

EDO Principal Correspondence Control

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FINAL REPLY:

Peter Crane
Seattle, Washington

TO:

Chairman Klein

FOR SIGNATURE OF :

** GRN **

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DESC:

Patient's Rights Advocate in the ACMUI (Advisory
Committee on the Medical Use of Isotopes)
(EDATS: SECY-2009-0077)

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AUTHOR: Peter Crane
AFFILIATION: WA
ADDRESSEE: Dale Klein
SUBJECT: National Association of Cancer Patients (NACP)...destinction between Section 501(c)3 charity and Section 501(c)4 lobbying organization ///

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February 5, 2009

Chairman Dale Klein
U.S. Nuclear Regulatory Commission
Washington, D.C. 20555

Dear Chairman Klein:

Nearly four months have passed since I wrote to the Commission to explain, yet again, that the National Association of Cancer Patients (NACP) is not a Section 501(c)(3) charity, as NRC has continued to insist, but a Section 501(c)(4) lobbying organization with a track record of partisan political activity of a singularly nasty sort. The clearest example of this was the NACP's despicable accusation, made two weeks before election day in 1998, that Senator Barbara Boxer, then running for reelection, had delayed the achievement of a cure for cancer by "many years, perhaps decades," by her opposition to the proposed Ward Valley waste dump site. Politics doesn't get much lower than that.

To date I have received no reply to this letter, which like its predecessors was addressed to you, as Chairman. If the problem is that the responsibility for preparing these responses has been delegated to someone unequal to the task, surely by this point those who gave him the assignment are at least as much to blame as the unfortunate official himself.

It is not my purpose today to explain for a fourth time the distinction between 501(c)(3) and 501(c)(4) organizations. I have done so already in terms simple and clear enough for any high school student to have grasped it. If the NRC does not understand the distinction by now, it can only be because it refuses to. Rather, I wish to explain why this matters.

The point of my original letter to the NRC was that by giving the "patient's rights advocate" job to one person after another from the National Association of Cancer Patients¹, the agency was making a mockery of the Commission's intent in creating that position almost 20 years ago. The NRC's response was to dodge that issue by quarreling with my premise, and claiming, contrary to the evidence, that the NACP was not in fact a lobbying organization, but a Section 501(c)(3) charitable group.

Thus if the NRC can bring itself to face the reality of what the NACP actually was - a lobbying group for licensee interests, sailing under false colors - it may then be able to focus on the real question, which is why it has allowed the "patient's rights advocate" position to fall under the exclusive control of licensee interests.

¹It is intriguing that though the last three "patient's rights advocates" have all served with the National Association of Cancer Patients, the NRC, in announcing the appointment of the current "patient's rights advocate" in 2007, described him as having been assistant to the director of the "American Association of Cancer Patients." (The ACMUI website initially carried the same information.) However, no such organization as the "American Association of Cancer Patients" ever existed. How could the NRC get this wrong, when it had been selecting people from the NACP for nearly a decade? Was this really an inadvertent error, unnoticed until I pointed it out, resulting from a simultaneous failure of memory on the part of the nominee, the ACMUI, and the staff? Or did some person or persons decide that the NACP's past record of below-the-belt political attacks made it prudent to come up with new identity for it, in what might be called a Witness Protection Program for lobbying organizations with unsavory pasts?

For the benefit of those who were not around the NRC in the early 1990's, as I was, the NRC Commissioners of that era recognized that the Advisory Committee on the Medical Uses of Isotopes (ACMUI) was overwhelmingly dominated by licensee interests, and that this one-sidedness served the agency's interests poorly. To partially redress the Committee's imbalance, the Commission created a new post, a representative whose primary function would be to advocate for patients' rights. The first appointee, a nurse named Judith Brown, fulfilled that role very effectively - for some in the licensee community, much too effectively. I would suggest that a principal reason for placing candidates with NACP affiliations in that slot in recent years has been to keep it out of the hands of a genuine patient's advocate, such as Ms. Brown.

