

## ACS-Led National Cancer Dialogue Beset By Patient Mistrust, Lack Of Openness

The American Cancer Society is constructing a political structure called the National Dialogue on Cancer and undertaking a related effort to rewrite the fundamental document of the cancer program, the National Cancer Act of 1971.

According to ACS officials, the Dialogue's goal is to bring together the major cancer groups in an effort to foster better coordination of cancer research and cancer control.

"We can almost guarantee no harm, but also the synergy that comes out of this could have a positive impact that could not be gained in the near term in any other way," ACS Chief Executive Officer John Seffrin said to **The Cancer Letter**.

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### In Brief:

#### Clinton To Propose \$1 Billion Increase And A New Minority Health Center For NIH

**PRESIDENT CLINTON** will propose \$19 billion for NIH, a \$1 billion increase, in his fiscal 2001 budget, the White House said this week. The budget proposal also will recommend loosening Congressional restrictions on \$4.3 billion more in research money. The increase would provide "new funding for research on every major disease," according to a White House statement. Clinton also will propose a \$20 million Center for Research on Minority Health at NIH, and \$27 million for the Center for Disease Control and Prevention's Environmental Health Lab to "assist communities investigating unusual incidence of cancer or other diseases; identify regions of the country in which individuals are at increased risk of dangerous exposure to carcinogens and other toxic substances; and ensure rapid evaluation of the impact of public health emergencies." Clinton also unveiled a health insurance initiative that would provide \$110 billion over 10 years to expand coverage to 5 million of the estimated 44 million uninsured Americans, and a proposal for a \$3,000 tax credit for persons providing long-term care for ill or disabled family members. . . .

**SUSUMU OHNO**, a scientist renowned for his work in genetics and evolution, died of complications due to lung cancer at City of Hope National Medical Center on Jan. 13. He was 71. He is credited with the discovery that new genes often evolve after there is duplication in the genetic sequence of an existing gene. During a period of independent research as the City of Hope Ben Horowitz Chair in Genetics Research, Ohno

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## Puzzling Decisions, Missteps In National Dialogue On Cancer

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If the Dialogue succeeds, ACS could be in a position to enhance its role among cancer groups and in the National Cancer Program.

If the Dialogue fails, the Society's national leadership will have to face the consequences of spending about \$1.2 million and wasting the time of some very prominent people. These include former President George Bush and Barbara Bush, co-chairmen of the Dialogue, and Sen. Dianne Feinstein (D-CA), the vice-chairman, and Governors Tom Ridge of Pennsylvania and Tommy Thompson of Wisconsin, "Collaborating Partners" in the process.

The outcome will depend on the Society's ability to build trust with advocacy groups as well as its ability to reverse the trend of puzzling strategic decisions and administrative missteps.

—Last August, ACS stunned the Dialogue participants by announcing the formation of a committee that would advise Feinstein in the rewriting of the National Cancer Act.

Critics say that the decision to form the committee and selection of its co-chairmen—Seffrin and former NCI Director Vincent DeVita—were made behind closed doors, without participation of Dialogue Collaborating Partners or the Steering Committee.

In a statement to **The Cancer Letter**, Andrew von Eschenbach, one of the founders of the Dialogue and a member of its Steering Committee, noted the "lack of input by the Dialogue partners into the formation of Sen. Feinstein's advisory committee."

"It is our responsibility and that of the leadership of the cancer community to resolve such problems," said von Eschenbach, director of the M.D. Anderson Cancer Center's Center for Genitourinary Cancers, who is in line to become ACS president in 2002.

—**The Cancer Letter** learned that Shandwick International, a public relations firm involved in running the Dialogue as well as the Cancer Act rewrite, also represents tobacco interests.

John Fish, vice president for federal government affairs at R.J. Reynolds Tobacco Holdings Inc., said the tobacco company is represented by Decision Management Inc., a Shandwick subsidiary. Shandwick purchased Decision Management last year.

The parent company said it's not involved in marketing tobacco products. "Other types of work, including public information campaigns on the terms of the [tobacco] settlement, anti-youth smoking campaigns, and some work on policy issues has been done in some offices," Shandwick officials acknowledged in a statement to **The Cancer Letter**. The company said "recent events have caused the company to take this policy under review."

ACS officials said they asked appropriate questions before hiring Shandwick, but were not aware of the company's work with R.J. Reynolds. "The Society does not make it a practice of monitoring the mergers and acquisitions of its vendors," Greg Donaldson, ACS national vice president, communications, said to **The Cancer Letter**. "However, if what is being reported is true, then obviously the Society would want to talk further about the matter with Shandwick."

ACS may want to consider finding a new contractor, said John Durant, executive vice president of the American Society for Clinical Oncology and a member of the Dialogue Steering Committee. "As a personal opinion, it would be unwise for a company that represents tobacco to be involved in the rewriting of the National Cancer Act," Durant said.

—According to documents obtained by **The Cancer Letter**, Allan Erickson, the staff coordinator of the Dialogue who serves as a senior consultant to Seffrin, was pursuing a dual agenda in his dealings with NCI.

While trying to keep the Institute collaborating



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**Founded Dec. 21, 1973, by Jerry D. Boyd**



with the process, he aggressively sought reinstatement of \$25,000 in Institute funds for development of tobacco control programs in Latin America, a project that NCI officials described as inappropriate for the research institute.

