

Romania's AIDS Children: A Lifeline Lost

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Thousands of the Romanian children who contracted the virus that causes AIDS from needless blood transfusions a decade ago are still alive, but hundreds are now at risk of dying rapidly because they can no longer get the medicine they need. The high prices charged by Western drug companies, Romania's deep poverty and the failures of the country's weak governments have ensured that life-saving anti-retroviral drugs are beyond the reach of many of the children infected in the dying days or aftermath of the despotic rule of Nicolae Ceausescu, who was overthrown and executed in December 1989. Hospitals, crippled by recent bungling of the national health budget, are taking children off their \$10,000-a-year AIDS cocktails. Nor can the hospitals afford another estimated \$10,000 a year per child for laboratory tests and the best drugs for secondary infections. American and European drug companies, doctors say, have largely declined their requests for cheaper drugs, and the government has so far proved incapable of forcing prices down, or managing budgets to afford the drugs. Across Romania, there are an estimated 9,000 H.I.V.-positive children -- more than half the total in Europe. Most are 9 to 13. Some live with their families, some in orphanages on the grounds of state hospitals, and some in small "apartment orphanages" like those run in this grim river port by a charity named **Heart of the Child**. For the last several months, seven H.I.V.-positive children have lived in Michael House, a cheerful three-bedroom apartment in a drab Stalinist block. In the United States, all would be on anti-retroviral therapy; here, only five are, and those only because the Romanian women and a Peace Corps volunteer who run the charity are such good beggars. Two get their medicines from the local state hospital. A Dutch charity pays for the drugs for another two. Bristol-Myers Squibb donates drugs for one. Two get nothing. All have a fairly clear idea of their possible fate. "Look! It's Andiana!" says Anisor, 8, as some photos accidentally slip out of a reporter's notebook. "Andiana! Andiana!" the others call out, gathering around. "She's dead, isn't she?" says Iulia, 11. Dr. Anna Burtea, the charity's vice president, nods sadly. "Andiana's dead, we know that," Stefan, 11, explains to the reporter, being helpful by sticking his tongue out and miming a hanged man. "She's so skinny!" remarks Maricica, 10, looking at the last picture of Andiana in her hospital bed, taken only three weeks before. They debate briefly about exactly when she died. After Dr. Burtea assures them that Andiana is in heaven, the subject changes.

Outcasts in the Hospital

Staff members at the hospital where they lived until they came here, she explained, told them regularly that they were going to die, and treated them as contaminated. All their

toys had to be separately marked "AIDS PATIENT." The staff was wary of touching them and would never eat with them. The first time she did, Dr. Burtea said, the children were very suspicious. "What are you doing?" they asked. "You will be sick, like us." In the 1980's, Romanian children got blood transfusions not just for hemophilia, surgery and other reasons common in the West, but also as a sort of "pick me up" for those anemic or undernourished. In Mr. Ceausescu's drive to pay off Romania's national debt and keep himself in grandiose palaces, state finances were starved, and milk, vitamins and fresh food were scarce, so blood from donors or sellers was used as a substitute. Also, school nurses often reused vaccination needles on dozens of children. Sometime in the mid-1980's, AIDS contaminated the blood supply, presumably first from sailors and prostitutes, because infection was later found to be concentrated in port cities like **Galati**, Constanta and Giurgiu. By 1990, with Mr. Ceausescu dead, health authorities who realized that tens of thousands of babies and children had been injected with H.I.V.-positive blood were able to be open about it. A scandal ensued, which was compounded by news of the appalling conditions that many abandoned children, sick or not, were enduring in state-run orphanages. Help poured in from around the world. Blood testing improved; hospitals got disposable syringes; nurses were retrained. But the children remained. Slowly, as the virus multiplied and sapped their immune systems, they began to sicken and die.

Measles Takes a Huge Toll

Anca Suhateanu, the head nurse at Doru House, the children's orphanage on the grounds of Dr. Victor Babes Hospital in Bucharest, recalled that in 1990 her center cared for about 140 children. Half of them, she said, perished in a measles epidemic. "Then, in 1993, when they were all 4 or 5, they began dying like that," she said, snapping her fingers. She can recall one day when two died in two hours. New children still trickle into Doru House, which is home to about 70 youngsters. A few are toddlers born to infected mothers, most of whom got the disease from sexual contact, Romanian health officials say. Some are transferred from rural orphanages. Some, even 10-year-olds, are newly discovered cases. The disease affects children at different rates, and some parents are just realizing that children they thought merely sickly actually have had AIDS most of their lives. In a country where a third of the 23 million people live on \$1 a day, many families are so poor that they leave the children. Mariana, 11, a quiet, sweet-natured girl about the size of an American 7-year-old, is from a family of tenant farmers 60 miles from Bucharest. They can rarely afford the \$5 train trip to see her, and the last time she went home for Christmas she was back within hours with lung problems and in intensive care for days. When she gets toys, Mrs. Suhateanu said, she saves them for the siblings she has not seen in three years. If more money or cheaper drugs do not arrive soon, said Mary C. Veal, 52, a Georgia native who has worked at Doru House since 1993 and counts the little girl among her favorites, Mariana and the other children will be taken off the anti-retrovirals that the state has made available to Doru House patients. "And within a month," she said, "they'll be human skeletons again, like they were a year ago, and then pretty soon it will be all over." The triple-therapy AIDS cocktails, which reached Bucharest in 1997, and small cities like **Galati** the following year, were a huge success, and death rates dropped sharply. Among the 400 or so children cared for by Victor Babes doctors, deaths went from 66 in 1998 to 19 in 1999 and 18 in 2000. Since the turnaround,

