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STATEMENT OF REPRESENTATIVE EDWARD J. MARKEY
BEFORE THE HOUSE JUDICIARY COMMITTEE
SUBCOMMITTEE ON ADMINISTRATIVE LAW AND GOVERNMENTAL RELATIONS
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Chairman Bryant and members of the Subcommittee, thank you for the opportunity to appear before you today. I wish to commend the Chairman and the Subcommittee for convening these hearings as the Congress begins to consider the remedies necessary to correct past wrongs which the U.S. government has committed against its own citizens.

The recent acknowledgement by federal officials that the government conducted radiation experiments with human guinea pigs has grabbed the attention of all U.S. citizens, and the reason is that most people assumed that our country would not engage in this kind of activity. I think the fact that the federal government -- our government -- funded or engaged in this kind of activity is the most disturbing aspect of this whole story. Most Americans thought that our country would not take that kind of action. To close the door on this regrettable legacy, we should focus on the proper remedies to respond to past wrongs, make certain these things can never happen again, and do the right thing today by compensating those who suffered injury.

With the Subcommittee's indulgence, I would like to briefly describe my involvement with these issues. In October 1986, I released "American Nuclear Guinea Pigs: Three Decades of Radiation Experiments on U.S. Citizens," a staff report of the House Subcommittee on Energy Conservation and Power. This report revealed the frequent and systematic use of human subjects as guinea pigs in experiments with ionizing radiation which provided little or no medical benefit to the subjects. With the permission of the Chairman and this Subcommittee, I wish to provide a copy of the 1986 report for the record.

The 1986 report also discussed some of the more repugnant or bizarre experiments. At the top of this list were the plutonium injection experiments, in which patients designated terminal within 10 years were given plutonium to determine how the body handled this radioactive material. This experiment provided no medical benefits to the subjects, and is marred by a lack of informed consent, since even the word "plutonium" was classified during the 1940s. Moreover, as my staff report documents, when the Atomic Energy Commission conducted a follow-up study in 1973 to determine the amounts of plutonium remaining in subjects' bodies, informed consent was not obtained from patients who were still alive, nor from families who were asked for permission to exhume the bodies of deceased subjects. Sadly, thirty years later, the word "plutonium" was still too explosive for the federal government to tell the victims.

In another set of experiments which have only recently come to light, at the Fernald School in Massachusetts during the 1940s and 50s, schoolboys classified as mentally retarded were fed radioactive calcium and iron with their breakfast meals. Yet parents of these children were deceived about the nature of the experiments when they gave their consent. With at least one experiment, the letter from the School requesting consent never mentioned that radioactive material would be fed, noted that experimental subjects were selected from a "group of our brighter patients," and implied that the experiment might result in "gains in weight and other improvements."

These experiments were funded by the Atomic Energy Commission, the National Institutes of Health, and the Quaker Oats Company, and research was conducted by faculty at MIT and Harvard. These experiments clearly fit within the scope of the documents that I requested from the Department of Energy in the mid-1980s, yet they were not revealed then. One question that I have today is whether we know the full scope of human experimentation; whether the 1986 staff report provides a reasonably accurate picture or whether the extent of testing is larger.

One reason why I find these experiments so repugnant is because of the vulnerable nature of the subjects used. It was no accident that the students at the Fernald School were fed radioactive iron, and not the students at MIT. It is no accident that the terminally ill were experimental subjects, including some who were comatose. It is no accident that prisoners, soldiers, and the elderly were used for testing with radioactive material. Such members of society are not fully enfranchised and lack control over their lives. They deserve protection, not exploitation as human guinea pigs. Certainly, experimental drugs or treatments intended to make the patient better may be used. But that was not the case with these experiments. We must again look at our ethical guidelines to make certain they protect the vulnerable.

The response of the Reagan administration to my 1986 staff report can be described as, "Thanks for the information, we're not going to do anything," and the report languished on a shelf at the Department of Energy until recently. Then in November 1993, a series of articles by Eileen Welsome, a reporter at the Albuquerque Tribune, identified some victims of the plutonium injection experiments and their families, and put a human face on the issue. When Secretary of Energy Hazel O'Leary learned of these experiments and my 1986 staff report, she decided that the appropriate course of action was full disclosure of all information on experiments with human subjects. I commend Secretary O'Leary and support her efforts to lift the shroud of secrecy on her Department, and bring the questionable past of the Department and its predecessor agencies into the sunshine of public scrutiny.

