The POZ 50, Part 1

Our list of 50 men and women who are directly influencing federal AIDS policy today

August 1, 1994 By Patrick Pacheco

How does one go about selecting the 50 men and women we have elevated to POZ 50 status? Not easily. Our list focuses very narrowly on the people who are directly influencing federal AIDS policy today. Many heroes in this international fight against AIDS -- researchers, educators, practitioners, service providers -- do valuable work but do not affect policy. Therein lies the distinction between, say, Elizabeth Taylor -- who has a hands-on commitment to shaping policy -- and Earvin (Magic) Johnson whose good work is mostly limited to AIDS education. Similarly, at GMHC, Executive Director Jeff Richardson runs the entire service organization, but Michael Isbell focuses exclusively on policy. The POZ 50 is comprised of the people who create and shape U.S. AIDS policy on a day-to-day basis. The list has been compiled by the editors of POZ in consultation with dozens of treatment activists and AIDS policymakers.

Beltway

“His support is crucial”
Representative John Dingell
House Committee on Energy and Commerce, Chairman
Washington, DC

“No member of Congress working on health-care reform is more respected or more powerful,” says Carl B. Feldbaum, president of the Biotechnology Industry Organization, of Representative John Dingell, who heads the House Energy and Commerce Committee. Dingell has been instrumental in the passage of the Americans with Disabilities Act and the Ryan White CARE Act. The reauthorization of that act is the flagship of AIDS legislation and the various subcommittees are eager to expedite it. For that, they need the cooperation of Dingell. “He’ll be one of three committee heads [Sam Gibbons (Ways and Means) and John Conyers (Government Operations) being the other two] sitting down to work out compromise health-care legislation in the House,” says AIDS PAC founder Tom Sheridan. “In that regard, his support for such items as confidentiality and access to specialized drug treatment and health-care for PWAs is crucial.”

“Those who complain of no national plan haven’t given the OAR a chance”
Patsy Fleming
Special assistant to Donna Shalala, Secretary of Health and Human Services

Washington, D.C.

“There are things we could do if Congress was not as conservative as it is,” says Patsy Fleming, special assistant to HHS secretary Donna Shalala. “But there are unprecedented collaborations going on.” For many years Fleming was a staffer for the late Ted Weiss, the Manhattan representative who was an early supporter of AIDS legislation and funding. “Now she’s on the inside, she listens to the community and she delivers,” says Jane Silver, policy director of AmFAR, adding that Fleming’s support for the re-organization of the Office of AIDS Research was crucial. “Those who complain of no national plan haven’t given the OAR a chance,” Fleming says. “We have to look for the gaps in our present plans and suggest priorities. We need input from experts both inside and outside the established disciplines and constituencies,” she says. Fleming gets high marks from some for being able to solidify Administration support around a bill and for follow-through once a bill is passed. But others, who consider her the de facto AIDS czar because of her access to Shalala, fault her for fumbling on issues such as HIV and immigration. “We are learning all the time,” she says. “These are complicated issues.”

“We should be organizing street by street, bar by bar, gym by gym”
Bob Hattoy
Department of the Interior, White House Office Liaison
Washington, D.C.

No more studies, no more reports, no more committee meetings, says Bob Hattoy, who became the Democratic Party’s AIDS poster boy at the successful 1992 National Convention. “We need to create a war room for AIDS. It’s got to be a top-action item, not just a speech once or twice a year.” One of Washington’s most outside insiders, Hattoy has resisted the pressure to be a team player. He disparages President Clinton’s “I feel your pain” comments made to AIDS advocates. “There is an emotional connection to AIDS, but the follow-through is lacking,” says Hattoy. “This Administration has proven that when it gets serious -- be it about the economy or assault rifles -- it can bring the most creative and brilliant minds together to win,” he says. What is needed from activists, according to Hattoy, is a change in strategic acting up. “Now, when we scream and yell, we get hugged,” he says. “We have to put that energy into organizing. If the religious right organizes pew by pew, ee should be organizing street by street, bar by bar, gym by gym.”

“Once you get their toes wet, you can try for the feet”
Michael Iskowitz
Aide to Senator Edward Kennedy, Chairman of Senate Labor Committee
Washington, D.C.

