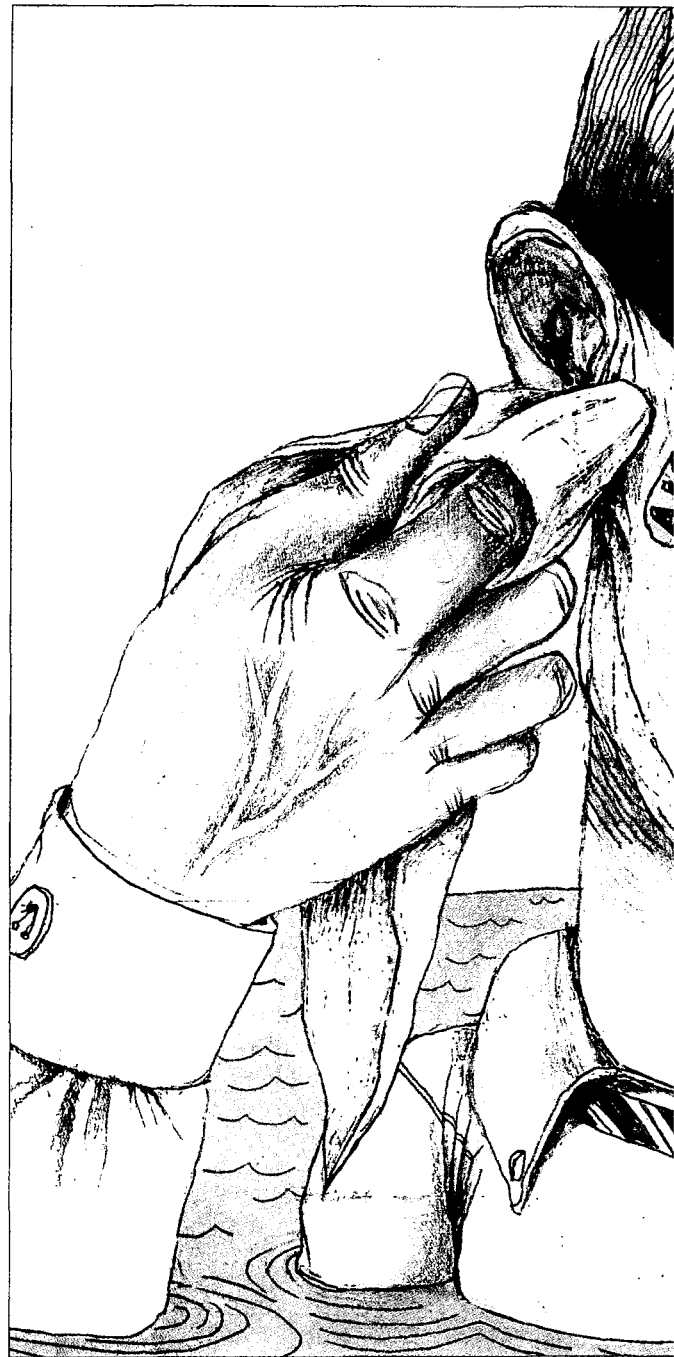


T H E SQUEAKY WHEEL SYNDROME

The federal government spends tax dollars disproportionately on a chosen few illnesses—notably AIDS and breast cancer—while underspending on bigger killers. It does so not on any medical criterion, but in response to the loudest cries of *J'Accuse*. Now activists are pitted against each other in an ongoing ordeal called "Disease Wars."

MICHAEL FUMENTO



his past September yet another special-interest group marched on the Mall in Washington, D.C. This group didn't even claim to have gathered a million persons, only 150,000. So why should we care? Because these people came to fight a disease to which virtually all of us have lost friends and relatives, and to which we have at least a one-in-five chance of dying ourselves.

MICHAEL FUMENTO, a science and health journalist, is author of *The Myth of Heterosexual AIDS* (Regnery).



TIM HUSSEY

No, there's no cancer epidemic and the demonstrators to their credit didn't claim there was. Cases and deaths have actually declined a bit in recent years. Yet the disease continues to kill more than half a million Americans annually, and given the recent advances against heart disease, cancer may soon become our leading cause of death.