Erickson said his dual relationship with NCI did not harm the Dialogue. “You’d have to use a million-mile yard stick to try to figure out that that has any connection to the National Dialogue on Cancer,” Erickson said to **The Cancer Letter**. “I don’t think [NCI Director] Rick Klausner even knew that I had any kind of a relationship.”

As a retired ACS official who serves as a consultant to the Society, Erickson can have multiple clients. Still, trying to convince NCI to cooperate with an undertaking that threatens to diminish its role in the National Cancer Program, while at the same time trying to obtain Institute funds for activities inconsistent with its mission may not be the most pragmatic strategy.

—ACS officials and some key volunteers appear to underestimate the reservations of patient advocacy groups about taking part in the Dialogue, and describe critics as a disgruntled minority.

Seffrin said the resistance of advocacy groups surprises him. “It’s amazing to me that we have had difficulty getting some people to participate, in terms of getting them directly involved,” he said to **The Cancer Letter**.

Dan Smith, ACS vice president for public policy, said the majority of Dialogue participants don’t criticize the process. “I think there are a great many people who feel good about the progress of the Dialogue, and obviously, there will be a number of people who are going to be upset with a number of things there, but I think that’s probably the minority,” said Smith.

Helene Brown, a member of the DeVita-Seffrin committee and an ACS volunteer for the past 50 years, said criticism comes with the territory for a group like ACS.

“Any time you have an organization like General Motors, the small automobile maker is going to complain about them,” Brown said. “Any time you have an organization that has the life-long series of accomplishments that the Cancer Society has had, you are going to hear people complaining.

“If there is somebody else out there that wants to take this on their shoulders, and wants to fund it, and wants to organize it, I am sure they are welcome to do it,” Brown said. “But there isn’t anybody else

that has that kind of freedom, because of the constituency and the size of the purse.”

The ACS purse is impressive—the Society raised over \$600 million last year. However, on Capitol Hill, the Society is just another player with a legislative agenda. In the halls of Congress, shoestring patient groups that possess expertise, grassroots support, and moral authority can be no less effective. Their opposition is not something to court.

“Survivors are extraordinarily important,” said ASCO’s Durant. “The people who have been affected by cancer have the attention of significant decision-makers. Leaving patients out, or making them feel left out is not a very smart idea.”

If the Dialogue fails to earn the support of patient advocacy groups, it will accomplish little on the Hill, agrees Robert Cook-Deegan, director of the National Cancer Policy Board of the Institute of Medicine. “Any national legislation is going to require the support from a broad base of cancer patient advocacy groups,” he said.

### **A Matter of Strategy**

Criticism of the Dialogue reaches beyond patient groups. “I don’t think the National Dialogue on Cancer has been designed as a smooth oncopolitical process,” said ASCO’s Durant. “I communicated my confusion over what the governance was and how decisions were made, and nothing happens. It goes right on. I can’t tell you that I have gotten wonderfully satisfying answers to the questions I’ve raised.”

Transparency is essential, agrees Donald Coffey, Johns Hopkins University professor and a participant in the Dialogue.

“Any flaw in decision-making or process that permits hidden agendas will foster mistrust and derail the cooperation needed for the important joint mission,” said Coffey, president-elect of the National Coalition for Cancer Research and former president of the American Association for Cancer Research. [Coffey’s commentary on the potential for cooperation between cancer groups appears on page 11.]

Some critics of the Dialogue say unanimity in cancer politics is a bad strategy.

“I have always believed that cancer organizations can work together where there is a shared agenda, but it would not be desirable for all of us to speak in the same voice on every issue,” said Fran Visco, president of the National Breast Cancer Coalition and a member of President’s Cancer Panel.



“What that does is keep in place the status quo, and the same people who have been in power remain in power.”

Advocates involved in the Dialogue do not dispute the need for an overarching cancer agenda, but question the ACS claim that the Dialogue is operated independently from the Society and are disappointed by what they describe as the absence of openness.

“I am trying to give them every benefit of the doubt, because I believe so strongly in the need for collaboration,” said Carl Dixon, president and executive director of the Chicago-based Kidney Cancer Association.

“I think there is confusion as to whether the Dialogue has its own charter or whether it’s simply an adjunct to ACS, and I think that tension is troubling to many people. When I hear people from ACS speaking on behalf of the Dialogue and using ‘we,’ I don’t know if they mean ‘we the Dialogue,’ of which I am a member, or ‘we the American Cancer Society’ of which I am not.”

Dixon is a Collaborating Partner in the Dialogue and a member of its Public Policy Roundtable.

### **Patients Demand “Transparency”**

Whatever support the Dialogue enjoys is extremely fragile. For one thing, not all the prominent people whose names figure on the list of Collaborating Partners actually show up at meetings.

NBCC President Visco, whose name appears on the list, does not regard herself as such.

“We did send someone to the first meeting, and then decided not to participate” Visco said to **The Cancer Letter**. “I don’t know how they are using my name as a Collaborating Partner. NBCC didn’t give them permission to use my name or any other as a representative. We chose not to participate.”

ACS officials say the names of Collaborating Partners are included after they are invited by the Bushes. Typically, the most senior official of an organization is invited to join.

“If Fran Visco’s name is still listed, it means that clerically [NBCC has] not designated the exact person they want to be listed or asked to be taken off the list,” said Harmon Eyre, executive vice president for research and cancer control.

