

Lobbyists Seek to Reslice NIH's Pie

Several organizations are complaining that they haven't been getting their fair share of NIH's budget growth; NIH officials say they are making simplistic and potentially damaging arguments

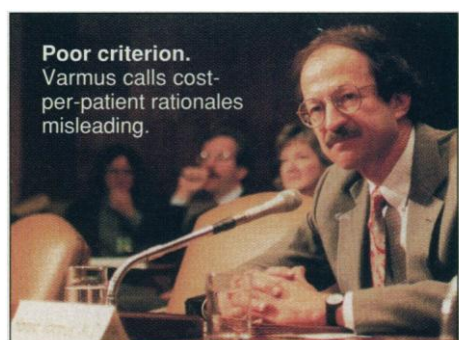
You might think this would be a year of harmony among the loose-knit coalition of groups that advocate increased funding for biomedical research. After all, they have already received a sympathetic hearing for their number-one priority: to double the budget of the National Institutes of Health (NIH) by 2002. Senator Connie Mack (R-FL) suggested this ambitious target in January, and leaders of the appropriations subcommittees—Arlen Specter (R-PA) in the Senate and John Porter (R-IL) in the House—say they like the idea, which would require a 15% increase per year. Even if the real increase for 1998 turns out to be closer to the 7.5% that Specter has proposed as a plausible target, it would be far more than any other research agency dreams of getting. But, as disease lobbies begin testifying this week to a House appropriations subcommittee, there is a sour note in the air—a threat of siblicide.

For years, biomedical research advocates have had a rule that everyone should close ranks behind a common goal: to increase the overall pot of money for biomedical research. But congressional aides and NIH staffers say that several lobby groups—in particular the American Heart Association (AHA), the Juvenile Diabetes Foundation International (JDF), and advocates for Parkinson's disease research—are making aggressive public appeals for a larger slice of NIH's pie for their own areas. And while the leaders of these groups deny it, they appear to covet the \$1.5 billion in NIH's \$12.7 billion budget spent on HIV and AIDS research.

The Parkinson's Action Network, for example, handed out a fact sheet on 9 April comparing NIH disease-based expenditures in six categories, along with a notice that a new bill was being introduced that day boosting Parkinson's research. The sheet claims that in 1994, NIH spent more than \$1000 per affected person on HIV/AIDS research, but only \$93 on heart disease and \$26 on Parkinson's (see table). The implication was obvious.

These arguments have been taken up by some conservative members of Congress, who are now demand-

ing that NIH justify how it divvies up the funding for various diseases. Last year, Representative Ernest Istook (R-OK), a member of Porter's NIH appropriations subcommittee, released graphs put together by James Crapo, a well-known pulmonary researcher and pathologist at Duke University, indicating that major diseases are not getting their fair share of funding increases. In a subcom-



mittee hearing earlier this year, Istook took up the subject again with a reference to the large sum NIH is spending on AIDS (see sidebar). Other legislators are using similar logic to advance their own causes. Representative Henry Bonilla (R-TX), for example, whose Hispanic constituency is affected by a high incidence of diabetes, argues that NIH should be earmarking more for diabetes research.

All this is putting NIH on the spot. NIH director Harold Varmus calls such cost-per-patient rationales "confusing" and "simplistic." He says the data come from different sources and are based on variable definitions.

And the analysis ignores critical things that can't be quantified, such as the judgment of scientists that research in a particular area is ripe for expansion. Varmus, spurred by legislators who have picked up the advocates' logic, has decided to counter it with a public education campaign: NIH staffers have been working for months on a pamphlet that is supposed to explain NIH's method of allocating funds.

The increasing pressure for targeted research funding has also put pressure on key legislators such as Porter—a champion of biomedical research and an enemy of earmarking. Porter's subcommittee and the Senate panel that writes NIH authorizing legislation, chaired by Senator William Frist (R-TN), have now scheduled special hearings to talk about how NIH sets priorities. The Frist panel will meet on 1 May; Porter's panel, on 13 May. An aide to Frist says that the hearing will allow everyone to debate NIH's priorities without asking members of Congress to vote "thumbs up or thumbs down on any amendment" for a specific disease. The aim, he says, is to ventilate the issue before voting begins.