The rally, which called for more attention and money to be directed to cancer, was the brainchild of a small but eclectic group that includes Larry King, Sam Donaldson, and H. Norman Schwarzkopf. Its largely unspoken impetus was frustration over politicians' inability to say "no" to the powerful AIDS and breast cancer lobbies. The Rev. Jesse Jackson counted the

TV cameras and decided to drop in. But it was the appearances of the president and vice president that attracted most attention—and belied the Clinton administration's irresponsible record on the matter.

How to Make Money and Influence People

That spending is disparately focused on AIDS is no longer disputed, and was documented earlier this year in "Scientific Opportunities and Public Needs," a report by the Institute of Medicine (IOM), a branch of the highly reputed, non-governmental National Academy of Sciences. A better title for the

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report might have been “The Squeaky Wheel Gets the Grease.”

The squeaking began with AIDS activists, who pursued a two-pronged strategy. First, they claimed that anyone who denied them the research money they demanded was a homophobe. Second, they insisted that AIDS was not just a gay disease but “an equal opportunity destroyer.” That these two positions are somewhat contradictory seemed to bother no one, and the strategy won firm backing from the federal health bureaucracy, including Reagan’s Surgeon General C. Everett Koop, who talked of a “heterosexual AIDS explosion,” and Clinton’s Health and Human Services Secretary Donna

Shalala, who told Congress in 1993 that we might not have “any Americans left unless we’re prepared to confront the crisis of AIDS.” Just a year ago Shalala told a reporter that “we have more kids infected,” though the latest data showed AIDS cases among children falling sharply.

The media did their part as well, rarely challenging the AIDS doomsayers. If Shalala said every last person in the country was threatened, who were journalists to report otherwise?

The effects on research spending were inevitable. Following a trend established in the late 1980’s, last year’s National Institutes of Health (NIH) budget allocated about \$70,000 for each AIDS death in 1997. Cancer received less than \$5,000 and heart disease less than \$2,000.

Breast cancer activists openly copied the AIDS campaign, replacing the word “homophobe” with “misogynist,” and the red ribbon with a pink one. While breast cancer activists couldn’t pretend that all—men and women alike—were at equal risk of getting the disease, they started the myth that research spending was almost entirely male-oriented. To prove this they compared research allocations for women’s diseases to the overall medical research budget. Had they compared female disease funding to male disease funding, they would have shown female disease research coming out well ahead.

Like their AIDS counterparts, breast cancer activists also grossly inflated a woman’s odds of getting the disease; and as with AIDS, the media again responded eagerly. In 1992, for example, the press referred to a breast cancer epidemic thirty-five times as often as to a prostate cancer epidemic, even

though the latter was killing almost as many people, and spreading much more quickly. (Prostate cancer in 1996 killed 41,400 Americans, near breast cancer’s toll of 44,560 and more than AIDS’s 38,780.)

Breast cancer became a cause celebre like AIDS. Fur retailers, seeking to ward off attacks from animal rights activists, widely advertised their contributions to breast cancer research. Other companies catering to women, such as Revlon, joined the crusade. States began soliciting donations to the cause on income tax forms.

As with AIDS, the breast cancer strategy worked brilliantly. In 1992, former Rep. Pat Schroeder, the militant Colorado feminist and fervent anti-militarist, killed two birds with one budget by diverting hundreds of millions of dollars from defense appropriations to breast cancer research. Tom Harkin (D-Iowa) sponsored the same legislation in the Senate. NIH allocations for the disease now outnumber those for prostate cancer by about five times per case and four times per death.

The National Cancer Institute (NCI) is the NIH branch responsible for almost all cancer research and much AIDS research. According to the IOM report, in 1993 NCI “allocations for breast cancer research increased by \$53 million, cervical cancer research funding increased by \$10 million, ovarian cancer research funding increased by \$6 million.” To pay for these increases and for the increase in AIDS spending, “NCI had to cut basic research funding for leukemia, non-Hodgkin’s lymphoma, and cancers of the colon, bladder, kidney, and brain, as well as for public information and chemoprevention.” Since 1993, the disparity has only widened.

