The Attack of the Killer Causes

AIDS activism birthed a litter of disease copycats. Now Cancer & Co. have made AIDS their scapegoat in a fight for funds. Esther Kaplan covers the disease wars.

May 1, 2000 By Esther Kaplan

Barbara Brenner remembers the first time she saw it.

The director of Breast Cancer Action, the scrappy left wing of an exploding movement, Brenner was at the annual Breast Cancer Symposium in San Antonio, Texas, in December 1998. She and some 1,500 others showed up to hear Amy Langer, head of the National Alliance of Breast Cancer Organizations, deliver the scientific event's only activist talk. Langer started with a rousing introduction to breast cancer activism -- campaigns to get advocates at the table, the push for more research funding -- and, says Brenner, there was a spirit in the room of "Wow, look at what these women have done!" Then Langer put up The Chart.

It's an image that has been deployed again and again over the past few years by people with diabetes, Parkinson's, prostate cancer, heart disease, you name it. Disease advocates use it to try to persuade you or me or the U.S. Congress that their particular illness receives far too little research funding. On one side is the number of deaths last year from their illness, and the amount of federal dollars devoted to finding a cure; on the other side is the number of AIDS deaths -- dwarfed by a few giant killers, like heart disease -- and its research budget. No matter what the dollar amount in the first column, the AIDS budget will make it look small.

"I was appalled," says Brenner, whose group has worked closely with AIDS activists. "If you're talking to an uninitiated group, and you want to bring people to your side, playing on homophobia is one way to do it: 'Look at what those boys got -- don't we deserve more?'"

Talk to any disease advocates today, and they all refer to AIDS. They tell you that ACT UP's fiery protests in the late '80s and early '90s sent an electric current through their support groups and charity balls. New, activist-minded organizations shot up, while more traditional disease associations retooled their strategies. The power of public demonstrations, of star charisma before Congress, of a constituency willing to be open about living with an illness -- none of this went unnoticed by people with cancer, Parkinson's or diabetes. "AIDS set the example," says former American Heart Association (AHA) president Jan Breslow.

But in late 1996, with new protease drugs causing AIDS death rates to drop, word came over the airwaves that the crisis was over. No sooner had AIDS become a role model than it was set up as

king of the hill, the activist bully you had to knock down to win your team media attention, donations, government aid. Whenever a new disease group held a march in Washington, reporters seized on this strange relationship to AIDS -- imitate, then retaliate -- as in this Knight-Ridder piece on a prostate cancer petition drive in June 1997. The new effort “borrow[s] the tactics” of AIDS activists, says the article, but “to make its point [about insufficient research funds] the coalition compares prostate cancer to AIDS and breast cancer.” Notice this remark from 58-year-old retired banker Bob Samuels, a prostate leader: “Certainly our lives are just as important. What’s happened is, the other groups have more political clout.” The epidemic, once an affliction of queers and junkies in the American imagination, is now hallucinated as a cause backed by invisible powerbrokers.

AIDS has often come under attack for getting “special treatment” through programs like the Ryan White CARE Act and AIDS Drug Assistance Program (ADAP). But nowhere have the disease wars gotten so intense as in the battle over how to spend the $13 billion budget of the National Institutes of Health (NIH). By the mid-’90s, advocates swarmed Congress every time there was a budget hearing, charging that NIH priorities were skewed unfairly toward AIDS. Congress finally demanded that the agency explain itself, kicking off a three-year-long war of words.

The first volley was a September 1997 report from the NIH, laying out the argument that then director Harold Varmus would hew to in the years to come: Science is hard to predict; the NIH tries to meet public health needs, but must follow the science where it’s most promising. Congress shot back by ordering an independent study. So many advocates signed up to testify during these 1998 Institute of Medicine (IOM) hearings that speaker slots were chosen by lottery. Gregg Gonsalves, the policy director of the Treatment Action Group and the only AIDS advocate to testify, recalls the sessions as grisly, with one group after another trotting out slides showing that AIDS got more than its fair share of dollars.

The much-anticipated IOM report, “Scientific Opportunities and Public Needs,” came out in July 1998. While no disease war détente -- it urged the NIH to collect better data on “disease burden” (the costs to society as whole) and on per-disease funding, as if to facilitate comparisons in the future -- the report argued that the agency’s current system for setting priorities “has generally served the NIH and the nation well.”