FDA Commissioner Jane Henney appears to fall into the same category as Visco. “She has received a letter from President Bush, and has not attended a Dialogue meeting, and the only issue would be, does

she ever want to come, or does she want to designate someone as her replacement, or does FDA not want to be involved,” Eyre said.

For those who attend, attendance does not necessarily equal support.

“I am watching, and I think that’s probably the attitude of a fair number of folks, who are watching to see if anything comes of it,” said ASCO’s Durant. Some of what Durant sees worries him. “It has always seemed to me that this was an issue of control by the ACS over the cancer agenda,” he said. “They are protecting their fundraising capacity.”

Several participants said they would quit the minute they feel that nothing is being accomplished. For advocates, who typically have limited resources and crowded schedules, this threshold is especially low, said Ilene Penn Miller, executive director of the New York-based Cure For Lymphoma Foundation.

To represent lymphoma policy issues, CFL joined three national coalitions, the Cancer Leadership Council, the National Coalition for Cancer Research, and the National Dialogue on Cancer.

“With a small and overworked staff, keeping up with even one, let alone all three of these coalitions, is a full-time job,” Miller said. “Not only is participation draining our time, but there are financial costs to participating in each of these forums as well.”

Miller said the Dialogue structure still mystifies her. “All partners should be briefed on decision-making process and goals,” she said. “The distrust that already exists among cancer organizations is fed when groups perceive behind-the-scenes decision-making.”

Still, a meaningful Dialogue would be worth the effort, Miller said. Cancer groups should share information and work together toward goals that include increased funding for cancer research and access to clinical trials, she said.

“At the end of the day, it matters less who gets the credit, but that the cancer community is coordinated in our efforts,” she said.

Gilles Frydman, founder and president of the Association of Cancer Online Resources, agreed.

“The reality is that if you want to start a meaningful Dialogue or rewrite the National Cancer Act, it can only be done by working together with all the advocacy organizations,” Frydman, a participant in the Dialogue, said to **The Cancer Letter**. “I don’t see them at the Dialogue; definitely not as equal partners. What a wasted opportunity.”

While governance issues frequently surface in



the Dialogue Steering Committee, ACS membership surveys do not reflect dissatisfaction, ACS officials said.

Recently, partners were asked to review a draft of the Dialogue structure. Altogether, 26 evaluations were returned, said Tom Kean, president of Strategic Health Concepts, of Englewood, CO, and chairman of the Dialogue Coordination Work Group. "Most of them were pretty positive, and most of them were suggesting editorial changes to the document," Kean said. "Few people raised comments about the makeup of the Steering Committee and how decisions are made."

### **Follow-up To The March**

For better or for worse, the Dialogue is trying to pick up the pieces left behind by the March: Coming Together To Conquer Cancer.

Though the March brought 125,000 people to the National Mall in Washington on Sept. 26, 1998, it failed to create a "cancer community" of researchers and patients unified by a common political agenda.

For months before the March, the writing was on the wall: far from producing a United Front, the process of organizing the event severely wore down the groups' willingness to collaborate, organizers of the March said.

"There was nothing that could sustain the continuation in terms of the fiscal and human capital required," said Richard Atkins, president of the CaP CURE government research initiatives group and vice chairman of the National Prostate Cancer Coalition, who served as chairman of the board of directors of the March. "We were volunteers who came from our own organizations, and we went back to them."

Meanwhile, the Atlanta-based ACS, a minor and reluctant player in the March, was preparing to take over political follow-up to the event.

According to materials obtained by **The Cancer Letter**, the Society convened a meeting of a small group of scientists, physicians, and ACS officials on Sept. 29, 1998, at a Northern Virginia hotel. There were no patient groups at the table.

"The National Dialogue on Cancer initiative has tremendous potential in terms of helping to identify and leverage the respective strengths of the key organizations and leaders involved in the cancer control effort," Washington surgeon LaSalle Leffall wrote in an Aug. 25, 1998, letter of invitation to prospective members of Dialogue Steering Committee. Leffall, professor of surgery at Howard

University, is the chairman of the Steering Committee.

The Society recruited the Bushes and Feinstein, as well as about 100 Collaborating Partners, the Dialogue's rank and-file.

After learning that no patients were involved in the ACS planning meetings for the Dialogue, Ellen Stovall, president of the March and executive director of the National Coalition for Cancer Survivorship, picked up the phone and called Leffall.

"Dr. Leffall assured me that patients would be invited later, and I would certainly be included," Stovall said to **The Cancer Letter**.

Patients should be involved from the start, Stovall objected. "If this had been 30 years ago, they may not have had any patients to invite, but because of the progress against cancer, they had about eight million of us out there," Stovall said. "That's a big constituency."

### **Control of the "National Cancer Control Act"**

More than a year after the Dialogue began, ACS chief executive Seffrin described the process to the President's Cancer Panel.

Addressing the panel at its meeting Dec. 6, Seffrin said the purpose of the Dialogue was to bring together the public sector, the private sector, and the not-for-profit organizations.

"We have a couple of important principles," Seffrin said to the panel. "First was to address the issue that seemed to be unanimously accepted: that coordination isn't what it needs to be. And, second, that we need at the highest levels to get all three sectors together around a common table."