The fact that an organization calls itself "The National Organization of Cancer Patients" does not necessarily mean that it is an advocacy group for patients. Surely anyone who follows the news understands that innumerable lobbying organizations and pressure groups cloak their political agendas under misleading names.

Let us therefore look individually at the NACP "patient's rights advocates" on the ACMUI. Nekita (Nicki) O. Hobson, NACP Executive Director, was named "patient's rights advocate" in 1998. According to my research, her expertise is in the area of low level radioactive waste disposal. She is the co-author of a 1995 study, published by the University of California at Irvine, entitled *Low-Level Radioactive Waste Management: The California Story*. According to one website, she was formerly employed by U.S. Ecology, the waste disposal company that planned to operate the Ward Valley dump. She participated in a 1995 Low Level Waste forum in San Diego, identified as President of Hobson & Company. She was at one point spokesman for the Cal-Rad Forum, which describes itself on its website as "an association of public and private institutions that use radioactive materials and generate low-level waste" in the Southwest. While I do not for a moment question Ms. Hobson's competence in the field of waste disposal, none of this seems to suggest a primary identification with patients' rights.

Ms. Hobson's successor as Executive Director of the NACP and as patient's rights advocate was Robert Schenter, formerly of Pacific Northwest National Laboratory (PNNL), and now associated with the Advanced Medical Isotope Corporation. He has a long and distinguished record of involvement with isotope production, but again, how does this qualify him to be the primary voice on the ACMUI for the interests of patients?

Mr. Schenter's former assistant at the NACP, Darrell Fisher, is the present patient's rights advocate. He is currently Scientific Director of the Office of National Isotope Programs at the Department of Energy. Before that, he was lead scientist in the radioisotopes program of PNNL. He too has a long and distinguished career, but it is in the field of isotope production. What basis is there to think him suited to be the primary representative of patients, whose interests may not coincide with that of licensees?²

² Take for example the question of notification of patients in cases of what used to be called "misadministrations," until the Commission bowed to the demands of its licensees and changed the term to "medical events." Licensees have historically opposed patient notification, on grounds that it creates a basis for lawsuits; patients typically want such information.

To speak plainly, the NRC's de facto abolition of the "patient's rights advocate" position - turning it into yet another reliable vote for licensee interests - is just one more symptom of the process by which the agency has, over the last 15 or 20 years, given away the store to the NRC's medical licensees.³ Today, it may fairly be asked whether the NRC can still be called an independent regulator in the medical area, or whether, having meekly surrendered to its so-called stakeholders, it functions principally to execute their orders, including appointing their chosen nominees to the ACMUI⁴.

In sum, the reason that it matters whether the NACP was a disinterested charity or a lobbying group devoted to bringing Ward Valley into being is that this helps to clarify whether the NRC, by appointing a series of persons from the NACP to the patient's rights advocate position, has frustrated the Commission's original intent in creating the position.

Finally, the question may be asked why I even bother to inform the Commission about the actions being taken in its name in the medical area, when the Commission has shown not the least interest in receiving this information, much less acting on it. The answer is twofold. First, I have not altogether given up hope of stimulating the Commission to address the deficiencies in its medical program - if not under the agency's present leadership, then perhaps under future leadership. Second, if the day ever comes that the NRC faces the kind of scrutiny for its regulatory failures that the Securities and Exchange Commission has faced this week, no one should be heard to say: "We had no idea, no one told us, we relied on our staff, etc."

Sincerely,



Peter Crane

cc:

Commissioner Peter B. Lyons
Commissioner Gregory B. Jaczko
Commissioner Kristine L. Svinicki
Chairman Ed Markey
Chairman Barbara Boxer
Rossana Raspa, OIG

³Former Chairman Meserve was an exception to this pattern, but did not command a majority of the Commission, where medical regulation was involved.

⁴It has come to my notice that about two years ago, the Commission approved changes in the way that ACMUI members are selected. However, the relevant SECY paper (SECY-06-0028), vote sheets, and Staff Requirements Memorandum do not appear on the lists of documents available through the NRC website. The justification for this omission is unclear. Was it an inadvertent error that kept these materials out of public view, and if not, what possible basis could there be for withholding them?