When Michaek Iskowitz arrived in Washington, D.C., seven years ago for a 10-week internship in Senator Edward Kennedy’s office, the mere mention of AIDS was enough to set off a flurry of anti-gay and anti-AIDS amendments from conservatives. Today AIDS is defined as a public health issue and the anti-gay efforts of Senator Jesse Helms and his allies have been largely defeated, in no small measure, according to activist David Hodel, to the work of Iskowitz. “Michael became an independent army to combat those amendments and draft substitute language that made it safe

for a lot of people to vote for AIDS legislation," says Pat Wright, governmental affairs director for the Disability Rights Education and Defense Fund. Pointing to such Kennedy-sponsored triumphs as the Americans with Disabilities and Ryan White Acts, she adds, "Nobody wants to be in a position to deny health-care to anyone, especially in a life-threatening situation. And once you get their toes wet, you can try for the feet."

"We can and must do better in developing drugs"
Dr. Philip Randolph Lee
Department of Health and Human Services, Assistant Secretary for Health
Washington, D.C.

Dr. Philip Lee chairs HHS Secretary Donna Shalala's new Task Force on AIDS Drug Development. Having spent four critical years of the AIDS epidemic as president of San Francisco's health commission, he says he's aware of how the best of intentions can get derailed. "Too often in the past, needed links have been missing or relationships have been adversarial resulting in unnecessary duplication of efforts or potential drugs not being developed and evaluated as rapidly as they might be. We can and must do better in developing drugs. Every aspect -- from drug discovery, to selection of candidates for screening, to early clinical development, data-sharing, to the clinical trial process -- will come under scrutiny," he says. "For the first time in the fight against HIV-related disease, the U.S. will have a systematic overarching effort to coordinate drug development."

"Hardly a week goes by that AIDS isn't often high up on the White House's agenda"
Carol Rasco
The White House, Domestic Policy Adviser
Washington, D.C.

Bill Clinton has been the target of ascerbic blasts from some activists for dropping the ball on AIDS and taking some of that heat is Carol Rasco, the White House domestic policy adviser. "She's the problem," say some Washington insiders who credit her with watering down the office of AIDS czar so that Kristine Gebbie reports to Rasco and HHS Secretary Donna Shalala. But the woman whom Administration insider Bob Hattoy describes as one of the most influential of Clinton's inner circle is eager to defend both her boss and herself. "Hardly a week goes by that AIDS isn't often high up on the White House's agenda. He [Clinton] may not be speaking out in a coliseum, but there have been numerous meetings," she adds. Rasco offers as proof Clinton's commitment to the Ryan White Re-authorization Act, the fiscal increases directed toward AIDS research, prevention and education and the health-care reforms that promise to benefit those affected by HIV and AIDS. "I wish we could be even more responsive and do things faster," she says of the urgency expressed in her meetings with Gebbie. "But we're making some progress in coordinating the various elements. At least in terms of health-care reforms, this country has turned the tide. There is a groundswell out there for change."

"We must nudge the pendulum back toward hope"
Donna E. Shalala

Department of Health and Human Services, Secretary
Washington, D.C.

A one-time athlete and competitive tennis player herself, HHS secretary Donna Shalala has fielded a team to fight AIDS which she characterizes as committed to “Nudging the pendulum back toward hope.” She credits President Clinton with re-energizing the fight against AIDS by increasing funds for research and services. “Department wide, they’re up by 17.6 percent,” she says. But she says that all the money in the world won’t be sufficient unless the effort is streamlined and tightly focused. Referring to the new National Task Force on AIDS Drug Development, which brings together an 18-member panel of activists, academics and industry executives, she says she’s aware of criticism that this is yet another committee to come up with a dust-collecting report. “It doesn’t automatically fix anything,” she says. “But I expect communication, collaboration -- and solutions,” she says. “I pick the best people, give them the support they need and hold them accountable for results.”

“In many ways, health reform could be the promised land”
Tim Westmoreland
Policy adviser to Rep. Henry Waxman, Chairman, House Subcommittee on Health and the Environment
Washington, D.C.

