

# Lung Cancer: Why Doesn't It Get the Respect Its Gargantuan Toll Demands?

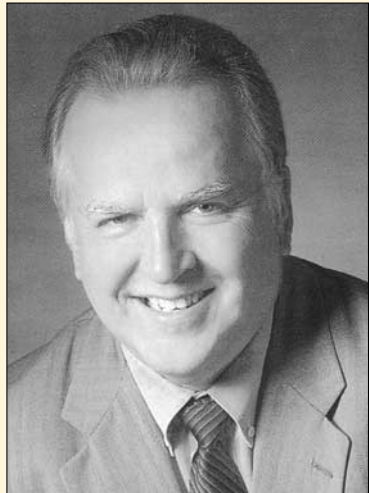
By Andrew Holtz

**W**here are all the lung cancer races and ribbons? And why does the nation's research investment in lung cancer lag behind other cancers?

The relative silence enveloping lung cancer seems to stem from a mix of disease characteristics, discouraging treatment outcomes, and a tendency to blame patients for their illness. Put it all together and it's clear that lung cancer doesn't get the respect its gargantuan toll would seem to demand.

Although lung cancer is the leading cancer killer of both men and women in the United States, that fact appears to be a relatively well-kept secret.

In a recent national survey by the American Legacy Foundation, a national public health organization committed to promoting tobacco-free environments, especially for future generations, most respondents, even most smokers, said they believed women are more likely to die of breast cancer than lung cancer. Three out of four respondents were unaware that lung cancer is the leading cancer killer of women.



**John C. Ruckdeschel, MD, says that he and others have to fight an enervating sense of futility that interferes with appropriate and comprehensive treatment for lung cancer patients.**

which treatment advances in other tumors have been measured.

"It was constantly used as the negative example. I think it distorted the views of a whole generation or

two of oncologists," says John C. Ruckdeschel, MD, President of the Barbara Ann Karmanos Cancer Institute.

## Allocation of Cancer Research Money Doesn't Match Incidence & Mortality Rates

The nation's allocation of lung cancer research money does not match up with the incidence and mortality rates. A 2001 report to the National Cancer Institute co-chaired by Dr. Ruckdeschel noted, "We have funded lung cancer research far below the levels that characterize other common malignancies and far out of proportion to its massive public health impact."

Indeed, based on the most recent reports, the NCI budget includes more than twice as much funding for breast cancer items as it does for lung cancer projects.

Dividing those budget totals by the number of cases of each cancer reveals that the NCI allocates less than half as much money per lung cancer patient as it does for each breast cancer patient. But since lung cancer is far more deadly, the amount allocated per lung cancer death is less than one eighth as much as the NCI spends per death due to breast cancer. (See box on page 22.)

## No Comment from NCI

Despite repeated requests, the NCI declined to respond to questions about research funding priorities.

By e-mail, an NCI spokeswoman listed public documents available on NCI budget policy, which, she wrote, "explain the complex interplay of factors behind funding levels. Again, we cannot comment on these because no one person can legitimately recall/narrate why one particular cancer was funded a particular way."

She acknowledged that as a federal agency, NCI is affected by the decisions of elected officials, who are influenced by politics.

In addition to the NCI budget, Congress earmarks part of the defense budget for medical research. The 2003 fiscal year appropriation included \$150 million for breast cancer and \$87 million for prostate cancer research. There are also special programs and budgets for ovarian cancer, neurofibromatosis, and chronic myelogenous leukemia.

However, the most recent annual report of the Department of Defense Congressionally Directed Medical Research Programs lists lung cancer only under "Other Programs" with a single \$24 million appropriation spread out over four years.

## Research Budgeting Isn't 'Paint-By-Numbers'

Of course, setting medical research budgets isn't a paint-by-numbers exercise in which spending levels are locked to incidence and mortality statistics.

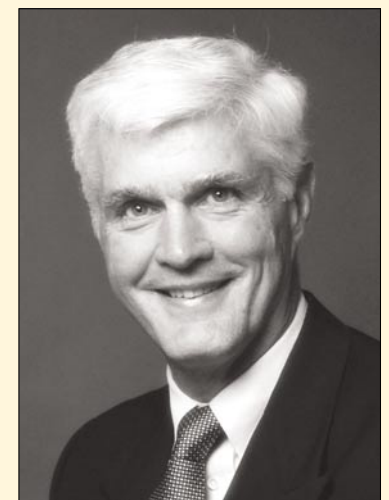
As an NCI document puts it, "The NCI's cancer research funding strategy is to enable scientists to pursue the research areas with the *greatest scientific opportunity* (italics in the original)—that is, the greatest opportunity to increase our knowledge of cancer."

