

prison health news

-better health care while you are in and when you get out-

Issue 17, Summer 2013

Who We Are...

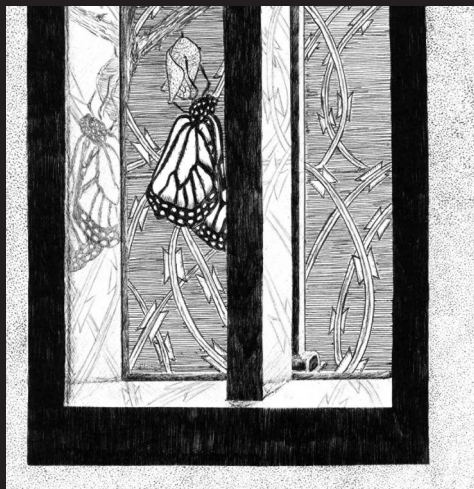
We are on the outside, but many of us were inside before... and survived it. We are formerly incarcerated people and allies talking about health issues and trying to bring about a positive change for all people who are in prison now or ever have been in the past. This newsletter is about all of us.

We will be talking about health issues. For example, what is good nutrition? Where can you get services and information on the outside? We want to take your health questions seriously and break down complicated health information so that it is understandable.

We're also here to help you learn how to get better health care within your facility and how to get answers to your health questions. Don't get frustrated. Be persistent. In prison, it's often hard to get what you want, but with health information, it doesn't have to be impossible. Join us in our fight for our right to health care and health information.

Read on...

From,
Gary, Laura, Lizzy,
Mala, Michael, Naseem,
Robert, Shadia, Suzy,
Teresa, and Tré



Transformations by Leonard Jefferson
CL-4135, SCI Albion, 10745 Route 18, Albion, PA 16475

In this Issue:

Who We Are.....	1
Write an Article!.....	2
Prison Yoga.....	2
One Day at a Time.....	3
The Pain, The Whole Pain, & Nothing BUT the Pain.....	4-5
Post-PREA Strategies for Health & Safety.....	6
When Liver Cancer Tests May Fail You.....	7-8
Heroes Wanted.....	8-9
Dogs in Prison? It's a Great Idea.....	10
Information Resources for People in Prison.....	11
Advocacy and Support Resources for People in Prison.....	12
Subscribe!.....	12

write an article!

We know that everyone who reads this newsletter will have questions or their own story to tell.

If you want to write an article on something you think is important for prison health, send it and we will consider publishing it in *Prison Health News*.

Tell us your story of struggling to receive quality health care, either for yourself or others. Do you have tips and tricks for staying healthy and taking care of yourself behind the walls that could be useful to others in the same position? Or perhaps you are an artist or a poet and want to share your work with *Prison Health News* readers.

You can also write us first to discuss ideas for articles.

If you want your full name kept confidential, you can sign your article with your first name or "Anonymous."

Please keep in mind that we may make small changes to your article for length or clarity. For any major changes to your work, we will try to get in touch with you first.

To submit your work, or if you have more questions about any health issues or anything you read in *Prison Health News*, please write us at:

Prison Health News
c/o Philadelphia FIGHT
1233 Locust Street, 5th Floor
Philadelphia, PA 19107

Prison Yoga

by Jeanine Campbell

The Prison Yoga Project is an organization based in California that seeks to establish yoga and mindfulness meditation programs in prisons and rehabilitation centers across the United States. They give trainings for yoga instructors interested in starting yoga programs in prisons, and have established over 20 prison yoga programs in correctional facilities across the country.

For prisoners who do not have access to a prison yoga program, founder James Fox created a manual that explains of the benefits of doing yoga and meditation, teaches the basics of yoga and mindfulness meditation, and gives instructions on how to start a yoga and meditation practice in prison. The Prison Yoga Project will ship the manual free to prisoners who do not have a yoga program in their prisons.

To order a manual, send a letter requesting a free copy of "Prison Yoga Project: A Path for Healing and Recovery." In your letter, explain you are a prisoner who would like to practice yoga and meditation but that you don't have access to a program. Tell them you would like a free copy of the manual sent to you. Include your name, your prison number, and your prison mailing address, and mail the letter to: Prison Yoga Project

P.O. Box 415
Bolin, CA 94924

As the demand for these manuals is high, you might have to wait anywhere from a few weeks to a few months to receive one. Be patient – it's well worth the wait!

