PRISONER ORGAN DONATIONS?

A CONSIDERATION OF PRISON INMATES VS. THE REST OF SOCIETY

"No other institution in this society has a higher concentration of people at substantial risk of HIV infection." - The National Commission on Acquired Immune Deficiency Syndrome (1990 statement regarding prisoners.)[1]

A study conducted in the early 90's by the National Institute of Justice showed that the incidence rate of AIDS in prisoners was over 200 cases per 100,000 in federal and state correction facilities. That was in comparison to approximately 15 cases per 100,000 in the general public.[2] Prisoners were reportedly infected with AIDS 13 times more per capita than the rest of the U.S. population.

Because of the prevalence of disease the Food and Drug Administration (FDA) in the early 90's advised blood and plasma clinics not to accept donations from prison inmates. The inability to screen such donations effectively enough to guarantee that no prisoner would infect the public outweighed the need for blood products in the U.S.

These references are now two decades old. Yet, these are some of the statements that those opposed to organ donations by inmates continue to rely on to prevent willing prisoner donations.

Are these views still valid today? How does today's prison population compare with the rest of the U.S. population?

With the increased awareness of HIV/AIDS and other diseases as well as the technological advances of modern day testing and organ transplant science, is it possible that these concerns might today be muted?

Given the increased need for organs in the U.S, should organ donations by willing prisoners now be reconsidered?

This article considers these questions and takes a deeper, more modern look into the comparisons between prisoners and the general public concerning infectious diseases and other stated reasons prohibiting inmate organ donations today.

INMATES VS THE REST OF THE UNITED STATES

Prisoners are at high risk for infectious disease. Due to the prison lifestyle, prisoners' propensity for drug abuse and dirty needles, dangerous sexual habits, and other unclean practices, there continues to be much concern over the transmission of AIDS and other diseases. And because prisoners often hail from segments of society that are considered to be at "high risk" in the first place, the possibility for infectious disease is a very real concern to have.

As recently as 2009 a Public Health Analyst from the U.S. Department of Health and Human Services responded to inquiries regarding continuing dilemmas and concerns over inmate donors, stating in part:

> *"Much concern regarding organ donation by inmates is related to their high risk of exposure to communicable infectious diseases during incarceration, e.g. HIV and various forms of hepatitis. While the availability of better tests for infectious diseases has improved the safety of the supply of donated organs, tissues, marrow, and blood, no test is 100% accurate..."*

The studies in the early 90's demonstrated the disparity between prisons and the rest of the country at that time. But have those numbers remained consistent?

The U.S Department of Justice through Bureau of Justice Statistics (BJS) reports on the rates of disease prevalence in U.S. prisons, the most detailed of which concerns HIV. This report provides the best barometer for measuring the spread of infectious disease in prisons throughout the years.

The latest (2007-08) report showed that out of 1.6 million prisoners in the U.S., 21,987 were reported to be HIV positive or to have confirmed AIDS. Looking at how this compares to recent years, the amount of prisoners who are reported to be HIV positive or who have confirmed AIDS have remained relatively stable.

	Total combined HIV/AIDS cases in prison			Percentage of prisoners infected		
	2006	**2007**	**2008**	**2006**	**2007**	**2008**
Reported	21,985	21,666	21,987	1.7%	1.5%	1.5%

The BJS report compares the prison infection rates with the rest of the U.S. finding that prisoners account for nearly 2 ½ times more AIDS infections than the U.S. general population.

	Percent of population estimated to have confirmed AIDS		Ratio of AIDS cases in prisons to cases in U.S. population
	Prisoners	**U.S. Population**	
2007	0.41	0.17	2.4

While that number may sound scary, it is far less than what the National Institute of Justice reported in the early 90's of 13 times greater. The gap in the infection rates of prisoners verses the U.S. general population has steadily declined year over year.

	Ratio of AIDS cases in prisons to cases in U.S. population
1992	13.3
2002	3.2
2003	3.1
2004	3.1
2005	2.7
2006	2.7
2007	2.4
2008	1.8

Yet that disparity between infection rates of prisons and the U.S. population is still significant. Or is it?

One important aspect of assuring accuracy in statistical data is ensuring that you are comparing apples to apples. The statistics cited thus far are misleading in that regard.

