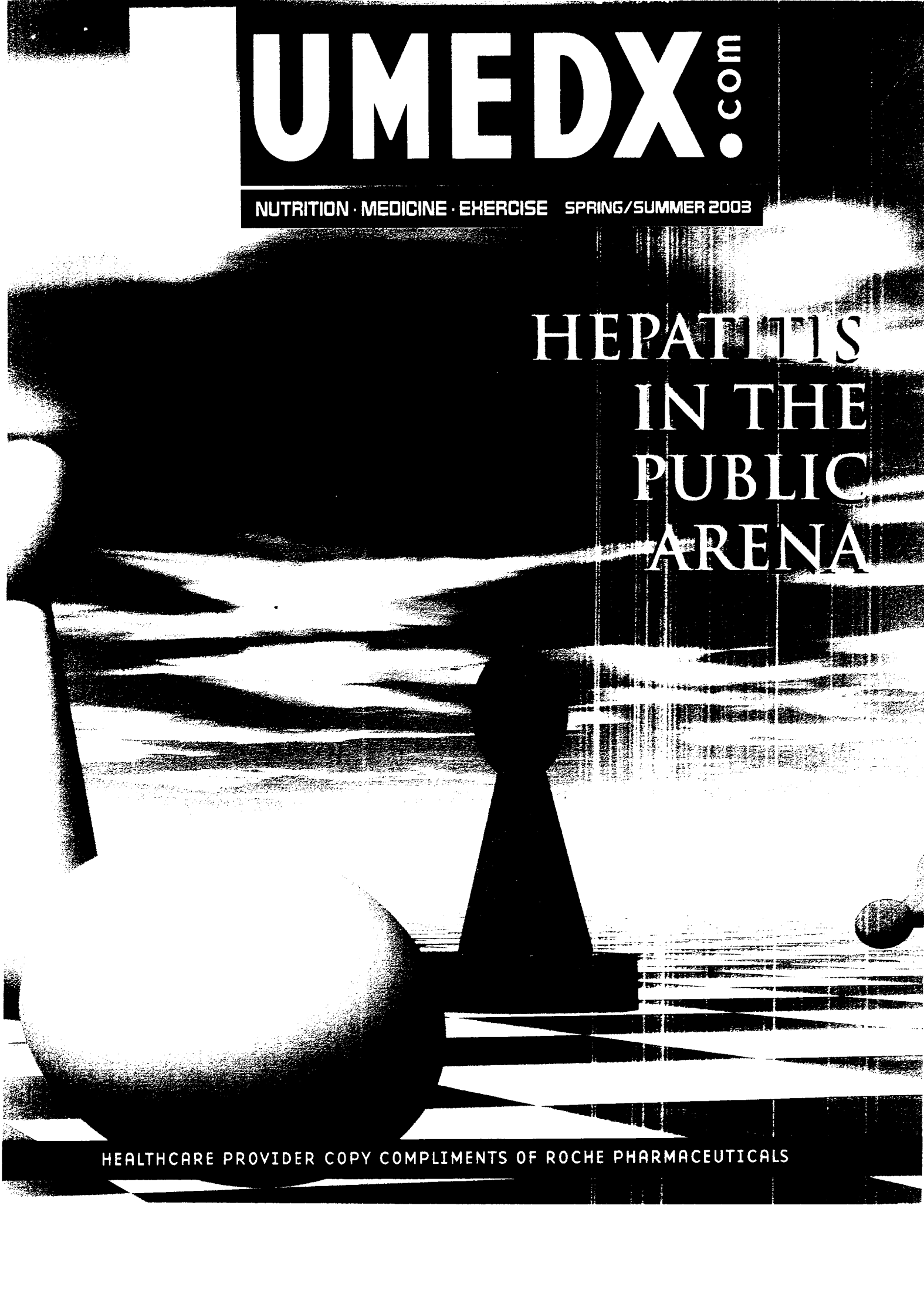
UMEDX.com

NUTRITION · MEDICINE · EXERCISE SPRING/SUMMER 2003

HEPATITIS IN THE PUBLIC ARENA



HEALTHCARE PROVIDER COPY COMPLIMENTS OF ROCHE PHARMACEUTICALS

POLITICS AND PERCEPTIONS: HEPATITIS IN THE PUBLIC ARENA

When President George W Bush pledged to fight AIDS in his 2003 State of the Union address, he further solidified the exponential growth of our country's commitment to a disease that in 22 years has changed the world as we know it.

