Hep Cat

The 30 percent of HIVers with hepatitis C crowd the death roll but not the halls of power. Could Jules Levin, their loudest advocate, be their biggest liability?

May 1, 2005 By Tim Murphy

HIVer Louis Zimmerman, 54, of Aurora, Colorado, will never forget the side effects he suffered from interferon therapy to eradicate, or “clear,” his hepatitis C virus (HCV). “First, you feel like you got the flu all the time,” remembers the former truck driver, diagnosed with HIV and liver-ravaging hep C in 1997. Soon, he was “shaking like hell with anxiety,” one of the mood disorders HCV treatment often causes. Zimmerman stuck with it. But like many with HCV genotype 1—the most common in the U.S. and the hardest to treat—he didn’t clear the virus. He’s trying again, however, and is optimistic: “Jules didn’t clear his hep C till his second time.”

By Jules, he means Brooklyn native and ex–Wall Street trader Jules Levin, whose name has become synonymous with advocating for the estimated one-third of HIVers coinfected with hep C. (About 10 percent of HIVers have a chronic form of blood-borne hepatitis B.) Diagnosed with HIV and HCV while kicking heroin in the ’80s, Levin in 1995 founded the National AIDS Treatment Advocacy Project (NATAP) to decipher scientific data for everyday HIVers. He has become one of the most respected voices with Big Pharma, federal AIDS honchos and countless HIVers like Zimmerman, who mob the forums he holds throughout the country, which star top researchers. NATAP also prints several data-packed newsletters a year, distributed to the tens of thousands.

Though treatment cleared Levin’s hep C in 2003, he maintains a deep bond with coinfected HIVers, who depend on him fo rlifesaving information. Many are, like Levin, current or former injection-drug users (IDUs), whom hep C affects most (it is transmitted through shared needles far more easily than HIV). Many are, like Levin, heterosexual men. But unlike him, they tend to be low-income people of color, underrepresented among the HCV-free gay white HIVers (and their HIV negative peers) who have dominated AIDS policymaking and treatment activism. They are beset with challenges ranging from HIV to addiction, mental illness, poverty and prison time.

But Levin says that right now, the main thing that’s killing them is hepatitis C. His own drawn, AIDS-weathered face and wiry frame spark with righteous fury: “If you go into the inpatient AIDS ward at Bellevue [a New York City public hospital], the people dying there are dying of hepatitis-related liver disease,” says the fiftyish-looking Levin, who won’t give his ge. “All the studies show that it’s the number one cause of death [among HIVers].”

Fact is, he’s right: Studies show that up to half of recent deaths among HIVers were attributable to liver disease caused by hep C, which afflicts up to 90 percent of HIVers who have injected drugs. Though people with HCV alone often see the virus progress so slowly that they never need treatment, several studies suggest that HIV at the very least doubles the speed of HCV-related liver disease.

What’s more, HIVers don’t respond to HCV treatment as well as those with HCV alone and are harder hit by the side effects. (On top of that, for unclear reasons, African Americans don’t respond as well to HCV treatment as whites.) Optimistically, the recent APRICOT study found that when HIVers with HCV genotype 1 were treated with a combination of pegylated interferon plus ribavirin, 29percent cleared HCV—a rate approaching the 40 percent clearance rates among non-HIVers with that genotype. That data led the FDA in February to approve drugmaker Roche’s versions of the two drugs specifically for coinfected people.

But standing before even such modest success rates are many obstacles, from too few coinfection-savvy HIV doctors and support programs for coinfecteds undergoing hep C treatment to the many states whose AIDS Drug Assistance Programs (ADAPs) don’t even cover the grueling, months-long regimen. (At press time, *POZ* learned that Schering-Plough would provide the treatment to 1,500 needy HIVers on ADAP; for information, call 800.521.7157.)

Clearly, coinfection is an urgent issue demanding a strong, effective leader. But numerous AIDS advocates, many focusing on coinfection themselves,wonder privately whether Levin is the best choice, calling him an abrasive, self-congratulatory lone wolf. “He’s better at alienating and making noise than forging coalitions,” says one advocate close to him,echoing many others interviewed for this story. “He’s not the best person to be carrying this message.” Levin’s response reflects his signature Brooklyn bravado, at once infuriating and weirdly endearing: “It’s easy to criticize me,” he says blithely, “because I’m very high-profile.”