Prisoners are people age 18 and older. But the figures used to compare the U.S. population prevalence to prisoners are derived from the 15 and older U.S. population (sometimes 13 and older).[3] Not exactly apples to apples. Those three years lend to some much skewed ratios.

This is not necessarily due to any bias on the part of the BJS statisticians. The source of their data for the U.S. population HIV/AIDS prevalence stems from the CDC's HIV Surveillance Reports. These reports only supply data age-ranges of 15-19 and then 20-24. Statisticians are forced to either add 3 years to the U.S. population data (Age 15-19) or to subtract 2 years from the prison data (Age 20-24). No matter how you cut it, the numbers won't be perfect. To go the other way and only utilize data from the 20 and older range, suddenly the ratio of AIDS between prisoners and the rest of the U.S. shrinks to from 2.4 to 1.9 for 2007 and to 1.4 for 2008. So the true numbers are somewhere in between.

The intent, though, is not to minimize the actual numbers of prisoners with HIV/AIDS diagnoses. There is no doubt that prisoners fit the "high risk" category. However, there is an aspect which does require a closer look.

***"No other institution...has a higher concentration of people at substantial risk of HIV infection."*–FALSE**

HIV/AIDS remains mostly an urban disease. Comparing concentrated prison populations to the much more diverse and varied populations of the United States when it comes to health is like trying to compare fish in a barrel to an ocean of fish. When a society is forced to live in such close proximity, especially given certain sociological and behavioral makeups, the numbers will always appear drastic and concerning over more sparse populations.

Therefore, it's important to compare like populations, in this case metropolitan/urban populations to gain a more realistic view of the differences between prisoners and the rest of U.S. society.

The following comparison of prisoners to other high risk populations shows that prisoners while "high risk" do not present the *greatest* risk for HIV/AIDS infections as previously believed:

HIV/AIDS INFECTIONS: PRISONERS VS OTHER HIGH RISK POPULATIONS

	HIV Diagnosis	AIDS Diagnosis	HIV/AIDS Combined
	RATE/100,000	RATE/100,000	RATE/100,000
Prisoners[1]	1027.8	364.8	1392.6
U.S. Population[2]	356.8	197.8	554.6

HIGHER RISK POPULATIONS OVER PRISONS (IN GRAY)

				Risk Differential
African American	1302.0	748.1	2050.3	+1.5x
• Ages 20-54	1620.8	895.5	2516.3	+1.8x
• Florida	2431.3	1190.0	3621.3	+2.6x
• New Jersey	2340.9	1185.4	3526.3	+2.5x
• New York	2803.1	1535.3	4338.4	+3.1x
• Washington DC	-	2943	2943*	+8.1x
Hispanic/Latino	549.9	306.8	856.7	
• Ages 20-54	658.0	357.3	1015.3	
• Florida	697.8	326.3	1003.7	
• Pennsylvania	-	661.7	661.7*	+1.8x
• Connecticut	1370.0	826.7	2196.7	+1.6x
• New York	1802.5	1024.9	2827.4	+2.0x
• Washington DC	-	1321.7	1321.7*	+3.6x
All Races				
• Males	535.2	313.1	848.3	
• Florida	697.8	343.2	1041.0	
• New York	909.6	496.2	1405.8	+1.0x
• Washington DC	-	1934.2	1934.2	+6.0x
• Maryland	-	384.2	384.2	+1.1x
Metropolitan Areas				
• Miami, Florida	1217.7	590.2	1807.9	+1.4x
• New York, NY	1108.6	620.4	1729.0	+1.2x
• San Francisco, CA	-	685.0	685.0*	+1.9x
• Washington DC	-	412.0	412.0*	+1.1x

[1] Prisoners data: Based on Bureau of Justice Statistics, *HIV in Prisons Bulletin*, Dec. 2009 (1,609,759 prisoners under the jurisdiction of state and federal correctional authorities for yearend 2008, minus 28,322 Indiana prisoners due to non-reporting of HIV/AIDS data.) 16,254 reported HIV cases, 5,733 estimated confirmed AIDS cases

[2] U.S. Population data: Based on *CDC HIV Surveillance Report*, 2008. All statistics based on 37 states available and persons age 15 or older, unless stated otherwise.