The bottom line of the IOM report is that tax dollars are spent disproportionately on a chosen few illnesses, not according to any medical criterion, but in response to the loudest cries of *J’Accuse*.

September’s cancer rally appeared to be a way of accusing Congress of caving in to the earlier accusers. This came through in news accounts. Amy Argetsinger and Craig Whitlock reported in the *Washington Post*: “Some speakers took pains to emphasize the sheer number of people struck by cancer each year—a far higher number than those killed by arguably more celebrated causes, such as AIDS or gun violence.” According to Vanessa Blum in the *Chicago Tribune*: “Many [marchers] complained of feeling overshadowed by the disproportionate attention given to breast cancer.” One woman told the Associated Press: “Lung cancer is the biggest killer of women. It’s bigger than breast and ovarian cancer combined.”

Disease Wars

The logical consequences of politicizing disease research are obvious on Capitol Hill. Seemingly every group of disease sufferers now employs professional lobbyists. Twenty-nine patient advocacy groups or associations submitted written or oral testimony to the IOM as it worked on its report. And the pursuit of public funding has inevitably led to conflict. Cancer activists are pitted against AIDS activists, prostate cancer activists against breast cancer activists, and so on.

Worse than unseemly, these "disease wars" are unscientific. "I do have significant concerns about whether Congress has played politics with the NIH budget and micromanaged difficult scientific questions," Rep. Greg Ganske (R-Iowa) said during an oversight hearing held by the House authorization subcommittee in September 1997. "I am concerned that these lobbying efforts are turning the floor of Congress into a scientific peer review panel," and "whether members of Congress have the scientific expertise to determine where the most promising areas of research are."

Some say the answer is simply to boost all federal disease research funding. "I think all biomedical research should be increased and I'm not willing to engage in 'Disease Wars,'" says Fran Visco, president of the National Breast Cancer Coalition. "The message we give to Congress year after year is the pie has to be bigger."

The pie is in fact getting bigger, but Congress is still slicing it up unfairly, ignoring objective standards for grant-giving such as mortality rates and numbers of sufferers. And as the IOM report notes, no increase can ever "be large enough to meet every need or fund every promising lead. Choices must be made and priorities must be set."

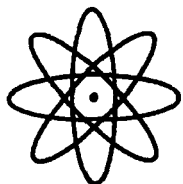
Resources will always be limited. It's not just a matter of funds but of researchers, whose numbers cannot be raised merely by legislative fiat. You can draft an unwilling civilian and have him passably fit for combat in sixteen weeks, but to become a scientist a

young person must willingly study for many years.

"It is a zero sum game," said Dr. Zack Hall, director of the Institute of Neurological Disorders and Stroke at NIH, in a recent PBS documentary. "Any time there's an increase in one area of research that we have, it must go down in other areas." In the same documentary, Rep. Ernest Istook (R-Okla.) said, "The media pressures and influences depict AIDS as *the* horrible disease as opposed to being one of many horrible diseases and there is frankly a fear among many members of Congress that they will be depicted as people lacking in compassion if they dare to mention that [these other

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New AIDS cases fell 12 percent in 1997, yet the next year AIDS activists announced a "growing HIV/AIDS rate," citing only statistics through 1995. Child AIDS cases fell from 671 to 473, yet in 1999 NIH will probably spend 10 percent of its pediatric budget on the disease.

diseases] afflict far, far more Americans and cost this country far, far more than AIDS does [and therefore] deserve a larger share of the limited money available."

Some Things Never Change

Ten years ago AIDS research had already absorbed so much funding that the NCI's ability to pay for promising new cancer research had fallen to its lowest level in two decades. During the 1970's, between 43 percent and 60 percent of cancer grant applications approved by review committees were funded. By 1989, this had fallen to about 25 percent and there it remains.

Two top NCI doctors left the agency in 1988, partly in frustration over this drop. "They bled cancer to feed AIDS," complained one. In an editorial entitled "Are We Spending Too Much on AIDS?", published in the medical newspaper the *Scientist*, two young researchers wrote of the danger of "seduction" by AIDS research money: "Unfortunately, many other young scientists may have no choice but to go into the field that offers the most easily obtained funding. If this happens, other areas of research important to the welfare of the U.S. public will be neglected for years to come." And so they have been.