DISSERS AND DISCIPLES

For everyone who criticized Levin privately (few would speak for attribution, saying that they still had to work with Levin on occasion), just as many praised him, especially coinfected HIVers like Zimmerman who don’t work at the top levels of AIDS advocacy. And he has certainly raised coinfection’s profile, enlisting nearly 100 groups in his National HIV/Hepatitis C Coinfection Coalition, which in recent years has pled its case before federal biggies like former health secretary Tommy Thompson and the staff of such lawmakers as Senator Teddy Kennedy (D-Mass.), Senator Arlen Specter (R-Penn.) and Rep. Maxine Waters (D-Calif.)—not to mention the nation’s biggest AIDS advocacy groups, including the National Association of People with AIDS (NAPWA), the CAEAR (Communities Advocating Emergency AIDS Relief) Coalition, the National Alliance of State and Territorial AIDS Directors (NASTAD) and the AIDS Institute.

For the coinfected folks in his coalition, he is unquestionably a hero. Coloradan Catherine McCartin, 48, who has accompanied Levin on Capitol Hill, says he “takes clinical information and makes it people-friendly.” Washington, DC’s Beri Hull, 49, a coinfected black female activist and former IDU, calls him “more of an advocate for…populations on the fringes than some so-called mainstream[AIDS] organizations.” AIDS activists, too, applaud his tenacity, passion and openness with his own HIV history, rare among straight male HIVers. “He is relentless, and that is a good thing,” says James Learned, director of treatment education at the AIDS Community Research Initiative of America. When it comes to coinfection, “Jules is the pioneer,” says Tracy Swan, a Levin coalition member who works on coinfection issues at Treatment Action Group.

But Levin’s critics say that as he shouts for more money and attention for coinfection services, he offers no clear plan to bring them into the AIDS infrastructure—and, worse, is unable or unwilling to collaborate with those who could help him design one. They call him rude,egotistical and reluctant to acknowledge that he isn’t the only one fighting. Says one: “He’s…very myopic. He needs to hire a good lobbyist and not come near the Hill, [where] he yells. He’s kind of scary.”

“Nobody has asked me to sit down with them and put together a program,” Levin counters. But he seems slyly delighted with his bad-boy reputation,repudiating it lushly: “For people who want to work with me, I’m easy—a pushover. I have a facade. If I really were so tough, I wouldn’t be doing this work.”

It’s his most recent work, though, that has advocates really worked up. He’s setting his sights on AIDS’ most precious—and overstretched—moneypot: the Ryan White CARE Act.

THE FIGHT OVER RYAN

Enacted in 1990, the $2.1 billion Ryan White CARE Act serves hundreds of thousands of HIVers not covered by Medicaid, Medicare or private insurance. It funds everything from state ADAPs, which dispense free meds, to primary-care clinics and peer-led treatment education. Yet the program has been flat-funded throughout the Bush administration as its caseload has risen, causing an estimated $425 million shortfall, ADAP wait lists in several states and a scramble to preserve services. This year, Congress will almost certainly reauthorize Ryan White for another five years—but amid across-the-board domestic cuts, all of Ryan White but ADAP (which may get a small increase) will likely be flat-funded again. Says Learned, “Some mind-bending choices will have to be made.”

In the middle of such anxiety, say AIDS advocates, Levin last year did the unthinkable: He called for a mandated amount for hep C within Ryan White. Levin denies that he did so. But Carl Schmid, who handles policy for the AIDS Institute, insists that, in a meeting, Levin proposed the earmark. Schmid says he told Levin he would never “receive support from the AIDS community” because shortages in Ryan White made it “difficult to support new set-asides.”

Plus, says AIDS Institute head Gene Copello, “The CARE Act is built on the concept of local planning” for anything deemed a priority in a given city or area, including coinfection. “So there’s always this hesitation to have any top-down mandate.” He is echoed by Robert Cordero of the CAEAR Coalition, whose reauthorization recommendations, issued in February with the group AIDS Action, don’t call for special focus or funds for hep C. Says Cordero,“We have to make sure that a shrinking pool of resources can address HIV first.”

At least one AIDS poobah, NAPWA executive director Terje Anderson, has echoed Levin's demand by suggesting a separate Ryan White funding stream for hep C. Though Anderson says he hasn't formally proposed the idea and acknowledges that "it's a crappy time for [new] appropriations," he says he has discussed it with "a number of congressional offices" crucial to Ryan White reauthorization. Anderson, it's worth noting, is perhaps the only top-level AIDS advocate besides Levin to have been coinfected (he cleared HCV with treatment in 1997).