So do the smaller funding numbers mean that lung cancer research offers less scientific opportunity? Not according to long-time lung cancer expert

*NCI Report: "We have funded lung cancer research far below the levels that characterize other common malignancies and far out of proportion to its massive public health impact."*

Paul A. Bunn, Jr., MD. "I think the scientific opportunities are as large in lung cancer as they are in other areas," he says.

Dr. Bunn, a member of OT's Editorial Board, is Director of the University of Colorado Cancer Center, Immediate Past President of the American Society of Clinical Oncology, and was recently selected as the Executive Director of the International Association for the Study of Lung Cancer.



**Lung cancer researcher and advocate Paul A. Bunn, Jr., MD, notes that the National Cancer Advisory Board, which advises the Secretary of Health and Human Services and the NCI Director, includes members who specialize in breast, urologic, and gynecologic cancer, but not a single member who has a career focused on lung cancer.**

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cancer, but not a single member who has a career focused on lung cancer.

Dr. Bunn says his lung cancer colleagues are eager to confront the disease with a research and treatment effort that is in line with the size of the health threat. "If you look at many of

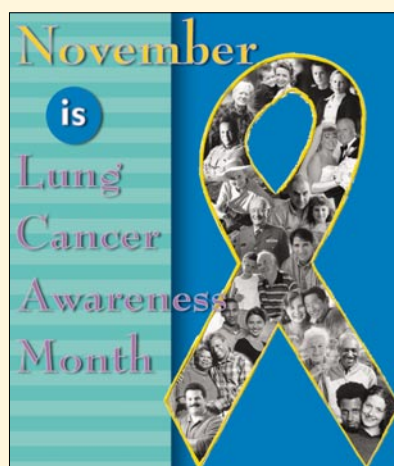
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*Politics and advocacy are central to understanding the relatively low status of lung cancer.*

Even physicians tend to turn away from lung cancer. With survival rates far below those of most common cancers, lung cancer has been used as a yardstick of failure against

## On the Cover:

This is part of a poster for this month from ALCASE, the Alliance for Lung Cancer Advocacy, Support, and Education ([www.alcase.org](http://www.alcase.org), 500 W. 8th St., Suite 240, Vancouver, WA 98660, 800-298-2436). "The poster celebrates hope," notes Janet M. Healy, Senior Program Manager, "and makes the point that no one deserves lung cancer."



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the leadership positions in ASCO, many of the symposia that ASCO is having, or the attention from oncologists, it is proportional. I think the only problems attracting people in the field are related to the funding issues."

Since lung cancer takes such a heavy toll, even modest advances in treatment could prolong many lives, notes Margaret R. Spitz, MD, MPH, who along with Dr. Ruckdeschel, co-chaired the 2001 Lung Cancer Progress Review Group (PRG) that called for more respect for lung cancer research, detection, and treatment (see box on page 27).

"If you were able to prevent just 10% of all lung cancer deaths, it would be equivalent to preventing all deaths from, say, glioma or ovarian cancer; so

*"It is a sobering reality that tobacco control will ameliorate but not, in the foreseeable future, eliminate the problem of lung cancer."*

you'd have a major impact, said Dr. Spitz, Professor and Chair of the Department of Epidemiology at the University of Texas M. D. Anderson Cancer Center.

"We are talking about huge numbers. The public health impact of lung cancer is enormous."

Carolyn Aldigé, President and founder of the Cancer Research and Prevention Foundation, says, "There's a

lot of promising stuff out there, but there just isn't the funding; and there isn't the funding because there aren't enough people asking for it."

### Roots & Accomplishments of Cancer Patient Activist Groups

Politics and advocacy are central to understanding the relatively low status of lung cancer.

At Winthrop University in Rock Hill, SC, just across the border from Charlotte, NC, Political Science Chair Karen Kedrowski, PhD, and Communications Professor Marilyn Sarow, MA have been researching the roots and accomplishments of cancer patient activist groups.

