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ACS Stirs Discord By Placing Its Own Logo On A Coalition's Petition, Then Reconsiders

The leaders of the National Prostate Cancer Coalition were informed last week that the American Cancer Society had "modified" the coalition's petition demanding a boost in the government's spending for prostate cancer.

"Our logo replaces that of the Coalition," Allan Erickson, an ACS official, wrote in a letter dated Jan. 31 and written on the stationery of the society's National Home Office. "There are no plans now to share the details from each signed petition with the National Coalition."

In a nutshell, ACS, a member of the coalition, was in the process

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In Brief

Hohn Named President, CEO Of Roswell Park; Mendelsohn Honored; AACE Elects Officers

DAVID HOHN was named president and CEO of Roswell Park Cancer Institute of Buffalo, NY. Hohn, vice president for patient care at University of Texas M.D. Anderson Cancer Center, will succeed **Gordon Hennessy**, who served as acting president after the Dec. 31 retirement of **Thomas Tomasi**. Hohn is recognized for his instrumental role in developing M.D. Anderson's multidisciplinary care centers for outpatient services and designing new patient care facilities. He will begin at Roswell on Feb. 15. . . . **JOHN MENDELSOHN**, president of M.D. Anderson Cancer Center, received the fourth Raymond Bourgine Award for achievements in cancer research at the Seventh International Congress on Anti-Cancer Treatments, held this week in Paris, France. Paris Mayor Jean Tiberi presented the award and the Gold Medal of Paris to Medelsohn, who was honored for his work on growth factor regulation of cancer cells. Bourgine was a French writer and former elected Paris official who died of cancer in 1990. . . . **BRUCE CHABNER**, clinical director of the Massachusetts General Hospital Cancer Center, was awarded the Kantor Family Prize for Cancer Research Excellence by the Hipple Cancer Research Center of Dayton, OH, and the Dayton Oncology Society. The award was established by Milt Kantor, a Dayton businessman. The award cited Chabner for achievements made during his 14-year tenure as director of the NCI Division of Cancer Treatment, including the development of antifolate cancer drugs and the drug Taxol. . . . **AMERICAN ASSOCIATION** for Cancer Education elected new officers for 1997: President, **Joseph O'Donnell**, Dartmouth Medical School; vice president,

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NPCC Leaders Said ACS Plan "Injured" Coalition's Drive

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of rolling out its own, parallel petition drive, and at the end of the drive, the society would exclusively keep the names and addresses collected. Mailing lists are a valuable asset in solicitation of donations and memberships as well as in mobilization of grassroots support for political issues.

Several leaders of NPCC said the society's action constituted betrayal both of NPCC and the principle of collaboration through coalitions. "I feel hurt and injured," NPCC chairman Robert Samuels said to **The Cancer Letter**. "We thought we were working toward the same objective. We didn't realize this is competitive."

After being contacted by a reporter, senior ACS officials conducted an informal investigation of the controversy, and reversed the actions described in Erickson's letter.

"The [logo on the petitions to be circulated by ACS] would be the National Prostate Cancer Coalition, and there could be a [secondary logo indicating] that ACS is a part of this," Harmon Eyre, ACS executive vice president for cancer control and research, said to **The Cancer Letter.** "The names would be shared [with NPCC]," he said.

"This has caused some turmoil that we will have to spend time and energy to resolve," Eyre said of the actions by ACS staff. "It was unnecessary. And yet when it happens, we have to resolve it."

Though the immediate dispute has been resolved, the fact that the controversy arose remains significant since it has brought into focus the obstacles ACS must overcome as it adjusts to the political necessity of collaborating with patient advocacy groups.

Names and Addresses

The dispute centered on who would be able to gain access to the names and addresses collected through the NPCC petition drive that seeks to deliver a million signatures to Capitol Hill and the White House on Father's Day.

For NPCC, the lists offer a way to communicate with supporters and solicit membership contributions.

For ACS, mailing lists mean survival. The society, which raises about 90 percent of its $400 million budget through donations of under $100, is, understandably, protective of its fundraising prospects.

Until Eyre's intervention, ACS was offering NPCC an arrangement that was markedly different from the ACS arrangement with the National Breast Cancer Coalition. The society circulates the petitions for that group as well.