In addition to bringing the players to the table through the Dialogue, the advisory committee Seffrin co-chairs with DeVita would seek to replace the National Cancer Act with something called the National Cancer *Control Act*, Seffrin said.

"I have a feeling that we can make a compelling case for new National Cancer Control Act that will see its public policy role enlarged in dealing with the issues of lack of access to state of the art cancer screening, diagnosis and treatment," Seffrin said to the panel.

Consider the amount of political TNT packed into these seemingly innocuous statements:

—Seffrin's central proposition that the federal and private sector cancer programs require "coordination" is quite controversial. Under the National Cancer Act, the federal program is research-driven and run by the NCI director.



Sources said that NCI Director Richard Klausner originally agreed to cooperate with the Dialogue only after receiving assurances that the process would be about “communication” rather than “coordination.”

—Seffrin’s reference to the “not-for-profit sector,” while technically correct, obscures the differences between gigantic voluntary health organizations like ACS and the cancer patient advocacy groups, which include the Society’s most vocal critics.

—The question of what happens when “all three sectors” come to the table has led to challenges from advocacy groups and professional societies. Does ACS get to set the agenda and write the record? For many ACS loyalists who believe in the goodness of the Society, this is not a problem; for many potential partners it is.

An examination of the Dialogue documents by **The Cancer Letter** reveals that members, or Collaborating Partners, are not systematically chosen, the lobbying function is not connected to the deliberations of the group, and the committee redrafting the National Cancer Act is independent from the Dialogue and not answerable to it.

The Cancer Act committee, which serves as “advisory” to Feinstein, was formed without discussion by the Collaborating Partners or the Steering Committee.

—An argument can be made that Seffrin’s reference to the “National Cancer Control Act” was a tad premature. The committee deciding whether an update of the 1971 law is necessary had yet to hold its first meeting. How did Seffrin know the title of the document it would produce? What would happen under the National Cancer Control Act? Would the cancer program be run by another entity?

In an interview, Seffrin said he has since abandoned the name. “I presume that was just my phraseology,” he said to **The Cancer Letter**. “We talked about it just last week. If you say the National Cancer Act, everybody thinks about the 1971 Act. And if you say something else, people say, well, are you overemphasizing cancer control? I believe the committee is going to look at some language like Cancer Legislative Initiatives.”

At the President’s Cancer Panel meeting, Seffrin said trust is replacing the “sense of territoriality” around the Dialogue table.

“I think early on—in the first couple of meetings—people were saying, does this have a

chance of succeeding?” Seffrin said. “Perhaps, there was some sense of territoriality. Whose is this? Is this the ACS initiative? No. Is it a new organization? We already have too many organizations. No, it’s not that.”

Now, skepticism is receding, Seffrin said. “To many people’s surprise, we now have over 100 Collaborating Partners, and that represents literally millions of dollars and millions of people, both professionals and volunteers,” he said. “There is a synergy that comes when most if not all the key players are sitting around the table, able to strategize and understand better what our strengths and our weaknesses are.”

### Unconnected Structures

According to ACS documents obtained by **The Cancer Letter**, organizers of the Dialogue seem to have taken special care to avoid creating any structure for the delegation of authority from the rank-and-file to the leadership.

A draft document distributed last October at a Dialogue meeting at the Bush home in Kennebunkport asserts that the Dialogue is not an organization, but a “forum.” By structuring the Dialogue as a forum, an entity that has no legal definition, ACS avoids getting bogged down in parliamentary disputes that often destroy coalitions, but, by the same token, accepts the absence of transparency.

How does one come to the forum?

By invitation only.

“Collaborating Partners are seated at the invitation of President and Mrs. George Bush after consulting with Sen. Feinstein,” the documents state.

Collaborating Partners—there are 103 of them, according to the Kennebunkport papers—serve on committees studying various aspects of cancer research and cancer control.

Do Collaborating Partners represent their organizations?

Not necessarily. They “represent themselves first,” the document states.

The Dialogue activities are managed by a 16-member Steering Committee, which includes at least one representative of ACS, NCI, Centers for Disease Control and Prevention, and the Pharmaceutical Research and Manufacturers of America. The Steering Committee also must include at least one cancer survivor and one member representing the underserved.

Are Steering Committee members elected?



Draft documents indicate no method for selection of committee members.

ACS appears to be especially thorough in severing any formal link between the will of the Collaborating Partners and the ultimate political agenda. In part, this link had to be severed because representatives of federal agencies—essential members of the process—are precluded from lobbying.

Resorting to the emphatic in-house parlance of ACS, which relies on an extensive use of underlining, capitalization and italics, the Kennebunkport documents describe this unusual separation:

“An independent *voluntary roundtable of public policy representatives* has been created to facilitate the efforts of those multiple participating entities that can engage in advocacy activities as they work together on collaborative and supportive agendas,” states an overview document describing the “Mission and Vision” of the Dialogue.

“This makes it absolutely clear that government agencies participating in the National Dialogue on Cancer are NOT challenged relative to the matter of lobbying, either directly or by implication,” the document declares.

Since the Dialogue is not an organization, it will not lobby, and will not need to be designated as either a 501(C)3 or 501(C)4 organization, documents state. Instead, Collaborating Partners who work in government relations would gather to explore areas of collaboration, the documents say. “It will serve as a forum for other groups that do lobby state and federal governments to work together,” the documents state.

### **Relationship With NCI**

For NCI, the Dialogue is a potential minefield.