"We've found a copious amount of literature written by medical doctors, biomedical researchers, and so forth. And frankly, I've found that their stats are fine when it comes to looking at

some of the numbers, but they really don't understand the political process very well. They seem appalled that politics becomes involved in health at all," Dr. Kedrowski said in an interview.

"The first thing medical doctors need to realize is that these are going to be political decisions, and that our political system is, by design, set up to be responsive to organized interests and organized voices. And this is something that has been both criticized and glorified in political science. I'm squarely on the fence on that one. This is a political system that responds well to squeaky wheels."

The fact is that, compared with other common cancers, squeaky wheels for lung cancer are in short supply.

During 2003, an estimated 1.5 million people are expected to participate in more than 100 breast cancer Race for the Cure events of the Susan G. Komen  
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## Lessons from Breast Cancer Advocacy

**A**dvocates for greater investment in lung cancer research and treatment look on with envy at the record of breast cancer activists.

Advocacy researchers Karen Kedrowski, PhD, and Marilyn Sarow, MA, point out that during the 1990s breast cancer funding increased dramatically, not only in terms of actual dollars, but also as a percentage of the NCI budget.

According to NCI documents, the agency allocated \$81 million to breast cancer programs during the 1990 fiscal year. Just five years later, the NCI's breast cancer budget had rocketed up, nearly quadrupling to almost \$309 million.

Of course, the 1990s was a growth period for most NIH agencies, but the lung cancer budget lagged behind, not even doubling from \$65 million in 1990 to almost \$114 million in 1995. For the 2003 fiscal year, the breast cancer budget was \$564 million, while the lung cancer budget was \$256 million.

What's more, breast cancer activists also succeeded in earmarking a chunk of the Defense Department Budget.

The DOD's Breast Cancer Research Program was established in the 1992 fiscal year. The total appropriation through the 2003 fiscal year was more than \$1.5 billion. The 2004 budget that President Bush recently signed includes \$150 million for breast cancer programs.

Frances Visco, President of the National Breast Cancer Coalition (NBCC), says her group tenaciously pursued a sophisticated political strategy to advance the interests of its members.

"When we were formed in 1991, we were formed specifically to focus on the political advocacy, focusing on

increasing federal funding for breast cancer research—that was our very first goal," she said.

### Raising Awareness Wasn't the Goal

While public awareness of breast cancer also has risen since the 1980s, raising awareness wasn't part of the NBCC game plan.

"We didn't have the public awareness when we had our political successes in the beginning," Ms. Visco explained. "There weren't all these races and runs. It wasn't like that in 1991 and 1992, and that's when we really first significantly increased federal funding for breast cancer research. That's when we brought together hundreds of organizations from around the country to form the Coalition."

Indeed, she says that awareness isn't always an advantage for a political strategy. "It's nice, and it makes you feel good, but the issues that we've been fighting for in the political arena are very difficult and complex and they are not the kind of thing that Congress just gets behind because there are a lot of people walking the streets about a disease. A lot of the issues that we take on are very controversial. Increasing federal funding for breast cancer research back in 1991 was incredibly controversial. We had a lot of opposition, and it was difficult."

### Misdirected Advocacy

While passionate support can be useful, it may have side effects. Ms. Visco says the demands for treatment using bone marrow transplants as part of high-dose treatment for advanced breast cancer, demands that hit a fevered pitch before large clinical trials were conducted, and calls for tests



**Fran Visco of the National Breast Cancer Coalition: "You can't just sound-bite the disease. What we did, that I think made us incredibly successful, was that we looked at the issues, we began to understand the complexity of the disease, planned a strategy that addressed our issues, identified and learned about our constituents, and brought them in. It was the women and their families and friends who did all the work and brought this movement forward."**

or exams that may not be grounded in solid science, are examples of how advocacy can be misdirected.

"Yes, there were women suing and getting laws passed in states to cover bone marrow transplants outside of clinical trials," she said. "That was the wrong thing to do. But a lot of it was fueled by the oncology community and the fact that there is this incredible infrastructure in place. There's a lot of money in bone marrow transplants. A lot of people's careers were devoted to bone marrow transplant.

"We're in the same situation when you look at the screening issue—breast self-exams, and so on. They've become a cottage industry unto themselves, without any scientific evidence that they save lives. Not all advocacy is good advocacy."