Following Eyre's intervention, ACS would capture the names and addresses on the petitions it collects, then turn them over to the coalition. NPCC would be able to offer information and membership solicitations to the prospects who request additional information.

However, the coalition would be expected to refrain from direct mail fundraising that goes beyond offers of memberships in NPCC.

"That's, in essence, the working agreement that is in place with the National Breast Cancer Coalition," Eyre said.

Working in coalitions is difficult for all members, Eyre said. "After you get more experienced at it, you learn that you have to work with a common goal in mind, and you have to be willing to be flexible in order to accommodate the outcomes you are working toward.

"We have recently made this a nationwide priority for ACS to join coalitions where they are appropriate to facilitate the mission.

"Everybody is learning how to do it better," Eyre said.

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Ralph Alterowitz, a business consultant and NPCC vice president who is running the petition drive, said coalitions built around cancer survivors are particularly challenging for a large institution like ACS.

"This was unfortunate," Alterowitz said to **The Cancer Letter.** "The controversy erupted because ACS took the strong position usually assumed by large bureaucratic institutions. That's not acceptable in any coalition, especially one built around cancer survivors. We don't have time for this kind of nonsense.

"It's time for ACS to remember that it joined this alliance to eradicate prostate cancer," Alterowitz said. "I think we should get on with the job."

The NPCC Petition

ACS has been a crucial supporter of the prostate cancer advocacy movement.

The society took part in the coalition's founding meeting earlier this summer, then gave a $10,000 grant to its Florida division to support the office for NPCC chairman Samuels, who lives in Tampa (**The Cancer Letter**, Aug. 16, 1996).

Also, Andrew von Eschenbach, a urologist at M.D. Anderson Cancer Center and chairman of the ACS National Prostate Cancer Advisory Committee, conducted a conference where patients and scientists proposed a research agenda for the emerging coalition (**The Cancer Letter**, Nov. 8, 1996).

These contributions notwithstanding, some constituencies within ACS were concerned about the emergence of a new coalition that has been modeled on NBCC and has the potential to become just as powerful.

Documents indicate that some of those officials were concerned about what would happen to the names and addresses collected by NPCC during its petition drive. Would these prospects be used by the coalition to raise money? Would this constitute competition with ACS?

These questions surfaced during an ACS "roundtable" which brought together staff members from 37 divisions and the National Home Office last October.

"Concern was raised about the emerging National Prostate Cancer Coalition," the consensus report from the roundtable said. "While the Society should participate, our role needs clarification. The coalition plan to gather names and addresses from future signature campaigns needs clarification."

Several observers at ACS and outside the society offered an explanation for some staff members' apprehensions about coalitions that involve patient groups.

While the staff of the society's Washington office routinely interacts with patient advocates, many of the division staff members do not. By the same token, not all the local groups that belong to umbrellas such as NBCC are aware of the society's contributions to their efforts. Thus, the cordial relationships and coalition spirit do not always extend beyond the Washington Beltway.

Splitting the Prospects: Evolution of a Deal

ACS has had to confront the question of dividing its prospects lists with grassroots coalitions. That issue first arose in the context of the society's participation in NBCC petition drives.

No contract exists between the two groups. Instead, the arrangement evolved historically and is reflected only in the minutes of NBCC board meetings.

Sources said no names were captured either by ACS or NBCC during the 1991 letter-writing campaign. Similarly, names and addresses were not captured by NBCC in the 1993 petition campaign. However, that campaign led the coalition members to devise methods for follow-up, sources said.

Now, ACS captures the names on the petitions it collects, then turns the petitions over to the coalition.

Both NBCC and ACS capture only the names of the people who request additional information. These people receive the coalition's follow-up packets which consist of a brochure and an offer of membership.

It appears that as the prostate cancer coalition came closer to launching its campaign, some ACS officials attempted to secure an arrangement that gave the society a more advantageous deal than one negotiated with NBCC.

The policy described in Erickson's letter to NPCC appeared to be in the works at least since last fall.

In a Nov. 7, 1996, memorandum critiquing a draft of a strategic plan for the coalition, Greta Durr, head of the ACS home office survivorship program, cautioned the new coalition about setting a broad agenda.

"My overall impression of the draft is that it is an ill-advised document that will alienate current key supporters of NPCC," wrote Durr, who at the time served as the society's liaison with the coalition. "I doubt that any organization that conducts research, delivers cancer information, or offers patient education and support programs will actively support a duplicative organization.

