THE PENNSYLVANIA PRISON SOCIETY
Promoting Prison Reform Since 1787

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TESTIMONY OF ANGUS R. LOVE ESQUIRE
ON BEHALF OF
THE PENNSYLVANIA PRISON SOCIETY
BEFORE THE
PENNSYLVANIA HOUSE JUDICIARY COMMITTEE
CHAIRMAN, THOMAS GANNON

SUBCOMMITTEE ON CRIME & CORRECTIONS
CHAIRMAN, JERRY BIRMELIN

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REGARDING MEDICAL ISSUES IN THE
PENNSYLVANIA DEPARTMENT OF CORRECTIONS SYSTEM

I am testifying today on behalf of the Pennsylvania Prison Society (P.P.S.) regarding a variety of concerns about the delivery of medical services to the inmate population of the Pennsylvania Department of Corrections. The P.P.S. was founded in 1787 by Dr. Benjamin Rush and several other prominent members of our community, including Benjamin Franklin. P.P.S. is the oldest prison reform organization in the United States. We are empowered by our Commonwealth with official visitor status in Pennsylvania prisons and jails. I am also the Executive Director of the Pennsylvania Institutional Law Project which provides civil legal services to institutionalized individuals in our Commonwealth.

Any discussion regarding medical issues in the prison context will involve a variety of different perspectives. Prison officials are primarily interested in custody and control. Health authorities are focusing on disease prevention and management. Civil libertarians and advocates address issues from the perspective of individual rights. Thus, there can

be much confusion and misunderstanding inherent in such a discussion. Despite the varying viewpoints, I hope that we can all agree that issues of public health affect not only the inmates but the staff and the general public as well. This is especially true regarding communicable diseases that do not recognize prison walls or prison uniforms. Epidemics are essentially the same inside the prison as they are in our communities from which the inmates come and to which, for the most part, they will one day return. Each year the Pennsylvania Prison Society and the Pennsylvania Institutional Law Project receive thousands of inquiries from inmates housed in the Pennsylvania Department of Corrections system. A large number of these inquiries involve medical issues. Families also are a regular source of complaints regarding similar issues. We come to this Committee as advocates for sound public health policy within the correctional context. We qualify our remarks by recognizing that we are not prison correctional experts nor are we medical professionals.

Prison populations have often been characterized by health care professionals as "sick" populations. The term "sick" refers to the fact that they have generally received poor health care prior to their incarceration. They are often from low income backgrounds, with limited access to public health, including prevention such as regular check-ups, vaccination and early detection systems. Significant risk factors for imprisonment, such as poverty, intravenous drug use and race correlate with the exposure to the leading communicable disease risk factors, especially Human Immunodeficiency Virus (HIV), Tuberculosis (TB) and Hepatitis. These factors are further complicated by the fact that prison life is based on the congregate living environment in a closed society. This

heightens the dangers of transmission between the inhabitants of the closed society. Prisons can serve as a breeding ground for communicable diseases.

The Pennsylvania Department of Corrections is to be commended for their recognition of these concerns and for their ability to respond in a positive way to challenges presented to them by the inmate and advocacy communities. A recent example of such was the litigation entitled Austin v. Lehman. Upon completion of the discovery phase in that case, including the inspection by various medical experts, the parties were able to reach a voluntary settlement agreement to upgrade the quality of health care in the system. A number of improvements were agreed upon and implemented over the last several years. This included development of a prototypical staffing pattern for all institutions within the DOC system. It further led to the development of a comprehensive statewide health care and medical policy modeled in scope and level of detail on the clinical and administrative guidelines as set forth by the Centers for Disease Control in Atlanta, Georgia. Protocols were developed for the management of chronic diseases such as HIV, diabetes, cardio-vascular diseases, seizure disorders and asthma. The DOC adopted a comprehensive systemwide quality assurance program designed to assure the implementation of the aforementioned policies. Negative pressure rooms were introduced to handle active tuberculosis patients. Special needs units and mental health units were added in several additional institutions. The overall result was a significant improvement in the delivery of medical, dental and mental health services in our system. All persons involved in that effort are to be commended.

We are now presented with new challenges to the delivery of medical services. As

we do not live in a static environment, new diseases, new treatments and new scientific breakthroughs regularly occur. It is important that we keep up with the latest medical discovery and advances. The two areas that we are receiving many complaints about and that we believe are in need of further examination are Hepatitis and organ transplantation. We qualify our remarks with an understanding that there have been new scientific discoveries in these areas that include recognition of new types of Hepatitis and new treatments available for the new and old types of Hepatitis. It is our hope that through a frank discussion of these issues we can keep current with these developments and provide state-of-the-art quality care to the inmate population in our prison system.

Until 1990, there was recognized to be two strains of Hepatitis labelled as A and B. At that time, an additional strain, given the title C, was developed and subsequent to that we have discovered several new strains. With the recognition of the new strains has come new treatments, primarily through drug regimes. Incident rates of Hepatitis generally run higher in minority populations. The African-American population has a rate of 3.2%; the Latino population, 2.1%; while Caucasians have a rate of 1.5%. Hepatitis is contracted primarily through transmission of bodily fluids. Transmission is often accomplished through many of the same ways that HIV is transmitted, i.e., drug injections, needle sticks, transfusions and unprotected sex. Hepatitis B has been termed one hundred times more infectious than HIV due to the fact that the virus can live outside the body, unlike HIV, for up to one week. The disease can also be fatal. Hepatitis C alone accounts for 8,- to 10,000 deaths per year. It is not an easily recognizable disease, nor is it easy to treat. One can have Hepatitis but not be symptomatic. One can become symptomatic and then

go into remission with the potential for reoccurrence. Some individuals respond to treatment while others can be infected for the rest of their lives. Hepatitis primarily affects the liver and is the leading reason for liver transplants.

