

## Test Case

*By Joanne Neuber*

*Working to heal the damage from years of nuclear testing, the Semipalatinsk-Houston partnership serves as a model for other health care systems struggling with the consequences of massive ecological destruction.*

Amir is just like any other active three-year-old child. He loves to play games, draw pictures and watch television long past his bedtime. But Amir has experienced more illness and pain than an average three-year-old. Diagnosed with a hematologic cancer, Amir has been confined to a hospital bed at Semipalatinsk Oblast Children's Hospital for three-month periods several times over the past two years.

Amir is one of an estimated 500 children a year who received inpatient care at the oblast's only long-term referral center providing children's oncological services. "We see some of the oblast's sickest patients," explained the hospital's Director Mukhtar Tuleutayev.

Children's Hospital is situated near Kazakstan's Semipalatinsk Nuclear Test Site, a main nuclear test site in the former Soviet Union. Between 1949 and 1989, more than 500 underground and atmospheric fission and thermonuclear bombs were detonated there, including 26 above-ground tests and 124 atmospheric tests. Radionuclides emanating from these explosions resulted in regional atmospheric and environmental contamination leading to acute and chronic radiation exposure.

Yet because of the dearth of available data, physicians still have not made a conclusive link between cancer and radiation exposure from these nuclear tests. Despite a lack of publicly available studies, Boris Gusev, MD, director of the Kazak Scientific Research Institute of Radiation Medicine, believes that cancer rates are three to five times higher in Semipalatinsk Oblast than in other Kazakstan oblasts. Gusev was formerly a physician at the Fourth Clinical Dispensary in Semipalatinsk, a health care facility that the Soviet military secretly ordered to collect information on radiation's potential environmental and health effects beginning in 1962.

"Of the 40,000 patients I saw, 80 percent were affected in some way by what I believe to be radiation exposure," he said. Gusev expects to publish results next year from his 30-year study of radiation exposure in Semipalatinsk Oblast.

Parents also believe there is a link between cancer cases and nuclear testing.

"Why did my little girl have to get leukemia?" asked Nadezhda Gagarina, mother of nine-year-old Oksana. "It should have happened to me. But we knew nothing - nothing about the testing or negative health effects - until now, when it is too late." Physicians at Children's Hospital in Semipalatinsk diagnosed Oksana with late-stage leukemia, and sent her to the Scientific Research Institute for Pediatrics and Children's Surgery in Almaty, Kazakstan, for advanced treatment.

Cancer is one of the most visible and frightening effects of the fallout over nuclear testing, but the partnership between Semipalatinsk and health care institutions in Houston, Texas addresses a range of health concerns - serving as a model for other communities struggling with ecological disasters.

In 1995, Semipalatinsk partners created patient education centers at each partnership hospital in Kurchatov (nearest the testing site) and Semipalatinsk to promote community-oriented prevention and wellness programs. Partners include the Oblast Clinical Hospital, the Oblast Children's Hospital, Emergency First Aid Hospital and Inter-Oblast Oncology Dispensary in

Semipalatinsk; Kurchatov Regional Treatment and Diagnostic Center in Kurchatov; and The Methodist Hospital, Baylor College of Medicine and the General Board of Global Ministries of the United Methodist Church in Houston.

Gusev said he considers a community-wide public health campaign developed by the partnership to be "one of the most important things we have done" to increase early detection of cancer and improve public awareness of the numerous risk factors leading to cancer, which include poor diet and unhealthy lifestyles.

The partnership has created a lot of energy in the community through its public awareness campaigns, noted Bakyt Tumenova, MD, head of the Social Services Department in the Semipalatinsk Oblast Administration and partnership coordinator. These partnership-sponsored campaigns have been very effective in responding to the health problems stemming from adverse environmental, psychological and socio-economic conditions in the oblast, she said.

"Our government is not prepared to deal with these social problems due to a lack of financial resources," explained Tumenova.

Since the fall of the Soviet system and the collapse of traditional economic ties, government-sponsored outreach and public health programs have been reduced or completely eliminated, especially in rural areas of Kazakhstan.

Covering a range of public health issues, including breast and thyroid cancer detection, stress reduction and the dangers of smoking and alcohol consumption, patient brochures provided through the partnership are important tools for education on healthy lifestyles and for alleviating patient fears of cancer, noted Adlet Mukanov, chief of oncology at Emergency First Aid Hospital.

"People need to know that a cancer diagnosis is not a death sentence," Mukanov said, adding that primary care physicians at partnership sites are being encouraged to raise the subject of regular cancer screening with patients to detect cancer in the early stages.

Poor nutrition in children is also a concern in the oblast, explained Children's Tuleutayev. He noted that 30 percent of women in the oblast have anemia, and their children are at a greater risk for developing similar iron deficiencies. So Kazak partners developed a prenatal care network with rural polyclinics, hospitals, and the media to provide nutritional information to expectant mothers. Valued as a preventive and cost-effective program, this initiative has helped many expectant mothers adopt healthier lifestyles. The mothers regularly consult with newly trained nurse educators at the polyclinic and the maternity ward at Children's Hospital to learn how to supplement their diet and combat malnutrition.

"Anemia can be managed by medications and nutrition, and this can prevent the development of a lot of complications which appear at later stages of the baby's growth," explained Anecita Fadol, MSN, RN, CCRN, CNS, supervisor of the critical care residency program at Methodist Hospital.

In addition to the partnership-sponsored public health campaigns, the Oblast Children's Fund was created by Karliagosh Jakianova, the wife of the governor of Semipalatinsk. This fund was created to assist the oblast's orphaned and sick children - a number that has risen in recent years due to an increase in abandoned children, noted Semipalatinsk Orphanage pediatrician Venere Rakhmetova. A recipient of funds from the Children's Fund, this orphanage is the only facility for the entire oblast. Current financial constraints complicate the facility's efforts to provide care to its 62 orphans, or to take an additional 30 orphans who are on a three-month waiting list to be housed at the facility, explained Rakhmetova. This places a lot of strain on

the oblast's health care facilities, which must care for abandoned and oftentimes sick babies until the orphanage is able to care for the children, Rakhmetova said.

Monetary donations from the fund, along with gifts from Semipalatinsk citizens, allowed Children's Hospital to refurbish its hematology department, where three-year-old Amir is staying. With renovations completed on May 15, the stark room with peeling paint has been replaced by more cheerful quarters, and Amir, round-faced and balding from chemotherapy, played with blocks and other toys in what has become his home away from home.