“The system is now truly broken,” says Tim Westmoreland, an aide to California Representative Henry Waxman who chairs the subcommittee responsible for many of the proposed health reform initiatives. “The financing kicks in for the PWA only when he or she is desperately ill. It doesn’t help them early on, when prophylaxis and early intervention can make a real difference.” Westmoreland says that “in many ways, health reform could be the promised land,” but only if it realistically addresses the needs of the people it is designed to help the most. In the cases of HIV positive individuals, Westmoreland says that what raises the red flags for him is any bill that doesn’t provide insurance companies with risk adjustments that make it worthwhile to take on chronic sufferers, a managed care system that doesn’t allow the PWA access to the specialized services he or she needs or any plan that doesn’t provide for premium drug benefits. Westmoreland insists that anything less will simply exacerbate the problems. “I worry that what we’ll end up with is market insurance reforms that eliminate pre-existing condition and waiting periods and allow for portability of insurance but don’t do anything else.”

Debaters

“I take the internal divisions very personally”
Moises Agosto
National Minority AIDS Council, Treatment Advocacy Manager
Washington, D.C.

Too often, the emergency room is the first stop for people of color seeking treatment. Early intervention has not really been an option for people separated from effective health care by

language and cultural differences. Moises Agosto, treatment advocacy manager for National Minority AIDS Council, believes the only way to bridge that gap is to groom leaders within the community who will scream and yell longer and louder. He wants his constituency to get a share of the funding now directed toward more established white-dominated groups, to be more fairly represented in clinical trials and to insure confidentiality from a medical authority which has not previously inspired much confidence. Unfortunately doing that is something of a Catch-22. “We’ve been so busy dealing with issues of poverty and lack of education and access to health-care, that we haven’t had either the time or resources to build up service organizations which can help us to break out of that cycle,” says the Puerto Rican-born former ACT UP/New York activist. “Too many people in powerful positions now are more concerned with their own personal agenda than with the epidemic and it’s splitting the communities,” he says. “As someone living with AIDS, I take the divisions very personally.”

“Keep your eyes on the prize”
Mario Cooper
AIDS Action Council, Chairman
New York, New York

“Keep your eyes on the prize” is the advice which Mario Cooper tenders to the numerous, sometimes contentious, community-based groups represented by the AIDS Action Council. “If we approach our battles divided, we’ll lose.” Cooper, who honed his consensus-oriented management style as manager of the 1992 Democratic National Convention, divides effective policy-making between “inside and outside the Beltway.” Inside: Master the unglamorous work of complex legislation and politics on the Hill and at the White House and bring competing interests together to speak with one voice. Outside: Keep AIDS upfront in the media and organize and focus activism. “The community, as a whole, is tired and frustrated,” he says. “But health care reform, done correctly, could have an incredibly positive impact for people with HIV or AIDS. We have to find a way to reignite the community around this issue.”

“You have to disarm your enemies with creative language”
Chai Feldblum
Federal legislation Clinic, Director
Washington, D.C.

Chai Feldblum says that she decided to study law when she discovered that, as a woman, she couldn’t become a rabbi. After clerking for Supreme Court Justice Henry Blackmun, the New York City-born lawyer became the chief lawyer for the AIDS Action Council where she helped to develop cleverly worded amendments to defang Senator Helms and his gang. “I’m the person who figures out how to write an alternative amendment that protects us but sounds hateful enough for our enemies to vote for,” she says. Responsible for writing provisions of the 1990 American Disabilities Act for the ACLU, Feldblum now teaches students at the Federal Legislation Clinic to master the intricacies of writing legislation while continuing her legislative career as a consultant. Feldblum says she’s cautiously optimistic about new legislative gains but warns that there are compromises to make. “It’s important never to undermine the essence of a bill,” she says. “But you have to

disarm your enemies with creative language. That means a lot of late-night writing and lots and lots of conference calls. I want laws which protect us even if they have some holes."

"You can't afford to write off anybody"
Derek Hodel
Gay Men's Health Crisis (GMHC), Director of Federal Affairs
New York, New York

Derek Hodel, whose sense of urgency stems from his work as a caregiver early in the epidemic, says that he intends to attack one of "the black holes" of AIDS research in his new position as Director of Federal Affairs for GMHC. "We need to do more research into human sexuality," he says. "We have to find out what will motivate people to change their behavior to avoid HIV infection." He also plans to pursue the federal agenda of his previous position as policy director of the AIDS Action Counci. The challenge is to squeeze funding out of the Congress for the re-evaluation going on across the board as to how best to attack AIDS. "We've underestimated how hard it is to crack the virus," he says, "and we've got to rethink our efforts." That means a return to basic research while continuing to pursue clinical studies. "We've got the most liberal Administration but also the most conservative Congress," he says, adding that the most potent weapon one can use against the opposition is to be smarter than they are. The Colorado-bred gay lobbyist says that his grasp of the issues and ability to stand up to the most right-wing of politicians earns respect in the Capital. "Sometimes I'm just 'that gay boy with an earring' to them, but you can't afford to write anybody off," he says. "It's useful just to swing somebody to opposing you less vigorously."

