

# TRENDS IN CANCER RESEARCH

Fifth part of a five-part series

## Financing the fight

Foundations are at ground zero in the battle against cancer

BY DAVID HUTTON

**S**CIENTIFICALLY DEFINED, cancer is a class of diseases in which a cell or group of cells display uncontrolled growth, invasion and sometimes metastasis. For decades, researchers have been working diligently to come up with new ways to target the disease. It is a never-ending effort with plenty of opportunity with new discovery always looming over the horizon.

It's also an area of research with plenty of need.

According to the National Cancer Institute, 1.5 million people will be diagnosed with cancer this year, and an estimated 500,000 people will die of cancer this year. The toll is astounding, emotionally and financially, and is a challenge that researchers are working hard to overcome.

Cancer researchers work endlessly to understand disease processes and discover possible therapies. The results of these efforts often offer a lifeline of hope for people stricken with this insidious disease. The improved understanding of molecular biology and cellular biology due to cancer research has led to a number of new, effective treatments for cancer since President Richard M. Nixon declared "War on Cancer" in 1971. Since that time, the United States has invested more than \$200 billion on cancer research. That total includes money invested by public and private sectors and foundations.

The shadow that cancer casts over the research landscape might best be exemplified in the number of foundations that exist to generate funding for continued research efforts for cancers of every form, from lung and breast to childhood forms of the disease.

In the fight against cancer, there are several fronts, and foundations are serving a key role in saving lives through prevention, education, research advocacy and support.

Among the myriad aims of foundations,

they create awareness about the disease and research new and better treatments for a cure.

Of course, all of this comes at a cost.

In this, the fifth and final installment of our Trends in Cancer Research series, we will examine foundation funding by examining what some groups are doing today and the challenges they face financially.

### Under-funded, under-researched

The Lung Cancer Foundation of America (LCFA) finds itself at the epicenter of the fight against cancer. Worldwide, lung cancer is the most common cancer. It is the leading cause of cancer deaths in the United States, Canada and the United Kingdom. In 2010, in the United States an estimated 222,520 people (116,750 men and 105,770 women) will be diagnosed with lung cancer. It also has a disheartening 15 percent, five-year survival rate, which has remained somewhat stagnant for the past 40 years. In spite of these dismal statistics, lung cancer remains the most under-funded and under-researched cancer, notwithstanding its nationwide and worldwide health impact.

"There is a tremendous stigma attached to lung cancer—because of the association between smoking and lung cancer, there is a sense that people with lung cancer brought the disease upon themselves," says Kim Norris, president of the LCFA. "Most people don't know that smoking is but one in a long list of



About 90 percent of the research funding that the Fred Hutchinson Cancer Research Center received this year—nearly \$324 million in research grants and contracts—came from federal sources.

behavioral, environmental and genetic risk factors that influence who will be diagnosed with lung cancer."

According to Norris, in 2008, \$1,249 in federal research funds was spent per lung cancer death. By contrast, \$6,590 was spent for colon cancer, \$14,336 for prostate cancer and \$27,480 for breast cancer.

In 2009, the total research funding for lung cancer from the NIH, CDC and DoD combined was \$199 million. By comparison, the total research funding from these federal institutions was (in millions) \$1,103.85 for breast cancer, \$392.24 for prostate cancer and \$328.97 for colon. In terms of the private sector, in 2008—the year with the most complete information available to date—only \$4.6 million total was disbursed for lung cancer research into early detection, treatment options and a cure.

In 2009 alone, the Susan G. Komen Foundation, which is just one of approximately 132 breast cancer research foundations in the United States, disbursed \$60 million to

back research that helps treat those coping with breast cancer today and rid future generations of the disease. Moreover, 95 percent of research funding for lung cancer is from the public sector—and public sector research funding is going down.

Michael D. Gingerich is executive director of the Foundation for Cancer Research & Wellness (FCRW), which is in its first year of incorporation.

"Many of our program services existed for 25 years under Cancer Recovery Foundation (CRF)," Gingerich explains. "But a research component was not part of the mission or services for CRF. With the advent of FCRW, as a new initiative under the Cancer Recovery Foundation Group of Charities, in January 2010, a research effort became a new and important part of our focus."

During the course of its first year, the FCRW has specifically and primarily focused upon developing a qualitative research study in

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**"PUBLICLY, WOULDN'T IT MAKE MORE SENSE** to create some kind of equation that correlates funding to incident rate and mortality? Lung cancer is the biggest cancer killer for men and women in the U.S., but it remains the least-funded," says Kim Norris, president of the Lung Cancer Foundation of America. Norris says that despite lung cancer's high mortality rate, it remains the most under-funded and under-researched segment of oncology research, "because of the association between smoking and lung cancer, there is a sense that people with lung cancer brought the disease upon themselves."

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partnership with the Pennsylvania State University College of Medicine.

"The focus is on patient/physician communications and interaction in regard to people living with cancer," Gingerich says. "We have spent this year determining the focus and identifying patient narratives in which to gain an analysis of the issues that affect the quality of patient care."

Gingerich points out that no money has been given to either FCRW or the PSU College of Medicine for this project.

