

Quixotic Quest

A Crusade to Publicize An Old Risk Affects Few but the Crusader

Radium Was Used to Shrink Adenoids; Stewart Farber Insists It Be Looked Into Six Years of Family Sacrifice

By MARK MAREMONT

Staff Reporter of THE WALL STREET JOURNAL
PAWTUCKET, R.I. — Stewart Farber sweats as he lugs boxes into a U-Haul truck. Mired in \$135,000 of debt and hounded by creditors, he has sold the Victorian house where his family lived for 13 years and is moving to a smaller home in Vermont, where he plans to file for bankruptcy.

"We're broke, we're losing everything," says Mr. Farber's wife, Anne, packing dishes in the kitchen. "I don't know why he can't move on and get a job."

A scientist by training, Mr. Farber, 53 years old, once worked measuring nuclear risks for utilities. But he hasn't held a job in six years. Instead, he has devoted his life to uncovering what he sees as a long-ignored medical scandal.

From about 1940 to the late 1960s, doctors stuck radium-tipped tubes up the nostrils and into the nasal passages of somewhere between 500,000 and 2.5 million Americans, exposing them to large doses of radiation. Mr. Farber is convinced that the procedure, usually aimed at shrinking adenoids, increased patients' risk of cancer and other diseases. He refers to it as "Nagasaki up the nose."

Research indicates the danger may be real. The Veterans Administration shortly will release a study of 1,214 Navy veterans who were treated with nasal radium. The study, ordered by Sen. Joseph Lieberman of Connecticut, found they had a 47% higher rate of death from head and neck cancers and a 29% higher overall mortality rate than veterans who weren't treated. The authors said that while the results may not be statistically significant, they do suggest "increased risk."



Stewart Farber

Sounding an Alarm

Convinced that lives could be saved, Mr. Farber has relentlessly prodded government and health officials to alert former patients and screen them for cancer and other problems, such as thyroid disorders. Because most of the patients had the procedure as children, many may not recall it or know of any danger.

"There's a lot of suffering out there," says Mr. Farber, who has been contacted by former patients plagued by disorders ranging from salivary-gland cancer to eroding jaw bones. "We can't undo the harm from this, but we can get these people better medical care."

Mr. Farber is no anti-nuke zealot. He spent two decades as an environmental-radiation expert for utilities and became convinced nuclear power was safe. He once did a study concluding that some kinds of bottled mineral water contained more radioactivity than waste water from nuclear power plants.

Moreover, unlike most medical activists, he has no personal connection to his subject. He heard about the nasal-radium treatment years ago and became fascinated.

But after years of work, about all he has accomplished is becoming the leading expert on a topic hardly anyone cares about. Fewer than 1,000 people have been notified they had the treatment. A large-scale health study sought by Mr. Farber has never been launched. Plaintiffs' lawyers have given up on filing lawsuits. "I feel like I've been kicking a dead chicken," he says bitterly.

Personal Cost

Mr. Farber has blown through almost his entire \$71,000 retirement account, run up debt on 23 credit cards and let his life insurance lapse. His commitment has put strains on his marriage and dashed the couple's hopes of sending their son to private school. Of Mr. Farber's cause, his wife says: "I don't admire it anymore. I've lost my whole life over it."

The nasal-radium procedure — technically, nasopharyngeal radium irradiation — was developed by Johns Hopkins University doctors in the 1930s after studies showed that lymphoid tissue such as adenoids shrank greatly in response to radiation. The procedure was used routinely in some parts of the country by the late 1940s to treat children with recurrent ear infections. It sometimes was used to prevent regrowth after surgical removal of tonsils and adenoids. The military used it on 8,000 to 20,000 aviators and submariners to shrink tissues that were blocking ear passages and hampering adjustment to sudden changes in air or water pressure.

Typically, long, thin rods with radium-filled tips were slipped into the nostrils and left there for 10 to 12 minutes. Then the procedure was repeated twice more over a number of weeks.