That’s not how it played in the press. “A better title for the report should have been ’The Squeaky Wheel Gets the Grease,’” wrote longtime AIDS gadfly Michael Fumento in *The American Spectator*. He used a dollars-per-death chart in the appendix of the 100-plus page report as proof that “spending is disparately focused on AIDS.” Even *The Washington Post* reprinted the chart in full.

The fray continued through last summer, with a major *New England Journal of Medicine* article analyzing the correlation between funding and “disease burden” in great detail, looking not just at total deaths but at incidence, cost of care, and years of life lost to death or disability. In tracking spending by each of these measures, the researchers appeared to excruciatingly confirm the received wisdom. The “squeaky wheels” of prostate cancer, breast cancer, diabetes and Parkinson’s all fell somewhat above the spending curve. But AIDS floated high above them all.

Months later, Gonsalves patiently explains the article's central flaw as if he's done so a hundred times. "AIDS figures include a lot of basic research in virology and immunology," he says, "but if you ask the NIH how much money is spent on, say, skin cancer, they'll only list the specific trials on skin cancer. If you standardized the way you report disease spending, it would be different." But the *Journal's* numbers are pretty convincing, making Gonsalves' argument sound a bit weak. It turns out that he and his counterpart at the American Foundation for AIDS Research, Jane Silver, argue it both ways. On the one hand, if you counted the dollars consistently, AIDS might not look so bloated. On the other hand -- and here you get to the heart of it -- unlike any other leading U.S. killer, AIDS is an infectious disease, a global pandemic threatening to bring down whole nations, so it requires a more urgent response -- and more cash.

When those arguments aren't enough, advocates pull out the Varmus-style line about scientific opportunity. In the words of amfAR founder and longtime cancer researcher Mathilde Krim: "It has been said that politics is the art of the possible. Well, science is also. It's not enough to say we want a cure for a disease -- the question is what do we do to get there? In AIDS we can zero in on the cause, so scientists are willing to support more money for AIDS research. They can see the light at the end of the tunnel." Gonsalves' version is to pull out a napkin and draw a series of flat and downward sloping lines, a mortality chart comparing scientific progress on infectious vs. noninfectious diseases. At midcentury, polio and TB deaths take a nose dive, while cancer and heart disease mortality soldier on, impervious. AIDS could hit the steep slopes soon. "You don't get a quarter of the way to your destination," he says, "and then say, 'Get out and walk.'"

"My Disease Is Bigger!"
The notorious dollars-per-death chart, from the 1998 Institute of Medicine Report, which no disease advocate could resist

DISEASE	# OF DEATHS 1994 Numbers	NIH SUPPORT* Fiscal Year 1996
Heart Diseases	732,400	$851.6
Cancer	534,300	$2,570.6
Stroke	153,300	$120.3
Lung Disease	101,600	$62.4
Pneumonia and Flu	81,500	$61.9
Diabetes	56,700	$298.9
AIDS	42,100	$1,410.9
Liver Disease	25,400	$169.8
Kidney Disease	23,000	$327.2
Septicemia	20,400	$10.9

Source: National Institutes of Health
** In millions of dollars*

Metaphors, like viruses, can spread quickly. In the disease wars, it's "A rising tide raises all boats." This is the vision of the coalition-minded advocates, who come together under awkward banners like The Ad Hoc Group for Medical Research Funding to advocate for "a bigger research pie," or, more specifically, for doubling the NIH budget in five years. It's an ambitious idea that could allow disease advocacy groups to push for more research dollars without having to propose that AIDS or cancer get less.

Right-wingers on Capitol Hill are disease warriors, says Silver, like "pro-family" Republican Rep. Ernest Istook, who "stood up with his charts and said, 'Why are we giving *them* money when they're doing this to themselves?'" But the effort to double the NIH has Republican moderates -- John Porter in the House and Arlen Specter in the Senate -- along with a Who's Who of AIDS drug companies as backers. It was Porter, chair of the House subcommittee that oversees NIH spending, along with a team of pharmaceutical CEOs, who confronted Newt Gringrich over his attempts to slash the agency back in 1995. By now, "NIHx2," as one corporate lobby dubbed it, is right on track, with the first two installments of 15 percent secured in the 1999 and 2000 budgets -- historic increases. But according to Martin Delaney, the contentious director of San Francisco's Project Inform, "The expansion of the NIH budget only delays the tougher fight, because the relative proportions stay pretty much the same."

