For Cryin’ Out Loud

As Congressional Republicans on the Hill slash government spending and attempt to reverse Obama’s health care reform, HIV advocates call cuts to AIDS funding and services “the real death panels.” Meanwhile, a scrappy group of activists from Ohio goes toe-to-toe with national lawmakers, including Ohio’s own John Boehner, the freshly minted Speaker of the U. S. House of Representatives. Ohio’s HIV-positive community’s fight to save the state’s ADAP program, and their lives, may well set the standard for battles to come nationwide.

February 3, 2011 By Mark Leydorf

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As Ohio goes, it is said, so goes the nation. Ohio has long signaled the outcome of U.S. politics; it has only voted for the losing presidential candidate twice since 1896. The state has been on the forefront in other areas too: The Wright Brothers first experimented with flight at their Dayton bicycle shop. Akron was the birthplace of Alcoholics Anonymous and rubber tires. And Ohio was the first destination for many escaped slaves on the Underground Railroad. Today, it could serve as a bellweather for the AIDS funding crisis in America: As we go to press, Ohio has nearly a thousand HIV-positive people unable to access care.

House of Representatives Speaker John Boehner

Ohio is also the home of the new Speaker of the House of Representatives, John Boehner, a Republican. He’s known for breaking into tears publicly over issues like the war in Iraq, working-class heroes and the passing of the gavel, and now there is talk about why the GOP leader is not shedding tears for his constituents living with HIV.

Budget cutters in Columbus are dismantling the state’s AIDS Drug Assistance Program (ADAP), an astoundingly hard-hearted and shortsighted decision that is repeating itself in statehouses across the country from Michigan to Florida. In response, one Buckeye AIDS activist (and his army of recruits) is putting up quite a fight. Gil Kudrin’s day job is director of development for Nightsweats and T-Cells, a screenprint and design shop that makes and markets products with HIV/AIDS

messages (the shop was cofounded by the writer Paul Monette, who lived with and chronicled AIDS until his death in 1995), where activism is part of the job description. Kudrin and a group of Ohio-based activists aim to ensure Boehner hears their cries loud and clear.

After Governor Ted Strickland (acting on advice from a secret "blue-ribbon panel") lowered the ax on Ohio's ADAP last year, Kudrin, 52, of Cleveland, helped start the Ohio ADAP Crisis Committee. The group traveled the state organizing town halls, launched a Facebook page (Ohio AIDS ADAP Crisis) and mounted a huge grassroots letter-and-phone campaign to save the ADAP funds.

It worked. On August 26, 2010, a Statewide Call to Action Day, "the governor received nearly 500 calls. The next week he shored up the program with $12.8 million from new Medicaid money from Washington," Kudrin says proudly. When asked why he decided to mobilize, he says, "I must do my part. I've seen the movie [of what happens when people with HIV don't get care]—I know how it ends!"

Indeed he does. He dates his life with HIV to 1978, long before ACT UP, GRID or even President Ronald Reagan. "I met a man I fell in love with the second time I went to a gay bar," he says. "He died in 1994." Kudrin didn't receive an AIDS diagnosis until May 1995, though his first CD4 count, in 1987, was 230. Since then, thanks to HIV drugs, his CD4 count has climbed above 1,100. "But I have paid a heavy price," he says. Taking meds has given him osteoporosis (three spine procedures in the past two years have helped with the pain), facial wasting from lipoatrophy, and macular degeneration. But he is grateful: "I know I got the meds in the nick of time."

However, as a man living with HIV in Ohio, he may be running out of luck. Despite the temporary fix of former Governor Strickland's emergency funds, Ohio's ADAP is an endangered program. On July 1, 2010, the state's Department of Health announced a plan to shrink Ohio's ADAP by redefining eligibility criteria taking into account "a combination of both financial and medical need," according to its press release. "The controlling factor will be based on the results of medical tests," the release stated, "to provide services to the most vulnerable clients."