"we don't know their prognosis," said Ms. Veal, whose work is sponsored by an American church foundation, Nobody's Children. "We never envisioned having teenagers. All those years we needed Pampers and suddenly one day I found myself going across the street to get Always pads for one of our girls. I didn't know whether to laugh or cry."

Many Are Denied the Cocktail

Of the 400 inpatient and outpatient children, about 120 are on anti-retroviral cocktails, said Dr. Dan Duiculescu, chief of pediatric AIDS. If he had enough money, 100 more would be, since they meet Romania's virus-level criteria. In the United States, all 400 would be. "We get no discounts on any prices from any companies," he said. He asks companies to put his children on drug trials, which he considers a good trade-off; he offers his cluster of 400 patients, whom he can monitor carefully. Glaxo Wellcome, which helped pay for his computer database, held two trials of different AZT combinations in 1997 and 1998. But only 20 children were in one trial and only 50 in the other, and each time for only six months. "After that, we had to buy," Dr. Duiculescu said. "We asked if they would donate for the life of the kids, but they said it was not possible. We ask all the companies for discounts or donations. They say 'Not possible.' " The Glaxo Wellcome company said that children had been dropped after earlier trials, but that other patients, more recently, were kept on free drugs after trials ended. Dr. Duiculescu said he was told that he would get part of a \$750,000 donation of medicine by Bristol-Myers Squibb for 500 patients, but has not received any yet. And he said he was interested in a proposed Merck & Company trial of two drugs, Crixivan and Stocrin, but worries that it will contain "conditions that will be difficult to accept." The hospital must buy medicine for one patient for every two the drug company supplies free, "and I don't think there will be enough money," he said. A Merck spokeswoman, Melinda Hanisch, said the trial would involve only 16 adults and the company was not yet willing to experiment on Romanian children because children's metabolisms are different and the company is "especially sensitive to ethical concerns."

How the Companies Help

Most of the five drug companies who sell anti-retrovirals in Romania do make some donations, usually a few months' worth of drugs for a few patients who lose state financing. Some make cash gifts; Merck, for example, has already given \$1 million for equipment for regional laboratories. Some also suggested that their own patience is a form of donation. A Glaxo Wellcome statement said that slow payments by the government while the Romanian currency, the leu, is steadily declining means the company is selling at an effective 36 percent discount. Ms. Hanisch said the company's response to the fiscal crisis was to keep shipping drugs and expect payment later. "We don't say, 'Gee, you can't pay us, so you're cut off,' " she said. But wholesale prices for the drugs remain high, and there are no imminent plans for price cuts. Last May, five drug companies announced that they would begin negotiating 80 percent cuts in their prices on AIDS drugs to poor countries. Most of the attention focused on Africa, but Romania was included. According to Unaid, the United Nations agency fighting the disease, only Senegal, Swaziland and Uganda have begun negotiations; Romania has not even formally expressed interest. Asked about their wholesale prices in Romania, five drug companies answered variously