Senior NCI officials describe the Institute’s position as detached. To avoid an appearance of boycotting the Dialogue, they show up at meetings, respond to specific proposals—and observe.

At the first meeting of the Dialogue Steering Committee, NCI Director Klausner cautioned against creating a new national organization. According to detailed notes kept by a participant of the Nov. 9, 1998, meeting, “Klausner had a great deal of concern that moving too far in the direction of action may create a situation in which the Dialogue would end up competing with its group members, or with NCI, and complicate or have negative impact on their own strategic planning.”

When ACS scheduled a March 19, 1999, press conference to announce the Dialogue, Klausner declined to participate, sources said.

The press conference lacked content, Klausner said to several people at the time. The fact that a group of prominent people agreed to talk about communications, or for that matter, coordination of cancer programs, cannot be expected to make the evening news, even if a former U.S. President and a U.S. Senator are among those doing the talking. Following the NCI pullout, ACS cancelled the press conference, blaming a minor snowfall.

Meanwhile, NCI officials were shocked to discover that the coordinator of the Dialogue was receiving \$25,000 a year in the Institute’s funds for organizing tobacco control in Latin America.

According to documents obtained by **The Cancer Letter**, Allan Erickson, the Dialogue coordinator, used the money for organizing a bureaucratic infrastructure for tobacco control and for fundraising from pharmaceutical companies.

The Erickson funds—and the nature of his work—were thoroughly hidden. The money went through two contractors before it reached Erickson, sources said.

The expenditures were found during examination of the NCI Division of Cancer Control and Population Sciences contracts, which began with appointment of the new director, Barbara Rimer.

“Although we recognize a need to improve public health infrastructure for tobacco control throughout the world, that is not our mission or responsibility at NCI,” Rimer said to **The Cancer Letter**. “We do make modest investments in international research, but these investments are above board and handled through the front door, not the back door.

“Our resources would be depleted rapidly if we took the path of building infrastructure for tobacco control around the world,” Rimer said. “Taxpayers and legislators would be rightly distressed.”

To find out what Erickson did with the money, NCI officials asked him to submit a detailed “deliverable” paper.

“Over the past several months, I have continued to spend an incredible amount of time in developing relationships and bonds with a wide range of individuals and entities to help facilitate the capacity-building and program outreach processes in an effort to expand the ‘reach’ and lifesaving impact of tobacco prevention and a wide range of control interventions



within 19 South and Central American countries,” Erickson wrote in a breezy, 15-page paper dated Aug. 15, 1999, and submitted to ROW Sciences, an NCI contractor.

The paper describes fundraising activities aimed at securing \$600,000 from pharmaceutical companies. “It took about four or five full days—by phone, fax, email, and one-on-one visits—to get the Glaxo Wellcome and Pharmacia-Upjohn folks to agree to supporting [a meeting of non-governmental organizations],” Erickson wrote about one of his ventures.

Erickson said he didn’t used NCI money to finance his visits to drug companies. “That was ACS money,” he said to **The Cancer Letter**. “Totally.”

For the most part, through extensive use of the word “we” and no less liberal use of passive construction, the document Erickson submitted did not clearly delineate his work from the work of others.

The paper indicates that exposure through the Dialogue gave Erickson opportunities to raise funds for the Latin American project.

“Of course, many of the organizations and agencies and institutions involved in this historic process have Latin American entities,” Erickson wrote. “It is for this reason that a special presentation on the tobacco control plight of Latin America be made to the 100-plus Collaborating Partners of the National Dialogue on Cancer. This intervention has already paid big dividends in terms of several organizations coming to me to express their desire to be supportive and to help them determine what they might do to advance the movement. This is exactly what we had in mind, and it has shown great promise and payoff.”

After Rimer declined to renew his funding, Erickson continued to place calls around the Institute in a futile search for a new patron. The telephone log of one NCI office shows seven calls and two faxes from Erickson over three months, sources said.

Ultimately, Erickson focused his efforts on Otis Brawley, director of the NCI Office of Special Populations Research. “It was not an appropriate area for this office to enter into,” Brawley said to **The Cancer Letter**. “My office supports research that has clear domestic implications.”

Erickson acknowledged raising funds through the Dialogue. “It’s a logical thing,” he said to **The Cancer Letter**. “I’ve not formally brought up [Latin American projects] to the Dialogue on the agenda. I brought it up to individuals, and it may be a topic—I

think it will—to be formally brought up there. There are some of the Collaborating Partners who actually are putting up money.”

International projects are consistent with the goals of the Dialogue, Erickson said. “George Bush has tried twice, and I think probably will succeed very soon to get Prince Charles here for a Dialogue meeting,” he said. “George wants to... globalize the Dialogue idea. He walked with Prince Charles behind King Hussein’s funeral procession, talking about cancer, how terrible it is, and Prince Charles said we’d like to try the Dialogue concept in UK, and we are trying to formulate that right now.”

Erickson said he would like to see a National Dialogue on Cancer in Latin America, too.

“They need it more than we do,” he said.

### **Cancer Act Rewrite: A Procedural Curveball**

Last summer, ACS sprung a procedural surprise on the Collaborating Partners.

At the Dialogue’s Public Policy Roundtable meeting Aug. 11, David Krawitz, head of Shandwick’s Washington office, casually mentioned that an independent committee had been formed to advise Feinstein on revising the National Cancer Act.