The financial requirement for ADAP qualification was altered to exclude anyone whose income exceeds 300 percent of the federal poverty level—about $32,000 a year—instead of the previous 500 percent, or about $54,000 yearly. Applicants who might be financially eligible but who "do not meet medical eligibility criteria"—who are not sick enough—"will be placed on a waiting list." In addition, medications for cardiac conditions, diabetes, depression, acid reflux and diarrhea, among other conditions, were removed from Ohio's ADAP formulary.

Never mind that many of these conditions may be brought on or exacerbated by HIV and the drugs. The state's health department helpfully promised that its staff would work "as closely as possible with case managers and clients to help those affected in identifying other resources, including patient assistance programs."

Furthermore, current ADAP recipients affected by the financial eligibility changes would be "notified and given the opportunity to provide updated financial documents within 30 days." But

for those desperate for meds, more paperwork might not be what the doctor ordered.

“Right now the state of Ohio’s party line is that no one is going without their meds,” Kudrin says. “How can they assure us of that? Three hundred fifty-seven people were no longer eligible for the ADAP program after the July 2010 cuts. There are now around an additional 380 on our waiting list. How are they keeping track of these more than 700 people living with HIV/AIDS?” He notes with some bitterness that no state employee has lost coverage despite the state’s difficult fiscal situation.

Considering the magnitude of Ohio’s ADAP funding crisis, some cuts were inevitable. Barbara M. Gripshover, MD, associate professor of medicine at Case Western Reserve University and director of the John T. Carey Special Immunology Unit at University Hospitals of Cleveland, says many of her colleagues believe trimming the formulary was a good cost-containment strategy. “Most of those medicines have generic versions available and can be obtained for $4 or less at many pharmacies locally,” she says. “It cost Ohio’s ADAP more than that to ship them. But unfortunately [cutting the formulary] does not save enough.”

The biggest savings will come from the state’s new “medical criteria,” which in 2011 could eliminate an additional 861 people from Ohio’s ADAP. “Only the sickest individuals will still qualify for the program, [and meanwhile] those who are ineligible are not counted on the waiting lists,” Kudrin says. “Must be that new math.” The state may have tried to limit the political fallout from these cuts—“dead people never look good,” Kudrin observes—by disbanding its Ryan White Part B Consortia Planning Body (which disperses federal funds) at the time of the 2010 cuts. “No planning body, no dissent,” he says, adding, “If it’s [a question of accessing] your meds, this is a ‘death panel.’”

BAD ECONOMICS

Drastic spending cuts are not unique to Ohio during the prolonged recession, but the state has been particularly draconian. Even the “briars” in Kentucky, butt of many an Ohioan joke, recently ended their waiting list for ADAP, if only for now. Especially in times of constrained resources, wait lists don’t make sense, advocates say. HIV practitioners and service providers have long known that a healthy patient costs less than a sick one. Yes, HIV drugs and other medications are expensive, but weighed against a decade of hospital stays, even 40 years of expensive prescriptions looks pretty cheap.

Kelly Gebo, MD, a researcher at Johns Hopkins University School of Medicine in Baltimore, found an economic correlation right down to CD4 cell counts. She and her team examined data from almost 15,000 HIV-positive adults who used high-volume HIV clinics in the United States in 2006, finding that the average annual cost of HIV care was $19,912. But for people with CD4s under 50, the average yearly cost was $40,678. In other words, the more compromised a person’s immune system, the more expensive the medical care.

Indeed, Gripshover has had to scramble to keep her patients on meds. “Our clinic cares for over 1,100 patients, and 38 were cut off when the eligibility criteria went from 500 percent to 300 percent of federal poverty level,” she says. “So far, we have been able to get meds for everyone who has been cut off ADAP for financial reasons. This has been due to the pharmaceutical companies stepping in—agreeing to cover anyone cut off.” Indeed, the best news for ADAP in 2011 came when the pharmaceutical companies that produce HIV meds agreed to help the ADAP crisis by lowering the cost of antiretroviral medications.