The offices of the P.P.S. and P.I.L.P. have received hundreds of inquiries regarding the treatment of Hepatitis. We have interviewed these individuals, obtained their medical records, reviewed various grievance procedures and have requested and received affidavits. The most frequent complaints concern Hepatitis B and C. These complaints often include the failure to notify the affected individual for several years that they have contracted the disease. They also complain that they are not getting the state-of-the-art treatment once they have been informed of their infection. There are also concerns regarding lack of uniform standards regarding the treatment of these diseases once they have been discovered and notified. Additional issues concern the availability of liver biopsies upon finding that one has been infected, the need for annual liver function tests, the use of the drug Interferon alone and in combination with the drug Ribavirin, a/k/a Rebatrin. We have heard several complaints that individuals have been diagnosed with Hepatitis but have not been informed of such for up to five years. We have heard complaints that liver biopsy tests do not accompany the initial diagnosis of Hepatitis. We have heard numerous complaints regarding lack of the initial Interferon drug regime and the subsequent treatment for up to a period of one year of the combination Interferon/Ribavirin (Rebatrin). We also recognize that as recently as December 1998 a new combination Interferon/Ribavirin (Rebatrin) drug has become available in the U.S. marketplace. As we understand it, the Pennsylvania Department of Corrections does not

have a standardized policy or protocol for treatment of all forms of Hepatitis. Inmates are being told that Interferon treatments are being withheld due to their limited applicability and often severe side effects. We are also cognizant of the fact that Interferon costs $300 per dose and is administered three times per week for up to three to twelve months. It is further our understanding that with regard to Hepatitis C, the Interferon treatments are effective in only 50% of the cases, with one-half of those individuals suffering relapses.

Based on the information we have received, there appears to be an atmosphere of confusion and suspicion. It is our hope that through the testimony today and with appropriate follow-up, we can reduce that confusion and educate all parties concerned regarding the particulars of Hepatitis. If there is not already a standard policy or protocol for all forms of Hepatitis, it is our belief that we are in dire need of such a policy. We welcome any response from the Department to these issues and are willing to meet with them in order to clear up any misunderstandings that currently exist and to work towards a better understanding and appropriate response to our concerns.

The second issue that we are here today to discuss involves organ transplantation. This is an issue that has been brought to our attention due to the incredible advances of modern medicine. It is not that long ago that I can recall the first heart transplant. Nowadays, transplants of kidneys, livers, hearts and various other organs are done on a regular basis. We commend the donor option programs that have encouraged the supply of organs for those in desperate need. We recognize that there are ethical issues involved in transplantation that go well beyond prison walls. We do not pretend to have all the answers in this or any other area but do wish to let this Committee know of our concerns.

These concerns are again based on numerous inquiries to our offices from inmates and family members alike. Once again we find a lack of procedures/protocols in this area. It is our hope that we can develop uniform standards for the decision-making process with regard to transplantation. The most frequently mentioned concerns involve treatment for kidney failure. Prior to 1995, the Pennsylvania Department of Corrections utilized dialysis as the mode of treatment for kidney failure. Individuals housed within the system routinely travelled to outside hospitals, usually three times per week, to receive their dialysis treatment. Around that time, the Department of Corrections decided to open the Renal Treatment Unit at Graterford and move all dialysis patients to that facility. Initially 40 to 50 inmates were housed in a special area called the Renal Treatment Unit and received their dialysis in the adjacent unit housed within the prison Infirmary. Prior to 1995, individuals treated in outside hospitals were presented with the same options as any other individual would receive at said hospital. This included the full range of what is known as modality choices. These include peritoneal dialysis, home dialysis, self-care dialysis and renal transplants. Renal transplant is considered the treatment of choice for medically qualified individuals in outside hospitals. Transplantation for young, otherwise healthy, patients provides a significant advantage in survival and quality of life. These issues were recently addressed in litigation entitled Calhoun v. Horn, (U.S.D.C.E.D.Pa), Civil Action No. 96-350. Dr. Joseph Bisordi, Chairman of the Medical Review Board for End-Stage Renal Dialysis Network No. 4, visited the Graterford unit and submitted a report to the Court. He testified that 80- to 90% of the patients on dialysis are eligible for renal transplants. He testified that the average cost of dialysis for one year is $50,000. The average cost of a

renal transplant is $100,000. Four out of five renal transplants are successful. He indicated that there was no compelling medical or social reason for the failure to provide for renal transplants or the renal transplant option. Financial incentives weigh in favor of such a transplant. Several individuals housed at Graterford have had renal transplants prior to the change in policy in 1995. One individual had a family member willing to donate a kidney but had been denied the opportunity. The private medical provider, in the person of Dr. Richard Freedman, acknowledged that the DOC practice excludes the transplant option. Discovery failed to produce any written policy that addresses this issue. The only oral explanation offered was that the individuals were inmates and, as such, would not receive transplants. In light of the important ethical and cost issues involved, we urge the Department to reevaluate their situation and come up with a policy/protocol that defines their position on this critical issue.

We thank the Committee for allowing us this opportunity to testify today.

Respectfully submitted,

Angus Love, Policy Director
Pennsylvania Prison Society