Levin seems to have since "backed away" from his earmark demand, says Schmid. Indeed, Levin never broached the earmark with *POZ*, saying only that his coalition has submitted "language" on beefing up hep C services that it hopes to see in a reauthorized Ryan White, then adding cryptically, "if and when the discussion moves to [money], I will assess the situation." But HRSA's Laura Cheever, MD, deputy associate administrator for HIV/AIDS, says, "It's up to [Ryan White]grantees to figure out how to best use the funds," while adding that HRSA will urge grantees to offer more hep C screening, even if ADAPs don't provide treatment.

Yet Levin blames not only Ryan White grantees. He says few HIV doctors know much about coinfection, telling patients that they're OK because their liver enzymes are normal. (Not so; see "Coinfection 411" below). HCV information "should be part of an infrastructure, just like HIV treatment education," says Levin. "Our ASOs [AIDS service organizations] are doing shit," he adds, saying they fail to screen clients for hep C, educate the coinfected ones and support those who undergo treatment.

THE ONE FOR ME?
Battling two bugs at once

How do I know if I have hep C?
Every HIVer should be tested for HCV. Ask for an HCV antibody test—but if you test positive, confirm it with an HCV viral-load test. You may have cleared HCV naturally.

If I have hep C, do I need treatment?
You need to assess hep C's damage to your liver. Blood tests can check your liver functions, but they can be normal even with liver damage. Learn your hep C genotype: 1 is more common and harder to treat than 2 and 3. An alpha-feto protein blood test screens for liver injury; an abdominal sonogram for liver cancer.   The best assessment is a liver biopsy, which will show the level of fibrosis (scarring).

What if I have advanced fibrosis?
Before you start hep C treatment (which combines pegylated interferon with ribavirin), you need a full evaluation, including a psychiatric screen. Women can't get pregnant during or for six months after treatment because ribavirin may cause birth defects You can't take ribavirin with the HIV meds Videx or AZT. You'll respond better to treatment if you start with 350 or more CD4s, but start with less if you really need to.

What is the goal of treatment?

The goal is to “clear” your hep C, defined as having negative HCV viral load six months after treatment ends. HIVers usually are on treatment for at least 48 weeks. Your HCV viral load at week 12 of treatment will predict whether you will clear,but even if it’s unlikely, consider staying on treatment to reverse liver damage. You need major support to get through treatment, so plan ahead with your job and a support group if possible. You can get HCV again after clearing it, so be careful.

What if I delay treatment?
Be sure to repeat your liver biopsy within the next three years. Love your liver by chugging lots of water; quitting or reducing drinking, drugging and cigarettes; and eating more leafy greens and less fatty, greasy foods. Get vaccinated for hepatitis A and B if your blood doesn’t show immunity to it.

Will there ever be better hep C treatment?
HCV protease inhibitors and polymerase inhibitors are in early development now, providing hope for HCVers who’ve failed or are putting off today’s treatment.

Where can I learn more?
Contact Jules Levin’s NATAP at www.natap.org or 888.26.NATAP—and his coalition at www.hepcadvocacy.org. Also check out Andi Thomas’ www.hep-c-alert.org, Alan Franciscus’ www.hcvadvocate.org,www.hivandhepatitis.com and www.lola-national.org (for Latino HCVers).

Simmering beneath these grievances is his conviction that coinfected people are the AIDS community’s undesirables: “Look at who [hep C] affects,” he says. “IV-drug users mostly—that group is completely stigmatized. People don’t care about them.” What people exactly? In a 2002 *POZ* interview, Levin asserted: “The gay white men who are still doing treatment advocacy aren’t as affected by hepatitis. They’re not sympathetic to the injection-drug users, blacks and Latinos who are coinfected.” Today, he’s careful not to go that far. He seems not to want to alienate people—too much.

COUNTERPUNCHES

ASOs in cities with significant coinfected percentages strongly deny they’re “doing shit.” Charles King, who leads New York City’s Housing Works, says, “We aggressively address coinfection” with hep C prevention and treatment counseling, testing and treatment. Uptown, Harlem United not only offers on-site hep C education but screens all clients for the virus and treats in conjunction with gastroenterologists at a major hospital, says the agency’s medical director L. Jeannine Bookhardt-Murray, MD.

Outside New York, the AIDS Foundation of Chicago’s Laird Petersen recites a long list of programs that the city’s ASOs, AIDS clinics and departments of health provide to increase hep C services for HIVers (but notes that few HIV doctors have signed on to a hep C training program). And at any one time at Philadelphia FIGHT, as many as 30 coinfected clients are treated for HCV onsite by a coinfection-specializing doctor and are offered support groups and peer education, says the agency’s Laura McTighe.