"Internal budgetary dollars have funded the development and initial phases of this project," he says. "But FCRW has identified a few dozen other foundations and non-profits that fund such research efforts and is applying to them for grant aid. PSU, it is hoped, will be applying for NIH funding in 2011."

When it comes to dollar amounts for the funding being sought, Gingerich says the amounts hoped for range from tens of thousands of dollars, hundreds of thousands of dollars to \$1 million or more.

### Government intervention

Herb Bone, controller of the finance department at the Fred Hutchinson Cancer Research Center, says the majority of the funding for research received at the Hutchinson Center comes from the government.

"About 90 percent of the research funding received in FY 2010 came from federal sources," he says. "In FY 2010, the center received research grants and contracts from all sources of \$323,819,000."

Of course, in the current economic landscape, even funding for cancer research can feel the pinch of turbulent economic times. Gingerich points out that funding of all sorts is harder to obtain in this current economy.

"There have been numerous private grant opportunities available for projects of our kind," he says. "Time will tell, as our proposals have just recently been submitted, to learn if we are approved for funding."

Gingerich points out that the recent changes in Congress and the need to consider cuts in spending will determine how much the government has to offer.

"But the economic climate has made obtaining funding much harder as foundations and the federal government have had increasingly more requests for increasingly fewer dollars available," he says.

For Norris, funding is a source of concern, with DoD funding for lung cancer falling.

"Publicly, wouldn't it make more sense to create some kind of equation that correlates funding to incident rate and mortality?" she asks. "Lung cancer is the biggest cancer killer for men and women in the U.S., but it remains the least-funded. While breast and prostate cancer do have a

**FIGHT** CONTINUED ON PAGE 28



**"THE ECONOMIC CLIMATE HAS MADE** obtaining funding much harder as foundations and the federal government have had increasingly more requests for increasingly fewer dollars available. There still remains a significant amount of money out there to be obtained. But it will take our very best efforts at creativity and ingenuity to gain the attention and support of funders, especially when they receive, as they do, such a huge volume of requests, with limited amounts of funding dollars available."

—Michael D. Gingerich, executive director of the Foundation for Cancer Research & Wellness (FCRW)



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huge incidence, the mortality rate is very low, which is great. Unfortunately, the statistics are very different in the world of lung cancer.”

Bone points out that there has been a recent infusion of federal funds available, but it isn't a permanent increase by any means.

“Government funding of medical research received a boost from the additional stimulus funding provided by the American Recovery and Reinvestment Act, but this boost is only temporary, and it is expected that reductions will be made after the stimulus funding is completed,” he says.

With the boost provided from stimulus funding, it is possible that there will be a drop in funding after the grant awards.

“Due to the downturn in the economy, the federal government provided additional funding to fund

research to allow companies to maintain the employees that they currently have or hire additional employees that may have been released from the private sector,” Bone explains. “However, this additional stimulus funding is temporary in nature (two-year grant awards), and there will likely be a decrease when these grants terminate.”

### Show me the money

When decisions are made regarding where money will be directed, the FCRW and the research team at PSU College of Medicine note it has been a joint effort.

“Once we identified a possible project and began the process of formulating the specifics of it, together we have and will continue to determine how the money will be used,” Gingerich says.

It is Gingerich who makes the call on money that FCRW seeks independently for its expenses, along with the board.

“For PSU, it is the administrators of the College of Medicine, working in conjunction with the research team,” he adds. “For joint funding for both FCRW and PSU, we will negotiate together.”

According to Bone, at the Hutchinson Center, money for research grants is awarded via a competitive proposal process, and for federal funding, there is a peer review process to review and rank the grant proposals to determine which ones are the most meritorious and should be funded with the dollars available.

“These decisions about the quality of the grant proposal are made by scientists within the same field as the research proposal so peers are the ones grading the merits of the proposal,” he says. “A ranking of the proposals is received and a ‘payline’ is established so that grants receiving a score above the payline are funded, and those that fall below the payline are not.”

Norris explains that for the LCFA, funding decisions are made by the organization's Scientific Advisory Board in consultation with LCFA's Board of Directors.

### Funding = survival

Looking toward the future for charitable efforts, groups like the FCRW may be feeling some anxiety about the present and future.

“We also believe that the work we are doing is of value and is needed,” Gingerich points out. “There still remains a significant amount of money out there to be obtained. But it will take our very best efforts at creativity and ingenuity to gain the attention and support of funders, especially when they receive, as they do, such a huge volume of requests, with limited amounts of funding dollars available.”

Bone points out that as the economy and individuals' investment portfolios rebound, there is hope that charitable giving will

once again increase.

“Large donors are likely to target their contributions towards specific projects where they feel their gift will make a difference and the Hutchinson Center has a number of opportunities where donors gifts have made a difference in the past,” he says. “Foundations have also been negatively impacted by the economy's downturn and are sometimes slowing down the pace of their new awards so that they can fund all of their existing commitments on previous awards.”

While funding for lung cancer has taken a hit in recent years, which Norris says has had an impact on the five-year mortality rate, the future may be a little brighter.