Surprised by this revelation, NPCC Vice Chairman Atkins and Kidney Cancer Association President Dixon questioned the process that led to the formation of the committee in a letter to Krawitz.

Three weeks later, Dialogue Collaborating Partners received a letter from Steering Committee Chairman Leffall. The impetus for creation of the National Cancer Act review committee came from Feinstein, not the Dialogue, he wrote in a letter dated Sept. 3.

“Sen. Feinstein has invited [DeVita and Seffrin] to co-chair a special advisory committee, and asked them to select a small group of individuals from the various components of the cancer community,” Leffall wrote. “Although this is not an initiative sponsored by the National Dialogue on Cancer, we want all NDC Collaborating Partners to have an opportunity to provide specific input.”

Thus, a year after Stovall warned Leffall about the flaws in the Society’s plan to invite patients to the table after the Dialogue was designed, she received an invitation from DeVita to join the new committee.

No soul-searching was required for Stovall to respond to the invitation.

“I declined,” Stovall said to **The Cancer Letter**.





Her reasons were similar to ones she outlined to Leffall a year earlier.

“I didn’t want to be the only patient on the committee, because that to me was basically ignoring the fact that there is a burgeoning constituency of hundreds of patient groups out there,” Stovall said.

The patient perspective is represented by the Cancer Leadership Council, Stovall said. “If Dianne Feinstein wanted to have the National Cancer Act rewritten, the first place she should have come to is the patients,” she said.

ACS volunteer Helene Brown said Stovall’s position amounts to a “poor, lame excuse” that does not serve the NCCS constituency.

“There is a complaint coming from Ms. Stovall about the representation of the survivor advocacy movement,” Brown said. “I was not there from the start, either. I was not invited. That’s no reason I should say no when I was invited. Is that a problem, or is it a complaint? It seems to me she is complaining.”

Unlike Stovall’s group, the National Prostate Cancer Coalition sought a seat on the Cancer Act committee once it was formed, but was not invited to join.

“That patient groups are not a core part of the decision-makers—are not widely represented at the committee table—is confusing and appalling,” Atkins said.

“The astonishing increases in this country’s investment in cancer research are largely the result of patient-driven advocacy,” Atkins said to **The Cancer Letter**.

“Because of survivor activism, several hundred thousand people gathered across the country last year, at March-sponsored events, to demand ‘No more cancer’ and continue to put legislative platforms for cancer research and cancer control into the public and Congressional Dialogue,” Atkins said.

“Where does the leadership of this committee imagine that the activist base that will help pass cancer-related legislation actually comes from?”

The proposed rewrite is no small issue, said NBCC President Visco, who is also a member of the President’s Cancer Panel. “If the National Cancer Act needs to be rewritten, it doesn’t need to be rewritten by everyone involved in cancer, because the result would not be a visionary document,” said Visco.

“It would look like something written by a committee, and would be a watered down version of

what needs to be done,” Visco said.

DeVita, director of the Yale Cancer Center, could not be reached for comment.

### **Separating Dialogue From Committee**

Steering Committee member von Eschenbach makes a distinction between the Dialogue, which he helped start, and the Cancer Act advisory committee, which he said raises questions of transparency.

“Cancer is a national tragedy—it is a pervasive scientific, medical, social, economic and political problem demanding our national focus and cooperation in achieving a comprehensive solution,” von Eschenbach said. “The National Dialogue on Cancer was born with the vision that a forum could be created where leaders from the public, private, and for-profit sectors of our society could come together to achieve that cooperation.

“Much good has already been accomplished in this first year and the ongoing work of nine priority teams discussing issues such as research and the disparity in access to quality cancer care offer great promise,” he said.

“But there are also problems and the lack of input by the Dialogue partners into the formation of Sen. Feinstein’s advisory committee is one. It is our responsibility and that of the leadership of the cancer community to resolve such problems. Those who have suffered and died from this disease not only expect it—they demand it,” von Eschenbach said.

Ellen Sigal, chairman of Friends of Cancer Research and a member of the Dialogue Steering Committee, said the Dialogue deserves another chance.

“There is no question there have been mistakes, and there are process issues,” Sigal said to **The Cancer Letter**.

“However, the Dialogue has done something that nobody else has done,” Sigal said. “It’s brought together people who have never been at the same table: governors, patient groups, people from government agencies, the pharmaceutical industry, research people. I believe that any time you have a venue for that kind of communication, the community has the responsibility and obligation to work with it, and to see where it can go, and to look at the potential.

“It’s easy to criticize, and it’s a little more difficult to work together,” Sigal said.

### **Procedural Surprises (Continued)**

Last October, at the Kennebunkport meeting,



ACS staff sprung another procedural surprise on the Dialogue Collaborating Partners.

A draft of a new organizational schema contained an unexpected change: introduction of “Sustaining Members” of the Dialogue Steering Committee.

The new category was to include ACS, CDC, NCI, and the Pharmaceutical Research and Manufacturers of America. “By virtue of the respective leadership roles they played in the development of NDC, as well as their nationwide outreach and grassroots constituencies... these four founding groups are granted ‘Sustaining’ positions on the 16-member Steering Committee,” the document said.