With 40 million people infected worldwide, and almost 1 million infected in the United States, there is increasing attention to the HIV pandemic. However, there is another widespread virus that is traveling beneath the public's radar, and the lack of public awareness of this other virus closely parallels the early days of the AIDS epidemic when resources were scarce, medical treatments were inadequate, and discrimination against those with the disease was high.

The hepatitis C virus (HCV) has infected 170 million people, or 3 percent of the world's population. It is the most common blood-borne viral infection in the United States, infecting an estimated 4 million people, or 1.8 percent of the population.

Each year, an estimated 10,000 to 12,000 Americans die from the effects of HCV—and that figure may climb to 30,000 by 2010. HCV is the source of one-third of liver-cancer cases and it is the number one leading cause for liver transplantation in the United States. The virus infects an estimated 20 to 30 percent of people living with HIV and accounts for 25 percent of deaths in people living with AIDS.[1] The estimated annual cost of HCV to society in lost wages and medical care is more than $600 million.

Like HIV, hepatitis C is a silent killer. HCV gradually destroys the liver, usually without pain or symptoms, over a period of years or decades. Like HIV, it can be spread through needle sharing. As with HIV, there is no vaccine.

Although the public has developed a general awareness of HIV/AIDS, the vast majority of Americans do not know what HCV is, how it is transmitted, or what the medical consequences of infection are. Many know that Pamela Anderson and Naomi Judd are HCV-positive, but this has not inspired increased public testing. Despite the fact that doctors first started to recognize the signs of HCV in the late 1960s, the virus was not isolated until 1988, and a diagnostic test was not available for widespread blood donor screening until 1990. Nevertheless, the public and governmental response has been measured. The Centers for Disease Control and Prevention (CDC) reports that less than half of all local and public health laboratories have the capacity to test for HCV.[2]

"AIDS is really the model," says Molli Conti, associate director of Pennsylvania's Hepatitis B Foundation. "Activists have gotten these stars to come out and advocate and raise huge amounts of money for AIDS. And AIDS also has the same stigma as hepatitis does...They've done it right, and hepatitis has kind of just struggled along."

Today HCV lives in the shadow of AIDS. In many ways, the lesser-known disease piggybacks on the beneficial changes that the AIDS challenge has brought about in the US public health infrastructure. The CDC has recommended that anti-hepatitis efforts be incorporated into the AIDS fight, since HIV risk factors overlap significantly with those for hepatitis B and C.

HCV financial numbers are as stark as the epidemiological statistics, particularly when compared to those of AIDS. The CDC's hepatitis budget for fiscal year 2004 is $21.9 million—and that is for ***all*** the strains of hepatitis. By comparison, the CDC will spend $984 million on AIDS in the same period. At the National Institutes of Health (NIH), an estimated $103 million is allocated for hepatitis this year. AIDS receives $2.77 billion.

But these numbers are actually a vast improvement. In 1995, government research funding for HCV was less than $1 million. In 1997, the NIH spent $4 million.

The financial devastation to the bank accounts of HCV-positive individuals is equally troublesome. Presently, there is no HCV equivalent of the AIDS Drug Assistance Program (ADAP) to help pay for combination anti-viral therapies that can cost $30,000 or more per year. Two major drug manufacturers of hepatitis therapies, Roche Laboratories and Schering-Plough, have patient-assistance programs. (For more information, please see the Hepatitis Drug Treatment Chart elsewhere in this issue.) For those who are co-infected with HIV, only a handful of state ADAP programs will cover HCV therapies.