It's estimated the treatments hit the adenoids — the lymphoid tissue at the back of the nose and upper throat — with at least 2,000 rads of radiation, although some guesses are much higher. Nearby organs

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Health Crusader Sacrifices, Achieves Little

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such as the brain, thyroid and pituitary glands received collateral radiation ranging from a few rads to perhaps 150. By comparison, cancer patients typically get a total of about 6,000 rads over a monthlong period to shrink their tumors; an average diagnostic X-ray delivers about one-twentieth of a rad.

"I remember sitting in a chair with these rods going up my nose," says Steven Nassau, a 59-year-old Connecticut lawyer whose adenoids were irradiated when he was seven or eight. Thirty years later, he was diagnosed with a rare cancer of the soft palate, and after several surgeries now wears a prosthetic device so he can talk and eat. About a decade ago, a benign tumor was found on his brain stem.

Mr. Nassau doesn't know whether the procedure contributed to his cancer, but he says nobody in his family has a history of similar malignancy. "It would have been nice" if someone had warned him to watch for possible problems, he says.

Campaign Begins

Nearly six years ago, Mr. Farber took up the cause. He had just taken a buyout offer from a Massachusetts utility that was downsizing. He was living off severance and renovating his attic when revelations of past government-sponsored radiation tests on civilians burst into the news. Retarded children were fed radioactive cereal at the Fernald School in Massachusetts decades ago, and prison inmates in the Pacific Northwest had their testicles irradiated.

Mr. Farber says he realized that given the number of people and radiation levels involved, these cases were minor compared with the nasal treatment, which he had heard about earlier from a friend who had it (and remains in good health). But nasal radium had been all but forgotten by the medical establishment. He figured that several months of raising public consciousness would prompt a wider study, in which he hoped to play a role.

At the time, everything seemed right in Mr. Farber's life. After 16 years of marriage and a long struggle with infertility, the Farbers had an infant son, Joshua. Vacations were spent at their second home in Vermont's Mad River Valley. They both drove Saabs.

Working from a small office next to the couple's bedroom, Mr. Farber began blitzing federal officials with calls for action and filing Freedom of Information Act requests. Early on, he found a supporter in Sen. Lieberman, some of whose constituents had the treatment at a naval base in Groton, Conn. In 1994, Mr. Farber testified at hearings the Democratic senator called, where he was commended for his "dedication and hard work." It was a heady moment. He recalls the flashes of photographers and the television cameras.

Little Follow-Up

His elation was short-lived. Although a top Navy doctor testified that treated veterans might face some risk, the Navy said it had no plans to notify them because it lacked data on who was treated. The Navy deferred to the federal Centers for Disease Control and Prevention.

But the CDC worried about alarming former patients and said there was only scanty evidence the procedure caused health problems. And the task of unearthing huge numbers of decades-old medical records was daunting. The CDC agreed only to hold a conference on the matter—a year later.

Disappointed, Mr. Farber set his sights on a presidential commission that had been formed to examine the old experiments at Fernald and elsewhere. He peppered the commission with documents and phone calls in 1994 and 1995, and succeeded in getting nasal radium on its agenda.

The panel concluded, based on exposures, that nasal radium treatment of children probably posed the highest cancer risk of any of the procedures it examined. But it recommended against notification or medical follow-up, saying that much of the risk had already "been expressed"—the victims already had diseases or were dead—and that most head and neck cancers couldn't be detected early enough to make a difference.

O.J. Day

Dan Guttman, a Washington plaintiffs' lawyer and former Ralph Nader activist who was executive director of the commission, says Mr. Farber was an effective advocate, and the panel probably would have favored notification "if there was evidence that people could be helped." But telling them a long-ago medical procedure might pose risk would produce "a national panic of a million people, and what would you do with them?"

To top it off, the report came out on Oct. 3, 1995, the day of the O.J. Simpson verdict. Media accounts of it received poor play.