One Day at a Time

by Casandra Castleberry

On November 10, 1998, I was told that I was HIV positive. I was only 18 years old, with a 1-year-old son. I thought I was going to die, so I started using cocaine (powder), marijuana, cigarettes, and alcohol.

Because of my age and everyone knowing my status, I moved to Columbus, Ohio. That's when I started medications, blood work, and attending support groups. Still, at the time, not too many young people wanted to disclose. By this time, I had another son, and my biological mother became my main support. I maintained employment and looked healthy, so I figured, "What the hell—I can still club and do my drugs."

Well, that started me to forget my responsibilities. In 2003, I came in contact with opportunistic infections and was close to death. My son was 3 years old, and he said, "Mommy, I need you and I miss you."

I had committed so many crimes trying to maintain the lifestyle I was living. I stayed on the run, but I cried out to God and said, "Help, please." Well, I did my first speak-out program to 2,500 high school students, and it changed my mindset. I knew I had to stay healthy—for myself, and my (now) 3 children. I had a baby girl in 2004. So I remained on medications and kept all my doctors' appointments, but then I started back on the deadly journey. I was traveling the wrong way all this time. So I was sentenced to 6 years in a Florida state prison (which I'm currently at since July 2010).

Here in prison, I learned, "Casandra, just take one day at a time." My health has started to fail. I have major side effects and can't get the proper treatment that I would receive in the free world. So today, and every day, I say to myself, "One day at a time." I had lost all hope, but here in prison I received my high school diploma, fashion design degree, and also culinary arts. I have made a major, positive transformation since being incarcerated.

HIV isn't a death sentence—it's a life sentence to move forward and only take one day at a time. I'm more focused on surviving. I can't worry about tomorrow. I can't do much about the health care here at the prison, because most people seem not to care. Negligence is a big part of the prison system. But I will continue to be persistent, ask questions, and take my medication. It might not change for the better while I'm here, but I will be a voice that will be heard all over the world, saying, "Let's take one day at a time."



Maze by Larry Walker,
Safe Streets Arts

The Pain, The Whole Pain, & Nothing

by Tré Alexander

Have you ever experienced numbness, burning sensations, or tingling in your hands or feet? These symptoms can be brought on by a number of illnesses but can be indicators of neuropathy.

Neuropathy, often referred to as peripheral neuropathy, is nerve damage. The nervous system is made up of an intricate network of nerves. The “peripheral” nerves connect the brain and spinal cord to other areas of the body, including muscles, skin, and internal organs.

Whenever there is damage to a single nerve, it is called mononeuropathy. People who are wheelchair-bound or bedridden may experience this type of neuropathy due to pressure placed on the nerves for long periods of time. This is also common for people who have carpal tunnel syndrome. When many peripheral nerves are damaged and/or break down at the same time, it is called polyneuropathy. People who experience chronic polyneuropathy can lose their ability to differentiate temperature.

Nerve damage can be caused by illness and disease, such as diabetes, lupus, kidney disease, liver disease, or an underactive thyroid. Trauma from accidents, pressure from casts, inherited disorders, tumors, exposure to poisons, and vitamin deficiencies can also cause neuropathy. Here, we are going to focus on HIV-related neuropathy.

As some of you might be aware, HIV (human immunodeficiency

virus) is the virus that causes AIDS. The HIV virus attacks the immune system’s T cells, destroying them and making copies of itself. This compromises the immune system and makes us less able to fight off disease. If left untreated, HIV can tear down the immune system to such a degree that it will not be able to defend the body from dangerous bacteria and illnesses that it normally fends off.

HIV can attack other systems of the body as well, including your peripheral nervous system. Damage to these nerves can interrupt the communication between the brain and various parts of the body. This can cause impairment of muscle movements and even create blockage of normal sensations to arms and legs, creating pain. Persons who experience HIV-related neuropathy can experience pain from a simple touch. In later stages, muscles can weaken in hands and feet. HIV neuropathy can affect your spinal nerves, also known as your thoracic nerves, and can cause problems with nerves connected to the face.

If you begin to feel weakness, tingling sensations, numbness, or loss of feeling, **document this!** Write down your symptoms. Rate your pain on a scale from one to ten, with ten being the worst. List the frequency of the pain, like how often does the pain occur? Is it constant, or does it go away and then come back again? Make a list of all medications you take, how often you take them, and the dosage. Write down your family’s

BUT the Pain: *HIV-Related Neuropathy*

medical history so the clinician is made aware of what illnesses, if any, exist within the family. Also, be prepared to talk about your past and present lifestyle, which may include drug and alcohol consumption, and your own past and present medical history and treatment. Talk to your health-care provider about your current diet and exercise regimen, if any. Doing all this will help the provider figure out the source of your pain.