Seeking a fair share

In the weeks leading up to those hearings, Congress will hear directly from groups that believe they are being shortchanged. No group has taken up the cudgels on its own behalf more determinedly than the AHA. Last year, advocates of heart research were so aggressive in making comparisons between their field and AIDS research that they drew criticism from Varmus behind the scenes. Varmus says that he has met with AHA President Jan Breslow—a well-regarded heart-disease geneticist at Rockefeller University in New York City and a member of the National Academy of Sciences—and that "we have a much better understanding ... at this point." Claude Lenfant, director of the National Heart, Lung, and Blood Institute (NHLBI), says he has also tried to temper Breslow's rhetoric. But Breslow is as insistent as ever.

Breslow says he is "appalled" at the deterioration of support for cardiovascular studies over the past decade, claiming they have been "gutted" by neglect. "The field has been depleted of young investigators," Breslow says, and he aims to combat the "myth that heart disease is going away." Breslow ticks off the numbers: 59 million Americans are afflicted by cardiovascular problems or stroke, 5 mil-

Disease	Federally funded research	Number afflicted	Research \$/afflicted
HIV/AIDS	\$1,486,221,000	1,390,000	\$1069
Cancer	\$2,356,578,000	8,000,000	\$295
Multiple Sclerosis	\$55,462,000	350,000	\$158
Heart disease	\$652,368,000	7,000,000	\$93
Alzheimer's	\$217,283,000	4,000,000	\$54
Parkinson's	\$26,066,000	1,000,000	\$26

SOURCE: PARKINSON'S ACTION NETWORK

Mixed bag of numbers. The Parkinson's Action Network compiled these data from a variety of sources to support its campaign for a \$100 million budget.

AIDS: A Justifiable Share

At an appropriations hearing on 26 February, Representative Ernest Istook (R-OK) asked whether the National Institutes of Health (NIH) had its research priorities straight. He suggested to the witness, NIH director Harold Varmus, that NIH ought to align its funding decisions more closely with health-care costs. Citing a small study of Medicare spending, Istook noted that NIH spends a relatively small percentage of its dollars on diabetes and other common diseases that rack up big Medicare bills. NIH research, complained Istook, "is focused instead on a disease that, although it is terrible, is not more terrible than many other diseases, and certainly does not represent the same degree of threat to nearly as many people in this country. ..."

At that point, Varmus cut to the chase: "Let's talk specifically about AIDS, because that's obviously what's on your mind."

Istook's thinly veiled attack on the AIDS budget at NIH—currently, about \$1.5 billion is spent on the disease—mirrors an approach used during the past few years by several disease advocacy groups (see main text). Some groups say they deserve a funding allocation that corresponds to the size of their patient population, noting that AIDS gets a large allocation, while the number of HIV-infected people is relatively small.

But many biomedical research leaders say it is risky to focus attention on whether specific diseases get their fair share of research dollars. Anthony Fauci, head of the National Institute of Allergy and Infectious Diseases, which gets most of NIH's AIDS funding, says he long has encouraged advocacy groups not to lobby Congress to increase funding by disease category. "When you start getting jockeying for more money by constituencies of a certain disease, that, in the long run, doesn't help. Everybody benefits," says Fauci, when the NIH budget increases "as a whole."

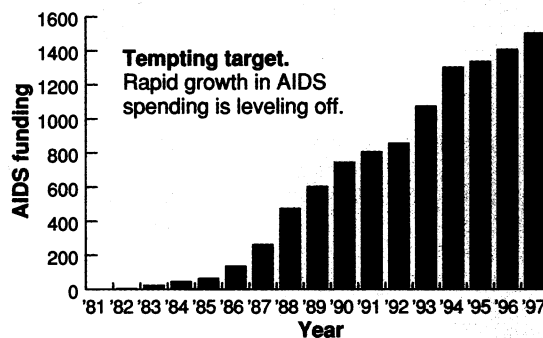
AIDS advocates offer a harsher judgment. "The American Heart Association and other groups are preying on the prejudices of certain members of Congress to advance their own parochial goals," says Gregg Gonsalves, an AIDS activist with the Treatment Action Group. "There's such a cross-pollination in the world of science that lobbying for specific diseases is counterproductive."

Varmus himself staunchly defends the spending on AIDS research. At the 26 February hearing, Varmus pointed out to Istook that AIDS is the country's leading cause of death for 25- to 44-year-olds. And in a phone interview, he argued that the disease should get special attention because it is new and still spreading. "We're responding to a public health emergency," adds William Paul, head of the NIH's Office of AIDS Research, who says that for this reason, AIDS should be evaluated differently from established diseases.