that they were "about what the competition charges," "in line with our international pricing policy," or "based on prices used across Europe." Romania, however, hardly resembles the rest of Europe; the average wage is only \$1,200 a year. Romania's epidemic is disproportionately among children, and disproportionately among orphans with little political clout. Successive governments have proved incapable of coming to grips with the crisis, failing to push the drug companies for price cuts, failing to collect taxes to fill state coffers and failing to attract the foreign investment that would be vital to stop Romania's slide into even more grinding poverty. The government normally gives state hospitals less than half of what they request for drugs. Early this year, the cash crisis became even more acute after a shift in the way health insurance deductions were handled. In Romania, bureaucracy and corruption often connive to drain the economy's lifeblood, and millions of dollars just vanished. No one yet knows whether the money was stolen or just mislaid in the accounting system, but it is not there. The children at Victor Babes are lucky. The hospital has a private ward for paying patients, and the sympathetic director is using some of that money to buy drugs for the sickest. In outlying cities, other decisions were made. In the northern city of Iasi, which lost 90 percent of its budget for AIDS drugs, health administrators earmarked the last 10 percent for adults only. The city's 137 H.I.V.-positive children, according to the respected daily *Adevarul*, have begun dying of flu, tuberculosis and other secondary infections. Southwest of Iasi, in Piatra Neamt, which has 241 registered AIDS patients, 222 of them children, enough money was budgeted for 50 patients. About 200 children were abruptly taken off the cocktails for five months, went back on for two, and are now off again. In **Galati**, with about 190 infected children and 22 adults, the situation is similar. Some children are cut off, some get interrupted treatment, some get only two drugs instead of the usual three. Like Iasi and Piatra Neamt, **Galati** is in Romania's impoverished northeast, "a forgotten area," Dr. Burtea said, and adults demanding medicine have more pull with local health administrators than abandoned orphans do. "Last year, one child died here every two or three months," Dr. Burtea said of the situation in **Galati**, where only the lucky few get to live at Michael House. "Now it's two or three a month." A few weeks ago, Dr. Burtea said, she, Daniela Ariton, the president of the foundation that runs Michael House, and a Peace Corps volunteer, Sonny Hwang, made what the doctor called a "begging trip" to the capital, four hours away. It was an exercise in frustration, Mrs. Ariton said. Drug company representatives told them to go see local health officials, who told them to see national health officials, who told them to approach the drug companies. A state hospital administrator promised them enough medicine for three children. A Hoffmann-LaRoche sales representative gave them a carton of pills on the spot, but it was only enough for double therapy for seven children for three months.

Where's the Money Going?

"I said, 'AIDS is supposed to be the new thing,' " said Ms. Hwang, " 'so where's that money going?' And they said, 'All that money is going to Africa -- that's where the focus is these days.' " Very few Romanians in AIDS care knew that generic anti-retrovirals are sold at a fraction of Western prices by companies in India, Thailand, Brazil and Canada. But importing them would mean voiding the patents Western companies have on their drugs, and the Ministry of Health has already agreed to keep those patents in place. In a press release last May acknowledging its "partnership" with five drug companies

over access to drugs, the ministry noted that patent laws guaranteeing intellectual property rights were an "enabling principle" for price-cut negotiations. In fact, a Unaid spokeswoman said, patent protection is not part of the United Nations agreement with the five pharmaceutical companies. Instead, it recognizes "compliance with international agreements," including the treaty on trade-related aspects of intellectual property. The treaty recognizes many exceptions to patent protection. "The Romanians have added this for some reason," she said. One Romanian demanding that the government either import cheaper generics or force the drug companies to lower their prices is Maria Georgescu, executive director of the Romanian Association Against AIDS, who has been involved in treating children since 1991. "We need to fight these companies," she said. Every time she approaches Western companies asking for lower prices, the local representatives say it is impossible. "They say these prices are set in London and America," she said. "They tell me they need the money to develop AIDS prevention in other countries. They show me brochures of their activities in Rwanda and Ghana and I don't know where, but it's not Romania." Mrs. Georgescu said government officials lacked the legal know-how and political will to fight big drug companies over prices or to use loopholes in complex and obscure patent laws to import cheaper generics. "There have been three changes of the minister of health in four years," she said. "It's chaos. Some talk of seizing the patents, but then they leave." "No one in government will do this by themselves," she said. "Not unless they have a personal interest, like an H.I.V.-infected friend or something. This is Romania. Here the bureaucrats say: 'What H.I.V. people? We need to get rid of them.' "

Lower Prices Not in Sight

Drug companies who sell anti-retrovirals in Romania declined to comment or say what their response would be if the country tried to negate their patents. A HoffmanLaRoche spokeswoman said the consequences of doing so "are clear: fewer new medicines would come to market." All mentioned the agreement announced in May, but none could estimate when lower prices might come to Romania. So far, only Senegal and Uganda are close to deep price cuts. Romanians, who were terrorized into silence under the Ceausescu, still have a hard time complaining aloud, or acting independently to redress perceived grievances. Their American partners, like Ms. Hwang and Ms. Veal, are often more outspoken. Foreigners are also less inclined to blame only Romania's hapless government and more inclined to criticize the multinationals. "The drug companies are helping us out some," Ms. Veal said. "But they're in this business to make money. It's the people with power who get heard here, and our children don't." "I have a friend in Zimbabwe who does the same kind of work and has the same problems," she went on. "She says things aren't getting any better there, and it's just a matter of tightening and tightening the belt." "I'm a mother, and I'm a grandmother," she added, getting angrier. "And I'm selfish. Romanian children are just as important as American children. African children are just as important as American children. Who makes these rules?"