Poke around the Parkinson's Action Network website today, and Delaney's words ring true. There you'll find an essay by Parkinson's advocate and *Beltway Boys* cohost Morton Kondracke that says, "Hollywood and the gay community have pushed Congress to make HIV/AIDS the government's top research priority." Stop by the American Diabetes Association site and, just a few clicks away from the AIDS moneybag cartoon, you'll be treated to a virtual slide show, which tells you: "For every $1 the government spends on diabetes research, it spends $7 on AIDS and breast cancer research. Before the government doubles the AIDS research budget to $3.4 billion ... Congress should make a multibillion dollar commitment to diabetes." The propaganda these organizations created to make their case before Congress they now use to rouse their troops, and from there, says Gonsalves, "it slowly leaks out into the popular culture." Last October, the disease wars went prime time.

20/20's John Stossel, a rangy attack dog of a broadcaster, began soft, with Parkinson's survivor Joan Samuelson struggling to get out of bed, but he soon cut the schmaltz: "Congress makes sure that they spend the lion's share of money on people who have the most political clout. If you want to know how to make money and influence the government, look no further than the AIDS lobby." He threw in interviews with AIDS detractors like Congressman Istook and then flashed the IOM's dollars-per-death chart.

For three years, Gonsalves, Silver and a weary handful of compatriots have been struggling to keep the wolves at bay, meeting with the diabetes, heart disease and Parkinson's groups, with members of the media. They even staged a protest outside of Rockefeller University, targeting

professor and then-American Heart Association president Breslow for his group's harsh references to AIDS. "I said, 'My father has Parkinson's -- we want you to succeed,'" recalls Silver. "'But we want you to stop implying that AIDS gets something it doesn't deserve.'" The response has been positive, if a bit tepid -- Breslow now says the language was "a misunderstanding; we never wanted to have less funding for AIDS"; Kondracke, who says he once "sat in a couple of congressmen's offices and said, 'Yeah, let's take the money [for Parkinson's] from AIDS,'" now calls that "a silly thing to do."

It's a strange turn of affairs that AIDS came to be seen by so many disease groups as the fat cat, the moneybags. Maybe those early years of the epidemic have simply been shuttered from memory, that time of quick and horrible deaths, a relentless rise in infections and President Reagan's pointed silence. As filmmaker and early ACT UPer Gregg Bordowitz recalls, "Most of us were queer or drug users or both. Quarantine was being discussed in *The New York Times* as a viable policy and William F. Buckley was calling for AIDS tattoos. This community formed out of a lack, out of stigma. Only then, once we were all together, we realized we could turn this into a positive offensive, and start demanding what we deserved."

But if AIDS' underdog years have been swept under the rug, the long, fruitful history of cooperation between AIDS and other health activists is at the bottom of the historical ashbin. Remember that the Americans with Disabilities Act was passed under the pressure of AIDS and disability activists working hand-in-hand. The bid for national health care, though unsuccessful, had a shot because of a sprawling coalition of disease advocates, health care workers and unions behind it. And then there are the scores of women, mostly lesbians, who joined the breast cancer ranks after years in the AIDS movement and who maintained, as even Langer acknowledges, "a special connection to AIDS." ACT UP/Golden Gate had a standing breast cancer committee. And early AIDS activists got some of their chops from veterans of the women's health movement, bringing them in for teach-ins and to consult on tactics for a major protest against the FDA. Why now, after years of scattered acts of cooperation, are health advocates squaring off?

It's impossible to ignore that these wars have played out almost entirely in the protease era, when the media has characterized the illness as "chronic" and "manageable." AIDS has become manageable enough, says Bordowitz, that many people with AIDS have had the space to consider "that illness alone isn't enough to support an identity." Craig Thompson, executive director of AIDS Project Los Angeles, sees "less urgency around AIDS" -- part of it, he says, is that "people in Hollywood aren't opening the trades every single day and seeing another obituary"; part is that "we've been asking people to support an issue for 16 years." Funders Concerned About AIDS released a report last spring showing that even as philanthropy was on the rise in the United States in 1997, AIDS giving was down 19 percent. During this same period, Elizabeth Taylor's public stumping for AIDS was matched by Lilly Tartikoff's for cancer and Michael J. Fox's for Parkinson's, and APLA's trademark annual AIDS Walk got buried under a dozen other walks -- for diabetes, Alzheimer's and breast cancer.