* Does not include HIV data due to unavailability of info. Risk over prisons rate is for AIDS only in these instances.

"High Risk" Donors Accepted!

It's evident that HIV and other diseases disproportionately affect certain populations. Blacks/African Americans represent the racial/ethnic group most affected, accounting for approximately 12% of the U.S. population but almost half of all new HIV infections.

Being primarily an urban disease, the majority of individuals diagnosed with AIDS reside in areas with more than 500,000 people. Areas hardest hit include Miami and Jacksonville, Florida; New Orleans and Baton Rouge, Louisiana; New York City; Baltimore, Maryland; Washington D.C.; and San Francisco, California. Many of these cities represent higher risk and prevalence rates for HIV/AIDS than prisons.

To follow the same reasoning which the transplant community expresses to reject organ donation from prisoners, the transplant community would likewise disallow organ donations from the entire populations of many U.S. cities, and especially from all African Americans. On the contrary, many of these populations are actually regions of focus for the transplant community to *increase* organ donations within these areas.

One look at the grants awarded by the Organ Procurement and Transplantation Network (OPTN) and the United Network for Organ Sharing (UNOS), the U.S. governments' organ donation policy-setters, and the double-standard between prisons and other "high risk" pools become evident.[4]

One such grant, awarded to the University of Miami Organ Procurement Organization, had a stated purpose to "increase the number of minority organ and tissue donors by increasing intent to donate coupled with family notification of intent to donate among Blacks, Haitians, and Hispanics living in Miami-Dade County, Florida." Miami's HIV/AIDS rate was nearly 1½ times that of prisons, and that's among all races. The minority HIV/AIDS prevalence rate there is well over twice the rate of prisons. Yet inmates are considered to be too high risk.

Even more pointedly, the transplant community has recently actually begun accepting some high risk donors that they categorize as "expanded-criteria organs" amongst populations with various "behavioral and social risks".[5] It's been reported that an example of those included in this category are deceased IV drug abusers.

At the University of Maryland's School of Medicine five patients recently received transplants of kidneys that already had cancerous masses on them. When asked why anyone would risk cancer, the Head Surgeon explained, "The ongoing shortage of organs from deceased donors, and the high risk of dying while waiting for a transplant, prompted five donors and recipients to push ahead for surgery." The times are that dire for organs in the U.S.

TO FOLLOW THE SAME REASONING...THE TRANSPLANT COMMUNITY WOULD LIKEWISE DISALLOW ORGAN DONATIONS FROM THE ENTIRE POPULATIONS OF MANY U.S. CITIES, AND ESPECIALLY FROM ALL AFRICAN AMERICANS.

The donation community already transplants organs between donors and patients who are known to be infected with hepatitis C, and there is some consideration under way to do the same for patients infected with HIV.[6]

Expanded-criteria and diseased organs, and donations from like-infected individuals are helping to fill that gap in the shortage of organs in the U.S, but needlessly. The fact that the transplant community has begun accepting those who they deem as in an even higher risk category than prisoners signifies the importance of now considering inmate anatomical gifts that can be medically proven to be disease-free and far safer than some of current options being used or considered.

If organ donations from these populations that show a higher prevalence, and thus risk for the spread of infectious disease, than prisons are acceptable to the transplant community, there should be no reason to continue preventing healthy willing inmates from becoming organ donors.

So why aren't inmates able to donate now?

Why Can't Inmates Donate?

While the high risk nature of prisons was the primary concern raised by the Public Health Analyst from the U.S. Department of Health and Human Services, it was not the only concern. The Analyst continues:

> *"While the availability of better tests for infectious diseases has improved the safety of the supply of donated organs, tissues, marrow, and blood, no test is 100% accurate...*
>
> *"The OPTN/UNOS Ethics Committee has also deliberated on many issues related to organ donations from incarcerated individuals including: assuring appropriate informed consent for both donors and recipients; the ethical issues of the act of organ donation itself; the uneven application of the death sentence among socio-economic and ethnic groups in many States; and the overall effect of such policies on organ donation in general. Based on these deliberations, the Committee is opposed to any strategy or proposed statute that would facilitate organ donation from prisoners, condemned or otherwise. It is my opinion that the Committee's position is unlikely to change unless all of these issues can be satisfactorily addressed."*

As the Organ Procurement and Transplantation Network (OPTN) & The United Network for Organ Sharing (UNOS), under the U.S. Department of Health and Human Services, is the government contracted resource in charge of organ donation policy-making in the U.S., and since most institutions, courts, and individuals will defer to this organization as the expert in the field, it is necessary to consider each of their objections to inmate organ donation carefully.