Show up with questions for the clinician. You might ask: What causes these symptoms? What treatment is available? If I have another illness in addition to HIV, like diabetes or high blood pressure, can they both be managed together? How will the treatment affect me physically, and will there be side effects? Preparation is the key to getting the most out of your sick call visit when behind the walls.

Once the clinician has thoroughly examined you and received all your information, they will perform a neurological exam. This can involve testing tendon reflexes, muscle strength and tone, your posture, and your ability to feel certain sensations. They may order blood work and a nerve function test called an EMG (electromyography), which reads the electrical activity in your muscles to determine how much weakness you have due to muscle or nerve damage. A nerve conduction study will also be done, in which they test your nerves’ response to small electrical pulses.

The response will be recorded by electrodes they place along your nerve pathways.

There are three main approaches to treatment. The course of treatment will be determined by the health-care provider and discussed with you. Which medicine group is used depends on the person.

Usually, a provider will start you with a “neuroleptic” like Neurontin (gabapentin) or Lyrica (pregabalin). These decrease nerve conduction (or the firing of impulses across the nerves) and sensitivity of the nerves to pain.

The second group, antidepressants, works to help the brain be less sensitive to the pain. If you have neuropathy and depression, your provider might choose an antidepressant to treat both the chronic pain and changes in mood.

The third group is pain killers like aspirin, ibuprofen, or naproxen. Unfortunately, most drugs work for the pain but not the numbness. There have also been some good results using acupuncture, but that also tends to work more for the pain than the numbness.

When behind the walls, advocate for yourself and be proactive about your medical care. Addressing the issues can make the difference between a good day and experiencing PAIN, the Whole PAIN and Nothing BUT the PAIN! So help You! Ouch!

Post-PREA Strategies for Health & Safety

by 'Gerrit Q,' New York

PREA (Prison Rape Elimination Act of 2003) standards are finally coming online, ten years late. This is a good news/bad news situation.

The good: The Federal Bureau of Prisons and the states' DOCs (Departments of Corrections) are subject to oversight on prevention, detection, and responding to prisoner sexual assault and abuse.

The bad: with a fear that federal funding and administrative jobs are at risk for facilities with higher than average sexual assault and abuse levels, there is strong motive for under-reporting and covering up sexual assault and abuse incidents.

If you are subjected to sexual assault or abuse, it's your choice whether or not to report it. If you choose not to report it, you are cutting yourself off from vital post-sexual assault treatment, such as medical care and sexually transmitted disease testing and counseling.

Once a prisoner has reported a sexual assault, they are advised to check (via Freedom of Information Law) that the DOC is properly documenting the incident and documenting what care has been requested and provided.

If documentation is not secured or verified, you may find yourself in a Kafkaesque "Groundhog Day" cycle, where every time you say the words "sexual assault," a new cycle of security interviews begins. I was spun through five times before I dug my heels in and refused to cooperate with the sixth

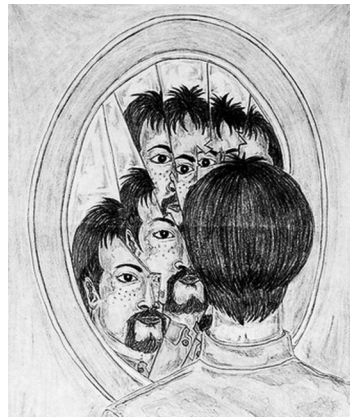
round. I am currently lobbying the DOC's PREA coordinator to reform this chaotic application of policy.

LGBTQ (lesbian, gay, bisexual, transgender, and queer) prisoners are the leading category of sexual assault and abuse victims. DOC security staff will often attempt to imply that their sexuality is a mitigating factor in responsibility and harm caused by sexual assault and abuse.

I urge all prisoners—LGBTQ or not—to stand firm in the fact that only DOCs and the predators are responsible and to blame for prison sexual assault and abuse.

DOCs may use tactics such as delays, resistance, and even intimidation to discourage prisoner sexual assault and abuse survivors from pursuing proper and federally mandated post-sexual assault/abuse services.

I say, stand fast, my fellow survivors! We have already survived the worst of it. Bureau of Prisons and DOC efforts at repression are nothing but time, paperwork, and frustration. Fight till you win, and you will win!