And Arthur Ammann, president of the American Foundation for AIDS Research, argues that AIDS should not be compared to diseases like cancer and diabetes for a practical reason: AIDS is caused by an identified virus, and history has shown that vaccines can stop such pathogens. "We put big resources into polio, and then there was a vaccine," he says. The same is true of many other infectious diseases.

Michael Stephens, a former staff director of the House subcommittee that monitors the NIH budget who now consults for biomedical research advocates, says that even if the critics are correct and AIDS is getting more than its fair share, the "distortion is not radical." Stephens takes a historical view, arguing that AIDS research is only following a pattern previously set by cancer. After Richard Nixon declared war on cancer in 1971, funding for cancer research shot up, leveling off in the '80s. And now with AIDS, says Stephens, "the system is in fact sort of settling itself back down."

—Jon Cohen



SOURCE: AMERICAN FOUNDATION FOR AIDS RESEARCH

lion suffer congestive heart failure, and this disease remains the nation's number-one killer.

Breslow plans to argue in testimony to Porter's panel this week that heart-related research suffered "a serious shortfall" at NHLBI and the National Institute of Neurological Disorders and Stroke (NINDS) during the decade when the AIDS budget grew rapidly. The AHA claims that while funding for NIH overall has increased 35.9% in constant dollars since 1986, the heart program at NHLBI and NINDS declined 5.5%. Breslow is planning to ask that NHLBI's budget be raised from \$1.4 billion in 1997 to \$1.65 billion in 1998. Asked if AHA is targeting the AIDS set-aside, Breslow says, "We're not trying to take anything away from other diseases." But he insists: "We are very upset that we have been neglected ... and we're not going to take it anymore."

The AHA isn't the only group singing the blues. The JDF is arguing that diabetes research, too, has been overlooked. The JDF is

pushing for special increases for the institute that chiefly funds its area—the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). It is using a different tactic, however—that of an eager partner demanding more attention. The JDF is unusual in that it plans to donate \$67 million over a decade to projects that are peer reviewed, co-selected, and co-funded by NIH.

On 1 April, JDF hired Robert Goldstein, an extramural research director for immunology at the National Institute of Allergy and Infectious Diseases, to be its own director of research. He is teaming up with the management firm of McKinsey & Co. to conduct a review of diabetes funding and develop a strategic plan for diabetes. JDF officials say NIDDK funding has grown only 53% in a 10-year period when overall NIH funding has increased 97%. And Goldstein says that when parents of a child with diabetes see these numbers, they ask, "Why isn't my child just as important" as other patients.

The JDF wants to increase funding for NIH by 9%, for NIDDK by 12%, and for diabetes research by 15%. Advocates have already prepared draft legislation to mandate a national diabetes research plan.

Another targeted bill—the Morris K. Udall Parkinson's Research and Education Act—was introduced into Congress last week. It would authorize NIH to spend \$100 million on Parkinson's research (NIH now spends about \$32 million) and create 10 special centers around the country for collaborative research. More than 100 members of the House and 34 senators are co-sponsors.

And it's not just the arguably neglected who are out campaigning. On 8 April, the National Breast Cancer Coalition, which has helped nudge hundreds of millions of dollars' worth of earmarks through Congress, announced that it is forming a political action committee. The purpose, says coalition president Fran Visco, a Philadelphia attorney, is to do "electioneering"—such as

registering voters—that is not permitted to regular nonprofits. “We wanted to let our voting members know who is really supporting us,” says Visco.

No more Mr. Nice Guy

It may seem odd that this new “targeted advocacy” is intensifying while NIH’s budget is increasing. Usually, coalitions start to fragment when resources are declining. David Moore, government liaison for the Association of American Medical Colleges, explains that after “two extraordinary years, with huge increases [for NIH],” more money has been “pumped into the system,” but it hasn’t been distributed at the same rate to all constituencies. The result, he says, is an “increasing level of frustration, ... some of it justified,” among those who feel that they have been left behind.

Joan Samuelson, leader of the Parkinson’s Action Network, adds that the more outspoken disease lobbies have set an example that others are now following. “We were self-sacrificing” wallflowers in the past, she says, but “the diseases that have accumulated the most research support have been very single-minded about their efforts. ... That seems to be the way to get the job done.” And JDF’s representative William Schmidt says, “There was a time when we were very good citizens and really went up to the Hill with one message—overall [funding] for NIH. But it becomes hard as you see other disease areas advance far beyond where we are.” Like many, these advocates think that political pressure makes good things happen. Or as Samuelson says, “With enough money, [scientific] potential can be created in almost any area.”