"NO TEST IS 100% ACCURATE"... ONLY 99%.

It's been established that the risk of infection is real amongst inmates. However, we've also established that there are other populations around the U.S. that are at even greater risk for disease transmission. How does the transplant community ensure that disease is not further spread from these populations through transplants?

Adequate testing is the answer. Logic has it that we can likewise adequately test each potential inmate donor to ensure that any infected prisoner is ruled ineligible to donate.

Unfortunately, though, as the Health and Human Services Public Health Analyst stated earlier, "no test is 100% accurate..."

Previously the biggest dilemma in determining whether an individual was infected involved the "window period" between exposure and detection of a disease. Literally an individual could contract HIV or Hepatitis and be tested for the disease several weeks or even months later with negative results. The reason for this was that the most standard tests never looked for the actual virus, but rather antibodies to the virus. The first thing that a body does once it detects invaders is to send out antibodies to combat them. Initial testing only looks for the buildup of such antibodies. During the window period, a person may in fact be infected but not have enough antibodies yet to show up on a typical test. Therefore, the result is a false negative and testing may not prevent the spread of infectious disease.

However, recent advances in diagnostic technology have taken this "window period" from several weeks or months to days. RNA testing, for instance, also called NAT[7] has been developed which detects the virus itself, as opposed to the buildup of antibodies, by looking for the virus' genetic material. Due to the nature of the test, there is actually more of a likelihood of a false positive than a false negative in this testing (2.6-5% of tests results in a false positive[8]).

A brief look at modern testing will prove that it has come a long way since those DHHS statements were adopted:

HIV/HEP TESTING	DATE INTRODUCED	DETECTS	DETECTABLE (WINDOW PERIOD)
ELISA I	1990	Antibody	16 weeks
RIBA I[9]	1991	Antibody	
ELISA II	1992	Antibody	9-10 weeks
RIBA II	1993	Antibody	
ELISA III	1996	Antibody	6-8 weeks
RIBA III	1997	Antibody	
Western Blot	1998	Antibody	4-6 weeks
Nucleic Acid Amp Test (NAAT)	2001	RNA (Actual virus)	12 days
RNA Polymerase (PCR)	2002	RNA (Actual virus)	7-13 days
RNA Target Mediated Amplification (TMA)	2003	RNA (Actual virus)	5-11 days

The evidence regarding the risks and benefits of modern screening was reviewed in July 2005 by the U.S. Preventative Services Task Force.[10] The authors concluded:

> *"...A large study of HIV testing in 752 U.S. laboratories reported a sensitivity of 99.7% and specificity of 98.5% for enzyme immunoassay, and studies in U.S. blood donors reported specificities of 99.8% and greater than 99.9%."*

No medical test is 100% accurate. But considering modern testing where a negative test result will now be correct more than 9,997 times in 10,000, the CDC recommends that a negative test result be considered conclusive evidence that an individual does not have HIV.

Typically, testing for the actual virus (RNA-type testing) is used as a confirmatory test after an antibody screening has produced a positive result. It is also used as an additional test for those who may have had a recent risk for infectious disease which the standard antibody tests might not catch. The reason for not administering the more conclusive RNA testing every time is cost.[11] But due to the concerns of inmates living in such a high risk environment and the necessity to guarantee that infection is not transferred to a donor, it would be recommended that RNA testing be used for every inmate wishing to donate an organ prior to approval.

As one Department of Corrections HIV/HEP Prevention Coordinator acknowledged:

> *"If a person has had both antibody and viral RNA testing and both are negative, there is no reason to believe that such person's organs, tissue, or blood products are infected with any communicable disease of interest."*[12]

Given modern technologies in accurate testing, there is no reason that an inmate should be summarily precluded from organ donation due to concerns over infections. Testing has now surpassed the concerns regarding the risks of inmate donations.

