



LIFELINES

of the National Association of Cancer Patients

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FFTF reactor gets a reprieve; could produce medical isotopes

Energy Secretary Spencer Abraham has postponed for 90 days the implementation of a decision made late last year by the Clinton Administration to permanently shut down the Fast Flux Test Facility (FFTF).

The delay, announced on April 25, gives the Bush Administration time to review the project and determine whether the Hanford, WA reactor should be brought to full power to produce medical and research isotopes and serve other national purposes such as materials and nuclear fuel research, or be permanently shut down.

FFTF was completed in 1992 at taxpayer expense, but has never been brought to full operational status, and for the past eight years has been idling in a "cold standby" mode instead. It has the potential to manufacture many medical and research radioisotopes that are currently not available at all in the U.S., or are available in such small quantities that clinical trials for promising new treatments cannot be conducted.

"FFTF is a valuable and unique national resource that absolutely must be preserved," said Dan Negroni, president of the

National Association of Cancer Patients. "Its operation literally means the difference between life and death for many cancer patients who could benefit from the isotopes it will produce."

Negroni said that even now, some research projects have been abandoned or put on hold because the researchers cannot obtain a reliable supply of needed isotopes.

"Smart bullet" medical isotope treatments target cancer cells without damaging surrounding healthy tissue, and are very effective in treating many types of cancers with few of the debilitating side effects of traditional treatments such as surgery and chemotherapy. For example, it has been shown that prostate cancer can be treated with seeds containing Palladium-103, a treatment that is equal in effectiveness to other standard treatments (including surgery) but has significantly fewer devastating side effects such as incontinence and impotence. Unfortunately, Palladium-103 is not readily available in the U.S., but could be produced by FFTF.

Secretary Abraham is expected to reach a decision on FFTF's future in July or August.

Legal information empowers cancer patients

What are the legal rights of cancer patients—in the workplace, in the community, and when it comes to insurance companies? Until 1997, short of consulting a private attorney which many cannot afford, there was no place in the U.S. that a patient could go to find answers to these and many other important legal questions.

That was when the Cancer Legal Resource Center was founded as a joint program of Loyola Law School and the

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You can help!

Let Secretary Abraham know that you support restarting FFTF so that it can produce needed medical and research isotopes, and urge him to do it quickly so that today's patients can benefit from it.

His e-mail address is thesecretary@hq.doe.gov or mail a letter to him at Department of Energy, 1000 Independence Ave., SW, Washington, DC 20585.

Legal information *(continued from p. 1)*

Western Law Center for Disability Rights.

Barbara Ullman Schwerin, J.D., is director of the Center. Located in Los Angeles, the Center serves clients all over the country.

About 75% of the problems people bring to the Center have to do with issues related to cancer and the workplace, insurance questions, and access to government benefits such as Social Security Disability Insurance or Supplemental Security Income, according to Schwerin.

“For instance, a caller may say, ‘I was just diagnosed and I need to figure out how I’m going to be able to work and keep my job and still take time off for treatment.’ We get calls like that from people who want to know what laws are in effect and how they might use them.”

The Center also offers information on dealing with discrimination in the workplace, such as the case where the caller said, “I’ve told my boss about my diagnosis and now I’m not getting favorable employment reviews like I used to get. What can I do?”

Or the California caller who said she had been taking time off for doctor’s appointments and her supervisor was starting to hassle her. The Cancer Legal Resource Center provided her with information on the Americans with Disabilities Act and the California Fair Employment and Housing Act so that she could educate herself and also educate her employer. She provided the information to the company

Human Resources person, and when she met later with the same person it was clear that her employer had read all the materials and had consulted with their legal counsel. As a result, they were able to work out a reasonable accommodation so that she could get the needed time off for medical treatment

What are a cancer patient's legal rights?

without constantly battling her supervisor over this issue.

Schwerin is assisted by second- through fourth-year law students who are trained to conduct preliminary interviews with callers and are a part of the consulting team that considers each case and decides the appropriate action to take.

“A lot of what we do is provide information. We cannot give legal advice, but we can provide legal information and education,” Schwerin said. “We basically try to let our callers know what options might be available. What action the caller takes is their decision, part of their empowerment.”

[Editor's note: Barbara Schwerin will be a speaker at the Cancer Survivorship: San Diego! celebration on September 9, 2001. See back page for more information. Also, thanks to Southern California Women's Cancer Connection for information used in this article.]

Promising new treatment for pediatric cancer

St. Jude Children’s Research Hospital in Memphis, TN, recently announced that a new treatment protocol now in clinical trials there could dramatically increase survival rates for two types of pediatric brain cancers. The relatively rare pediatric cancers being treated are medulloblastoma and supratentorial primitive neuroectodermal tumor (PNET).

Reported in the May 15 issue of the *Journal of Clinical Oncology*, the team leader and Principal Investigator Amar Gajjar, M.D., said he is encouraged with the midpoint results of the study which has been underway since 1996. It involves a 16-week course of high-dose chemotherapy followed by a stem cell transplantation which reintroduces the patient’s own stem cells.