"The mission statement of NPCC was to be advanced solely through advocacy efforts to increase funding for prostate cancer research... Direct fundraising efforts by NPCC for anything beyond the operating expenses needed for successful advocacy campaign goes beyond the role of NPCC as conceived at the [initial] meeting.

"Should NPCC persist in expanding into areas already developed by its current constituents, it will be perceived as a direct threat to them. However, advocacy efforts to increase funding for prostate cancer research and already-existing education and support program is something everyone can get behind," Durr wrote.

The memorandum also describes the society's emerging plans to run the signature campaign under its own logo rather than that of the coalition. "Any effort we undertake would most likely be under the ACS banner, but designed to dovetail with the NPCC effort.

"Signatures would be forwarded from [ACS] units to divisions, so divisions would have the option of developing [their] own databases. Divisions would then forward signatures to a national site for warehousing," Durr wrote.

Policy Recommended by Advisory Committee?

While Durr's memo to NPCC was an update on development of a policy, the communication from Erickson, her successor as liaison with the coalition, was presented as *fait accompli:*

"To accommodate the actions of [the ACS National Prostate Cancer Advisory Committee], we modified the original petition form developed by the Coalition. Our logo replaces that of the Coalition..."

According to Erickson's account, the advisory committee made its recommendation on Jan. 18, and six days later the ACS National Home Office issued an "executive notice" that informed the society's divisions about the ground rules for participation in the NPCC petition drive.

Did the ACS advisory committee recommend "modifying" NPCC's logo off its own petition? Not according to von Eschenbach, chairman of the committee.

"The committee said: Support the drive," von Eschenbach said to **The Cancer Letter**. "We recognize there is a legitimate concern about protecting the ACS fundraising, but the staff should work this out. It didn't say: Take their name off the petition, put our name on it, and make it a completely separate signature campaign. That would be in violation of the spirit of our resolution to support the drive. This is the National Prostate Cancer Coalition's let's-establish-our-presence event. We want it to succeed."

Richard Howe, a member of the ACS advisory committee and the NPCC board, has a similar recollection of the committee discussion:

"As I saw it, there were at least three courses of action," Howe said to **The Cancer Letter**. As Howe saw it, one possibility was to take no action. The second was to mail information out to ACS divisions with no recommendation, leaving the decision to them. The third was to modify the return address on the bottom on the petitions, directing them to ACS offices.

"There was certainly no discussion of taking the NPCC logo off the petition and putting the ACS logo on," Howe said.

Erickson, a retired ACS staff member who is now employed as a consultant to the society, was traveling and could not be reached for comment.

What Went Wrong?

After making several inquiries into how the controversy got started, the ACS official Eyre was unable to point to a cause.

"Perhaps it's a miscommunication, perhaps a misinterpretation," he said. "The people who were at the [advisory committee] meeting very clearly, uniformly backed the statement that we should agree to work with [NPCC] and support a common outcome."

NPCC chairman Samuels said he would like to believe that the entire problem was the result of a miscommunication.

"I'd like to think this was all a mistake," Samuels said. "I don't want to believe that there was any intent to hurt the coalition's effort."

Donald Coffey, a prostate cancer researcher at Johns Hopkins University, said NPCC should learn

from the experience and bury the hatchet.

"The lesson is that the growing pains cannot be avoided," said Coffey, president-elect of the American Association for Cancer Research.

"You have to sit down with the patient advocates, take them seriously, and communicate with them," said Coffey, who has been following the controversy through telephone conversations with several participants.

"I just care about one thing: a lot of different groups coming together for a common cause. Hopefully, everybody would be in-step. But they are not. It takes a while for the people to see which way we should be moving.

"It's not good-guys/bad-guys. It's simply a balance between everybody trying to find out what *the common need is*, and trying to do it," Coffey said.

The groups involved in the NPCC petition drive include ACS, the American Foundation for Urologic Disease, The American Prostate Society, CaP CURE, the Mathews Foundation, MENCANACT, National Coalition for Cancer Patients, New England Prostate Cancer Network, Patient Advocates for Advanced Cancer Treatments, The Prostate Cancer Communication Resource, The Prostate Cancer Education Council, Real Men Can Cook, Tampa Bay Men's Cancer Task Force, and US TOO International.