While statements regarding the lack of *100%* accuracy may still be technically valid, a rational look at modern advances should determine that the probability of lives being saved by willing inmate donors far outweigh the now extremely slight chances of previously concerning infections. This, combined with the continual need for organs, should prompt prison administration to allow for organ donations by anyone who is voluntary and able.

PRISONERS CAN'T GIVE INFORMED CONSENT?

Assuring appropriate informed consent for both donors and recipients is a key issue when dealing with inmates especially. The concern stems from a time decades ago when inmates were being misused as medical test subjects despite the fact that the inmates had "consented" to be involved in the projects. The belief is that prisoners are subject to coercion by virtue of the circumstances of their environment and they should be protected from doing things they might not do were they not in the prison environment.

The requirement of informed consent comes from a long-standing common law principle of self-determination which recognizes, in part, that every individual has the right to refuse unwanted medical treatment.[13] The medical community has provided an explicitly detailed method by which to obtain prisoner consent for any medical treatment.[14] Courts have ruled explicitly that prisoners can give consent to medical treatment generally, or choose to exercise their constitutionally protected right to refuse medical treatment, even at the risk of death.[15] It must therefore be presumed that inmates are capable of consenting to organ donation.

However, the only way to avoid the negative perceptions associated with inmate organ donations and the issues of consent or coercion is to assure that the inmate who is about to give his organs has done so absolutely voluntarily. This is no different than with any other potential donor. They must go through counseling to ensure that they are aware of the potential ramifications physically and psychologically before giving consent to go through with the donation. Given the same consideration, there should be no doubt as to the inmates' ability to appropriately consent.

It is likewise important to allay concerns over coercion. Problems arise when consent is coupled with any sort of perceived advantage or inducement that the prisoner may receive upon giving his consent that takes it over the threshold of coercion. In the past cases of medical experimentation, prisoners were given inducements to participate which were oftentimes so great, relatively speaking, that the prisoners' participation in the medical research program was virtually coerced. The medical community was therefore exploiting these inmates to become research subjects for studies that nobody else would subject themselves to under ordinary circumstances.

The only way for an inmate to truly be able to give consent or volunteer is if there is nothing for them to gain by doing so, apart from the satisfaction in the act of saving a life.

RECIPIENTS MUST BE FULLY INFORMED

From the potential recipient's perspective, typically there is confidentiality regarding the donor unless the donor's family specifies otherwise. In the case of inmates however, the recipient should have a right to be informed that the donor is in fact a prisoner, especially given previously discussed concerns over the high-risk environment of prison. This is nothing new to the donation community. Recently, reportedly due to the ever-expanding need for organs in the U.S., those "expanded-criteria" high risk deceased donors with various "behavioral and social risks" are being accepted with the expectation that all available information will be provided to all involved.[16]

It's equally as important that the recipient know of the steps the inmate had to take to be able to give his consent so that the concerns over other countries organ procurement practices do not weigh on the recipient. The issue of appropriate consent is easily satisfied for both the donor and the recipient.

RACIAL & ECONOMIC CLASS IMBALANCE OF PRISON

There is an expressed concern regarding the uneven application of prison sentencing among socio-economic and ethnic groups in many States. Many believe that prison sentencing discriminates against African-Americans and the poor. This, coupled with law allowing organ procurement from prisoners, could potentially have tragic effects. The fear is that any negative perception of organ procurement could have the effect of wiping out every potential African-American donor.

While it is clear that there is a racial and economic class imbalance in prisons, there is likewise such an imbalance within every metropolitan area that the organ donation community actively seeks donors from. As with the prevalence of infectious disease in these populations, the imbalance is actually greater in these areas than in prisons. To continue to justify disallowing organ donations from prisoners on this basis is disingenuous and incongruent with the transplant community's current views and the dire need for organs in the U.S.

If historical trends that were established in medical research programs for prisoners continue, African-American and other minority prisoners will likely choose to participate at lower levels than Caucasian prisoners. For reasons not exactly clear, prisoners who participated in medical research programs tended to be predominantly white, even in institutions where the population as a whole was predominantly non-white. This is likewise true for organ donations in general.