### No Template

Ms. Visco argues that the successful strategies of breast cancer advocacy cannot be used as a ready-made template for other diseases, and that it is not easy to explain why breast cancer activists have made so much more progress than advocates for other causes, including lung cancer.

"I've had this conversation with so many different people who ask me about so many different diseases. Every situation is different, and it doesn't help to point a finger and say, 'This is why they are successful,'" she said.

Still, Ms. Visco does have general words of advice: "Just look at what you need to do to achieve your own goals. Plan your own strategy. You can't just sound-bite the disease. What we did, that I think made us incredibly successful, was that we looked at the issues, we began to understand the complexity of the disease, we planned a strategy that addressed our issues, we identified our constituents, we learned about and understood what was important to that constituency, and we brought them in. It was the women and their families and friends that did all the work and brought this movement forward.

"There's no magic to it," she emphasizes. "There's a lot of very, very hard work, taking on very controversial issues, getting slammed about them over and over again, but never losing your focus."

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Breast Cancer Foundation, flooding streets, newspapers, and TV newscasts with a sea of pink. There is nothing comparable related to lung cancer.

Dr. Ruckdeschel has seen the disparity first-hand. "In my role as a center director and formerly as President of the American Cancer Society for the state of Florida, I went to a lot of patient and advocate events. I would ask, 'How many people here are lung cancer survivors?' There'd be one or two, compared with thousands of breast and prostate and colon survivors."

Two key characteristics of lung cancer help explain the lack of activism by lung cancer patients, friends and families: death and stigma.

*The most recent annual report of the Department of Defense Congressionally Directed Medical Research Programs lists lung cancer only under "Other Programs" with a single \$24 million appropriation spread out over four years.*

### 'Damn Difficult Disease'

"Part of the problem is that our patient group has tended to do so poorly that we don't have a big survivor advocate group out there," Dr. Ruckdeschel said. "It is just a damn difficult disease."

"On any given day, if I'm seeing five or six follow-up patients in the office, at least one or two of them are

## Reforming Perceptions & Media Depictions

Professor Marilyn Sarow and Dr. Karen Kedrowski of Winthrop University say that part of improving the climate for congressional appropriations involves reforming the public perceptions and media depictions of cancer.

They have studied what they term the "public face" of cancer—that is, the typical profile of patients as depicted in the media. While the common image of a lung cancer patient is an older smoker, the average "public face" of breast cancer in the news stories they reviewed was a woman in her 40s, much younger than the average breast cancer patient.

The researchers suggest that

going to recur that day."

According to the NCI's Surveillance, Epidemiology, and End Results (SEER) program, the five-year relative survival rate for patients diagnosed with breast cancer is 87.9%.

Almost all prostate cancer patients (98.4%) are still alive five years later. But less than one of every seven lung cancer patients (15.1%) lives to see the fifth anniversary of his or her diagnosis.

Dr. Ruckdeschel says physicians and surgeons often develop a "therapeutic nihilism" toward lung cancer that obscures even the occasional successes. He points out that lung cancer survival rates in the US, although low, are more than twice the rates in Britain or Ireland.

Still, he says he and others have to fight an enervating sense of futility that interferes with appropriate and comprehensive treatment for lung cancer patients.

The dismal lung cancer survival rates make Dr. Kedrowski doubtful of the ability of lung cancer groups to assemble the cadres of organized patient activists upon which effective advocacy efforts are built.

"It has worked for breast cancer and prostate cancer—fabulously well—for two reasons: one, they are both incredibly common diseases; and two, the women and men who develop these diseases have high survival rates," she said.

"So we've argued that it cannot happen in other kinds of diseases—either ones that are very rare, whether

physicians should take an active role in countering commonly held, but skewed, perceptions, not only with their patients, but also with politicians and policy makers.

"All of these factors that distort the public's perceptions will also distort the perceptions of lay people who are in decision-making positions," Dr. Kedrowski said.

"That's why it's all the more important that oncologists and other people who have a more sophisticated understanding of things like issues of risk and the potential for medical discoveries and treatment advances and so forth need to organize and be willing to 'speak truth to power.'"