According to a year-end survey by the National Association of States and Territories AIDS Directors (NASTAD), “ADAP Crisis Task Force (ACTF) agreements with manufacturers of HIV drugs produced an estimated $259 million in savings for 2009, bringing the total savings since the task force’s inception in 2003 to approximately $1.1 billion.” NASTAD has negotiated new ACTF agreements with Abbott Laboratories, Boehringer Ingelheim, Bristol-Myers Squibb, Gilead, Merck, Tibotec and ViiV Healthcare.

Gripshover notes that many patients in the upper end of the former financial range of Ohio’s ADAP have been all right, as they had private insurance and only used ADAP to cover their co-pays. But she worries about those who are on Medicare. “By law, [pharmaceutical companies] cannot cover their co-pays,” she says. Her clinic has also struggled to help those shunted to the new ADAP waiting list, hooking them up with pharma companies willing to help.

Whether drug companies will continue filling in where the government cannot pay remains to be seen. Gripshover worries that the situation will only worsen: “My biggest fear is Ohio’s ADAP may not have enough funds next year to cover those still on the program—even with the waiting list. We needed a one-time $12 million infusion this year just to stay solvent.”

As of December 2010, according to the NASTAD survey, there were 4,543 individuals on waiting lists to receive their HIV-related medications through ADAPs in nine states. Over half of these were in Florida; Ohio, with 347 wait-listed people, ranked fourth, between Louisiana and South Carolina. Meanwhile, a total of 23 states were implementing additional cost-cutting measures. NASTAD’s survey noted that ADAP enrollment had increased during 2010, as people lost jobs and health insurance. In December, a budgetary bill presented to Congress included an additional $60 million for ADAP nationwide, but the additional emergency funds did not materialize in the final version of the budget bill.

It is important to note that budgetary cuts in Ohio were not the product of some misguided Tea Party fiscal conservative; they were initiated by former Governor Strickland, a Democrat. Kudrin points out that states received no new money to shore up the ADAP system even as more HIV-positive people have come to need it. The logic strikes Kudrin as more than cruel. “[Our government] knows that keeping us healthy saves money,” he says, “they just don’t seem to give a fuck.”

It is likely the situation will worsen under the new Republican regime voters swept into office in November. Ohio’s new governor, John Kasich, is planning to cut Medicaid and other programs,

which he has called “costly and ineffective,” and the new speaker of the Ohio House of Representatives, Bill Batchelder of Medina, has said Republicans may cut Medicaid eligibility by half. If that’s how Columbus plans to treat thousands of children and expecting mothers-—a constituency loved even by conservatives—what do they have in store for people living with HIV?

BAD POLITICS

In the coming struggle, these state lawmakers may be less pivotal than another Ohioan, John Boehner, who, riding the great wave of voter dissatisfaction, just replaced Nancy Pelosi as Speaker of the House in Washington, DC. Brandon Macsata, CEO of the ADAP Advocacy Association, a frequent critic of Congressional Democrats, believes that Boehner’s fiscal and social conservatism will take a back seat to his state’s HIV crisis. He believes Boehner will reckon with the growing number of people on ADAP waiting lists—especially in his district.

Kudrin is not so sure. Republicans are masters at pitting constituencies against each other, he says. He predicts that Republicans in Columbus and DC may again try to divert stimulus money to cover ADAP and Medicaid shortfalls. (Last May, Senator Richard Burr, R–N.C., sponsored a bill to cover the ADAP shortfall with stimulus money. The bill has not been voted on.*) Using stimulus funds this way would be both shortsighted (the funds would run out, but the need would persist) and disruptive, setting various projects and groups against one another.

Mitch McConnell, the minority leader in the Senate from nearby Kentucky, famously said before the election that making Obama a one-term president would be the new Congress’s No. 1 goal, and even in the lame duck session, Republicans seemed devoted to handing him defeats at any cost, stalling the New START Treaty, killing the Dream Act and even quibbling about medical aid for 9/11 responders. One of Kasich’s first acts—before he even took office—was to cancel plans to build a high-speed train across the Buckeye State using stimulus money, despite the jobs the federal funds would create.