"I've been screamed at, kicked and punched -- and that's by people I like"
Paul Kawata
National Minority AIDS Council, Founder
Washington, D.C.

"I've been screamed at, kicked and punched -- and that's by people I've liked," says Paul Kawata, the founder of the National Minority AIDS Council, an umbrella organization which fights for a place and voice in the decisions which affect people of color. The fact that people in these communities are dying four times faster than whites lends an urgency to the self-empowering goals articulated by Kawata, who was a longtime Seattle-based activist before he came to Washington. To develop leadership and management within the communities, to effectively advocate better treatment, to secure cheap, if not free, availability of prophylactic drugs and to build long-term institutions are all Kawata's goals. "You have to define your vision and commit," says Kawata. For the Asian-American activist that requires listening to his constituency. "There are too many self-appointed leaders who speak for a community but don't check in with anybody," he says. Kawata fights racism and homophobia to build consensus among his wildly divergent constituents but, not surprisingly, he sees the challenge as an opportunity. "Diversity is what makes us powerful," he says.

"They have to deal with me. I speak their language. I can sue them"

Terry McGovern
HIV Law Project, Director
Washington, D.C.

Long an activist in the poverty law community, Terry McGovern discovered in 1987 that marginalized populations were falling between the cracks when it came to AIDS services, legal protection and financial aid. “Nobody had ever dealt with gay men who were living in the projects,” says the one-time ACT UP lawyer. “Nobody was paying attention to the needs of women with HIV who weren’t being warned of the gynecological side effects of drugs.” McGovern and her staff of six give them voice through the HIV Law Project which has had notable success in class action suits that have, among other things, forced Social Security to expand the legal definition of AIDS and forced the FDA to allow women into clinical trials. “The government uses these various definitions to save money,” she says, “but that often means that people are not getting what they need to stay alive.” On the front butner these days is ensuring first-rate health-care for her clients, ending discrimination against HIV positive parents in child care, and amending the Ryan White Re-Authorization Bill so that it is more responsive to women’s needs. “They have to deal with me. I speak their language. I can sue them,” she says of her federal and state legislative efforts. McGovern passes on everything she knows about law and policy to her clients. “We are training leaders on the local level so that they can be a source of information for their communities,” she says. “But it’s still frustrating when you see 17 year olds walking in here with HIV, and it’s been so difficult just to get a condom on television. There’s so much to do, and all of it is urgent.”

“AIDS must be addressed by everyone all the time”
William Rubenstein
ACLU Foundation AIDS Project, Director
New York, New York

“We need AIDS policymakers everywhere -- in government, in court and as activists who chain themselves to desks,” says William Rubenstein, the director of the ACLU Foundation’s AIDS Project. “There’s been a lot of attention paid to AIDS but it hasn’t translated into better policy.” Since 1986, the AIDS Project has sought to redress that through litigation concerning issues such as discrimination, quarantine and forced HIV testing. Its greatest achievement was steering through Congress the 1990 Americans with Disabilities Act. Rubenstein -- a Harvard Law School graduate who argued a landmark case recognizing a gay couple as the legal equivalent of a family -- chides the government for its pathetic campaign in education and prevention. “No more studies. It’s time for advocacy,” he says, noting that needle exchange does no harm and can save people’s lives. “Damn the Clinton Administration for creating an atmosphere of false hope. You shouldn’t be allowed to think you can address AIDS by going to a movie or being in a walkathon,” he says. “It must be addressed by everyone all the time.”