"AIDS has prompted a general de-emphasis of other medical problems," I wrote in these pages almost a decade ago ("The Incredible Shrinking AIDS Epidemic," *TAS*, May 1989). "The blunt fact is that people will die of these other diseases because of the overemphasis on AIDS. We will never know their exact numbers. But they will die nonetheless." And so they have.

NIH is the largest government provider of research grants, but private industry, especially the pharmaceutical industry, spends more. Here, too, apocalyptic thinking about AIDS prevails. "I went around to drug companies in the late 1980's and early 1990's," says Joel Hay, chairman of the department of pharmaceutical economics at UCLA, "and they were absolutely convinced that AIDS was soon going to account for a huge portion of health care expenditures. I tried to set them straight. Nevertheless, they made major decisions to put huge portions of research and development funding into AIDS based on improper information," he said. "But for that, who knows where we'd be on cancer or Alzheimer's or diabetes?"

Slicing Up the Pie

There's no simple formula for how research money should be allocated, but chief among the considerations should be:

- How many people have the disease; and are their numbers increasing, decreasing, or holding steady?
- What is the fatality rate of the disease?
- How many years of lost life and how much lost productivity does the disease cause?
- What does this disease cost society, particularly through Medicaid and Medicare?
- How much bang can we get for the buck (e.g., spending \$1 billion to save 10,000 lives versus perhaps \$2 billion to save 1,000 lives)?
- Will research on this disease likely lead to developments useful against others?
- Aside from sheer incidence and death rates, how much suffering does the disease cause?

These are but a few factors we must consider. Yet the first step is to stop rewarding those who artificially make their wheels squeak; the media must demand proof of their assertions.

Just last July, an article in *USA Today* began this way: "Alarmed at the spread of AIDS nationwide, AIDS advocates on Monday demanded millions for HIV prevention and decried the nation's 'paralyzed' prevention efforts." Spread? A few weeks earlier, the CDC released its 1997 statistics showing exactly the opposite. The report (available at www.cdc.gov/nchstp/hiv_aids/stats/haslink.htm) shows that new AIDS cases fell 12 percent from 68,808 in 1996 to 60,634 in 1997. Male cases dropped, female cases dropped, cases attributed to heterosexual transmission dropped not only in absolute numbers but as a percentage of all new AIDS cases. Child AIDS cases fell from 671 to 473, or about one live birth per 24,000.

But since nobody seems to know this, the 1999 estimated NIH budget allocates \$188 million for pediatric AIDS: over \$380,000 a case. AIDS gets 10 percent of *all* NIH pediatric spending. Meanwhile, cancer is the leading cause of non-accidental death in children under the age of 15, with about 9,000 pediatric cases annually.

Knowing that the media will not call their bluff, AIDS activists continue twisting data. A press release of September 10, 1998 entitled "National Task Force Addresses Growing HIV/AIDS Rate in Rural America—Kicks Off Rural Health AIDS Conference," declared that "AIDS cases increased by 80 percent between 1991 and 1995 in rural areas compared to a 47 percent increase in urban areas, according to the CDC." What's missing here? Only the most recent and hence most important years, 1996 and 1997. They were omitted because rural AIDS cases *fell* from 8.8 percent of all U.S. cases in 1995 to 8 percent in 1997.

One reason AIDS activists gave for overspending on their disease was that it was an epidemic with sharply rising numbers. What do they and press allies say now, with the number of cases falling and the death rate dropping through the basement floor? (In October the CDC announced that, in a single year, the disease getting the most money per victim fell from America's eighth leading killer to its fourteenth.)

The media insistently attributed this progress to medical research, specifically drug therapies. Most newspapers worked the word “drugs” into their headlines. What they ignored is that in 1988, data was presented at that year’s international AIDS conference indicating that HIV among homosexuals in major cities had peaked in the early 1980’s. Probably this applied to the population as a whole by 1985. With a ten-year lag time from infection to full-blown AIDS, we could have expected AIDS diagnoses to peak by 1995, and deaths to peak shortly thereafter. That’s what I predicted in 1989, and that is exactly what has happened.