> THE ONLY WAY TO AVOID THE NEGATIVE PERCEPTIONS ASSOCIATED WITH INMATE ORGAN DONATIONS...IS TO ASSURE THAT THE INMATE WHO IS ABOUT TO GIVE HIS ORGANS HAS DONE SO ABSOLUTELY VOLUNTARILY...NO DIFFERENT THAN WITH ANY OTHER POTENTIAL DONOR.

One of the reasons that there is so much emphasis in the community for minority organ donations, despite the higher risk, is that there are typically far fewer willing donors within the ethnic communities. Minority organs are badly needed.

Whether the addition of allowing prisoners into the donor pool will further isolate the African-American community or boost donation numbers amongst minorities is unknown. The trend will likely stay the same as it is now. However, speculation is not proof and there is really no way of knowing until new policies are adopted.

Regardless, as the donation community is willing to accept organ donations from groups with greater racial and economic disparities than exist in prisons, the argument is unnecessary and moot.

ALLOWING PRISONERS TO DONATE WILL STIGMATIZE ORGAN DONATION

There is a fear that if organ donations by inmates were allowed there would be a stigma attached to organ donation which would result in fewer donations from the typical donor pool. Thus, the impact on the current altruistic donation system would be damaged beyond any benefit than may be derived from a policy allowing for donations by prisoners.

The fact is that nobody knows what sort of impact such a policy may have on existing organ donation efforts. Any proposals for change usually engender opposition where every effort is made to decipher reasons something will not work.

Conversely, it's possible that the fresh light placed on organ donations upon the allowance of prisoners to donate may serve to raise awareness for the issue, prompting non-prisoners to learn of the dire necessity of such donations in the U.S.

Controversy tends to stir stagnant waters.

Whether those arguments accord with reality remains to be seen. But practical reasoning and the necessity for additional methods for obtaining organs in the U.S. should afford opportunities that might otherwise appear controversial, so long as the appropriate steps are taken to ensure as many rights and protections as possible.

Conclusion

The OPTN/UNOS Ethics Committee continues to be opposed to any strategy or proposed statute that would facilitate organ donation from prisoners. They regurgitate the same arguments that were posed decades ago as a justification to prevent inmates from donating today. As the government Public Health Analyst put it,

> *"It is my opinion that the Committee's position is unlikely to change unless all of these issues can be satisfactorily addressed."*

These issues have been addressed.

- Inmates are high risk, but less high risk than other populations that OPTN/UNOS actively seek organ donations from today.
- Testing for infectious disease is not 100%, but it is greater than 99%. Appropriate testing will effectively weed out any realistic concerns.
- Prisoners can give appropriate and fully informed consent, as the courts have stated repeatedly, and recipients can be made aware of all available information, as the transplant community offers now with other high risk donations.
- Racial and economic class imbalance in prison, while lopsided, is no greater than in communities where donations are being actively sought by the transplant organizations now.
- There is no basis for a belief that organ donations made by willing prisoners will stigmatize donations amongst the general population.

When presented with the need for organ donations and the possibility of such donations coming from truly altruistic willing prisoner donations with nothing to gain but a satisfaction from helping another human survive, it's only rational that the possibility be given careful consideration.

Thanks to modern awareness of infectious diseases coupled with advanced testing protocols to ferret out those infected the concerns of decades past are no longer valid, not when considering the transplant communities use of higher risk populations and "expanded-criteria" organs today.

Appropriately tested willing inmate donors now present less risk than many segments of U.S. society that are currently being sought after by the organ donation group efforts.

Given that all other concerns related to inmate donations can be satisfied, there is no reason to continue denying informed, healthy and willing inmates the opportunity to donate healthy organs, not when there is such a dire need for organs now.

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[9] RIBA testing is a supplemental test typically performed on positive samples from initial screening tests to further define the results.

[10] *Screeming for HIV: A review of the evidence for the U.S. Preventative Services Task Force,* Chou R, Huffman LH, Fu R, Smits AK, Jorthuis PT (July 2005), Ann. Intern. Med. 143 (1):55-73(www.annals.org/cgi/content/full/143/1/55)

[11] Initial screening tests for HIV/HEP cost approx. $5, compared with $50 - $295 for RNA (NAT) testing.

[12] Ann Shindo, PhD, Oregon Department of Corrections. Response to author regarding testing protocols of ODOC.

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