“Long-term prospects aren’t good for people facing short-term problems”
Mark Scherzer
Insurance Lawyer
New York, New York

Private practice often informs public policy and when insurance attorney Mark Scherzer won a landmark judgment against Empire Blue Cross, it sent a signal to the insurance companies that AIDS patients were going to fight for, and maybe win, state-of-the-art treatment. Following many years of pro bono work for GMHC and Lambda Legal Defense and Education Fund, the 42-year-old attorney took on the entrenched powers when Empire refused to pay for his client's bone marrow transplantation which they termed "experimental." Within six weeks, Scherzer won an injunction from a New York State Supreme Court Judge that essentially compelled coverage. "You have to be able to match the arguments -- and the committment -- of a powerful and well-financed industry," says Scherzer. How to do that? Marshal broad public support, know your adversaries' tactics and build coalitions. The lawyer sees joint efforts between other health advocates and people with AIDS as a way of gaining victories in such critical areas as the portability of disability insurance, expanded coverage of off-label drugs and experimental treatments and equitable domestic partner coverage on insurance. Scherzer counsels vigilance for the rough days ahead which will include more and more court challenges under federal laws to the hard-fought victories against insurance companies. "The long-term prospects look good but that doesn't help those who are facing desperate short-term problems," he says.

"A politician is never more educable than when he's running for office"
Tom Sheridan
The Sheridan Group, Executive Director
Washington, D.C.

"The challenge is to get more than rhetoric on AIDS, and the weapon to do that is cash," says Tom Sheridan, who recently organized AIDS PAC, the first political action group devoted exclusively to AIDS. "A politician is never more educable than when he's running for office." Though the PAC has been criticized by some as just another way to put money in members of Congress's pockets, Sheridan considers it essential to restoring the urgency on AIDS in political terms so that it doesn't become just another health problem. That means not only rallying big-city mayors around the Ryan White Re-authorization Act to insure full federal funding but also building a grsss-roots political structure. "If only the people who get services under the Ryan White Act were to write a letter once a year," he says, "we'd have a lot less political headaches. We're now lucky if a congressman gets 10 letters a year on AIDS whereas they once got 100. People get very grandiose in their thinking, but the way to go is one person, one vote, one letter at a time. It isn't cheap, and it isn't easy, but it's still very effective."

Media

"Research has changed dramatically. But is it better?"
Dr. Deborah M. Barnes
Journal of the National Institutes of Health, Editor
Washington, D.C.

Deborah M. Barnes is editor of the Journal of the National Institutes of Health, a for-profit, corporately-owned news and information magazine with a circulation of some 30,000. It has

alerted scientists to innovations and promising studies. But the journal also functions as something of an industry watchdog. “There are proposed large-scale trials of candidate vaccines and drugs which are probably pointless,” says Dr. Barnes. “In private, scientists will say, ’It’s not worth pursuing.’ In public, ’Maybe we’ll learn something.’ For reasons not at all clear to me -- other than political pressure -- these tests will go forward.” Pointing out injudicious uses of resources is part of the journal’s purview. Through her editorials, Barnes also comments on the growth of AIDS research. “The integration of AIDS activists -- many of whom are the best-informed people around -- is probably the most tangible indication of how it’s changed,” she says. “But is it better? Certainly the communication is better than ever, and that’s positive. But the political pressures that come with it have had a negative effect on how research is being done,” adding that it makes scientists and drug companies far less willing to take the risks that could lead to a breakthrough. “Like every human endeavor, it’s a mixed bag,” she says.

“The minute we become flag-wavers, we lose our value to the system”
Martin Delaney
Project Inform, Founder
San Francisco, California

In 1991, when Martin Delaney testified before an Institute of Medicine panel then reviewing AIDS research efforts, he was scolded for daring to criticize the National Institutes of Health. At Project Inform, a pioneer organization in treatment education which he founded in 1985, Delaney is still scolding. “Harold Varmus and William Paul wouldn’t know a managing plan if it bit them on the ass,” he says. “I find the change in leadership at the NIH very scary.” He believes advances in research are now threatened. “They believe in the ’serendipity’ school of research. Water the garden and great things will come up,” he says. “But history has shown that the breakthroughs come through concentrated research.” Delaney suggests that an independent scientific panel be convened to consider where AIDS research is and suggest priorities. “We should be constantly asking the NIH what they’ve come up with for their billions of dollars. Drugs that everybody hates? A lot of the federal funding is a welfare boondoggle for the university network.” Delaney is quite happy playing the skeptical gadfly, throwing barbs at the kissing-up of his fellow activists. “I drive Varmus crazy, but that’s my job,” he says. “The minute we become flag-wavers, we lose our value to the system.”