Broken Mirror by Anthony Ware,
Safe Streets Arts

When Liver Cancer Tests May Fail You

by Dennis Jewell

Editor's note: The following article is an inspiring example of how patients can educate ourselves about our health and work with our doctors. Testing for liver cancer is a difficult subject. Complex and expensive testing may save a life, but if everyone with hepatitis C who didn't have cirrhosis got an imaging test, it could be invasive and unnecessary for large numbers of people. There are guidelines for doctors to follow, but guidelines do change sometimes. As this writer points out, staying informed about the virus is you and your doctor's best bet.

Liver cancer (hepatocellular carcinoma, or "HCC") has become the third leading cause of cancer death worldwide, and I am one who has contracted it. Caught early, surgery is very effective as a cure. Caught late—as was my liver tumor, which has metastasized into my lung—the disease is fatal. Minus half a lung and on Nexavar (sorafenib) chemotherapy, I'm trying to carry a message of warning to the next guy or gal concerning early detection.

Twenty-five years after getting hepatitis C from a blood transfusion, and after a decade of ongoing routine screening for liver malfunction, my doctor and I were in shock when a large liver tumor was stumbled upon in a sonogram-assisted liver biopsy prior to clearance for treatment with the new protease inhibitor combination of peginterferon, ribavirin, and boceprevir or telaprevir.

At no time had I ever had a bad liver panel test. I had never shown elevated

levels of alpha-fetoprotein ("AFP"). AFP is the most widely used test for liver tumors. Recent research has found, though, that AFP's inexpensive and easy assay may not be the best way to go, given its high rate of false negatives and positives. That opinion comes from the recently discovered fact that some people with full-blown liver cancer, such as me, have normal AFP levels. Eight months after stumbling upon the tumor, we've stopped wasting money on AFP testing. One of my tumor specialists has concluded that I am one of nature's freaks whose body won't ever produce any abundance of it.

There are two newly developed biomarkers whose detection of liver cancer is much more accurate. One is the AFP-L3 positive blood test. The second test looks at a different protein, not AFP. It is the DCP positive test.

The utter disbelief my doctor and I experienced when that solid mass was detected via sonogram came from the fact that I am totally free of any cirrhosis, with only the most minimal fibrosis (scarring from the hepatitis C). My liver's good state owes in greatest part to my having never used alcohol or other drugs in over 28 years of imprisonment. Experts are just now collecting statistics as to people developing cancer with no attendant cirrhosis, fibrosis, or even any detectable hepatitis C virus after years of sustained virologic response to the peg-ribavirin treatment. HCC touchstones are being re-written.

(continued on page 8)

Heroes Wanted

by Shannon Ross

(continued from page 7)

There are several imaging tests available today that can detect potentially malignant solid masses with great success. There is the sonogram (ultrasound), the device that detected mine; there is computed tomography (CT scan); and there is magnetic resonance imaging (MRI). These methods are unfortunately quite expensive. Moreover, they are typically not used when the tumors are still small enough to remove surgically, often because there are no symptoms affecting the sufferer at that early stage. It seems they need to become the norm of ongoing semi-annual screening, but money is the obstacle, even for folks in the free world with cost-conscious insurance companies.

Do not let what I have presented here give you reason to feel depressed. At least you now know the deadly subtleties of the hepatitis C “Silent Killer,” so you can inform your doctor of these potential problems and needs. It’s your life at stake. To keep yourself and your doctor totally up to date, spend the few dollars it takes to get the best, easiest-to-comprehend hepatitis C monthly publication I’ve found (\$12 for one year for those with fixed incomes; \$22 for a standard subscription): HCV Advocate; P.O. Box 427037; San Francisco, CA 94142-7037. I found their information too late. Don’t make the same mistake.

The organ transplant waiting list currently holds over 118,000 people, 18 of whom die every day. Nevertheless, the list continues to grow every day with mothers, sons, best friends, and more, many of them praying their lives will be extended and their quality of life improved by the generosity of someone choosing to part with a vital organ. These individuals, of course, may now or very well one day be our loved ones, or even us.

Unfortunately, only a couple of states allow people in prison to donate, and then only in certain cases. If allowed to donate, less than 5% of the U.S. incarcerated population could eliminate the current need for kidneys (about 103,000). Evidence demonstrates considerable desire to donate among those of us doing time. In Arizona, as part of the I.DO! program, more than 10,000 Maricopa County jail residents registered to be donors. The problem is that medical policymakers are letting outdated concerns prevent those in need from accessing this wellspring of healthy organs.

