

October 12, 2001  
NIOSH Docket Office  
Robert A. Taft Laboratories M/S C34  
4676 Columbia Parkway  
Cincinnati, OH 45226

Re: Public Comments, 42 CFR Part 82

Thank you for allowing public input into the interim final rule of the EEOICPA. As one who has been involved with the Act since before its present inception, I have a strong interest in seeing a meaningful and adequate program for the injured workers of the Cold War and their families. There are a number of shortcomings to the Act, but it is the one we have to work with. Hopefully, I can use my experience to point to some of these shortcomings, and emerge with a better Bill.

Let me first preface my comments with a few facts involving my own situation. I was diagnosed with Chronic Beryllium Disease in 1993, and have symptoms ranging from mild to quite severe. I have educated myself in the peculiarities of this disease for the last eight years, and feel competent to comment on how knowledge of this illness might show avenues of approaching the issues of dose reconstruction in the claimed cancer cases. CBD has been called an "orphan disease", although its presence has been documented since the 1940's. Presently, we have a number of tools at our disposal to detect and confirm the disease. However, these diagnostic tools are not without fault. Beryllium sensitivity can be detected by a blood test called a Lymphocyte Proliferation Test, or LPT. However, the test has its limits, and a positive predicted value of 44-50%<sup>1</sup>. "False negative" tests are common, while the chance of a false positive is much smaller, on the order of approximately one in ten thousand<sup>1</sup>. I have seen testing results of at least a half dozen individuals who have had repeat tests that did little more than confuse. One would receive a positive, then a negative, followed by a 'borderline' or 'uninterpretable' test result. Knowing the limits of the test, I understand the range of results, but this information is often not conveyed to the participant. In my own case, I have had three "normal" sets of test results, despite being confirmed with CBD, and being symptomatic for a number of years. This is most likely due to medicines and a depleted immune system, which masked an accurate test. It is common knowledge that some medicines mask these results<sup>2,3</sup>. A close friend of mine underwent the second step of testing, the invasive Bronchoalveolar Lavage, or BAL, which produced negative results, following an unconfirmed abnormal BeLPT. She had been on steroid treatment recently prior to the procedure, so results are in question. She is symptomatic and the single abnormal LPT shows, in my opinion, exposure, and reaction.

<sup>1</sup> DOE-SPEC-11142-2001, April, 2001

<sup>2</sup> ORISE LPT Results, 02/27/97

<sup>3</sup> Immune System Test Results, AML Laboratories, September, 2000

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I take the time to examine the shortcomings of the Beryllium testing to make a point of why I feel the dose reconstruction process being considered will be grossly flawed. CBD is supposed to be the "most provable" of the covered illnesses, and the above examples are but a few of the inconsistencies in testing. In considering the dose reconstruction of the covered cancers, "sound science" will never overcome the inconsistencies that have been public knowledge since the beginning of the investigation into the formation of the EEOICPA. In many cases, records were incomplete, inaccurate, or in the shredder. Dosimetry records were also unreliable, and as noted in the 2000 DOE Public Hearings <sup>4</sup>, badges sometimes did not even have film in them. The best of scientific information will be inconclusive if based on flawed data. Presumption of causation should not be the burden of the worker or survivor. Records were simply too haphazard, for whatever reason. Let me say, I am adamantly opposed to giving a blank check to anyone who ever drove by one of these sites, but benefit of the doubt must go to the claimant, or justice, such as it is, will not be served. Those of us who devoted our careers to the winning of the Cold War deserve truly adequate compensation. There is more than enough supporting evidence:

NEC Report of 2000 <sup>5</sup>, the 2000 report from the testimony of the Ohio Bureau of Workers' Compensation <sup>6</sup>, testimonies from the March 2000 Senate Hearings, chaired by Senator Fred Thompson of Tennessee <sup>7</sup>, comments from members of the Oak Ridge Citizens Advisory Committee on Public Health Service Activities <sup>8</sup>, Worker Advocacy Advisory Committee meeting, July 2001 <sup>9</sup>, comments from the PACE and AFL-CIO unions, individual letters to local newspapers, comments on the [www.beryllium.org](http://www.beryllium.org), [www.downwinders.org](http://www.downwinders.org), [www.che-or.org](http://www.che-or.org), [www.state.nv.us/nucwaste/index.htm](http://www.state.nv.us/nucwaste/index.htm), the list could go on forever, and I apologize both for leaving out some of the key players, and the length of the comments. However, this is perhaps a start to the most important legislation for American workers in years. We do not want to see the mistakes of the past repeated, hospitals will not accept IOU's for a lung transplant. Presumption of causation must be the key to assuring at least a limited justice to those who gave so much- some enduring ridicule and an agonizing death- in winning the Cold War. Last week Secretary Chao pledged support for those devastated by the WTC and Pentagon disasters, and deservedly so. Those who gave so much, be it less spectacular, deserve no less.

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<sup>4</sup> <http://tis.eh.doe.gov/advocacy>

<sup>5</sup> National Economic Council Report, March 2000

Part 1: The Link Between Exposure to Occupational Hazards and Illnesses In the Department of Energy Contractor Workforce

Part 2: Benefits Available to Department of Energy Contractor Personnel from State Workers' Compensation Programs

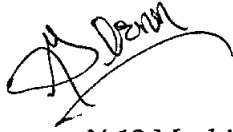
<sup>6</sup> May 2000 Testimony of the Ohio Bureau of Workers' Compensation, Columbus, Ohio

<sup>7</sup> Committee on Government Affairs, U.S. Senate, March 2000

<sup>8</sup> ATSDR Meeting, Oak Ridge, TN, May 25, 2001

<sup>9</sup> Worker Advocacy Advisory Committee, USDOE, Public Meeting Transcript, July 20, 2001

Glenn Bell



Y-12 Machinist, & CBD Victim

Beryllium Victims Alliance

Y-12 Beryllium Support Group

Coalition for a Healthy Environment

DOE Chronic Beryllium Disease Protection Program Member

DOE Risk Analysis Committee, Worker Representative

Contacts and Resources:

<http://www.beryllium.org>

<http://www.che-or.org>

<http://www.downwinders.org>

<http://www.state.nv.us/nucwaste/index.htm> ("What's News")

[http://www.oakridge.doe.gov/foia/doe\\_public\\_reading\\_room.htm](http://www.oakridge.doe.gov/foia/doe_public_reading_room.htm)

<http://tis.eh.doe.gov/advocacy/index.html>

<http://www.eh.doe.gov/be>