

# The children of CHERNOBYL

In 1986, an unimaginable disaster struck a Russian town. Today, a group of American families are opening their hearts and homes to youngsters still suffering from the physical aftereffects.

BY ELIZABETH GEHRMAN

**W**hen Bill and Joanne Sweeney throw a birthday party, they do it right. On this warm Sunday in July, Joanne and her two daughters, Rebecca and Marissa, load two long

tables—and their kitchen counter—with platters of cheese and cold cuts, baskets of rolls, plates of antipasto, 15 pizzas, and hot dogs and hamburgers fresh from Bill's outdoor grill. Kids of all ages race across the huge suburban Boston backyard; others dance to Beach Boys tunes and other oldies blaring from a jukebox in the basement.

After the Sweeneys' 75 guests have polished off lunch, Joanne carries out the dessert: an extra-large chocolate sheet cake decorated with a clown and the words *Happy Birthday, Michael & Ruslan*. As everyone sings "Happy Birthday," Michael, who is 15 today, conducts

with an imaginary baton and takes a few bows. Ruslan, who turned 16 three weeks ago, stands back a little, smiling shyly. As they blow out the candles together, they could easily be taken for typical American brothers.

Yet Ruslan and Michael are not brothers. Nor are they American, which becomes apparent when half the party guests sing a second round of "Happy Birthday"—in their native Russian. And, sadly, when it comes to their health, they are far from typical. Ruslan Sobol is in remission from thyroid cancer; Mikhail Bovtunov—for now, he prefers to go by Michael, the American version of his first name—has a bone disorder so unusual, his Boston doctor has said, "There's no textbook I can turn to that has a picture of him in it." Both teenagers are human legacies of the worst nuclear accident in history: Chernobyl.

The meltdown at the Ukrainian nuclear power plant happened in April 1986. Today, food and water remain contaminated over a 62,000-square-mile swath covering part of Belarus, Russia, and Ukraine. According to Russian doctors interviewed in the United States, fertility rates for women in the region continue to be far lower than normal, and the number of babies born with birth defects is higher. Children who weren't even born at the time of the disaster—like Ruslan and Michael—suffer from myriad cancers and other illnesses.

But this day is not for talk of sickness. The Sweeney party is going full tilt; in addition to the other Russian children, guests include host families and American volunteers. More than 100 children are staying with families in the Boston area for a month of medical care and



Ruslan, far left, and Michael, far right, entertain Joanne and Bill with their new rock 'n' roll moves.



For Ruslan and Michael, adolescence carries a special burden: health troubles.

American hospitality, arranged by the Chernobyl Children Project USA (CCPUSA). As several children jump in the Sweeneys' pool for a game of Marco Polo, the adults gather to chat on the screened porch.

Kevin Petitti, a real estate developer and a member of CCPUSA's management team, sits on a cooler and watches the kids frolic while he finishes his chocolate cake. "The transformation is amazing," he says, pointing toward the children with his plastic fork. "When they arrived a couple of weeks ago, they were sort of shell-shocked. Today, you can't tell them apart from the American kids."

INSPIRED BY A SIMILAR PROGRAM IN IRELAND, THE Chernobyl Children Project USA began in 1994, when five Boston families opened their homes to ten ailing

children from Belarus. Five years later, the group's fledgling board of directors was able to hire one employee, Executive Director Patty Doyle (for more on Doyle, see "The 2002 Heroes for Health Awards," page 86). Everyone else who participates is a volunteer.

This year, the youngsters arrived on June 26 to stay with 60 host families. Some of the children were returning to families they had stayed with before; others were new to the program. Accompanying the children each year are about a dozen Russian and Ukrainian physicians who are here to learn new procedures and confer with American doctors. Translators help bridge the language gap.

There are other forms of culture shock. Back home, many of the children live in dilapidated houses about the size of a single-car garage. If they come from one of



Tanya, in her bedroom and with host parents Mike and Jan, and her own mother, Tanya, below

## TANYA: HOLDING ON TO HOPE

Tanya Lepeeva, 17, is helping Jan McTeague, her host mother, with some grocery shopping when something happens that surprises the Russian girl: Jan starts to dance. The song "Stand By Me" by Ben E. King is trilling on the sound system at the Chelmsford, Massachusetts, market. Jan, a choreographer and teacher, can't help but take a few steps in the produce department.

Seeing Tanya's puzzled expression, Jan turns the moment into a language lesson. "Stand," she says, going still and placing her feet together and her arms by her side. "By me—" she takes Tanya's arm and moves beside her. "Be my friend," she concludes, giving the teenager a hug.

Though Tanya speaks little English and Jan speaks no Russian, they have little problem communicating. They use gestures, exaggerated facial expressions, a few common words, and many smiles. In the six years Tanya has been a part of the McTeagues' lives, they have grown very close.

"My whole family and Jan's whole family know Tanya and her mother and grandmother," says Jan's husband, Mike, a vice president of information systems for a private-equity firm. "We've really come to think of her as our daughter."