“Drug companies are susceptible to embarrassment”
David Gold
GMHC Treatment News, Editor
New York, New York
John James
AIDS Treatment News, Editor
San Francisco, California

Both David Gold and John James think of their respective newsletters as up-to-date, comprehensive fact sheets for care givers and people with HIV as well as bully pulpits from which to harangue the government and pharmaceutical companies for more effective research. “We’re

skeptical advocates," says Gold, who edits the newsletter out of the offices of the Gay Mens' Health Crisis (GMHC). "There are very few sources that are not funded by either the government or pharmaceuticals. We can hold their feet to the fire. Drug companies are susceptible to embarrassment." The editor says that writing about the efficacy of new drugs as well as reporting on alternative therapies is a scary process. "We're careful not to create hype," he says. Like Gold, John James says that monitoring federally funded research is a priority. "It's a mess and the consequences are huge and tragic," he says. "There is an old boy network at the research institutes that compromises the national effort. It has to change." James also notes that he refuses to be drawn into the controversy over HIV as the cause of AIDS. "The bottom line is: Does [the controversy] contribute to saving people's lives?" he says. "Those who are stirring the pot aren't offering any alternatives."

"It would be naive of me to think that all my reporting on AIDS is objective"
Laurie Garret
New York Newsday, Reporter
Long Island, New York

"Describe fisting to me" was a question which Laurie Garret posed to one of her interview subjects when she was a reporter for National Public Radio (NPR) covering the early stages of the AIDS epidemic in San Francisco. "It became glaringly obvious to me that my straight colleagues were incapable of putting their own personal judgments aside and move beyond the shock value," recalls the New York Newsday science reporter whose unflinching articles have earned her the respect of activists and scientists alike. "That continues to happen on AIDS with every single subpopulation interacting with the media." That myopia has made Garret wary of dismissing any sociological or political dimension of the crisis. "Not stating the full dimensions of the disease is itself biasing the story," she says. For her, that means following the arduous process of basic research every step of the way, while commenting on the more polarizing issues such as education and prevention. "It would be naive of me to think that all my reporting on AIDS is objective," she says. "When I write, 'HIV, the virus which causes AIDS,' that is not an absolutely neutral choice."

"Key to survival: a patient-doctor relationship"
Gordon Nary
Physicians Association for AIDS Care, Executive Director
Chicago, Illinois

Early in the AIDS epidemic, the Physicians Association for AIDS Care took a lot of flack from the medical community for pushing a simple but then-revolutionary idea: That the best chance of survival lay in a partnership between the informed patient and his or her physician. Created eight years ago primarily as a network to help track approaches to AIDS treatment and develop standards of care and practice, the 10,000-member organization continues to push for a more patient-centered focus. That means paying attention to non-medical issues such as finance, housing, individual rights and access to information. "AIDS has magnified all the problems in health-care in this country," says Nary. One of the current policy initiatives is to see that national

health reform authorizes the primary care physician to determine what drugs will be covered. “Right now survival is more affected by off-label drugs,” he says, referring to those drugs which have been approved to treat one specific ailment but which the doctor feels will cure or alleviate a different one. The group is also eager to help change the structure of the clinical trials process. “We’re setting up a pre-screening database,” says Nary. “We want to bring the trials to the patient rather than vice versa. It’s a revolutionary approach to speeding up the process.”

Performing Arts

“We are being led into dangerous, treacherous waters”
Larry Kramer
Writer/Activist
New York, New York

Tell Larry Kramer that POZ is doing a list of the AIDS 50 and he says, “Fifty? There can’t be more than 10. The rest of us don’t amount to a hill of beans.” It’s vintage Kramer, who is the uncompromising author of the polemical dramas, The Normal Heart and The Destiny of Me. Kramer’s legendary diatribes, which initially broke the silence on AIDS, are now being directed toward Bill Clinton (“a scumbag on this issue”) and Kramer’s fellow activists, namely “Mark Harrington and his team,” who he accuses of becoming “more bureaucratic than the bureaucrats.” “They haven’t been co-opted,” he says. “They’ve gone willingly into the system. We are being led into dangerous and treacherous waters.” The problem, in Kramer’s opinion, is that the Office of AIDS Research (OAR) is creating bureaucratic problems it was meant to resolve. “It’s a $1 billion a year cesspool.” He endorses the Madison Project -- a massive, multipronged effort to treat each unanswered question in AIDS research as a separate, specially funded entity -- which he feels has been sabotaged by the OAR. “All I can do is write columns, make phone calls and try to untie the knots we keep making for ourselves.”

