

OFFICE OF THE SECRETARY
CORRESPONDENCE CONTROL TICKET

Date Printed: Jan 13, 2009 07:58

PAPER NUMBER: LTR-09-0012 **LOGGING DATE:** 01/12/2009

ACTION OFFICE: EDO *To: Miller, FSME*

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ADDRESSEE: Sen. Barbara Boxer *DEDR*

SUBJECT: Patient's rights advocate...on the Advisory Committee on the Medical Uses of Isotopes (ACMUI) *DEDCM*

ACTION: Information *AO*

DISTRIBUTION: RF, *DBA* *ASLBP*

LETTER DATE: 01/01/2009 *Rivera*

ACKNOWLEDGED: No

SPECIAL HANDLING: Made publicly available in ADAMS via EDO/DPC

NOTES:

FILE LOCATION: ADAMS

DATE DUE: **DATE SIGNED:**

January 1, 2009

Chairman Barbara Boxer
Committee on Environment and Public Works
United States Senate
Washington, D.C. 20510

Dear Chairman Boxer:

I am writing to you today about what may seem an unlikely topic: the position of the "patient's rights advocate" on the Advisory Committee on the Medical Uses of Isotopes (ACMUI). This committee advises the Nuclear Regulatory Commission on issues involving nuclear medicine.

You may recall that shortly before election day in 1998, a group calling itself the "National Association of Cancer Patients" issued a press release accusing you of "delaying a cure for cancer, by many years, perhaps decades," according to the publication "Business Wire." The National Association of Cancer Patients described itself as a "non-profit grassroots advocacy group," and many well-meaning people no doubt contributed to it under the mistaken impression that it was a charity. In reality, the NACP was an industry front group, organized under section 501(c)(4) of the Tax Code, with the declared intention of lobbying for the Ward Valley nuclear waste dump. It targeted you for defeat because of your opposition to that proposal.

This was not the first time that the NACP had injected itself into partisan politics. In the runup to the 1996 Presidential election, the NACP boasted in its newsletter that it had contacted 1000 Clinton-Gore donors with a similar message: that the Clinton administration's failure to back the Ward Valley facility meant impeding the search for a cure for cancer.

With the defeat of Ward Valley, the organization seems to have shut up shop, and the people who used to run it, one after another, have since turned up in the position of "patients' rights advocate" on the ACMUI. One of these was Robert Schenter, now chief science officer of the Advanced Medical Isotope Corporation; another was Nekita Hobson, reportedly a former official with U.S. Ecology, the waste management company that planned to run the Ward Valley site. The current incumbent is Darrell Fisher, who currently heads the Department of Energy's isotope program. (At the time Mr. Fisher was named, the NRC press release and the ACMUI website described him as affiliated with the "American Association of Cancer Patients," a non-existent organization, but this error has since been corrected.)

These individuals may all be worthy people, with valuable knowledge and insights to contribute, but their appointment nevertheless makes a mockery, I believe, of what the NRC Commissioners intended when, in the early 1990's, they created the "patients' rights advocate" position. At the time, the Commissioners were trying to give at least some voice to the interests of patients, and redress the serious imbalance on that advisory committee, which overwhelmingly represented licensee interests. The first such appointee, Judith I. Brown, a nurse, brought extremely valuable patient-oriented perspectives to the ACMUI, to the fury of some elements in the regulated

community. The more recent appointments, on the other hand, have exacerbated the imbalance on the ACMUI instead of reducing it.

The membership of the Commission has changed completely since the early 1990's, and with the NRC increasingly under the domination of the entities it is supposed to regulate, the agency has evidently lost all interest in seeing that patients' interests are actually represented on the ACMUI. Accordingly, I wrote to NRC Chairman Dale Klein in April 2008, suggesting that in the interest of truth in advertising, the agency should drop the term "patients' rights advocate," since it had become a misnomer. I explained that the NACP was a 501(C)(4) lobbying organization, and pointed the NRC to the NACP website and newsletter.

The NRC's response, sent over the signature of an NRC Office Director, was to make the bizarre claim that the NACP was in fact a Section 501(C)(3) charity. Assuming that the author of the letter was the victim of misinformation, I wrote back, quoting at length from the NACP newsletter, in which the NACP explained that it was a 501(C)(4) lobbying organization and was creating a separate 501(C)(3) foundation to work in tandem with it.

But the NRC had its story and was sticking to it, regardless of the facts, including what the NACP itself might say. The NRC's next letter to me said that the NRC had confirmed with the IRS that the NACP was a 501(c)(3) charity; the NACP website was "misleading," it suggested. In short, the NRC knew the NACP's tax status better than did the NACP itself. I wrote to the NRC once more, in mid-October 2008, to point out the error, but I have had no reply, and enough time has passed that it seems unlikely I will get one. It is, alas, an old story with the NRC that when it has no good answer to offer, it pretends not to have heard the question.

During the last session of Congress, the House passed legislation to amend the Federal Advisory Committee Act to promote balance on these committees. My understanding is that this legislation was not acted on by the Senate, but that the bills will be reintroduced in the new Congress. I hope that you will support such legislation, and I suggest that when the Senate takes it up, the NRC and its "patient's rights advocate" should be made a case study in the way agencies sometimes flout their statutory obligation to ensure balance on advisory committees.

Sincerely,



Peter Crane
Counsel for Special Projects, NRC (retired)

cc: Chairman Henry Waxman
Chairman Ed Markey
Chairman Dale Klein and Commissioners