Tanya met the McTeagues in 1997, the first year they volunteered as host parents. Doctors in Russia had just replaced her right tibia with a metal rod in hopes of halting the bone cancer she'd developed as a result of radiation exposure. The second year, the family hosted Tanya again and paid privately for her grandmother to accompany her. This year, her mother—also named Tanya—is staying with the McTeagues.

Tanya has faced harsher setbacks than any teen should have to bear. In 1999, the cancer spread to the rest of her leg, which had to be amputated. Parts of both lungs were removed, and earlier this year, the cancer metastasized to her shoulder.

But Tanya has hope. "I feel my soul is resting here," she says through an interpreter. "I've been very depressed, but right now I have a great desire to live. To be alive."



the smaller villages, their families cook with coal and wood, and in the winter, they sleep in little lofts above the stove to keep warm. Sometimes there's no running water, so they have to walk across a field to reach the outhouse. "There are no good living conditions," says Leonid Avramenko, M.D., a surgeon at Klinty City Hospital and the head of the CCPUSA in Russia.

Coming to America can make a critical difference. In 1995, Lena Phillipova, then 13, and Anna Shaleiko, then 12, flew to Boston as part of the first wave. Lena was a thyroid patient; Anna had a heart condition. Seven years later, both are looking toward the future. Lena is studying languages at the University of Minsk and has just received a full scholarship to spend a year in Sweden; Anna attended a vocational school and is now working as a seamstress.

But not every child gets better. Sixteen-year-old Olessya Belyay, for example, came to America in 1999, in apparent remission from leukemia. She spent a carefree month seeing the sights and returned home with the other children. But when tests conducted in Boston were studied after her departure, they indicated she needed treatment the Russian hospitals couldn't provide. Two months later, she came back to Boston for a six-month course of chemotherapy.

During that time, Olessya lived at Patty Doyle's house. "My kids were off at college, and when my husband was at work, it was just the two of us," Patty remembers. "Sometimes Olessya slept with me, holding my hand. Putting her on the plane at the end was tough, because I knew I'd never see her again." One year after she returned to Klinty, Olessya Belyay died.

BILL SWEENEY SITS PLACIDLY IN the waiting room of the dental

The radiant Yulia; below, with host mother Sarah and her son, Geoffrey



## YULIA: LEARNING TO MAKE DO

Sixteen-year-old Yulia Lapinskaya stands behind an enormous island in a sleek new kitchen in Canton, Massachusetts, checking and rechecking her ingredients: flour, milk, salt, sugar, butter, and four eggs. Everything she needs to teach her host mother, Sarah Bonnanzio, how to make *blinis*, traditional Russian pancakes.

Yulia, who has studied English back home in Russia, says, "You can make without sugar, but I like with sugar." She flashes her riveting smile, but an instant later her eyebrows knit together as she realizes something is missing: "I need, um...." Yulia doesn't know the word for spoon, so she circles her fist over the flour bowl a few times to demonstrate.

"One of the ways to communicate is through cooking," says Sarah, as she places her two-year-old son, Geoffrey, in a high chair and turns to grab a wooden spoon. "And it's a nice way for her to show me a little bit of her world." A world, sadly, that has been clouded by thyroid cancer, a common aftereffect of the 1986 Chernobyl nuclear disaster.

Yulia picks up an egg. "OK?" she asks, just to make sure Sarah is still paying attention. "OK. We start." She's all business, determined to create the best blinis this particular American family has ever eaten, as she taps the last egg on the side of the mixing bowl—only to find that it's hard-boiled. And there are no more left in the refrigerator.

But instead of being upset, Yulia falls against Sarah's shoulder, laughing. When she recovers, she shrugs. "We use three this time," she says.

Yulia is used to making the best of what she has been given. She became ill in 1991; since then, she's had five surgeries, as the cancer spread to her lymph nodes. Last summer, she was sent to Boston's Tufts–New England Medical Center Floating Hospital for Children for a complete evaluation of the treatment she received in Russia. Lab tests and a high-resolution MRI confirmed that her disease was in remission, for the second year in a row.

And the blinis? "We had them for dinner that night," Sarah later reports. "They turned out fine."



clinic at Boston's Tufts University. He is surrounded by dozens of Russian children coming and going, various host parents and their own kids, and a few translators. These youngsters don't receive regular dental care at home, so they are each scheduled for at least two visits during their month in the United States. Some appointments stretch on for hours.

In the large examining room, Ruslan reclines in one of the ten chairs, a blinding light hovering over his wide-open mouth. As the dentist reaches for the dreaded drill, Michael is by Ruslan's side, joking around with a couple of teenage-girl translators. Michael's idea of moral support is to sing a death-march tune to his stoic housemate: "Dum-dum-da-dum," he intones repeatedly, while Ruslan rolls his eyes.