“Only results count”
Rodger McFarlane
Broadway Cares/Equity Fights AIDS, Executive Director
New York, New York

“The standard I judge myself by is Machiavellian,” says Rodger McFarlane. “Only results count. I don’t give a shit if the politics were wrong.” McFarlane has been in the front lines for 13 years, helping to found Gay Men’s Health Crisis (GMHC) and spending the last several years as the director of Broadway Cares/Equity Fights AIDS, one of the most powerful AIDS funding organizations in the country. McFarlane recently announced his resignation to write a book, How To Take Care of the Terminally Ill, but he could just as easily write one about effective policymaking. “You need money, you need a platform and you need to be tough as steel. The people I admire are those whose feelings you can’t hurt enough to stop them.” McFarlane says that he’s feeling better than he’s felt in years about the movement, despite the infighting. “We’re working better now than we ever have. The nerds are gone. The ones who will survive are those who take the risks, not the ones who sit around arguing about what inclusion looks like.”

“The reaction was so angry that I knew we’d done something right”
Susan Sarandon
Actor/Activist
New York, New York

Susan Sarandon and Tim Robbins, as presenters on the Oscar telecast last year, used part of their 27 seconds to draw attention to the plight of a group of Haitian emigres who were then being detained in a Guantanamo Bay camp because they were HIV positive. “I’d been arrested while demonstrating on their behalf, but it wasn’t getting the press attention that it needed,” says Sarandon, who’s been an AIDS activist since the early 1980s. “That’s why we decided to hijack the Academy Awards. It was important not only for their sake but for the sake of everyone in this country living with HIV -- that they not be labeled as criminal.” The ploy changed policy. The White House ordered the Haitians released within days. For their pains, Sarandon and Robbins were vilified in Hollywood. “The reaction was so angry, so ignorant and so threatening that I knew we’d done something right,” she says. “The primal fears which people have about AIDS mean we have to educate people more effectively on a grass-roots level. It’s really going to take people living productively with HIV to come out publicly.”

“I’m on the verge of being obnoxious”
Elizabeth Taylor
The Elizabeth Taylor AIDS Foundation, Founder
Los Angeles, California

“You have to have a lot of chutzpah, baby,” says Elizabeth Taylor when asked what has made her so successful in raising funds for AIDS through the foundation she began in 1992 after splitting with AmFAR. “You have to be forceful and not mind rejection. When I started in 1983, I never had so many doors slammed in my face.” More doors have since opened but the legendary actress says that she is exasperated because so many people remain blindly indifferent. "I hear over and over again, ’Well, the people I go to bed with aren’t associated with those kind of people,’ which is incredibly stupid,“ she says. ”You have to keep on hitting them to be safe, responsible and, for God’s sake, to open their pocketbooks." The star of The Flintstones says she worries that people have become burned-out and feels President Clinton has not been doing nearly enough. “I wouldn’t hold my breath,” she says with a distinctive girlish laugh about the current Administration. Still, she says, “I’m cautiously optimistic. It just takes banging away and not stopping and not giving up hope and just making yourself heard. I’ve been yelling so long and so loud, I’m on the verge of being obnoxious.”

Corporate

“Where the rubber meets the road”
Dr. David Barry
Burroughs Wellcome, Group Director of Research, Development and Medical
Research Triangle Park, North Carolina

Dr. David Barry has been touted as an effective advocate for his company and there's little question as to where his allegiance lies. Dr. Barry has been instrumental in pushing through quick FDA approval for Burroughs Wellcome (BW) drugs and for helping to put together innovative intercompany collaborations in a search for new therapeutic drugs. "Our involvement with the academic institutions and with each other is where the rubber meets the road," he says, referring to BW's new collaboration with six drug companies to pick up the pace of clinical trials of multi-drug regimens. "We currently have six drugs in various states of research which will be used in these multi-drug experiments," he says. "We're moving very rapidly on solid concepts which we hope will make a very big difference." But Barry adds that BW -- who was the target of vitriolic protests for price-gouging when AZT first hit the market -- has learned to reach out first to the AIDS communities for input. "Both sides were too doctrinaire for their own advantage," he now says. "We've both matured a lot. We learned that the sooner and more completely we get input from patient advocates, the better off we can be. Too much criticism can impede research, but the exchange of ideas has been quite valuable."

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