

Helping a Little Girl Change Her Outlook on Life

The past four years have not been easy for 11-year-old Nargiz. When the bright and cheerful young girl from the village of Komsomolsky just outside of Bishkek, Kyrgyzstan, was 7, she developed disfiguring tumors near her eye and on her chest. Shy and embarrassed because she didn't look like other children, Nargiz found herself increasingly uncomfortable around her peers. "I hated being sick. . . . I didn't go to school because of the way I



PHOTO: COURTESY OF GALINA SERGEEVA

After four courses of chemotherapy, Nargiz was able to return to school without feeling uncomfortable and embarrassed around her classmates.

looked—my eye was horribly ugly and all the children stared at me. Even though the teacher tried to explain the situation to the other kids, some of them were scared and others just laughed and called me 'one-eye.' That was really hard."

Before being referred to the Kyrgyz Republican Oncology Institute in Bishkek, Nargiz and her mother, Tursunai, a 45-year-old widow, had spent four years consulting with more than 20 physicians. "We knew that Nargiz needed to get some sort of care, but nobody at the other clinics could diagnose her problem," Tursunai says. "Finally, the doctors at the Institute were able to tell us what her condition was and recommend a course of treatment." Initially, that treat-

ment included diagnostic surgery to identify the type of tumors and several months of hormone therapy to shrink the growths.

"When Dr. Baizakova told me that I needed to have surgery, I was very scared, but then she explained how the treatment would help me and this calmed my fears," Nargiz says. Unfortunately, the hormone therapy proved ineffective, so Baizakova turned to the Institute's LRC for help. Galina Sergeeva, then information coordinator at the LRC, arranged for teleconsultations with both their AIHA partners in Kansas City and a specialist from the Czech Republic, using the Internet. Through this Web-based collaboration, it was determined that chemotherapy would be the best option for Nargiz. She began the first course in a series of treatments in March 2000.

While Nargiz is not completely cured, thanks to the treatment she has received, she is getting better. She and her mother continue to make the 30-kilometer trip to Bishkek every six weeks for a 10-day course of chemotherapy. Noting that she actually looks forward to her periodic stays at the Center, Nargiz, who, like many 11-year-old girls the world over, loves playing with her girlfriends and her dolls—especially Barbie, says, "I visit my doctor with a sense of hope in my heart. I trust her and like the people at the hospital. I'm not afraid of the medicine because it always makes my eye feel better. I look like all the other children now and have returned to school even though I am still a little shy and scared."

Expressing her hope that no other children ever have to suffer with an illness such as hers, Nargiz continues, "If they did, I would tell them not to be afraid because the doctors here can help." Tursunai agrees. "When all others lost hope, the doctors here found a solution and made my daughter feel better. I trust them to take good care of her and, after four very difficult years, we finally believe in a happy future."

Now that Nargiz is feeling better both emotionally and physically, she is able to focus on her favorite activities—reading and drawing—and enjoy life with her family and friends. "I feel as if everything will be fine now that I'm not so ill. It is as if my life has become more worth living."

For partners in the NIS and CEE, consulting with colleagues throughout the region and around the world can be accomplished with a few key strokes, thanks to the Learning Resource Centers (LRCs) established through the AIHA partnership program. Clinicians prepare a brief patient history—often including digital photographs, scanned X-ray images, and laboratory test results—then use e-mail as a fast and convenient way to discuss rare or difficult cases with their partners in the United States and other experts worldwide. Whether utilized as a diagnostic tool, a second opinion, or a way to obtain information on treatment options, these consultations have proved invaluable for countless patients and practitioners. Below is the story of how the information resources available through AIHA's partnership programs affected the life of a young girl in Kyrgyzstan; the story of how her doctor—along with the former information coordinator of the Bishkek/Kansas City partnership—used the Internet to help her is on the other side.

For more information on AIHA visit www.aiha.com.