“Ohio’s ADAP clearly needs more money,” Gripshover says. “I fear [that the issue of] access to these lifesaving medications—which also decrease transmission and new infections by the way—is going to get caught on the chopping block.” She has a point: As Gebo’s research showed, people with failing immune systems are more expensive to care for. HIV-positive people not on meds (those stuck on waiting lists, perhaps?) have also been shown to be more infectious if they have higher viral loads. Withholding meds today, Gripshover points out, only means that potentially more people will need them tomorrow.

Kudrin fears that people with HIV will become pawns in the coming political games for party power. “I would ask [Boehner] to stop playing politics with our lives,” he says. “A small amount of money in the national budget will allow us to provide treatment to working poor Americans who need no more additional stress wondering where next month’s medicine will come from, or if they will be left by the side of the road by their government to die.” Kudrin adds, “The Ryan White

CARE Act has traditionally received bipartisan support. Without [Senator] Ted Kennedy to back us up, I wonder if [we can hope for the same support for ADAP]. It may not happen without community outrage."

THE POWER OF PASSION

Kudrin believes that community outrage is where it's at—and all that's left. Kudrin, who relies on his cocktail (comprised of five HIV drugs) and half a dozen other medications to survive, is the ideal poster child in the fight for ADAP. He remembers fighting off opportunistic infections all too well: "I have had pneumonia three times, a viral infection in my brain stem, shingles, repeated staph infections…."

Without ADAP coverage, he says, "all the people [including myself] who have stabilized their health with these medications will be cut off, left to their own devices or [hoping for] the generosity of the pharmaceutical industry…. [Many will] see a return to poor health, and many will die." He has been fighting for his life—for most of his life. "Like many long-term survivors, I have been involved in AIDS activism for more than 25 years," he says. "I was the spokesperson for ACT UP Cleveland for more than three years in the early 1990s. I had the best teachers imaginable—death and grief."

Cleveland's large activist community, especially among the clients and staff of the AIDS Taskforce of Greater Cleveland, provides backup. "We also have a host of the most talented infectious disease doctors, who encourage and support activism among their clients," Kudrin says. The encouragement is needed, he says. "Too many people choose to die of embarrassment—not AIDS. The fear of AIDS stigma is so powerful that even when you take away their meds, they would rather die than say anything about it." Because saying something about it requires saying that you have HIV. He wonders if the fear, despair or apathy are generational: "Too many younger people living with the virus don't know the history of what we did in the early years. They don't know how strong we can be. But they want to know," he says, "that is the upside."

Kudrin is keenly focused on Valentine's Day 2011, the second Statewide Call to Action day. "We are hoping to generate 3,000 calls [that day] to the new governor, to both of our senators and [to Speaker Boehner]." Organizing for the big day is right on track, including town hall meetings—"all planned except Toledo"—and outpourings of support from AIDS task forces and local public health officials statewide. Kudrin hopes activists nationwide will join in, not just for Ohio's ADAP warriors, but for all Americans living with HIV: "Stand with us. Call Boehner's office on February 14. Don't accept this! These further cuts are not inevitable—do not go quietly to your deaths! There are people actively dismantling the work that we did in the 1980s and '90s. You must make your voice heard, or our community will relive the nightmare that us long-term survivors lived with."

"We want each city to own their part of this," he says. We are not telling [activists around the state] what to do, besides the Call to Action day. What we hear most is the willingness to participate in the movement—and many questions on activism, as most people have never participated in anything like [it before]. They are scared now though." The most common question Kudrin gets is, "'What do we do if this does not work?' I tell them we have a plan B. That's when

we start the ACT UP shit again."

After all, the most important skill for an activist is "a refusal to go home and wait to die, or to allow others to do the same," he says. "Passion [for our survival] is the greatest asset we all have."

Our hope is that Speaker Boehner—and his fellow members of Congress—will honor their constitutional duty to protect the lives and welfare of American citizens, including those with HIV.

**This article has been revised to reflect the following correction: In the original article we mistakenly reported that this bill failed when Democrats overwhelmingly voted nay. The bill has not been voted on.*

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http://beta.docker.poz.com/article/Ohio-ADAP-Crisis-19799-2367