In terms of *realpolitik*, the “Sustaining Member” category was not a success. At least two groups—NCI and PhRMA—did not seek the honor and were unpleasantly surprised to be designated as more equal than other Steering Committee members. On the other end of the spectrum, the oncology professional societies were infuriated to be relegated to the less equal status.

Naturally, this triggered protest from both ASCO and the American Association for Cancer Research, sources said.

The year of surprises concluded in December, when Collaborating Partners received a slick binder with a document titled “Tobacco Tool Kit.” The kit was designed to help lobby state legislatures to spend tobacco settlement money on cancer needs.

“Using the resource materials in the enclosed binder, you can make certain that state governments use a majority of the settlement money for public health and tobacco control programs,” Brown, then chairman of the Dialogue’s Cancer Control Priority Team, wrote in a cover letter dated Dec. 1.

What about cancer research? Was there a reason to leave it out?

“I was surprised when research was omitted,” said Kidney Cancer Association’s Dixon. “I don’t recall the Dialogue Collaborating Partners making the decision to omit research.”

Brown said research was left out deliberately, because few states fund cancer research programs.

“Research is not carried out on state level, with very, very few exceptions,” Brown said to **The Cancer Letter**. “Come on, now, where’s their sense of reality?”

“This is a battle for the money that is at the state level,” Brown said. “How many states have

cancer research programs? There are a handful. States are using those monies to fill potholes, and that’s what our argument was.”

### Promoting the Dialogue Agenda

Last week, ACS Washington staff and Shandwick employees attempted to win the hearts and minds of the patient groups at a meeting of the Cancer Leadership Council.

After the March, the CLC has become the patients’ single most important forum. Though professional societies and ACS are represented at the table, there is no question that the Council is the patients’ turf.

First, ACS staff asked to be invited to the Jan. 11 meeting, which was called to coordinate Congressional appropriations requests and election agendas of groups that included CLC, the National Prostate Cancer Coalition, National Coalition for Cancer Research, and Friends of Cancer Research.

Once invited, ACS attempted to shift the venue to their turf, a conference room at Shandwick, sources said. Unable to move the meeting, ACS staff submitted an agenda. In big bold letters, the proposed agenda read: “National Public Policy Roundtable on Cancer.”

Bringing an agenda to someone else’s meeting is a move of questionable wisdom, even in situations where trust abounds. Bringing an agenda to a CLC meeting also happens to run counter to the group’s traditions. CLC does not use agendas. If members choose to discuss an issue, they do so until nothing remains to be said.

Stovall and Atkins told ACS staff that their attempt was impolitic. “This is no way to do business with the patient groups,” Stovall said to **The Cancer Letter**. “At best, it was poor manners; at worst, it was an insult.”

ACS public policy vice president Smith said the Society staff thought the CLC would have its meeting in the morning, then reconvene as the Dialogue Public Policy Roundtable.

“There were some crossed signals about how the meeting would be set up,” Smith said.

At the meeting, Smith, a former aide to Sen. Tom Harkin (D-IA) who recently joined the Society, acknowledged that the Society may not have been always open and forthcoming about its plans. That done, he asked CLC to send a representative to the Public Policy Roundtable.

The value of having CLC represented at the



Roundtable would have been largely symbolic: Nine of the CLC's 20 member organizations are also represented at the Dialogue, and four take part in the Roundtable.

Moreover, CLC takes no positions as a group, and does not seek to reach consensus positions. "We are not trying to blend and amalgamate people's thinking or their participation," Stovall said. "What we are looking for is independent thought and good analysis. It's very simple. They know how we operate. Their representatives have sat at that table for a long period of time."

The Dialogue was free to apply for participation in the CLC, she said.

Smith said he was not aware of the manner in which CLC conducts business. "Being new to the community, I wasn't familiar with their internal processes," he said. "My point in being there is that the Dialogue and all the spin-offs of the Dialogue are an important exercise and an important activity. I am a person who always tries to find a common ground, and if there are problems, to deal with them openly and honestly."

Later that day, Stovall learned that ACS was planning a Jan. 13 press conference announcing a voter education campaign pegged to the 2000 elections. Failure to disclose the effort during discussion of the cancer groups' agenda stunned Stovall.

"They were saying that they want to work with the patient groups, yet they didn't mention what they were doing," Stovall said. "If you want patients and consumers to be part of a political process, you have to put your cards on the table. If you don't, it means you really don't want patients around," she said.

Smith said no insult was intended. "Frankly, that wasn't on my mind when I was at the meeting," he said.

"There are always going to be skeptics."

### Commentary:

## **Time-Out For A New Sense Of Cooperation, Urgency**

**By Donald S. Coffey**

These are exciting days in cancer research because the long-awaited clinical harvest—the initial payoff from startling discoveries emanating from the nation's increased investment—is just beginning. This federal support resulted from the political efforts of many individuals, advocates, and organizations.

Strong and effective leadership at the NCI has created many new programs to accelerate molecular frontiers and clinical trials. Private philanthropy has also risen to a remarkable level. Biotech and big pharma are activating more programs.

Very disheartening is the bitter dissension hidden among our cancer organizations. This is creating a cloud of mistrust. No one can experience the internal politics of cancer without feeling disgusted. This is a shame, not only for those suffering from cancer, but also for the many wonderful and dedicated volunteers and professionals who work tirelessly in the cancer field. It is very unfortunate that so often the mistrust and acrimony between many of the major groups undermine much of their good services. This petty bickering and jealousy not only cloud their many excellent contributions, but also tarnish the public image of the cancer effort.