Many AIDS leaders agreed with Levin that “there needs to be much more advocacy about HCV,” as King puts it, but most disagreed that the deficit stemmed from indifference. “Most of my colleagues in other national organizations are very concerned,” says Coppello. “It’s impacting the very population we exist to serve.” Again, such advocates say, it’s all about the money. “People are terrified that things are going to get cut,” says Swan, “and their first line is to preserve what’s there.”

But at least a few people think Levin is on to something—a breach between coinfected HIVers and their C-free, IDU-free, often gay male counterparts who influence policy and funding. “The HIV community has never been particularly welcoming of [IDUs],” says Learned. “I worked at NAPWA for years,” says black female coinfected Beri Hull, “and always felt like it should have been called the National Association of Gay Men With AIDS. When you have a certain group running [things], they look out for themselves.” Even NAPWA chief Anderson, a gay white HIVer, says that as a former heroin injector, “I feel disconnected from part of the [AIDS] movement. [My former injecting] sometimes makes people profoundly uncomfortable.”

Others insist that the true issue is Levin’s contentious work style, which undermines his worthy agenda. “He considers himself a one-man show,” says a dissenter. “He’s a Wall Street guy. He only hears what he wants to hear. He doesn’t understand the policy realities in Washington. He makes it seem so simple: Put this in the CARE Act. You have to give a little more detail than that.A lot of [coinfection programs] are happening through Ryan White [already].” Says another: “I’ve heard that his coalition isn’t really a coalition—it’s just Jules.”

A MAN POSSESSED

While *POZ* was reporting this story, it discovered an entire network of people and programs dedicated to hep C and coinfection, from both the AIDS world and the budding world of hep C advocacy. So it was strange, to say the least, that even when prompted, Levin hadn’t mentioned more than one or two. Why hadn’t he joined the National Hepatitis C Advocacy Council (NHCAC), chock-full of AIDS and HCV advocates lobbying for an independent hep C funding stream, even after being “personally invited,” says council president Andi Thomas. According to Levin, council members “tend to focus their efforts on [HCVers-only] who were not infected by injection-drug use and are not coinfected.” He adds that he belongs to the Hepatitis C Appropriations Partnership (HCAP), a similar effort.

But San Francisco hep C advocate and councilmember Alan Franciscus calls Levin’s characterization of the group “totally false. How could you have a group that doesn’t advocate for people at highest risk for HCV?” he asks, referring to IDUs. NASTAD hepatitis expert Laurie Schowalter, who works with the council, agrees, describing the group as “focused on helping all people with HCV, coinfected or not.” An HCAP member, she also questions Levin’s involvement with that group: “I have reached out to him several times, but he has put little effort forward. I respect his passion, but I’m not yet convinced Jules is willing to do the hard work necessary to get money and attention for this disease.”

Asked why he hadn’t mentioned a CDC-funded program of the New York State’s respected AIDS

Institute to integrate “hep ed” into relevant services, such as those for HIVers, Levin scoffs: “It’s not doing nearly enough.” What of the frequent complaints that he offers no HCV implementation program of his own? He admits that he doesn’t have one, adding, “I put my eye not so much on the day to day” but “the end goal.” Why hadn’t he at least mentioned Swan, a member of his own coalition, whom many regard as a coinfection expert? Or her boyfriend, Daniel Raymond, who addresses coinfection at New York City’s IDU-serving Harm Reduction Coalition? “They try—but if you look at a great ballplayer like Larry Bird, how do you compare?” he laughs. It’s hard to tell if he’s joking.

Reluctant to discuss his past, he allows that in his early years of recovery, he practiced meditation. Today, he says, “my meditation is hep C education and advocacy.” Is his work driven by memories of friends in Narcotics Anonymous whom he says he lost to AIDS in the 1980s and who would likely have been coinfected today? “Absolutely,” he snaps. Does he remember their names? “There was Dennis,” he mumbles. “And Anthony. And what’s-his-name.” He appears unable or unwilling to continue. “I’ve put this behind me. It was 23 years ago.”

Yet in many ways he seems driven by an anger—and perhaps a grief—so strong that he can’t believe anyone could care for coinfected people as much as he does or advocate for them as robustly. Inevitably, he provokes comparison to famed AIDS activist Larry Kramer, who didn’t play well with others but effectively scolded and shamed enemies and acolytes alike into action. Perhaps this is why AIDS advocates hold a soft spot for him, griping anonymously but publicly applauding a survivor who devotes his life to nabbing the top killer of HIVers. “Being able to spend time with Jules is always rewarding,” says Learned. “He’s an incredibly warm man. I wish more people could see that. They might hear his message more clearly.”