Some of these concerns were actually valid in the past, such as the above average disease rate in incarcerated communities and the fact that incarcerated people are more susceptible to abuse and coercion. However, these concerns have been largely addressed by medical advancements (like HIV and Hepatitis C screening), the government’s active solicitation of donors from

communities with higher disease rates than jails and prisons, and the public’s and media’s (thus the government’s) heightened sensitivity toward the mistreatment of disadvantaged groups such as the incarcerated. However, continued vigilance is needed to continue to protect the rights and health of currently incarcerated people, who may still be susceptible to coercion prior to donation and will need post-operative care within the prison system after donation.

So many of us in prison wish, and in some cases are starving, to do something positive. Whether in response to the constant feeling of insignificance brought on by incarceration, or for atonement or the self-fulfillment of helping others, we are eager to show our value, to be relevant in the real world. Donating an organ is undoubtedly one of the best ways to do this. With kidney donation, the most viable option for incarcerated people, one kidney is capable of handling the body’s required workload. Additionally, one study of kidney donors on the outside showed that those who donate lead healthy lives and enjoy an excellent quality of life. Donors may come out of the experience happier, as the pride of donating can increase their contentment and self-worth. This can potentially, among other things, lower stress and depression.

I’m currently trying to get an exemption from the DOC regulation here in Wisconsin that allows people in prison to donate only to family members. This would allow me to donate my kidney to one of the dozens of interested individuals on matchingdonors.com who share my blood type. In the long run, though, I’m trying to get the restrictions on organ donation by incarcerated people removed, not only here but nationwide. Ideally, many of you will push for identical progress in your respective states or join the existing effort spearheaded by GAVE (Gifts of Anatomical Value for Everyone). But if not, check out www.gavelife.org to get virtually any info you need on the issue—such as the bill Utah just passed essentially rejecting the exaggerated claims of high-disease risk in the prison system—and sign yourself up on the incarcerated donor registry, which is a tool used to demonstrate the willingness to donate among the incarcerated (it doesn’t obligate you to do anything). Or you can contact GAVE directly at the address below to request any info or be put on the registry.

Because we’re so abandoned and ignored, it’s easy for us to forget just how much we have to offer. Don’t let the circumstance win; fight for your relevance. Be a donor.

GAVE
1631 NE Broadway, #533
Portland, OR 97232



Attraction by Larry Brown,
Safe Streets Arts

Dogs in Prison? It's a Great Idea

by Jeanine Campbell

Prison dog-training programs, usually started by an outside organization, bring dogs into prison to be trained by incarcerated people who become their trainers. Usually directed toward either rehabilitation for the human trainers or behavioral training for service dogs and shelter dogs, the best programs do both.

Often, dogs live with the trainers on their cell blocks, where they sleep, accompany the incarcerated person to appointments and meals, and are cared for by them. Professional dog trainers lead intensive dog-training classes where incarcerated trainers teach the dogs to obey commands and basic canine manners. The programs usually last a few months.

For shelters, one advantage is that incarcerated trainers can devote more time to focused handling and social interaction than volunteers outside can. This ensures that shelter dogs are given enough behavior training to become adoptable—thus saving their lives. The deep animal-human bond mimics what the dogs need to form with human families that will adopt them.

Incarcerated trainers experience the unconditional love of caring for an animal, and they can build skills for successful re-entry. A few programs also provide internship opportunities and additional training in the animal control field. New Leash on Life USA helps graduates from its program in the Philadelphia Prison System with securing internship

opportunities on the outside. New Leash on Life's Linda Loi says, "The skills they learn through our program (which include life skills, résumé building, dog training, veterinary care, etc.) help in their success once they're released. Many of our former participants are now working full-time in the animal care field. We even have one graduate training to become a veterinary technician."

Puppies Behind Bars is a New York-based program that teaches incarcerated people to raise service dogs for wounded war veterans and explosive-detection canines for law enforcement. The incarcerated trainers are responsible for all aspects of raising the puppies for 16 weeks.

Training dogs, especially dogs with behavioral challenges, teaches that persistence, patience, and positive reinforcement create long-term results more effectively than violence. Pet ownership reduces the incidence of severe heart disease, and simply petting an animal has been proven to decrease blood pressure. Prison dog-training programs can also reduce the feelings of loneliness, isolation, and boredom that contribute to depression, anxiety, and other mental illnesses.