Of course the wonderful new medicines have played a part; they’ve surely speeded up the decline. We ought to keep a large number of AIDS researchers plying away. But if a rapidly growing epidemic was an excuse for a rapidly growing budget, shouldn’t a rapidly shrinking epidemic prompt reallocation of funds? Shouldn’t it be of *some* import that AIDS now kills about as many persons in a year as cancer kills every twelve days?

Clinton-Gore Feel Their Pain

The marchers on the Mall in September didn’t come to criticize private industry—pharmaceutical companies largely bankrolled their demonstration. The protesters were after the group they could influence most, the government.

Clinton and Gore made it clear they were moved, and this is easy to believe. The president lost his mother to cancer, and the vice president a sister. Yet their cynicism is hard to ignore. Clinton boasted that he’d asked Congress to increase the NIH cancer budget by 65 percent, but didn’t mention his prime role in the cancer-AIDS research funding disparity. He is clearly aware of it, though. During his speech at a gay rights dinner in November of 1997, a heckler shouted: “People with AIDS are dying!” Clinton snapped back: “Since I’ve become president, we’re spending ten times as much per fatality on people with AIDS as people with breast cancer or prostate cancer.” The figures were a bit off, but showed that he knew full well he had given AIDS most favored disease status. Under Clinton, AIDS spending went up at almost twice the rate of cancer spending.

In a press release just after the cancer rally, the White House made it sound as if Clinton were twisting Congress’s arm for more cancer funding: “Today, the President and Vice President called on Congress to pass the Administration’s historic five-year, 65-percent increase in cancer research at the National Institutes of Health.” It went unsaid that both the House and Senate had proposed much *higher* figures.

Gore’s Gaffes and Manipulation

In his keynote address to the rally, the vice president committed a typical Gore gaffe. “Some people still say it is impossible to find a cure for cancer,” he boomed. “A hundred years ago, people said exactly the same thing about smallpox.” And they were right: No cure ever was found for smallpox. It was wiped out by a vaccination, the first disease ever to be so prevented.

This was far from the first time that Gore had used cancer to score points. The most famous was his speech to the 1996

Democratic National Convention, built around his sister’s agonizing death from lung cancer, presumably due to smoking, in 1984. Yet when he ran for president in 1988, Gore boasted to North Carolina farmers that “throughout most of my life, I raised tobacco.” He took tobacco company contributions for six years after his sister’s death.

Until quite recently, Gore seems to have been hardly aware of cancer at all. Aside from joining his wife in a yearly fundraising run against breast cancer, he has been a one-disease politician, focused overwhelmingly on AIDS. Last year at the National Gay and Lesbian Task Force’s annual awards ceremony, the vice president pledged not only “to stop anti-gay hate crime” and “end workplace discrimination” against homosexuals, but to raise AIDS funding further. Last December the *New York Times* reported that Clinton and Gore were seeking a 35-percent spending increase for “AIDS drug-assistance programs.” There is no equivalent for cancer patients. The *Times* noted: “The request has a big political dimension. Federal health officials said that the Administration and Vice President Al Gore in particular were eager to address the concerns of advocacy groups that focus on AIDS and gay rights.” *Newsweek* reported that in late October of this year Gore worked “behind the scenes to nail down budget victories that will help him with key Democratic constituencies in 2000,” including more support for AIDS research. Before 1998 there is no record of Gore’s supporting increased cancer research.

Most of us couldn’t care less if Clinton or Gore feel our pain. What we want is for them (and Congress) to represent us—all of us, not just those who scream the loudest, sew the biggest quilts, or chain themselves to fences. The president and vice president are no allies of cancer sufferers or their loved ones. They have no interest in the equitable spending of tax money for medical research. They are political animals through and through. It’s only fitting, then, that although they can’t be blamed for the politicization of research funding, its institutionalization will be their legacy. As Gore wrote in a *Washington Post* op-ed on October 18: “For too long, cancer patients, their families and their care givers have had to fight cancer without the resources necessary to win the war.” He wasn’t apologizing, but merely trotting out a major slogan for his next political campaign. ❧

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