The threat to American liver health doesn't stop at HCV. Despite the fact that there has been an effective vaccine for the hepatitis B virus (which is also potentially fatal, though less so than HCV) since 1981, the public health system has so far failed to get Americans to submit to a vaccine course of three injections. One of the highest risk groups for contracting hepatitis B (HBV), men who have sex with men, had a 20 percent seroprevalence rate when the CDC recommended they be vaccinated 22 years ago. Today, the rate remains about the same, which, according to Rob Lyerla, an epidemiologist in the CDC hepatitis division, indicates a lack of widespread vaccination.

However, there has been some recent progress on the hepatitis front. In June 2002 the NIH convened a second and unprecedented Consensus Development Conference on HCV to set new guidelines for treatment, and to discuss ways to better study and prevent the spread of HCV.

While the Consensus Conference made some progress in encouraging hepatitis activism, the hepatitis movement lacks the spark of the early days of AIDS activism. AIDS had the gay community to galvanize funding and public attention, but the HCV community is made up of disparate groups, many of whom who are unwilling or unable to step up to the plate.

"As a general rule, we're a much older population; we're not very well organized," says Alan Franciscus, executive director and founder of the Hepatitis C Support Project in San Francisco. "And we don't have the resources that we'd like to have to initiate all the things that need to be done, [although] I think that's changing now."

Marginalization by Association: Drug Use

"There is a perception that Hepatitis C actually only hits people who are marginalized: rockers, drug addicts, people with lots of tattoos," says Alan P Brownstein, president and CEO of the American Liver Foundation. "But, in actuality, hepatitis really mirrors America: lots of people have it, from Soccer Moms on."

But even if mom contracts HCV from a transfusion, she is hard pressed to align herself with a disease often associated with injection drug users. On the other hand, according to Brownstein, she is still lucky not to suffer the vilification heaped on gay men in the early days of AIDS. "There's not that kind of condemnation with hepatitis C," he says. "The perception is that these are fringe people as opposed to evil people."

"Hepatitis C activism has always suffered from stigma," says Joey Tranchina, CEO of the Hepatitis C Global Foundation. "The association with the fact that, once you factor out those infected by transfusion, you then have the majority of people who contracted HCV from injecting drugs."

Baby Boomers, many of whom injected heroin during the counterculture 60s and 70s, have the highest HCV seroprevalance of any age group in the United States. The virus infects an estimated 3 percent of Caucasians and 6.3 percent of African Americans between the ages of 40 to 59. But these scattered Boomers are not an activist movement because they often do not know they are infected. Many of the Boomers associate any risk factors with their past, and don't translate them into a present danger.

Joey Tranchina, a former rock photographer in the 1960s, says he knows of dozens of musicians infected with HCV; none of them are willing to follow the lead of the HCV-positive Grateful Dead member Phil Lesh, who made his HCV status public and started his own hepatitis foundation.

But the HCV movement suffers even more from ignorance than from shame—the vast majority of people do not even know they are infected. According to Andi Thomas, executive director of Miami's Hep-C Alert, although some efforts are being made to reach "mainstream risk populations," which include the young and those getting tattooed, pierced, and injecting street drugs, there are still real obstacles to progress. "There is no infrastructure to serve the population of people who are today at the greatest risk of progression to liver disease. The group of people my age and above are going to expire without an intervention," the 44-year-old Thomas says.

The public health infrastructure is not meeting the needs of the current injection drug user (IDU) population. According to various studies, 80 to 90 percent of IDUs in major urban areas have HCV. This includes a recent Johns Hopkins study of Baltimore residents that revealed a 92 percent seroprevalence rate in the city's IDUs.[4] And although the number of new infections is dropping, it is probably for the wrong reason. Some theorize that the decline results from the fact that the IDU population is almost saturated—meaning that there are few people left to infect.

Joey Tranchina faults a conservative government for turning its back on harm-reduction tactics like needle-exchange programs (NEPs). But even Democrats have historically shied away from the hot potato topic of providing clean needles to active drug users. In 1990, the first Bush administration instituted a federal ban on NEPs until government scientists could prove the programs both curbed the spread of HIV and did not promote drug use. When this proof came in 1998, President Clinton maintained the ban just the same.

In the meantime, therefore, needle-exchange programs hobble on with a paucity of funds—or simply collapse, like the program in Contra Costa County, California, that was shut down in February 2003.