If there is no program like this in your facility, Loi suggests "talking to the COs, wardens, prison superintendents, inmate committees, social workers, attorneys, and judges, and ask how a program like ours can become part of their facility."

information resources for people in prison

If you need information while you are locked up, contact:

Black and Pink

614 Columbia Rd.
Dorchester, MA 02125
monthly newsletter & pen pal program for incarcerated LGBTQ people; expect replies to take about 2 months.

Center for Health Justice

Phone: (213) 229-0979 collect
a free national HIV prevention & treatment hotline service that accepts collect calls from people in prison Monday-Friday, 8am-3pm

Fortune News

The Fortune Society
ATTN: Fortune News Subscriptions
29-76 Northern Boulevard
Long Island City, NY 11101
newsletter on criminal justice issues;
to subscribe, send your first name, last name, ID number, correctional facility, address, city, state, zipcode
*free to people in prison

HCV Advocate

PO Box 427037
San Francisco, CA 94142
monthly newsletter on hepatitis C events, clinical research, and education (materials also available in Spanish).
*sample issue free to people in prison;
\$12 for a year's subscription



Federico Rivera practicing the "down" command with Baby Howie. By Love Shack Photo. Courtesy of New Leash on Life USA

Just Detention International

3325 Wilshire Blvd, Ste 340
Los Angeles, CA 90010
support, resources and advocacy to address sexual violence behind bars; survivors should address Legal Mail to Cynthia Totten, Esq. CA Attorney Reg. #199266.
*free to people in prison

Partnership for Safety and Justice

825 NE 20th Avenue, #250
Portland, OR 97232
support directory with health and legal organizations, prison book programs, resources for LGBT people, and more!
*free to people in prison

Prison Legal News

P.O. Box 1151
Lake Worth, FL 33460
Phone: (561) 360-2523 no collect calls
newsletter on the legal rights of people in prison & recent court rulings
*sample issue \$3.50, unused stamps OK;
\$30 for 1-year subscription

Protecting Your Health & Safety: Prisoners' Rights

325-pg bound manual explains the legal rights to health and safety in prison, and how to enforce those rights when they are violated; publication of the Southern Poverty Law Center, distributed by: Prison Legal News
P.O. Box 1151
Lake Worth, FL 33460
*\$16 for people in prison

Safe Streets Arts

PO Box 58043
Washington DC 20037
resource for incarcerated artists and writers who seek an agent to present their work, free of charge; write to the address above or call (202) 393-1511

advocacy and support resources for people in prison

If you need help while you are locked up, or when you get out, contact:

In Austin, TX:

AIDS Services of Austin
P.O. Box 4874
Austin, TX 78765
Phone: (512) 458-2437
Web: www.asaustin.org

In New Orleans, LA:

Women With A Vision
215 N Jeff Davis Pkwy
New Orleans, LA 70119
Phone: (504) 301-0428
Web: www.wwav-no.org

In Boston, MA:

SPAN Inc.
105 Chauncy Street, 6th Floor
Boston, MA 02111
Phone: (617) 423-0750
Web: www.spaninc.org

In New York, NY:

New York Harm Reduction Educators
953 Southern Boulevard, Suite 302
Bronx, NY 10459
Phone: (718) 842-6050
Web: www.nyhre.org

In Chicago, IL:

Men and Women in Prison Ministries
10 W. 35th Street # 9C5-2
Chicago, IL 60616
Phone: (312) 328-9610
Web: www.mwipm.com

In Philadelphia, PA:

Philadelphia FIGHT
1233 Locust Street, 5th Floor
Philadelphia, PA 19107
Phone: (215) 985-4448
Web: www.fight.org

In Los Angeles, CA:

Center for Health Justice
900 Avila Street #301
Los Angeles, CA 90012
Phone: (213) 229-0985
Prison Hotline: (213) 229-0979 collect
Web: www.centerforhealthjustice.org

If you need resources in a city not listed here, **write to us!** We will help you track down answers to your specific questions.

Write to us if you know about a great organization that is not yet listed here as a PHN partner.

prison health news

Edited By:

Laura McTighe
Lizzy Schmidt,
MSN, CRNP
Naseem Bazargan
Suzy Subways
Teresa Sullivan
Tré Alexander

PHN is a project of the AIDS Library and the Institute for Community Justice at Philadelphia FIGHT.

For subscriptions, resources and all other inquiries write to us at:

**Prison Health News
c/o Philadelphia FIGHT
1233 Locust Street, 5th Floor
Philadelphia PA 19107**

All subscriptions are FREE!