The petition drive's Web site is http://rattler.cameron.edu/npcc.

National Research Council Names Cancer Board Members

The National Research Council's Commission *on Life Sciences* and the Institute of Medicine have appointed 17 individuals to the National Cancer Policy Board.

The board was established at the request of NCI to serve as an independent forum to address obstacles in furthering cancer research, treatment and control.

The IOM had previously selected Peter Howley, George Fabyan Professor and chair of the Department of Pathology, Harvard Medical School, as chairman of the policy board.

Joseph Simone, medical director of the Huntsman Cancer Foundation and Institute, Univeristy of Utah, will serve as vice chairman of the policy board.

In a Feb. 5 announcement, IOM said it appointed the following members of the board:

John Bailar, chair, Department of Health Studies, University of Chicago, IL.

Norman Daniels, Goldthwaite Professor of Rhetoric, Tufts University, Medford, MA.

Joseph Davie, vice president, Department of Research, Biogen Inc., Cambridge, MA.

Robert Day, president and director, Fred Hutchinson Cancer Research Center, Seattle, WA.

Kathleen Foley, chief of Pain Service, Department of Neurology, Memorial Sloan-Kettering Cancer Center, New York City.

Ellen Gritz, professor and chair, Department of Behavioral Sciences, University of Texas M.D. Anderson Cancer Center.

Margaret Hamburg, Health Commissioner, New York City Department of Health.

Elizabeth Hart, president and CEO, Hart International, Dallas, TX.

John Laszlo, national vice president for research, emeritus, American Cancer Society, Atlanta, GA.

Daniel Nathans, professor of molecular biology and genetics, Johns Hopkins University School of Medicine, Baltimore, MD.

Diana Petitti, director, research and evaluation, Kaiser Permanente Medical Care Program, Pasadena, CA.

Amelie Ramirez, associate director, community health promotion, South Texas Health Research Center, San Antonio, TX.

Ellen Stovall, executive director, National Coalition for Cancer Survivorship, Silver Spring, MD.

Judith Wagner, senior associate consultant, Department of Health Sciences Research, Mayo Clinic, Rochester, MN.

Robert Young, president, Fox Chase Cancer Center, Philadelphia, PA.

Public Forum March 31

The board will hold an organizational meeting March 4-5, after which the board may decide to add up to three more members, said Robert Cook-Deegan, an IOM official who serves as the board's director.

The board has scheduled its first public forum March 31 to discuss its priorities for the coming year.

The priorities "may include standards of clinical care and for research and training; public policy and

the scientific measures of its impact on cancer risk and prevention; sociological factors that lead to cancer and successful medical intervention; the impact of cancer research discoveries on national economic growth as well as on the health and welfare of the American people; and training the next generation of cancer researchers and medical practitioners," according to an IOM statement.

The board's Web site address is http://www2.nas.edu/cancerbd/. There also is a listserv network for information about the board's activities. To subscribe, type "subscribe cancer-policy" in the body of the message to listserv@cyrus.nas.edu.

Patient Advocacy

FDA, NCI Seek To Involve Survivors In Advisory Roles

FDA and NCI are developing separate processes for involving cancer survivors in formal advisory roles to the agencies.

FDA, as part of the White House initiative on "Reinventing the Regulation of Cancer Drugs" announced last March, has proposed a process for selecting patient representatives to serve on committees that advise the agency on cancer-related drug and device approvals.

The agency is seeking public comment on the proposed process.

NCI plans to form an advisory committee of patient advocates that would establish the processes for identifying advocates to serve on the Institute's many other advisory committees.

The Institute is seeking submissions of proposed eligibility criteria and categories to identify individuals to serve on the proposed Director's Consumer Liaison Group.

FDA Lists Proposed Qualifications

In a notice in the Federal Register, Jan. 15, FDA requested comments on a proposed process for selecting patient representatives to serve on cancer-related advisory committees.

In the past few years, patient representatives were selected through an informal process to serve as members of the Antiviral Drugs Advisory Committee, the Blood Products Advisory Committee, the Oncologic Drugs Advisory Committee, the Biological Response Modifiers Advisory Committee, and the Medical Imaging Drugs Advisory Committee. The patients did not generally have voting privileges.