Even medical treatment is often kept from the IDU population. The 2002 NIH Consensus Development Conference report tried to dispel the long-held belief that drug treatment for HCV-positive people who are using street drugs is ineffective. But doctors have other reasons for excluding substance users from care.

"A lot of physicians are not willing to treat active IDUs, because they feel adherence will not work, because of the difficulty of the regimen," says Nina Grossman, director of the needle-exchange program at the San Francisco AIDS Foundation. "Which is an absolute falsehood. Anybody, given the right support, can stick to a Hep C regimen."

Prisoners: The Invisible Majority

Reversing the invisibility and degraded status of HCV is made even more problematic by the fact that an overwhelming number of infections are in the one group that is even more disenfranchised than IDUs. They are the nation's prisoners, many of who are incarcerated on drug charges.

According to a National Commission on Correctional Health Care 2002 report to Congress about inmate health care, an estimated 17 to 18.6 percent of prisoners are HCV-positive and 3 percent have HBV. (These figures are only extrapolations since there is no widespread hepatitis testing in prisons or jails.) And the CDC estimates that 1.3 million people with HCV and 155,000 with HBV were released from prison in 1996—all of whom could have received some kind of care or counseling.[5] But efforts to provide screening, prevention, or treatment have been spotty at best, negligent at worst, in the US correctional system. Some correctional facilities require that, in order to qualify for drug treatment, inmates be more than 2 years from parole (even if the date doesn't guarantee release) and that they enroll in substance-abuse courses or refrain from smoking.

Money seems to be the main obstacle: it costs too much to treat this rampant disease. Increasingly, correctional systems simply contract with for-profit medical supplier companies for healthcare services, since these companies can only make a profit by holding down costs, they have little incentive to provide the adequate, continuing, and expensive treatment that inmates with HCV require. The American Civil Liberties Union (ACLU) is suing one such national healthcare provider, Correction Medical Services, for allegedly providing negligent care to HCV-infected inmates in both New Jersey and Michigan.

Society's indifference about the health of the incarcerated has resulted in a tragic irony. Prevailing attitudes consider prisoners to be unworthy of proper medical care, and since they are safely tucked away in quarantine, they are not seen as a public health threat. But 99 percent of all prisoners will eventually be released. And by then, not only will many be sicker, but they are even more *likely* to carry—and transmit—HCV than they were before incarceration. This is because prisoners, uneducated about hepatitis risk behaviors, are likely to spread HBV and HCV among themselves through unprotected sex, needle or razor sharing, or possibly tattooing. And this infected, largely untreated, population will return into the general public. Failure to vaccinate inmates against hepatitis A and B may have a devastating impact on the public health. In the year 2000 alone, more than 8 million inmates were released back into their communities.

Eric Balaban is staff counsel with the ACLU National Prison Project, which has requested a Congressional investigation into the US correctional healthcare system. He says that many systems will withhold treatment with the gamble that a prisoner will be released before ever becoming ill from the disease.

"So the question is: do you pay now when it'll be cheaper and their care can be monitored closely while they're in a controlled environment?" asks Balaban. "Or do you pay a lot more later when their treatment is dictated by the severity of their condition: when they go to an emergency room and when state Medicaid or some other form of state assistance is going to have to pay?"

Recently, there have been encouraging signs of progress among government agencies on the matter of inmate health. The National Institute of Corrections stated in a December 2001 report that many departments of corrections have failed to create adequate healthcare plans to serve the influx of prisoners with special healthcare needs as the US incarcerated population continues to grow.[6] And the Federal Bureau of Prisons intends to adopt guidelines published by the CDC in January that recommend improved disease screening, treatment, and education, as well as discharge planning to help inmates with the transition to outside medical care. But it remains to be seen how these proposed changes will play out, especially given the current state budget crises. The CDC has recently issued recommendations published in *Morbidity and Mortality Weekly* that call for prison vaccination against HBV regardless of length of stay, and vaccination against hepatitis A for high risk inmates. The extent to which these recommendations will be followed remains unclear.