## NCI Research Funding Budget

Cancer Site	2002 Spending (actual, in millions)	2003 Spending (estimated, in millions)	Estimated Cases (2003)	\$/Case	Estimated Deaths (2003)	\$/Death
Breast	\$522.6	\$564.6	212,600	\$2,656	40,200	\$14,045
Prostate	\$278.4	\$311.0	220,900	\$1,408	28,900	\$10,761
Colorectal	\$245.0	\$267.0	147,500	\$1,810	57,100	\$4,676
Lung	\$237.5	\$256.6	171,900	\$1,493	157,200	\$1,632

Sources: NCI, 2003, [http://cis.nci.nih.gov/fact/1\\_1.htm](http://cis.nci.nih.gov/fact/1_1.htm); and American Cancer Society, *Cancer Statistics 2003*

they are long-lived or not, because there are not going to be huge numbers of activists who can swarm Capitol Hill and meet with all these people and talk about it to address their particular disease. It also will not happen for diseases that are very common, but also incredibly deadly, like lung cancer."

### Lobbying

Sheila Ross hopes to disprove that prediction. As a two-time lung cancer survivor, she's already used to defying the odds. "Stage I in 1992. Stage II in 2000. I don't have that much time. That's why I'm very blunt with everyone I talk to," she says.

She lobbies on behalf of the Alliance for Lung Cancer Advocacy, Support and Education (ALCASE) to rally political support for increased spending on lung cancer programs.

Although she's determined to make progress, Ms. Ross says she's been grimly reminded of the poor lung cancer survival statistics since she began her lobbying effort with ALCASE last winter.

"Politically, it's very hard to get it off the ground. I can't tell you how many people I've been excited to work with on some of these projects who have already died just since December. It breaks my heart," Ms. Ross says.

For instance, one of her allies, who was a chief of staff in the US House of Representatives, now has metastases from her lung cancer. "She's fighting to the end. She is still going up to the Hill at least once a week and talking to people."

Ms. Ross also is a veteran Capitol Hill staffer. She says her message that lung cancer deserves more respect is getting attention. "Without exception, I am finding that people are completely unaware of the statistics on lung cancer. And they usually say, 'Why didn't I know that?'"

In a way, being an underdog has worked to her advantage, she says. "The overkill by the 'Big Three' has also made staff in the House and Senate more sympathetic to the cancers that are being ignored."

Still, she knows that getting a few light bulbs of awareness to pop on won't instantly bring substantial new funding to lung cancer programs.

"It's really not the numbers that are setting public health policy; it's politics that set public health policy. And until and unless lung cancer makes itself more of a force politically, I don't think you're going to see a change in attitudes among the health organizations."

### Some Successes

Ms. Ross says she has had some successes. For example, there is language in a committee report for the 2004 budget urging the Department of Defense to work with the Veterans Administration on a lung cancer screening program.



**Carolyn Aldigé says that the smoking-related stigma can even affect the quality of treatment offered to patients.**

Also, the FDA is instructed to develop a plan to speed the development of cancer chemoprevention agents.

At the ALCASE headquarters in Vancouver, Washington, founder Margaret McCarthy says the group, which bills itself as the only national lung cancer advocacy group, has struggled to grow beyond a nucleus of people who offer information, referrals, and support to lung cancer patients and their families.

"All of the programs that ALCASE has always done have continued, but the organization hasn't really blossomed. I think now is the time it's really going to take off again," Ms. McCarthy said.

"One of the things we are doing is trying to follow the National Breast Cancer Coalition model of having

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advocates in every state to both raise money and to educate the public about lung cancer." (see box on page 19)

In part because lung cancer survivors are in short supply, another advocacy effort, the three-year-old Global Lung Cancer Coalition, makes a point of including lung cancer experts

and others who can speak on behalf of patients.

"The nice thing about the Coalition is that it is comprised of pulmonologists, oncologists, psychologists, communications people, and patient-oriented groups; so it's a very broad spectrum," says Dierdre Freiheit, President of the Canadian Lung Association.

"One aim of the coalition is to destigmatize lung cancer. What we are saying as a coalition is that nobody deserves to die from lung cancer."

### Up in Smoke

Any discussion of lung cancer eventually confronts a fogbank of tobacco smoke. For many people, the discussion ends there. Rather than being a motivating event to fight the disease or rally support for research, a diagnosis of lung cancer is frequently seen as an indictment of the patient.