Around the same time, the CDC finally convened its nasal radium conference. Its panelists also voted against screening and widespread notification. "I wouldn't be surprised if there were marginal adverse effects," says Richard Jackson, head of a CDC environmental-health center. But he says the CDC can't spend part of its limited resources on an effort likely to have little impact. The panel suggested further research on two small patient groups already being followed, not the enlarged study Mr. Farber sought.

Family Stress

In effect, Mr. Farber was caught in a bureaucratic Catch-22. Because existing studies were too small to conclusively link nasal radium to health problems, officials could say there wasn't enough evidence to justify tracking down and alarming so many people. But the government wasn't willing to pay for a larger study that might provide the evidence.

By late 1995, Mr. Farber had spent two years on his crusade and had little to show for it. His wife was getting increasingly angry.

"He was totally focused on radium. He couldn't do anything else," Mrs. Farber says, sitting with her husband outside their Vermont house amid a clutter of toys and building materials. Joshua was two years old before he moved out of their bedroom, she says, because Mr. Farber was so consumed by his work he couldn't make time to clear out the child's room.

After Mrs. Farber went back to work part time, the couple hired a baby sitter to care for Josh. That angered Mrs. Farber, who felt her husband, not earning a living, should be helping more. "Why pay a baby sitter when Stewart was sitting right there?" she asks.

Tired of the phone ringing day and night, she at one point made her husband



Joshua & Anne Farber

move operations to a rented apartment next door. He strung a phone line between the places to save money. But later to save costs he moved into the family dining room.

The couple took a short trip to Oregon and California two years ago for their 20th wedding anniversary, but Mr. Farber "couldn't leave it behind," his wife recalls. From the road, he repeatedly called his sister-in-law, who was staying with their son, to get her to fax off materials to various people.

Financial Plight

Mrs. Farber was only dimly aware of the family's growing financial squeeze; her husband handled the bills. But one day in early 1997, they received a foreclosure notice on the Vermont home. She was stunned. Mr. Farber recalls his wife crying, calling him a "stupid idiot." He reluctantly tapped into his retirement fund to pay some of the arrears on the Vermont mortgage and other, mounting bills.

Mrs. Farber, handy with a sewing machine, made clothes for their son to save money. Mr. Farber stopped taking his cholesterol-lowering medication because he couldn't afford the \$60 to \$70 monthly tab. Last year, he volunteered for a cholesterol-drug study just to get a decent health exam and a shot at free medication.

Mr. Farber kept telling his wife and friends he would eventually be able to parlay his expertise into some kind of paid role in an epidemiology study. Today, he admits he was "naive." As an activist, he was unlikely to play a role in any unbiased scientific research. "In my desire to get something done," he says, "I didn't pay enough attention to the fact that I'd be excluded from involvement."

Along the way, Mr. Farber alienated some potential allies, who regarded him as overbearing and often self-righteous. When the American Brain Tumor Association declined to call for nasal-radium notification, he fired off a letter questioning whether the group "was committed to its own goals." Mr. Farber seldom writes broadsides without copying the recipient's superiors. One 1996 critique sent to a CDC staffer copied 16 people, including four cabinet secretaries, three senators and the White House. A 1997 news release ran to 48 pages, with three appendices, a 30-item bibliography and radiation-risk calculations incomprehensible to most.

Mr. Farber was "incredibly difficult to work with," says Wally Cummins, whose Washington lobbying and research firm worked with him on the issue. "He talks too damn much. He makes me crazy."

Playing the Tort Card

Beginning in 1996, Mr. Farber started research for law firms considering suits on behalf of nasal-radium patients. If the government and medical establishment "weren't ready to help the people," he reasoned, "maybe we could hit them over the head with a two-by-four." The consulting brought in about \$50,000 through last year, not enough to shave much from the debt pile. Mr. Farber thought he might eventually get expert-witness fees or even a small share of the lawyers' take from any winning suits.

But one by one, the law firms concluded that the issue was hopeless. The company that made the radium applicators was out of business. Proving negligence against in-

dividual doctors or Johns Hopkins in Baltimore would be difficult because using nasal radium had been accepted practice. Linking the treatment to harm would be tough. The issue is a "legal morass," says one lawyer who gave up on suing.