We all need a time-out to refocus on our true missions. We are desperately in need of a new sense of urgency and true cooperation that rises above the issues of our own control and protecting our individual interests and organizations. Not to do so may place the conquering of cancer at a lower priority and accentuate mistrust.

Other serious conflicts are on our horizon. Issues of access to proper care for all, the cost of cancer control and cancer research are all essential elements. But we must not pit them against each other. At present, too many are underserved, and they are angry and believe that too much of our limited resources are being drained into research. In a humane and rich society, we should be able to accomplish both of these goals, but will our government respond?

Highly effective treatments could relieve this disparity. For example, very few in our society are ever deprived of the proper protection from smallpox, typhoid, or polio. We should strive for this same accomplishment for cancer. It will only come through research to develop better preventions and treatments.

There are no highly effective treatments, nor proven prevention, to adequately control many of the major forms of cancer. NCI can fund only 22 percent of its peer-reviewed investigator-initiated grant applications. I propose 50 percent. What would it cost? Too many of our people are dying in the lost time. Will we always fight each year in Washington for a 6 percent to 15 percent increase, or is it time for a national effort to expedite the conquering of cancer? The issues of cancer extend beyond research to the



delivery of medical care. Cancer programs now appear throughout government agencies and institutes. The inability of the cancer community to work together and with the government was exemplified last year in how we mishandled the national tobacco settlement: Divided we failed. Will we ever cooperate on critical issues?

The March and the National Dialogue are good ideas. However, they only magnified the disharmony between our groups. Any flaw in decision-making or process that permits hidden agendas will foster mistrust and derail the cooperation needed for the important joint mission. History demonstrates that democracy and open communications are slow and sometimes painful, but are the only way to go when combined with strong and trusted leadership and a responsive system.

Until we can conquer cancer, many will feel frustrated and deprived. Until then, all of our motivations and interactions should be as constructive and inclusive as is possible. We should demand that our organizations and leaders minimize strife and seek harmony. Cancer patients certainly expect us to cooperate, and government is hearing too many conflicting opinions from our groups. In joint efforts, advocates must be at the decision table from the beginning and not signed on at the end.

Can we really conquer cancer or should we accept it like the weather? We can defeat it and it should be done sooner. Just recall that after extensive metastasis throughout his body and following intensive treatment, Lance Armstrong still biked to victory in the grueling Tour de France. Now is the time to increase our efforts over lung, breast, prostate, and other common cancers through discoveries of better methods of diagnosis, treatment, and prevention. We need to cooperate and take our efforts to a much higher level. We can do it by recalling that cancer is our common enemy and that patients are our allies.

*The writer is professor of urology, oncology, pathology, pharmacology and molecular sciences, and director of research in the Department of Urology at the Johns Hopkins University School of Medicine.*

**The Cancer Letter** welcomes Letters to the Editor or guest commentary in response to articles. Text may be sent via e-mail to Editor and Publisher Kirsten Boyd Goldberg, [kirsten@cancerletter.com](mailto:kirsten@cancerletter.com), by fax to 202-362-1681, or to PO Box 9905, Washington DC 20016.

*In Brief:*

## Susumu Ohno, 71, Geneticist At City Of Hope Medical Center

(Continued from page 1)

established a link between musical composition and gene coding sequences, as musical scores and genetic codes are based on repetition. He tested this correlation by translating various gene sequences to music. As chairman of the Division of Biology, Ohno recruited molecular biologists such as **Arthur Riggs** and **Keiichi Itakura**, who in competition with Genentech Inc. created the gene to make human insulin and human growth hormone bacteria. In 1992, Ohno was elected to the Royal Danish Academy of Sciences and Letters, an honor most often bestowed upon Nobel Prize recipients. Memorial contributions may be made to the Susumu Ohno Distinguished Scientist Fellowship at City of Hope Cancer Center; 1500 E. Duarte Rd., Duarte, CA 91010-0269 . . . **STEFANIE SPIELMAN FUND** For Breast Cancer Research at the Arthur G. James Cancer Hospital and Richard J. Solove Research Institute at Ohio State University has reached \$1 million, through a gift of \$500,000 from the William H. Davis, Dorothy M. Davis, and William H. Davis Foundation. In 1998, Stefanie Spielman, wife of NFL linebacker **Chris Spielman**, was diagnosed with breast cancer at the age of 30. . . . **RICHARD NAHIN** was named director of the Division of Extramural Research, Training and Review of the National Center for Complementary and Alternative Medicine at NIH. Nahin will be responsible for research and training, administration of grants as well as overseeing teams of scientists and grants management personnel. Nahin, a career NIH scientist, had been acting director of DERTR since early 1999. . . . **AMY LANGER**, executive director of the National Alliance of Breast Cancer Organizations, received the Gilda Radner Courage Award from the Roswell Park Cancer Institute's Alliance Community Fund-Raising Board. . . . **LEUKEMIA & LYMPHOMA SOCIETY** will be the new name for the Leukemia Society. The name change was prompted not only by the related nature of the blood diseases, but also by the 70 percent increase in lymphoma incidence since the 1970's, the society said. **Dwayne Howell**, president and CEO of the society, said the organization will continue its mission of fighting all hematological malignancies including leukemia, lymphoma, and myeloma.



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