In the few weeks they've been a part of the Sweeney household, the boys have won the family's affection in very different ways. Ruslan, who is studying German in school and knows virtually no English, is cooperative and quiet, happy to spend time alone watching TV or reading a donated copy of *The Chronicles of Narnia* in Russian. Michael, on the other hand, never sits still. He shoots baskets in the driveway, teases then 18-year-old Marissa Sweeney, bickers with Ruslan, sneaks junk food, and has even been known to fib. He is studying English back home, and his language skills have improved so much, "he can be a pain in the butt in two languages," Bill sighs. Summing up the boys' temperaments, he says, "Ruslan fixes things around the house. Michael breaks things around the house."

The Sweeneys, who are both teachers, have little problem coping with the time commitment involved in hosting a pair of active children in the middle of the summer. But

with two daughters in college and a son only a couple of years behind, the expense is another matter. Because the Russian children usually arrive with no money and only the clothes on their backs—along with a suitcase full of traditional gifts from their family to the host family—the costs for entertainment, food, and clothing quickly add up. (Host families foot the bill for the vast majority of living expenses.)

And like their American counterparts, the visiting children can be a handful—testing limits, falling into sibling rivalry, whining over small stuff. “There are moments when I want to strangle them,” Joanne admits. “When I say, Why are we doing this? But in the end, I think we get a lot more out of it than they do.”

Now it is Michael’s turn in the dentist’s chair. At first, when the boy takes his seat, he pretends to be unafraid. “I’m asleep,” he boasts. After a quick exam, the dentist announces she will be doing four fillings in the next hour or so.

“Four?” Michael cries, his bravado rapidly disintegrating into panic. “No four! No four!” As the dentist begins her work, it becomes obvious that Michael’s bone deformities will make his visit much more uncomfortable than Ruslan’s. The angle of Michael’s head makes it difficult for him to swallow, and, because he must breathe through his mouth, the dental dam is suffocating him.

Bill comes in from the waiting room and takes Michael’s hand. “I’m sorry,” he says quietly.

BECAUSE THE RUSSIAN DOCTORS WHO ARRIVE WITH THE kids say their equipment is so out-of-date, it becomes imperative to accurately pin down the youngsters’ problems during their time in Boston: verifying diagnoses, working out treatments, making sure medications such as thyroid-replacement hormones are being taken in the most effective doses.

“What we try to do here is make sure the treatments the children are getting elsewhere make sense,” says Larry Wolfe, M.D., a pediatric oncologist at the Tufts–New England Medical Center Floating Hospital for Children, in Boston. “We make recommendations to the Russian physicians who come over with the children, and, when we can, use our relationships with the pharmacies and supply companies to send medications and equipment back with them.”

Every child the project sponsors receives a thorough physical exam in a Boston-area hospital, including blood and urine tests, and MRIs, EKGs, and X rays as needed. Each year about 25 visitors arrive in remission from, or undergoing active treatment for, thyroid cancer; several of the

children are fitted with prostheses or with orthopedic devices to correct birth defects. Another 30 are evaluated for more serious radiation-related problems, from brain tumors to kidney disease. If a child requires a therapy that’s unavailable in Belarus, Russia, or Ukraine, CCPUSA will try to raise the money to bring her back for treatment in a high-tech Boston medical center.

“The doctors who volunteer their time to see these children are all so happy to do it,” says Jacoba van Schaik, a Tufts–New England Medical Center administrator who schedules the medical and dental appointments. “They just want to fix these kids’ problems.”

THE PARKING LOT AT ST. AGATHA’S CHURCH IN MILTON, Massachusetts, where buses wait to take the children to the airport, slowly fills with station wagons and SUVs. Stressed-out fathers secure overburdened suitcases with duct tape; frantic mothers try to make sure nothing has been forgotten.

This is not an easy time for the Sweeneys. In the past two weeks, one of Michael’s favorite phrases in English has become, “I no go home to Russia. Stay with Bill.”

At first, Michael’s attention is on the waves of girls. Two daughters of a neighboring host family fling themselves into Michael’s and Ruslan’s arms and beg them not to go. The boys pick up the girls and hug them, spinning them in the air. Then some older girls come along to say their goodbyes. It isn’t easy, but Joanne finally gets the boys’ attention as she hands them each a wad of American money and drills into their heads the words: “For Mama. Don’t lose.” After a debate over where the cash would be safest, Joanne slips the bills behind a photograph in each of their new albums. She also gives them a sheet of labels bearing the Sweeneys’ address. Hugs and kisses are exchanged. Bill tousles the boys’ hair, feints chin jabs, and puts his arms around their shoulders.

Finally, the buses can wait no longer. Michael and Ruslan are the last Russian children to board; the Sweeneys must let go. The couple scurry along the side of the bus, trying to keep track of the boys as they walk down the aisle. Once Michael and Ruslan have settled into their shared seat, there is nothing left to distract them, only a final goodbye. When the boys see Joanne standing beside the bus, sobbing, they crumble; tears roll down their cheeks. Ruslan smiles weakly and makes a heart shape with his fingers. Michael frantically presses his face and hands against the glass. Bill simply looks stricken.

Joanne and Bill Sweeney stand on the edge of the church lawn, hugging each other tight in the hot late-morning air, as the bus to the airport finally disappears down the suburban street. ★