Mr. Farber's last hope on the legal front died a few weeks ago, when a Maryland firm that had been examining whether to sue the Belgian company that mined the radium told him it was dropping the case.

Even some of Mr. Farber's triumphs failed to have wide impact. After long insisting it had almost no records of treated veterans, the Navy in 1996 found an old medical log. It appeared to contain names of about 1,200 men who had the treatment. The VA agreed to notify them so they could ask their doctors to do careful exams. But the VA so far has contacted just 138 veterans, partly because it says it is having trouble finding them.

Short Reach

As for the CDC, it eventually agreed to do "outreach" to tell doctors about the long-ago treatments, including a satellite-television conference beamed to VA hospitals. But when Mr. Farber went to a Providence, R.I., site, he was the only one there. In all, just 100 people, including 41 doctors, watched the presentation.

Mr. Farber also is angry about a study by a Johns Hopkins researcher, a follow-up to earlier work by the university. Completed two years ago, the latest study found seven brain tumors among about 900 people who had the nasal radium treatment as children decades ago, versus none in a nontreated control group of about 2,000. It also found elevated risks for other head and neck cancers, and strong evidence of hormonal changes that could be related to pituitary-gland damage.

But the study hasn't been published. Mr. Farber suspects a cover-up by Hopkins. "That's not true," says the main researcher, Jessica H.C. Yeh, who says publication has been delayed by her own "family issues." She hopes the work will get into print around year-end. The results aren't conclusive because of the sample size, she says, but they "suggest something is probably going on with the treatment."

Since their move to Vermont this spring, Mrs. Farber has been pushing her husband to end his quest and find a job. He admits he can sometimes be unrealistic. He is still holding onto a decade-old investment in a biotech stock that is now worth less than three cents a share. "I've got some psychological thing. I hang onto something. I never let go," he says.

Zappa Zapped

But at last, he says, "I'm through playing Don Quixote. I'm just going to have to back away from this and get my life in order." He worries about finding money to send his son to college, and he is afraid his advocacy work has harmed his chances to do consulting for the nuclear industry.

But then, Mr. Farber hears a rumor that the late rock star Frank Zappa had the treatment, and rushes to the library. Sure enough, Mr. Zappa revealed in his autobiography that a doctor had stuffed a "a long wire thing" with a pellet of radium up his nose and jokingly wondered whether "my handkerchief is glowing in the dark." Like a bird watcher finding a rare species, Mr. Farber posts the discovery on his Web site, saying "Zappa got zapped." Mr. Zappa died in 1993 from prostate cancer, which is unlikely to be related.

Sitting in his tiny guest bedroom, surrounded by unopened boxes, Mr. Farber scrolls through his computer database of about 1,000 nasal-radium recipients. He is familiar with many. The woman in Pennsylvania with a history of reproductive problems. The Maryland man who had the treatments every week of the school year for three years. "They found parts of his brain had been fried," Mr. Farber says.

He picks up the phone to call a Maryland insurance salesman, John T. Binebrink Jr. Mr. Binebrink, 52 years old, had the treatment at a Hopkins-affiliated clinic in the late 1950s, saw a local TV report on the subject, and contacted Mr. Farber for help. Mr. Binebrink says he has mole-like growths cropping up on his neck, constant nosebleeds and severe migraines. He says he is concerned about getting cancer but has hit a "brick wall" trying to get information from Hopkins or his own doctors.

Mr. Farber advises him to get regular exams, then directs him to his Web site for further information. "I wish I could do more," Mr. Farber says. "But we have limited funds." Reached later, Mr. Binebrink expresses gratitude. "If it wasn't for Mr. Farber, we wouldn't know anything about this," he says. "I've never met the man, but I love him."

Mr. Farber puts Mr. Binebrink's name in a pile to be added to his database. "Someday," he says, "maybe this will come in handy."