Ms. McCarthy says smoking's clench on the public perception of lung cancer discourages both political and corporate support for lung cancer projects. Families resent the patient, rather than the disease.

Even patients turn their anger inward. Ms. McCarthy has heard the story many times, relating two recent phone calls: "One was a woman who called who had just been diagnosed with lung cancer. She was hysterical.

## Calls from Drug Companies

Some pharmaceutical companies are joining the calls of physicians and patients for spending more on lung cancer research and treatment.

Lucie Kutikova, PhD, at Eli Lilly and Company says economic analyses performed by her and her colleagues indicate the nation is paying a huge price for failing to cure most cases of lung cancer.

"The burden is enormous," Dr. Kutikova said. "The cost of failure is not only the potential risk to your survival, but society is going to make a much more concerted effort

to try to bring you around."

The company's calculations indicate that initial rounds of lung cancer treatment tend to cost about \$11,000 per month per patient. But if that treatment fails, then subsequent treatments are almost twice as expensive—about \$20,000 per month.

Looking at the economic cost of treatment failure in this way, she said, may justify spending more on newer first-line therapies, even if they are more costly than standard treatments.

She had just walked out of the physician's office and stopped at a pay phone. She said, 'My family has been trying to get me to quit smoking for years. There is no way I can tell them I have lung cancer; that I have Stage IV disease.

"Another woman said, 'I've just been to the doctor's with my husband and he's been diagnosed with lung cancer. He's a smoker and I've been trying to get him to quit, and now I'm supposed to take care of the SOB. He just retired, and we were supposed to have fun. Now I'm saddled with this guy

who's going to be dying and he caused it himself."

Carolyn Aldigé says that not only is the smoky stigma a fundamental reason lung cancer does not get the attention given other cancers but that it can even affect the quality of treatment offered to patients.

"People don't want to talk about having lung cancer because there is such a "blame the victim" mentality, not just in this country, but globally," she said. "Lung cancer patients should be given access to the best available treatments; they should be referred to the proper specialists. Quite often the referral patterns are just dismal. People think, 'you engaged in a dangerous habit, so you deserve what you get.'"

Fragmentation in the health care system can also interfere with cohesive and comprehensive treatment, Dr. Ruckdeschel notes.

"I still see things in the community, where a surgeon sees a patient and does an operation that is totally unindicated. It isn't going to help the patient one iota, but the surgeons says, 'I de-bulked it.'

## Lung Cancer Peer Review Group: Report is Harsh Assessment of Lack of Progress

Three years ago, the NCI convened a group of 30 clinicians, scientists, industry representatives, and consumer advocates to identify bottlenecks impeding research and treatment of lung cancer, and to propose solutions.

The August 2001 report of the Lung Cancer Progress Review Group (PRG) is a harsh assessment of the lack of progress against the leading cause of cancer death.

"If the disease itself were not malignant enough, we as scientists, clinicians, patients, and lay people have made the problem worse," the report states.

The report says progress against lung cancer is impeded by a "blame the victim" bias against smokers, "therapeutic nihilism" by clinicians who fail to effectively employ available treatments, poor coordination of health care services, disproportionately low funding for research and treatment compared with other cancers, and other problems.

Co-chair John C. Ruckdeschel, MD, says the NCI should reverse a policy decision made 15 years ago that disbanded the Lung Cancer Study Group and dispersed lung cancer research: "To do away with that group and then to say you could divvy these people up among the big

general oncology groups, and things would be fine, was a huge mistake.

"I continue to argue that that was a huge mistake, and so did most of the people in the PRG who felt that reorganizing around a disease-specific group was a much better way to tackle the problem of lung cancer. And unfortunately that's not been well addressed yet."

Opinions about the result of the PRG effort range from optimism to frustration. The group's co-chairs generally praise the process and say they are satisfied with the NCI's follow-up to their report.

The other co-chair, Margaret R. Spitz, MD, MPH, said, "We presented this [report] to the National Cancer Advisory Board. It was very well received. Since then there has been an implementation group meeting. I feel that NCI has been very responsive and is trying to implement several of these recommendations."

Dr. Ruckdeschel says the Progress Review Group process is excellent, though he acknowledges that NCI Director Andrew C. von Eschenbach, MD, will not have an easy time carrying out the lung cancer group's recommendations.