Under the formal process proposed by FDA, the agency would develop a listing of qualifications to be considered in selecting patient representatives and a plan for soliciting nominations.

The patient representatives would be voting members of the committees and subject to the same conflict of interest requirements as other committee members.

"The primary role of the patient representative would be to provide to the advisory committee the perspective of the patients with the disease for which the therapeutic agent is being considered," the FDA notice said. "Currently, many of the FDA advisory committees, including those that provide advice on cancer-related issues, include a representative who is broadly identified with consumer interests and who has been nominated and recommended by a consumer-oriented organization."

"However, because there are so many cancers, the number of appropriate perspectives is larger than a single consumer can represent," FDA said. "To more specifically represent the interests of the patients, the FDA believes that a patient representative who understands issues specific to the cancer for which a drug, device or biologic approval is being sought would bring valuable insights to the FDA advisory committee process."

FDA is considering the following qualifications for patient representatives:

- Personal experience with an illness, condition or treatment.
- Experience as a patient advocate.
- Formal affiliation with a patient advocacy organization.
- Ability to articulate the perspective of the patient.
- Ability to identify issues through communications with patient constituencies.
- Ability to access mechanisms to disseminate information from an advisory committee meeting to the affected community.
- Experience in technical before the committee.

A mechanism for soliciting nominations should ensure broad representation in the nominee pool, FDA said.

The agency proposes to solicit nominations through Federal Register announcements, Internet announcements, direct mailings and letters to patient advocacy groups, community organizations and

other public interest organizations; announcements in patient newsletters and display announcements at meetings attended by FDA staff.

Nominations could be submitted by individuals, patient advocacy groups and organizations. Self nominations also would be acceptable.

FDA welcomed comment on the proposed selection process; the deadline is March 17. Comments should reference Docket No. 96N-0478 and mailed to Dockets Management Branch, HFA-305, Food and Drug Administration, 5600 Fishers Lane, Rockville, MD 20857.

For further information, contact JoAnn Minor, of the Office of AIDS and Special Health Issues, tel: 301/827-4460, email: Jminor@bangate.fda.gov.

NCI To Form Consumer Liaison Group

NCI plans to establish a Director's Consumer Liaison Group, a committee of about 15 members who are patient advocates or members of voluntary organizations.

According to a notice in the Federal Register, Jan. 28, the purpose of the DCLG would be to:

- "Help develop and establish processes, mechanisms and criteria for identifying appropriate consumer-advocates to serve on a variety of program and policy advisory committees responsible for advancing the mission of the NCI;"
- "Serve as a primary forum for discussing issues and concerns and exchanging viewpoints that are important to the broad development of NCI programmatic and research priorities, e.g., the development of the annual Bypass Budget;"
- "Establish and maintain strong collaborations between NCI and the cancer advocacy community to reach common goals."

The group's first meeting would be scheduled for sometime in June.

NCI plans to hold a meeting of a Planning Group to assist the Institute in establishing the DCLG. The meeting is open to the public and scheduled for March 13-14, at the Holiday Inn, Bethesda, MD.

The purpose of the Planning Group, according to the NCI notice, is to "define the initial role of the DCLG and define the DCLG membership solicitation process, as well as the criteria, categories, and rating system to identify and rank potential members of the DCLG."

Members of the Planning Group will be unable to serve as DCLG members in its first year, but their organizations may be represented by other individuals, NCI said.

NCI invited comment from members of advocacy or voluntary organizations on eligibility criteria and categories to identify individuals to serve on the DCLG. Comment should be sent to Fran Oscar, Palladian Partners, 7315 Wisconsin Ave. Suite 440W, Bethesda, MD 20814, fax: 301/985-5047, email: palladianp@aol.com.

Comments must be received no later than Feb. 15 to be included in materials provided to the Planning Group *prior to the meeting*. Submissions must include name and address of individual making the comments, and name and address of cancer advocacy or voluntary organization to which the individual is affiliated.

Regulatory Agencies

FDA Proposes New Procedure For Treatment Use Of Devices

FDA has proposed new procedures to make it easier for patients to be treated with promising but as yet unapproved medical devices that are in research.

Currently, patients may be treated with an unapproved medical device on a crisis basis under FDA's "emergency use" policy.

The proposed policy would broaden availability, allowing patients "treatment use" of an unapproved medical device in a planned, controlled way, rather than on the current *crisis basis*, the agency said.