Successes, it seems, have put the AIDS movement on the defensive. AIDS Action, a DC lobby, published a pamphlet, "Talking About AIDS So America Listens," which used market research to

coach AIDS advocates on how to convey their sense of urgency. AmfAR produced the more substantial “The Broad Benefits of AIDS Research,” which details the research advances AIDS has produced for Alzheimer’s, arthritis and breast cancer and lists the AIDS treatments that also work for chemo-induced infections and hepatitis. Last August, bruised AIDS advocates got together with NIH bureaucrats and a few of the friendliest disease advocates to figure out what went wrong. When Gonsalves looks back at that daylong meeting, he lets out a deep sigh. “And yeah,” he says, “it’s not good. People think the epidemic is over.”

Just last fall the disease wars wafted up to the rarefied air of the Center for Scientific Review, the office that allocates 83 percent of all NIH dollars by deciding which research applications get funded. The Center asked a panel of researchers to revamp its integrated review groups, or IRGs, the field-specific groups of scientists who evaluate grant proposals. When the panel -- which didn’t include a single AIDS researcher -- put forward its draft recommendations in November, they had eliminated the AIDS IRG. The new system would throw AIDS proposals into general virology or immunology pools, where, says Gonsalves, “the people reviewing them wouldn’t know about AIDS, meaning a drastic decline in the quality and quantity of AIDS research.” “We saw this as the thin edge of the wedge,” says John Moore, PhD, of the Aaron Diamond AIDS Research Center, who had seen this same process in Britain five years ago, when the AIDS Directed Program was eliminated and became, in his words, the "AIDS Directed *Pogrom*.“ So this time he hit the phones, along with a handful of other AIDS researchers and activists, to keep critical government research flowing. After producing almost 800 letters of protest, and after Office of AIDS Research head Neil Nathanson, according to Gonsalves, ”really went to the mat," they won back the AIDS IRG.

“There’s a lot of jealousy in the [U.S.] biomedical research community over the amount of money spent on AIDS,” says Moore. "And that jealousy is somewhat justified because so much of the money is badly spent. But as AIDS researchers, we should put our *own* house in order."

Project Inform’s Delaney got into trouble three years ago for suggesting that AIDS advocacy was due for a housecleaning, too. “The problems faced by people with AIDS,” he wrote in his agency’s newsletter, “while substantial and severe, are not totally unique.” Speaking about carve-outs like ADAP that cover AIDS care, he asked, “How much longer can special programs be maintained for AIDS that are not available for people with other devastating life-threatening illnesses?” He called for AIDS lobbyists to quit stumping for Ryan White appropriations every year -- he believes the program’s days are numbered anyway -- and start imagining more expansive, long-term solutions: “a massive coalition to reform the health care system.”

When I asked how such a coalition was possible when other disease advocates are on the attack, Delaney said, “OK, they are. But the solution isn’t necessarily to turn and fight. Maybe it’s to slow down and say, ’What’s on your mind?’” In fact, when you ask even the most divisive of the disease lobbyists about their own cause, they can be pretty persuasive. Consider the ADA’s Mike Mawby: “There are 16 million Americans with diabetes, and by 2005 there will be 300 million worldwide. It kills almost 200,000 Americans each year and is the leading cause of blindness, limb amputation and kidney disease, the leading indicator of stroke and heart attack. By any measure of disease burden, diabetes is up there in the top three or four, yet relative to funding for cancer, AIDS, heart disease, we’re clearly the caboose, bringing up the rear.”

Delaney says AIDS advocates must grapple with the fact that other illnesses don't get what they need. "If there's some big breakthrough drug for, say, heart disease, and it's priced out of most people's reach, will there be a program like ADAP to pay for that?" asks Delaney. "Why not?"

This summer, two epidemiologists at George Washington University will publish a scholarly article confronting the funding inequities head on, by coming up with a new measure of disease burden that would account for the implications of infectious spread on a global scale. GWU's Jeff Levi, a former AIDS lobbyist, says, "We asked whether you just say all these arguments about disease burden are irrelevant, and make other arguments for AIDS research, or, since it's clearly becoming an accepted mechanism for setting priorities, do we come up with a model that reflects the true disease burden of HIV?" If the researchers succeed, we may be able to quantify, with our own chart, the gut feeling we have, from lived experience, that AIDS is *the* defining illness of our time. But if, after the epidemiologists take their best crack, the numbers still don't add up, will we really believe AIDS gets too much money? And as for those who feel no urgency around the epidemic, could a new chart convince them AIDS doesn't?