"He faces the same problems every other director does: availability

of resources, entrenched people, both within and without the NCI, who are vested in the current way we do things," Dr. Ruckdeschel said.

However, at least one prominent member of the group is dissatisfied with the follow-up. Paul A. Bunn, Jr., MD, Immediate Past President of ASCO, said, "That report has never seen the light of day or received much public attention."

He criticized the NCI for a lack of public response. "It makes you wonder why they called an advisory group together, if they don't act on it. It's sort of a waste of time. So the next time they call you, it makes you wonder about spending your time doing it," he said.

Despite repeated requests, the NCI declined to comment on the report of the Lung Cancer Progress Review Group. Some members of Congress also want to know what the NCI is doing to respond. Early this year, Representative C.W. Bill Young (R-Florida) submitted language into a conference report requesting that the NCI submit a report on the Lung Cancer PRG by June 30, 2003.

The NCI did not meet that deadline, and last month an NCI spokeswoman said the agency was still preparing its response.

*While the common image of a lung cancer patient is an older smoker, the average "public face" of breast cancer is a woman in her 40s, much younger than the average breast cancer patient.*

"That's nonsense. It's that review of the alternatives, prospectively, that is important. I think a lot of oncologists push for that, but have problems with some of their surgical colleagues."

He noted that the interrelationship of tobacco and lung cancer sparked lively debate within the Lung Cancer Progress Review Group between those who wanted to focus on prevention

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# Sweeping New NIH Research 'Roadmap' Will Enhance, Not Change, NCI's 2015 Mission

By Peggy Eastman

**W**ASHINGTON, DC—National Institutes of Health Director Elias A. Zerhouni, MD, recently announced a comprehensive NIH-wide strategy to accelerate translational research and turn new discoveries into new therapies more rapidly. That institute-wide strategy—known as the NIH Roadmap for Medical Research—will not change the ambitious 2015 mission of NCI Director Andrew von Eschenbach, MD.

*NCI has standardized its clinical trials patient consent form, which Dr. Zerhouni wants other institutes and academic centers to do.*

"As you know, we have an aggressive mission to eliminate suffering and death from cancer by 2015; we need to stay mission-oriented," Dr. von Eschenbach said at a National Press Club news briefing here on NIH's new strategy.

But, he added, the new NIH roadmap—with its emphasis on collaboration among scientists in different disciplines, public/private partnerships, and a re-engineering of clinical research, among other initiatives—should allow NCI to accomplish its ambitious 2015 goal more effectively.

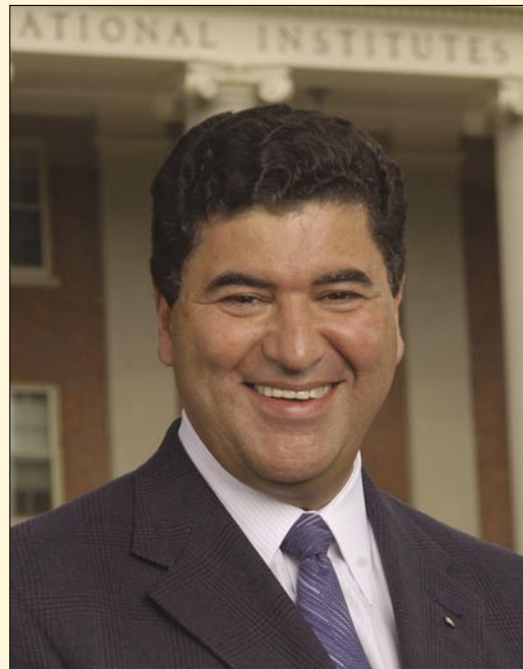
In fact, NCI already has many working collaborations of the kind envisioned by Dr. Zerhouni for all of NIH.

## NCI: Different Position from Other NIH Institutes

Because of its Congressional mandate to conquer cancer—the National Cancer Act of 1971—NCI is in a somewhat different position from the other NIH institutes.

For example, the act mandates that NCI prepare a budget request for supporting the US cancer research enterprise (about \$5.7 billion in 2003) and send it directly to the sitting US President so that he can formulate his budget request to Congress.

NIH's new research strategy—which has been in the planning process for a year—"will transform the way all NIH research is done," Dr. Zerhouni emphasized at the news briefing.