One thing is certain: Right now, he’s the only lived-to-tell leader that coinfected HIVers have, and they’re standing by him. When Levin and his posse presented on Capitol Hill, says McCartin, “he made us feel good—like a team.” And don’t even ask Zimmerman if Levin’s the guy for the job. “Oh, definitely,” he says. “Jules is number one.”

COINFECTION CHRONICLES…

Melvin Littles
Age: 51 Yonkers, NY
HIV treatment educator at St. John’s Riverside Hospital
Dx’d HIV 1992 Dx’d HCV 1996

HEP C STORY:
Three years ago, a liver biopsy revealed Littles didn’t need hep C treatment yet—but he’s due for another biopsy this year. “I want to wait for a hep C protease inhibitor,” he says, “because the [current] treatment doesn’t work as well in African Americans with genotype 1, like me.”

HOW HE COPES:

"I smoke half a pack a day, but I've been clean from drinking or drugs for 18 years."

SHOUT-OUT:
"Even though I almost died from HIV and two of my brothers died from it, I'm more afraid of hep C. When your liver's gone, it's gone. But I don't want to inject myself [with HCV treatment] once a week. I used to shoot drugs, and injecting might open some desires."

LIFE BEYOND COINFECTION:
"Helping people who are newly infected with HIV get through the system—that's what makes me happy."

Carmen Rivera Age: 55 Bronx, NY
HIV/AIDS peer educator at St. John's Riverside Hospital
Dx'd HIV 1989 Dx'd HCV 2000

HEP C STORY:
Rivera prepared herself for hep C treatment last year, only to find out after a biopsy that she didn't need it yet. She was relieved because she also has diabetes. "Sometimes I get very tired," says Rivera. "My mind wants to keep going, and my body says no, no, no. I'm also going through menopause!"

HOW SHE COPES:
"I used to drink tequila like water—now I'll maybe have one or two. But Ieat everything I'm not supposed to eat—oxtails, pork chops. I try to stay away from that stuff, but I'm Puerto Rican!"

SHOUT-OUT:
"I think hepatitis C is scarier than HIV. I had a friend with HIV who died from hep C."

LIFE BEYOND COINFECTION:
"My boyfriend of 13 years makes me happy. When I feel achy, he'll rub me all over. When I see so many lonely people with HIV, I realize how fortunate I am."

Robert Lewis
Age: 55 New York, NY
HIV/AIDS case manager at Project Samaritan
Dx'd HIV 1987 Dx'd HCV 1993

HEP C STORY:
Lewis improved his liver-disease stage from grade 3 to 1 but didn't clear HCV on treatment last year. "I wanted to quit it," he says. "The cold chills, the depression—I would take my shot on Friday and have to stay in bed all weekend. Sometimes on Monday I couldn't go into work."

HOW HE COPES:

By taking a hiatus from his stressful job. “If I have to do the treatment again, hopefully I’ll be home resting.”

SHOUT-OUT:
Lewis gives props to Levin: “He convinced me that I needed my biopsy. He breaks down the information for those of us who don’t have degrees.” And he agrees that hep C gets short shrift compared to HIV: “We have [meds] to control HIV now, but look at all the other complications!”

LIFE BEYOND COINFECTION:
“I like helping others [with HIV and HCV]. It’s hard for me not to be at work right now, but my clients still call me.”

Elizabeth Parrilla
Age: 44 Bronx, NY
Social work student at Lehman College
Dx’d HIV 1998 Dx’d HCV early ’90s

HEP C STORY:
“Right now, I’m on my fourth hep C treatment since 2001. I’m in the last stage of cirrhosis. I worry about not clearing hep C. I feel a little crabby, but I try to overcome that.”

HOW SHE COPES:
By postponing her duties as a peer volunteer at a residential treatment program—but she’s sticking with classes toward her social-work degree.“I’ll be doing my internship before September,” she says proudly.

SHOUT-OUT:
Her message to other coinfected folks: “Keep your head up. Be hopeful that there’ll be new meds. If I have to try hep C treatment a fifth time, I will. I’m not a quitter. And I don’t have anything to lose.”

LIFE BEYOND COINFECTION:
“I like to travel—I went to Cancun last year. Plus, my man makes me happy. And I’m the grandmother of four boys. They’re little darlings.”