That view is “naïve,” Varmus says. “Money is an attractant, but it’s not sufficient. You really have to be convinced that there are good experiments to do.” He plans to explain at the upcoming House and Senate hearings why he thinks scientific judgment works better than political directives in stimulating research. NIH also hopes to spell out this rationale in the public report it is preparing.

As for the growing list of targeted research demands, Varmus says: “The way to respond ... is not to be defensive, but to have a big workshop, have all the institute directors there, have the leaders in the field, ... and see if we can identify new opportunities.” In that case, advocacy groups can count on one thing at NIH: There will be lots of big workshops.

—Eliot Marshall

ASTRONOMY

Follow Up on Findings, Panel Tells NASA

A panel of astronomers is urging NASA to follow up quickly on the field’s recent successes. Convened by the National Research Council (NRC) at NASA’s request, the 50-member panel, chaired by Patrick Thaddeus of the Harvard-Smithsonian Center for Astrophysics in Cambridge, Massachusetts, has urged NASA to give priority to space-based instruments that would build on some of the most stunning feats of recent years: the mapping of the cosmic microwave background, the discovery of galaxies in the early universe and planets around other stars, and the detection of objects that are almost certainly black holes.

The panel, which briefed NASA space science head Wesley Huntress on 8 April and will formally present its report in a month, did not draw up a wish list of instruments. Instead, it described the areas of science that should receive top priority in NASA’s space science plans. “We picked the science ideas that have staying power,” says Thaddeus. But its recommendations give a boost to several missions that are now being planned, from new gamma-ray satellites to a successor to the Hubble Space Telescope.

NASA asked for the list because most of the projects astronomers recommended in their last priority-setting exercise, the so-called decade report issued by the NRC in 1990, are already under way. The next decade report, which will list priorities for both space- and ground-based facilities, is not due until 2000. In the meantime, says Alan Bunner, a science

program director in NASA’s Office of Space Science, “[we] needed priorities ... and we needed them on a fairly short time scale.” To speed things along, the NRC panel, convened just a year ago, debated research priorities in space science only.



Eagerly awaited. The MAP mission will chart details of the microwave background radiation.

At the top of the list for the next 10 years or so, said the committee, is refining a map of the microwave background radiation. In the early 1990s, the Cosmic Background Explorer revealed tiny temperature variations in this uniform bath of microwaves—the imprint of primordial “seeds” that grew into great structures in today’s universe. A finer scale map of these ripples would yield clues not just to structure formation but

also to the density and makeup of the universe, Thaddeus and his colleagues say—implicitly nudging NASA to keep a planned satellite called the Microwave Anisotropy Probe (MAP) on track for its August 2000 launch.

The report also recommends following up on recent spectacular successes in finding galaxies near the time they were born. Bunner calls it “strong endorsement for the [proposed] Next Generation Space Telescope and for a U.S. role in the European FIRST”—the planned Far Infrared and Submillimeter Space Telescope.

While listing the search for more planets around other stars as their third priority, the astronomers also urge some restraint, recommending that NASA hold off on trying to image planets like Earth. The planets cur-

rently being found are giants, the size of Jupiter or larger. NASA’s proposed 1998 budget includes funding for a small, space-based interferometer—a linked array of telescopes—which could pick out indirect clues to planets as small as Earth. Actually photographing such planets, however, would require a large, costly interferometer positioned out near Jupiter, a dream that Thaddeus says should be deferred. “First, we should put our arms around as many planets as we can,” he says, “before doing the very difficult thing of finding terrestrials.”

The final priority he and his colleagues cite is measuring the properties of black holes—objects that have recently moved from the domain of theory to that of observation. Both star-sized black holes and the giant black holes at the centers of some galaxies trigger bursts of x-rays and gamma radiation as they suck in material. Bunner says the recommendation that NASA focus on the study of these objects supports the need for the Gamma-Ray Large Area Space Telescope and the High Throughput X-ray Spectroscopy Mission, two proposed midsize projects.

The astronomy community hasn’t had a chance to react yet to the NRC committee’s assessment of its field. But Bunner says, “We’re pleased with the process—it wasn’t cantankerous and it achieved consensus.” Whether these science recommendations will guide NRC’s next decade report is not clear. “The decade process, once started, has a life of its own,” says John Bahcall of the Institute for Advanced Study in Princeton, New Jersey, who was chair of the previous decade report. But Thaddeus is hopeful: “I suppose the next decade committee could throw this in the wastebasket. But in a well-ordered world, this would be grist for their mill.”

—Ann Finkbeiner

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