame.

The persistence of outworn ideas about disease in general and AIDS in particular means that we have to address two epidemics: the epidemic of AIDS, and an epidemic of fear: first, the fear that comes from not knowing -- fear of getting the disease from a handshake or a salad, or from mosquitoes; and next the fear in people with HIV that arises from society's fear -- fear of discrimination, of losing one's home, one's job, one's family,

if one's HIV status becomes known. We cannot fight the epidemic of AIDS without dealing with the epidemic of fear.

And so we come to the heart of what the General Assembly can do about AIDS through leadership. You understand how disease is spread. You understand the modern medical approach to disease and how public health is protected in the twentieth century. You understand that your constituents are often afraid, but they trust you and they will follow your example. You are in a unique position to take the lead in the task of mobilizing a whole society to understand the complexities of how a disease spreads, to overcome groundless fears of casual transmission or illusions of divine punishment, and to work together against a serious medical problem in a rational and effective way.

How do you do this? Allow me to offer a few guidelines:

First, **look at the whole picture.** AIDS is like a giant squid in your bathtub. You cannot just pull out one tentacle and expect to enjoy an untroubled soak. Every part of the problem is connected to every other part. Our response has got to be coherent, and the benefit of each discrete thing we do has got to be weighed not simply against the problem it solves, but against its cost in terms of the overall effort. A good example was House Bill 437, making it a crime for people with HIV to have sex without telling the partner. Its sponsor recognized an area of uncertainty in the criminal law, and introduced a carefully-crafted bill to deal with it. But seen in the big picture of the AIDS epidemic, it raised serious problems. It brought the police into the bedroom and into the public health effort, and, because

we do not have adequate statutory protection of public health records, it raised the very real threat of frequent subpoenas of records the public health department has been telling people are all but absolutely confidential.

Second, **focus on the biggest problems first.** As one who wrote a book on it, I know that AIDS touches almost every area of life. But it does not touch every area to the same degree. Given the fact that the General Assembly cannot solve every problem right now, it is important to do the things that will do the most to slow the epidemic. A good example of a small problem getting a lot of attention is HIV transmission by prostitutes. People may be worried about this -- it is biologically possible and it may even happen occasionally -- but it is not where we are getting thousands of cases. AIDS is being spread in this state and nation by drug use and by consensual sex between lovers. Except for a few isolated pockets, prostitutes are not even a major reservoir of HIV.

What's wrong with dealing with those few possible cases? Well, for one thing, it will not work. Prostitutes have always been a target of restrictive public health measures, including mass roundups in war-time, which have never stemmed the progress of sexually transmitted diseases. What it really does is give people we need to help -- through drug treatment, and risk-reduction counseling -- a good reason to hide, and it gives the public a chance to sink back into safe old attitudes: AIDS is a problem for those bad people; we good people don't have to worry. It tells people that as long as they stay away from prostitutes, they can relax with their boyfriends and girlfriends and spouses

-- who just happen to be the people who are giving them AIDS. More importantly, I think spending too much of your limited legislative and public health resources on dealing with a population which is not a major vector of HIV transmission suggests that the epidemic is beyond our ability to handle rationally. By restricting prostitutes, we might possibly stop a couple of new cases, while literally thousands and thousands of people are being infected because there are not enough outreach workers to intervene, because there are not enough drug treatment slots, because we are not filling every t.v. set in this state with information about AIDS. In a world of limited resources, that just does not make sense.

Third, **avoid the temptation to make meaningless gestures.** Several proposed bills, e.g., House Bill 824, would make a new crime: assault by an HIV carrier. Biting or scratching or throwing bodily fluids with intent to spread HIV would be made illegal. Such behavior is decidedly unpleasant, but a crime? There is simply no real chance of HIV being transmitted in that way. Of the hundreds of reported incidents, not one has led to infection. A new study in the Journal of Acquired Immune Deficiency Syndromes has concluded that the risk is, at most, quite small. Legislation that suggests otherwise not only sends a message to people with AIDS that their infection is a criminal matter, it tells the public that people transmitting HIV through biting is a serious problem. Why else would the General Assembly pass that law? Why else would a prosecutor bring an action? Instead of reassuring people, instead of teaching people to deal with dis-

ease rationally, this kind of law tells people that they were right to be worried.

Similarly, there have been throughout the country and in Congress efforts to require ambulance drivers to be notified after they have carried an HIV positive person. I always say this is for the benefit not of the ambulance driver but his or her next-of-kin: if the emergency worker has been exposed, it is just too late. Maybe people think they're helping, but it is just that old stone-age response again, the delusion that identifying the sick will help. Of course, it does not, and in modern public health law it is always necessary to ask if knowing someone's private health information will, in fact, make a medical difference. If we are really interested in helping emergency medical workers, the thing to do is provide them with training in universal precautions and with the equipment they need -- gloves, and masks, and anti-feedback mouthpieces -- to implement them. Emergency workers may not always know the serostatus of the people they have transported -- but then again, they won't get AIDS.

Fourth, **follow the advice of the people who have studied the problem.** AIDS has a way of creating consensus -- if you really study it. Who would have thought that a man as deeply conservative as Surgeon General Koop would have come out in favor of AIDS education in the schools from the earliest grades? I can tell you that most people in the AIDS community thought the President's Commission on HIV was going to reflect Ronald Reagan's indifference or William Dannemeyer's malevolence, or both. Instead, people from all different starting points came together

with a set of solid recommendations that people on all sides of the issue have supported.

The most pressing instance of something universally supported by the experts and commissions is the passage of legislation protecting the confidentiality of AIDS-related medical records, providing for informed consent for testing with pre- and post-test counseling, and strengthening the protections against discrimination. Supporters of this kind of legislation include the President's Commission, the National Academy of Sciences, the American Bar Association, the Pennsylvania Bar Association AIDS Task Force, and the Philadelphia Commission on AIDS. Several other states, including most notably New York, Florida and Washington, have already passed important legislation.

There is no question this is state-of-the-art public health legislation. Protecting confidentiality and prohibiting discrimination tells people with HIV that it is safe to cooperate with health authorities. But it does more than that. It actually reassures people suffering from that other disease, afrAIDS. It tells them that they do not need to know who has the disease; it tells them that they do not need to discriminate. Numerous responsible groups have been working together on proposals for legislation of this kind, and we urge you to give it full and bipartisan support when it comes before you.

And finally, **trust the people to follow your example.** Remember Proposition 102 in California, the ballot initiative that would have sent the state back into the public health stone age? It called for a series of measures that would have made

confidential testing almost unobtainable, completely undermining the health effort. It was soundly rejected. People are afraid, yes. They have gaps in their knowledge. But they can learn; and telling them that their fear is okay only makes things worse. We cannot run a society unless problems are dealt with rationally: We do not require airlines to supply parachutes because people are afraid of flying; we do not ban buildings over four stories because people are afraid of heights.

I would like to leave you, in this vein, with the story of Ryan White, the hemophiliac in Indiana who had such a hard time going to school. In his hometown, people were afraid and the school administration fed the fear. They kept Ryan out of school by one legal maneuver after another, despite the medical fact that he posed no risk to other students. In the end he moved to another town. There the leaders had prepared the way for his arrival, educating students and parents and setting an example of ease and comfort with Ryan. In that town, Ryan doesn't have a school problem, and the school doesn't have an AIDS problem.

That is an example. Thank you.