When I released my staff report in 1986, I had assumed that experiments of such nature were the product of the arrogance of the early Atomic Age, and the paranoia of the Cold War. But as these experiments have gained new attention, I have been shocked and dismayed to find that individual scientists feel compelled even today to defend these experiments of years ago. Some have stepped forward to claim that such experiments should

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not be judged according to today's standards, and besides, the doses given were low. To these attitudes, I have two responses: First, contrary to such opinions, the 1940s and 1950s were not devoid of patient knowledge or ethical standards. Radiation and its health effects were widely discussed in the era of bomb shelters and air raid drills. Moreover, the Nuremberg Code was in effect, written by the United States and the Allies in the aftermath of World War II, and it established guidelines on obtaining informed consent for experiments. Clearly, the Fernald School experiments violate this basic human rights standard.

In this regard, I commend the recent statement of Charles Vest, president of MIT, who acknowledged that while doses at the Fernald School may have been relatively low, he was "sorry" for the experiments, because of the children selected and the lack of informed consent. MIT explained that President Vest issued his statement because "it seemed the decent thing to do," and I applaud his decency.

It is not my desire to blame present leaders of organizations and institutions for past mistakes. My concern is that institutions work with Congress today to do the right thing to address past abuses. I therefore welcome the leadership by the Clinton Administration, and I look forward to working with the Administration, this Subcommittee, and the scientific community in formulating proper responses today. Clearly, this Subcommittee has much experience in crafting compensation plans.

I have already circulated to our colleagues a letter inviting them to co-sponsor legislation with me that would accomplish three goals:

- Require full disclosure from the Department of Energy, while protecting the privacy of subjects and their families, on experiments with ionizing radiation that provided little or no benefit to the subjects and were funded by the Department or its predecessor agencies;
- Require the Department of Energy to formulate a plan to conduct proper medical follow-up of subjects where it seems feasible and indicated; and to provide free medical care for injuries related to experiments;
- Require the Secretary of Energy, after consultation with other appropriate federal officials, to recommend appropriate compensation for those subjects or their families who have suffered damages, and make any other recommendation for appropriate compensation for those who have been wronged.

The legislation I will propose does not impose a particular compensation plan, but rather directs the Secretary of Energy to report to Congress in six months on what should be the appropriate scheme. I recognize that there is some debate on the effectiveness of the Downwinder legislation and the Radiation Exposed Veterans Compensation Act of 1988 -- two subjects that this Subcommittee knows well. In light of that debate, I think it is

appropriate for the Administration to review these and other compensation systems and then develop an appropriate system for the victims identified here today. The best system would merge science with compassion in determining standards for compassion. Provision should also be made for appropriate remedies other than monetary compensation to unwitting subjects who suffered "dignity injury."

The legislation that I will introduce will focus on the Department of Energy and the information it possesses because of my previous involvement with that Department. However, I note that other witnesses before this Subcommittee will discuss experiments conducted by the federal government using chemical or biological agents. Unfortunately, the sad history of the government's use of its own citizens as guinea pigs is not limited to ionizing radiation. I think it is important for this Subcommittee to explore other areas where Americans may have been used as experimental subjects and exposed to danger.

For example, a recent report from a scientific panel convened by the Institute of Medicine, Veterans at Risk, investigated the long-secret exposure of soldiers as experimental subjects to chemical warfare agents. This report noted that over 60,000 military personnel were used as subjects, including 4,000 soldiers exposed to mustard gas and Lewisite, a related chemical. The panel concluded that although experimental subjects were designated "volunteers," it was clear from official reports that recruitment of subjects "was accomplished through lies and half-truths," during World War II and later experiments as well. The panel found it "most appalling" that no long term medical follow-up was conducted on the subjects, despite knowledge available by 1933 that mustard gas and Lewisite could produce long term detrimental health effects.

Mr. Chairman and members of this Subcommittee, what this Congress has encountered is no less than the frequent and systematic use of U.S. citizens as guinea pigs during experiments with a variety of dangerous radiation, chemical, and biological agents. These experiments shock the conscience and demand a response. I look forward to working with you and our colleagues to gain full disclosure of this shameful past, to provide the medical follow-up and treatment that experimental subjects deserve, and to provide restitution those citizens who have suffered injury.