The proposed policy applies only to devices intended to treat or diagnose a serious or immediately life-threatening disease or condition.

Normally, the sponsor of a new medical device obtains an Investigational Device Exemption (IDE) to conduct studies of the device on human patients before the device is approved for marketing. The data gathered in these studies are used to demonstrate the device's safety and effectiveness when the sponsor applies for approval to market it. The device can only be used on patients enrolled in the studies.

The proposal would allow treatment of desperately ill patients with investigational devices that show great promise but have not yet been shown to be safe and effective.

Manufacturers would submit Treatment Use IDE applications in order to have their medical device considered for such use.

FDA would have 30 days to consider the application, the same time allowed for standard IDEs.

To get a Treatment Use IDE, the following criteria would have to be met:

- The device is intended to treat or diagnose a serious or immediately life-threatening disease or condition;
- No comparable or satisfactory alternative device or other therapy is commercially available;
- The device is under investigation in an approved IDE or such studies have been completed;
- The manufacturer is actively pursuing marketing approval.

The proposed policy was published in the Federal Register Dec. 19. There is a 90-day comment period, after which FDA will consider the comments and issue a final rule.

Society Invites Nominations For Women's Health Awards

The Society for the Advancement of Women's Health Research invites nominations for the 1997 Achievement Awards in Women's Health.

The awards honor individuals for their contributions to improving the health of women. Individuals may be nominated for an award in one of five categories: basic science, clinical services, public policy, advocacy, and communications. In addition, the Georgeanna Seegar Jones Award honors a lifetime of achievement.

Deadline for submissions is March 31.

The awards will be presented June 24 in Washington, DC, in conjunction with the annual Congress on Women's Health.

Inquiries: Society for the Advancement of Women's Health Research, 1920 L St. NW, Room 510, Washington, DC 20036, tel: 202/223-8224, fax: 202/833-3472, email: bev@womens-health.org.

The Cancer Letter welcomes the submission of news items for the In Brief section and Funding Opportunities, as well as Letters to the Editors.

Material may be sent by email to: kirsten@www.cancerletter.com or paul@www.cancerletter.com, by mail to: PO Box 9905, Washington, DC 20016; or by fax to: 202-362-1681.

In Brief

NCI Selects Associate Director For Frederick Research Center

(Continued from page 1)

Anne Kessinger, University of Nebraska Medical Center; treasurer, **Charles Kupchella**, SE Missouri State University; and secretary, **Virginia Krawiec**, American Cancer Society. The AACE annual meeting is scheduled for Oct. 23-26, in Atlanta. Abstracts are due in April. Abstract forms are available from the Virginia Krawiec, tel: 404-329-7612 or email gkrawiec@ cancer.org. . . . **DONALD SUMMERS** was appointed NCI associate director for the Frederick Cancer Research and Development Center, Frederick, MD. Summers was senior associate dean for research and graduate studies, University of California, Irvine, College of Medicine. . . . **NORKA RUIZ-BRAVO** was named deputy director of the NCI Division of Cancer Biology. She had been a program director in the Genetic Mechanisms Branch, National Institute of General Medical Sciences. The division director is **Faye Austin**. . . . **V. CRAIG JORDAN** received the Herbert J. Block Memorial Lectureship Award, given by the Arthur G. James Cancer Hospital and Research Institute. Jordan, director of the breast cancer research program at Robert H. Lurie Cancer Center of Northwestern University, will present a lecture Feb. 27 in Columbus, OH. . . . **CORRECTION:** A story in the Jan. 31 issue of **The Cancer Letter** incorrectly identified Daniel Sullivan, who served as a member of the NIH Consensus Development Panel on Breast Cancer Screening for Women Ages 40-49. Sullivan is an associate professor of radiology at the University of Pennsylvania Medical Center. . . . **CLARIFICATION:** A story in the Jan. 17 issue of **The Cancer Letter** on the NCI agreement with the Department of Veterans Affairs should have stated that the agreement covers reimbursement for patient care costs for veterans enrolled in NCI-sponsored trials at VA hospitals. The article also inaccurately described the NCI-Department of Defense demonstration project. The project covers members of CHAMPUS, the medical program for families of military personnel and retirees. Active-duty personnel access clinical trials through military hospitals.