“I'm hopeful that lung cancer is on the cusp of receiving the attention it deserves after being neglected for so long,” she says. “In the world of lung cancer, with its dismal mortality, funding equates to survival.” **ddn**

EDITCONNECT: E121030

# Pink ribbons and yellow bracelets

The strange paradox of cancer's persistence in the face of public optimism about progress toward a cure

BY LLOYD DUNLAP

**T**HE STATISTICS, if not without areas that show glimmers of hope, are unsettling. As reported in the *New York Times*, data from the National Center for Health Statistics show that death rates since 1950 plummeted for heart disease, stroke and influenza and pneumonia. But for cancer, they dropped a meager 5 percent—to about 200 deaths a year per 100,000 people of all ages, and 1,000 deaths per 100,000 people over age 65. In comparison, the death rate from heart disease is only a third of what it was in 1950. Even though more people die of heart disease than from cancer, cancer deaths have been edging closer to heart disease deaths each year.

Paradoxically, according to a *Time Magazine* poll, almost as many respondents believe we are making great progress in curing cancer (74 percent) as believe this about curing heart disease (81 percent). It can be posited that improved detection at earlier stages of the disease has resulted in a greater number of people who are living with or have been cured from the disease, but the nearly flat death rate means we are still a long way from effective treatments—not to mention cures—for those who are sickest.

Which brings us to the “crusade against cancer,” a phrase used by numerous charitable organizers and which, broadly construed, has undoubtedly helped shape public opinion about progress against the disease. Other slogans add to the heady mix: “We're in it to end it,” says Avon, which sponsors a three-day walk in major cities around the country. Susan G. Komen for the Cure foresees “Ending breast

cancer forever.” The Lance Armstrong Foundation urges us to “Live Strong.” And the venerable American Cancer Society (ACS) states its dedication to “eliminating cancer as a major health problem.”

Charity Navigator, an independent charity evaluator, “works to advance a more efficient and responsive philanthropic marketplace by evaluating the financial health of more than 5,500 of America's largest charities.” A search on its website using “cancer” as the keyword turns up 122 organizations that raise funds for everything from promoting awareness to funding research. And though the National Cancer Institute outspends all the charities combined, the money it raises is not trivial by any measure. ACS cites revenue of more than \$1 billion for fiscal 2008. The Dana Farber Research Institute in Boston weighs in at about \$800 million/year; Susan G. Komen is at almost \$300 million. A sprinkling of lesser-known organizations such as the American Institute for Cancer Research, ASCO Cancer Foundation and Living Beyond Breast Cancer collect between \$30 million and \$50 million per year. More modestly, 93 of the 122 organizations spend less than \$15 million each year.

In terms of area of emphasis, a rough count based on occurrence of the word in each organization's name reveals that breast cancer is the focus of about 10 percent of all cancer charities tracked by Charity Navigator, with skin/myeloma, leukemia, lung, ovarian and prostate, each with fewer than 5 percent of the total and pancreatic cancer receiving a single mention.

Charity Navigator uses a four-star system to rate overall efficiency of each organization at delivering promised services, and 75 cancer charities receive either a three- or four-star score. To briefly cite examples, Susan G. Komen for the Cure (four stars) distributes 83.4 percent of its revenues into its programs and spends only 7 cents raising funds for every dollar it collects. Its administrative expenses are also low at 10.5 percent. At three stars, the American Cancer Society spends about 20 cents to raise a dollar. The John Wayne Cancer Institute

directs 61.4 percent of its revenue into programs, spends 32 percent on administrative expenses and receives a two-star rating. One-star and zero-star rated groups spend 25 percent to 75 percent on fundraising expenses with commensurate reductions in dollars invested in programs.

A final issue revolves around what each charity means by the term “programs.” For example, Susan G. Komen for the Cure defines itself as “the world's largest grassroots net-

million in research since 1999.

Many organizations fund education and support of patients and families, but not research. For example, Living Beyond Breast Cancer provides “breast-cancer-related information, connection and support after completing treatment.” The six regional Gilda's Clubs provide similar services in support of the whole family, as do the renowned Ronald McDonald houses.

All of this makes it difficult to determine

**“WE'RE IN IT TO END IT,”** says Avon, which sponsors a three-day walk in major cities around the country. Susan G. Komen for the Cure foresees “Ending breast cancer forever.” The Lance Armstrong Foundation urges us to “Live Strong.” And the venerable American Cancer Society (ACS) states its dedication to “eliminating cancer as a major health problem.” But what does this mean in terms of funding for these charitable organizations?

work of breast cancer survivors and activists fighting to save lives, empower people, ensure quality care for all and energize science to find the cures.” Does this phrase mean “dollars invested in promising research” or something else?

Of the several organizations queried at press time, only the Lance Armstrong Foundation responded, stating that it has invested \$22

the financial contribution of charities to cancer research while perhaps helping to explain why fervent optimism is so widely expressed. The acts of providing education and support to those stricken and their families virtually demand it. Or as Winston Churchill put it: “For myself I am an optimist—it does not seem to be much use being anything else.” **ddn**

EDITCONNECT: E121031