

Heart Versus Head

Autism and breast-cancer advocates are getting Congress to carve out money for their causes. Critics say it's a bad way to set priorities. By Margot Sanger-Katz



Single-disease lobbying:
Is breast cancer more important than lung cancer?

The autism activists weren't going to let anyone stop them. For months, they had pushed lawmakers to provide about \$231 million a year for research into the disease. When they thought House Majority Leader Eric Cantor, R-Va., was dragging his feet, they ran a radio ad in his district warning that “our congressman, Eric Cantor, has held the autism law in his hands.” When Sen. Tom Coburn, R-Okla., argued that the bill amounted to a special-interest earmark, they unleashed a barrage of last-minute lobbying and rolled right over him. Coburn backed down, and Congress passed the authorization this week.

But on this issue, Coburn had a point. His objections were not about autism research specifically but about a larger concern: that single-disease legislation, decided largely on the basis of which groups lobby the loudest, is not the best way to set priorities for medical research. Autism funding, as Coburn sees it, is just another earmark that circumvents processes for evaluating programs on their merit.

“What we are opposed to is tying the hands of the researchers and the directors at [the National Institutes of Health] and telling them what they should do and how they should do it,” Coburn said on the floor of the Senate last week.

Coburn, a physician, has been fighting these battles for years, even opposing carve-outs of money for Lou Gehrig's disease. On

its face, such opposition seems heartless, effectively saying no to people with devastating health problems. But every disease has a face. And while congressional action has led to important shifts in priorities—recall the expansion of the National Cancer Institute in the 1970s or dedicated funding for AIDS research in the 1980s—it has also led to some wildly distorted funding decisions.

Lung cancer is the nation's biggest cancer killer, but it gets less than one-third as much research money as breast cancer in part because breast cancer has well-organized and well-connected advocacy groups like the Susan G. Komen for the Cure. Equally important, lung cancer carries a political onus: People falsely assume that all lung-cancer victims are to blame for their illness because they smoked. “It is a very stigmatized disease, and we have very few survivors,” said Laurie Fenton-Ambrose, the president and CEO of the Lung Cancer Alliance. “So there have not been a lot of voices.”

At the Centers for Disease Control and Prevention, the priorities are even more dictated by Congress, because nearly all the agency's budget is tied up in line-item programs to fund research and tracking of specific diseases. President Obama's recent budget proposal asked Congress to combine several related programs into a “consolidated” chronic-disease program, but that was stymied when advocates fought to preserve the current siloed approach. So CDC often

scrambles to find dollars when a disease like mumps breaks out unexpectedly. Dr. Thomas Frieden, the CDC's director, has only about one-tenth of the discretionary budget that he had when he was director of New York City's health department.

Advocates for the current system argue that line items for individual disease research are one of the few ways they can monitor spending from year to year. They also say it keeps Congress invested in funding medical research, because it's harder to cut funding for AIDS or colon cancer than it is to make across-the-board trims to overall budgets.

New programs are often the easiest way to add to NIH or CDC budgets, and traditionally the government has used these programs to shift resources toward new health threats that otherwise might not have attracted research attention. Overall, research funding on autism was only around \$5 million in 1995, when the advocacy groups started organizing.

But reliance on legislative earmarks has also created something of an arms race among disease advocates, who feel that the only way to get noticed is to find a legislator with a personal connection to their disease who will champion their cause. Groups with quieter voices can end up shortchanged.

Last week, leaders of the Hydrocephalus Association came to the Hill to meet with lawmakers. Hydrocephalus, in which damaging fluid builds up around the brain, affects about 1 million people, and there have been no major breakthroughs in treatment for 50 years. For years, the association focused on providing support to patients and families, but the group is raising its Washington presence by moving its office here and hiring a full-time director. “The system relies on people getting organized and making their case to the powers that be,” said Rick Smith, the group's acting chief executive.

Coburn relented on the autism bill, saying that because it was reauthorizing an existing program, he was more concerned with eliminating fraud in its budget than stopping it in its tracks. But he promises that “there's not going to be a new disease-specific bill that goes through Congress while I'm here.”

“Nobody's against trying to solve all the problems,” Coburn told *National Journal*. But singling out diseases for special funding “means somebody else is not going to live because we've directed it to one place and not somewhere else.” ■