“While it is still early, the results are very promising,” Gajjar said. “It will be interesting to see where the numbers are in five years, but clearly children enrolled on this protocol are doing better than those enrolled on standard therapy.”

Founded by the late entertainer Danny Thomas, the hospital’s work is supported through funds raised by the American Lebanese Syrian Associated Charities(R), which covers all costs of treatment beyond those reimbursed by third-party insurers, and total costs for families who have no insurance. All St. Jude patients are treated regardless of their family’s ability to pay.

Congressman recognizes Medicare/Medicaid cost savings potential *by Marlene Oliver*

Representative Doc Hastings, (R-WA) has asked that a medical isotope cost study be performed to determine whether expanded use of medical isotopes has the potential to save billions of Medicare and Medicaid dollars annually.

Here are a few examples where Hastings believes alternative treatments using isotopes can save the federal government money—and produce a better result for the patient:

For prostate cancer patients whose disease is confined to the prostate, tiny metallic seed implants filled with a radioactive isotope are implanted directly into the prostate. This procedure, called brachytherapy, takes about an hour, with men returning to normal activities within a day or two. Surgery requires a four or five day hospital stay, a painful four to six week recovery, and about a 50% chance that the patient will be forced to wear a diaper for the rest of his life and/or become impotent. Side effects from brachytherapy are far less common. Surgery costs about twice as much as brachytherapy.

For breast cancer patients with confined disease, the lump may be removed and seed implants placed temporarily where the cancer was so that radiation may “zap” stray cancer cells that may have been missed during surgery. For both prostate and breast cancer patients receiving seed implants, ten-year survival is the same as for total prostate or total breast removal. For breast cancer

patients, a two or three day hospital stay with seed implants replaces weeks of external beam radiation that is routinely given after surgery.

"These implants mean that a patient can keep a breast and still have the same chances of survival and the same chances of local control as they could with mastectomy," says Dr. Carl Mansfield. "In this country, the majority of women are still having their breasts removed! On the basis of all the evidence that we have obtained in treating over 900 patients, that should not be the case." Since treatment time is reduced, so are costs.

For many women having mammography, especially those with dense breasts, it is difficult to interpret the results. By adding a test specific for breast cancer, where a medical isotope travels to the cancer but not to tissue without cancer, these patients may avoid having unnecessary biopsies. Biopsies are where breast tissue from suspicious areas is removed and sampled to determine whether or not these areas contain cancer. In 80% of cases, the tissue is benign, showing no cancer. By avoiding unnecessary breast biopsies, Dr. D. B. Sodee and his colleagues from State University of New York at Buffalo estimate that Medicare could save over \$800 million dollars per year by adding this medical isotope test to such mammograms.

In all, Hastings believes there is potential saving of tens

of billions of dollars to Medicare and Medicaid each year, simply by switching to more effective, precise tests such as those outlined above. The money saved could then be devoted to additional cancer research or covering prescription drugs for Medicare patients.

[A list of clinical trials using medical isotopes for therapy may be found at www.medicalisotopes.org]

Welcome to new board member

Eric Otterson has been selected to fill the NACP board of directors vacancy created by the death of his father, Bill Otterson. Bill was a founding director of NACP, and lost a long battle with multiple myeloma in November, 1999.

Eric joins cancer war veterans Keith Boesky and Mary Raabe on the board, and Dan Negroni, who continues as president of NACP. Nicki Hobson has also been reappointed Executive Director.

Lifelines is published by the National Association of Cancer Patients. Comments on its content and suggestions for future articles are welcome.

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**Check out our web site:
www.cancerpatients.org**



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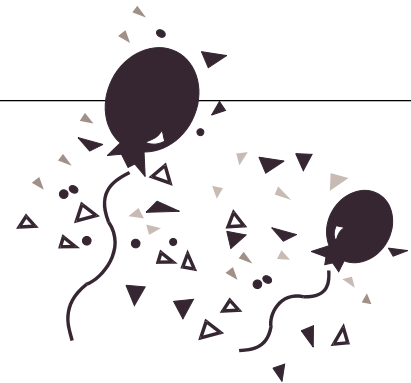
A free health fair and celebration of life

Sunday, September 9, 2001

1:00 p.m. - 5:00 p.m.
Balboa Park, San Diego
(Park Blvd. & President's Way)

Featuring:

- Information on living with cancer
- Group activities and demonstrations
- Programs in English, Spanish and Asian/Pacific Islander languages
- Conversations with health care professionals
- Networking opportunities
- Entertainment, refreshments, doorprizes
- Sponsored by more than 20 local cancer support organizations
- And it's all free



It's free, but we'd like to
know you're coming!

Register today—mail, fax or e-mail your name (and the names of others coming with you), your address (include zip code), phone & e-mail address to:
Cancer Survivorship: San Diego
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