Veterans: Forgotten Soldiers

Yet another population that suffers disproportionately from HCV is America's 25 million veterans. Veterans Administration (VA) physicians have estimated that 8 to 13 percent of all veterans are infected, and there is an unusually high incidence among Vietnam-era veterans. *[Editor's Note: This subject is addressed in a separate article elsewhere in this issue.]*

And yet, Terry Baker, of Veterans Aimed Toward Awareness, says that the VA sent a letter to the NIH last year demanding that veterans be removed from the list of major risk categories in the recent Management of Hepatitis C Consensus Conference statement. The VA told the NIH that there was no significant data to prove that veterans are at risk. Baker claims that the reason for this position is that the VA has only researched the seroprevalance of the 4.2 million veterans who use the VA healthcare system, and not the remaining 21 million.

Michael Rigsby, director of the HIV and Hepatitis C Program Office for the VA, says: "It's certainly true that in some subgroups [of veterans], rates appear to be quite high." Rigsby expressed concern about the high number of HCV veterans who seek care in the VA system. He says there is a study currently examining the veterans who do use the system to determine their seroprevalence. Results will be available in about 6 months. The VA is not, however, studying all 25 million veterans.

When the NIH released its report after the Consensus Conference (which was sponsored in part by the VA), veterans were no longer on the list.

Addressing the Needs of Disparate Populations

"There are only 20 some-odd [HCV] organizations in the whole damn country," laments Andi Thomas of Hep-C Alert. "Most of them are hotlines. Very few of them do any type of care coordination or referrals."

ALF president Alan Brownstein is more optimistic, saying that "The mobilization has begun and progress is now underway. Hepatitis awareness is basically increasing across America."

But as HCV inspires at least some sputtering mobilization, HBV's quiet voice has become even more silent. According to Molli Conti, of the Hepatitis B Foundation, HCV's sudden jump to prominence has dried up resources for HBV. "Most of the research dollars that were in B have gone into hepatitis C," she says.

"It's very important that there be a separate, significant funding stream for Hepatitis C," Tranchin says. "So that Hepatitis C doesn't become what we all fear it will be, which is a vampire disease sucking off the blood of HIV."

Probably the most promising progress in the history of the HCV movement could be right around the corner, assuming that it makes its way through Congress.

A coalition of more than 20 HCV groups has pushed a bill to the floor of the Senate which would authorize the US Department of Health and Human Services to create programs for the education, prevention, and study of HCV. Bill number HR 371 is co-sponsored by Stephen Lynch (D-MA) and Jack Quinn (R-NY). It was introduced on the Senate floor in early March.

"It's been quite phenomenal," says Lolita Sandt, president of the National Hepatitis C Advocacy Council, about the response she has received in Washington to her lobbying on behalf of the legislation. Last summer, then-Senate Majority Leader Tom Daschle gave her 20 minutes of personal time and another 45 minutes with his staff to discuss the issue.

"Everyone that we've visited [in Washington] has said, 'It's time,'" Sandt reports, adding that Congressional aides, largely sensitive to the HCV cause, have been "blown away" when told there is no federal legislation for the disease.

But she has also felt resistance, reminiscent of the beginning years of AIDS, that is related to the long-term nature of the disease. "A lot of the resentment I get in the offices [of Congress] is: 'We gave too much to the AIDS people. So how much are you going to cost us?' Which is one of the reasons we couldn't even begin to approach them with a treatment bill. But on the other hand, they also don't want to be in a position where they're stuck with their heads in the sand."

If the bill does pass, it would finally lay solid groundwork to legitimize the plight of hepatitis in Washington. But the fact remains that hepatitis activism is still in its infancy.

The National AIDS Treatment Advocacy Project (NATAP) is spearheading a move to organize a national coalition to promote awareness of HCV/HIV co-infection. The coalition will include individuals that represent HIV organizations from around the country as well as consumer and professional advocates. Other organizations, such as the Hepatitis C Outreach Project (HCOP), have been advocating for HCV awareness and treatment for years yet the true advances that need to occur are still far in the future.

To quote the final line of Tony Kushner's seminal AIDS drama, *Angels in America*: "The Great Work Begins."

Benjamin Ryan is a freelance reporter specializing the in healthcare politics. He lives in New York City. N