It may be too late for a new chart, anyway. Last fall, Varmus, who has steadfastly defended AIDS research, resigned as head of the NIH. In December, Congressman Porter, who calls biomedical research "the highest priority I know of," will retire, and he says Istook is angling to take his place as chair of the subcommittee overseeing health spending. This is the same Istook who told *20/20*, "If you have the politically correct disease, the prospects of getting federal funding to help find the cure are 100 times greater." And if George W. ends up in the White House, it's hard to tell how long the "lift all boats" consensus, let alone support for "exceptional" AIDS programs like Ryan White, will hold. "We're totally vulnerable," says Gonsalves. "The groundwork has already been laid, the rhetoric is there that says AIDS gets more than it deserves."

In the 1988 anthology *AIDS: Cultural Analysis, Cultural Activism*, Douglas Crimp wrote: "The ignorance and confusion enforced by government and the dominant media; the disenfranchisement and immiseration of many of the people thus far hardest hit by AIDS; and the psychic resistance to confronting sex, disease and death in a society where those subjects are largely taboo -- all of these conditions must be faced by anyone doing work on AIDS." That sense of the far-reaching implications of the epidemic was part of why AIDS was never, in the March of Dimes tradition, simply a "disease cause," but became, exceptionally, a true social movement, challenging homophobia, racism, even the drug wars.

Now government priorities so closely reflect the demands of AIDS advocates that Gonsalves can say, echoing Porter, "The NIH does a pretty good job setting priorities." If AIDS advocates continue to focus their attention so narrowly on research, detaching the virus from its social impact, AIDS will be reduced to just another disease lobby, and will remain a disease wars target. But there's another choice: As AIDS cuts a swath through sub-Saharan Africa and India, as African American AIDS organizing finally hits its stride, as HIV transmission is criminalized nationwide, advocates could revive AIDS as a true social movement, one with relevance across disease boundaries, with the power to change how society responds to illness and inequity as a whole.

One provocative reaction to AIDS exceptionalism is that taken by San Francisco's Project Open Hand, which, on Valentine's Day, extended its meal services for people with AIDS to include anyone incapacitated by illness. The decision was made in response to this post-crisis moment, marked by fewer donations and volunteers, says executive director Tom Nolan; he predicts the group's expanded mission will revitalize support. But the former divinity student is also philosophical about the change, saying, "The gift of our community to the larger world may well be these institutions we created. Maybe AIDS organizations need to acknowledge that the time has come for that."

Long before AIDS, there were "wars" on polio and TB, on cancer, diabetes, and arthritis, but AIDS was the first disease around which people built identity and community. As Delaney says, "Just like the drugs, nothing has just one effect. They have a mix of good and bad effects, and that's true of the disease community model as well. When it works, it can be an enormous source of empowerment for people, but one of the toxic side effects is it puts people into competition with others."

He believes that if politics doesn't force us into cooperation, the disease itself may. People with AIDS, whose lives have been prolonged by combination therapy, now find themselves increasingly at risk for diabetes, cancer and heart disease. We may soon find ourselves fighting for research on the very illnesses whose advocates are at war with us now.

SIGN OF THE TIMES

The four blood-red letters loom from the stark black billboard off the shoulder of the highway: "A-I-D-S." Another PSA for the 20-year-old epidemic? Not this time. As you speed by, the sign's fine-print punch line becomes legible: Above the word AIDS is "Affects 4.5 million more children than…" and, below, "Now will you take asthma seriously?"—followed by a toll-free number for the American Lung Association.

A little Coke/Pepsi rivalry in disease fundraising? The Lung Association's national reps say no, but even its own regional directors are blushing—and apologizing. "That they would take something as serious as AIDS and try to make asthma compare to that is ridiculous," says Carol Ruggeri, assistant executive director for South Florida, home to at least four billboards. "I've apologized to just about anyone I could think of who might be offended."

The national office, for its part, refused to disclose how many billboards it placed, or where. Spokesperson Abby Nash denied that she had heard any complaints, adding that the campaign's TV and radio (not the "AIDS" billboards) ads won industry honors. Campaign manager Asad Laljee of the New York–based Hill-Holliday ad firm, promised "another approach" in the next round because "some people didn't understand that we're not talking about cancer or AIDS," he said. "We're just trying to emphasize how important it is to prevent asthma attacks in children."

Still, Ruggeri spied a saving grace: "They're so bad that all they will do is remind people about AIDS," she said. "And if you're in your car, you can't really make out the fine print."

—Steve Friess

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