**In summing up the sweeping new NIH research strategy, NIH Director Elias A. Zerhouni, MD, said he knows full well that "We're going into roads untraveled" and that "There's no guarantee of success." But, he said, after the past year of intensive study, working-group meetings, and talk, "This is something we at NIH thought should be done."**

## 'Not Business as Usual'

"This is truly not business as usual...We're just basically turbocharging NIH. Our goal is to bring our best research to people's homes."

Dr. Zerhouni added, "There is no great organization that remains great without change." He said the main goal of the new plan is to "synergize research efforts across NIH."

In the future, he said, clinical research will no longer be done in a "linear fashion," but rather will benefit from the efforts of scientists from many different specialties at different NIH institutes, in academia, and in industry working together on the same research problem.

Dr. Zerhouni said the NIH research redesign will cost an estimated \$130 million in the first year, with a projected cumulative

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through tobacco control and others who felt detection and treatment deserved more prominence.

While it is true that tobacco is the root cause of most cases of lung cancer, he argues that tobacco control is only part of the answer.

"I think there are many people in the tobacco arena who have blinders on and forget that there are 30 to 40 million former smokers," Dr. Ruckdeschel said.

He and others note that at least half of all people newly diagnosed with lung cancer are former smokers. These patients are success stories of tobacco control, but smoking cessation didn't prevent their cancers. As the Review Group report put it: "[I]t is a sobering reality that tobacco control will ameliorate but not, in the foreseeable future, eliminate the problem of lung cancer."

Danny McGoldrick, Director of Research at the National Center for Tobacco-Free Kids, doesn't see a conflict between improving lung cancer treatment and maintaining a strong campaign against tobacco.

"People do in fact hold smokers responsible for their own behavior; but what we have found is that does not at

all undercut their support for policies and programs to help these people," he said.

Polls done by the center indicate that the public doesn't consider it an "either/or" question—that is, there is support for both anti-tobacco efforts and more lung cancer research and treatment.

"One can safely say that there is broad support for spending tobacco revenue on tobacco-related research, including the health effects of tobacco, research on disease treatment, and research on prevention or cessation," Mr. McGoldrick said.

"It's not so much the public's attitudes about it, we have a very entrenched and very powerful interest

that has worked for decades to stop action on reducing tobacco use."

Nevertheless, ALCASE lobbyist Sheila Ross says that tobacco smoke often obscures the needs of lung cancer patients: "I am not trying to mitigate the guilt of 'Big Tobacco' in all this and the very sad role of tobacco addiction, but the fact remains that our public health agencies are ignoring a massive public health problem, and escaping their responsibility for addressing it, by blaming it all on tobacco. I find it outrageous."

## Inertial Funding

Even as advocates lay out their case that the leading cause of cancer death should not lag behind other cancers in terms of public awareness or research investment, they acknowledge that re-ordering federal budget priorities is a slow and difficult process.

Dr. Kedrowski says the first step is the hardest: "One of the best predictors of what will be spent this year is what was spent last year. So if you are able to move rapidly from a small amount to a large amount, sustaining the large amount is going to be easier than making that initial jump."


Ms. Sarow says that research investments can fuel attention that then promotes greater investments: "Once

work on a disease is funded by federal agencies to a greater extent, there is a kind of self-perpetuating. More research leads to more findings, and more findings lead to more media coverage, etc. etc. Congressmen start reading what's happening," thus helping them to justify further appropriations.

## Rising Respect?

Lung cancer activists look forward to the day when the leading cause of cancer death gets more respect, both in order to rally efforts to knock the disease off its perch and to improve care for patients.

They point to AIDS as an example of a disease that overcame both stigma and poor outcomes. They believe lung cancer could see a similar turnaround in attitudes and medical advances someday. "I absolutely do, though I don't know when the tipping point is going to come," Ms. Aldigé said.

She was on the program at this summer's 10th World Conference on Lung Cancer, along with Ms. Freiheit, who also saw signs of progress at the meeting. "What's nice about this conference," she said, "is that while it's the 10th World Conference on Lung Cancer, it's the first time they've allowed a patient group to come and speak to the patient side of the disease." 

## Promise of New Technology

**S**everal activists place hope in the promise of new technology. For example, ALCASE'S Margaret McCarthy said, if trials indicate that spiral CT and earlier treatment reduce lung cancer mortality, then the pessimism that surrounds lung cancer could ease.