

# Saving the lives of Romanian children with HIV

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Dr Paul Marinescu has chosen to meet me on a cold winter's day in a room stocked with plants, fish tanks and two parrots singing in their cages. It's a room as lively as its incumbent's life. This grey-haired man with a gentle voice acts as father to 18 – two his own children and 16 HIV-positive orphans that he took in at a time when nobody wanted them.

The official statistics show that during Romania's communist rule more than 10,000 children were infected with HIV. What happened is described as an epidemiological accident. What followed is something of a miracle – around 65 per cent of the children are still alive today.

"Everybody saw them as having no hope; doctors, parents, everyone actually expected them to die," says Monica Dan, a psychologist at the Romanian Anti-Aids Association who has worked in the field for 20 years. "I'm still astonished by how strong they are and by what many of them have accomplished."

Marinescu's act of patronage saved the lives of a small group of children. Their story is also that of all Romanians with HIV, of managing to live with a once-lethal disease in a poor country recovering after the collapse of communism.

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The fall of Nicolae Ceaușescu's regime left Romania with many orphans, the roots of which lie in Decree No. 770 of 1966. People born around

this time were known as Decreței, the decree children.

Ceaușescu, the country's communist president, had a wish that became an obsession. He wanted to be the leader of a great number of people, to raise Romania's population from 19 million to 25 million. Having grown up in the countryside, where poverty hadn't affected birth rates, and being the third of his parents' ten children, he couldn't understand why people wouldn't want to have large families. So he made it into a law. The decree banned women from having abortions and using any type of contraception. Families with more children were entitled to several benefits, while childless families had to pay additional tax. This, he reasoned, would increase the birth rate of the entire country. The irony was that among these decree children, born out of the ruler's wish, were the ones who would, as young adults, bring the streets to life in December 1989, ending his rule.

As the number of Decreței grew, the country's economy shrank. Orphanages became overcrowded. Living standards had become precarious, with insufficient food in the stores and no heating or warm water in homes. Many children were abandoned at birth and wound up in institutions where living conditions were even more despicable: electricity and heating were supplied sporadically, food was rationed and children frequently fell ill.

According to testimony from orderlies and nurses around the country, many orphanage children didn't even have a change of clothes – clothes were washed and their carers had to decide whether to leave the children sitting around undressed or dress them in wet clothes. These poor conditions made children anaemic and malnourished, so they were given blood transfusions or injections for their frequent colds.

Then in 1985 came the first documented HIV case in Romania. As doctors investigated, they realised there was a massive problem among

the country's children, especially those in orphanages, who needed medical care more frequently than those living with their families. According to reports from the Stefan S Nicolau Institute of Virology in Romania, 1,168 cases of AIDS were reported in December 1990, 99 per cent of which were in children less than four years old. Around 62 per cent were abandoned children living in public institutions.

The southern counties of Giurgiu and Constanța, along with the capital, Bucharest, were among those with the largest numbers of infected children in both orphanages and families. Border areas like the coastal Constanța were the first to be affected with HIV. Where it came from exactly is unclear, but blood donations played a key part. Under the communist regime, donating blood was seen as a moral obligation. "Constanța was the opening of the country to the world," said Rodica Mătușa, who was head of the Paediatric Infectious Disease Division at Constanța County Hospital in the 1990s. "There were sailors who came from all over, and our sailors who travelled worldwide. There was a coastline where we had foreign tourists. All these groups of people were donating blood." Romania's blood stocks were low, and the donations welcome. According to a 1990 Human Rights Watch report, blood was a form of baksheesh in Romania, donated in return for favours done and papers processed. The regime did not coerce donations but there was an 'official' exchange rate of a meal or a day or two off work for every donation. Unofficially, donation could get you a driver's licence, a student visa renewal or a job. "Ordinary citizens, foreign students and workers, including dock workers, had little choice but to comply, and whether through ignorance or self-interest, those who were HIV positive also donated blood," says the report. But donated blood was never tested for any disease, let alone HIV.

The situation was compounded by the poor hygiene measures of the time. The same needles were used multiple times for multiple patients in transfusions and vaccinations. Even if needles were sterilised, it was

often done improperly – power cuts and shortages were frequent, so there was never any guarantee that sterilisation equipment or procedures had been run properly.

In orphanages all around the country children were getting transfusions to treat colds and malnutrition. Doctors estimate that a single infected donor could pass the virus to up to 80 children.

Romania's doctors knew the country was at risk of an epidemic, but government officials ignored their pleas. The communist state was projecting a facade of perfection – the best leaders, the best health system – that nothing would be allowed to shatter. To ensure the doctors' silence, they stationed Special Service agents at their workplaces and monitored their calls. No measures to combat HIV were taken until after the 1989 revolution, when the borders opened and the horrendous situation finally came into public view. Then, journalists and photographers from all over the world showed what life was like for the orphans of Romania. In Constanța alone, thousands were found to be infected with HIV. Many more did not even make the statistics – they were already in the morgue.

In 1999, Paul Marinescu was working as an infectious-disease specialist in a small hospital in Singureni, a village in Giurgiu county about 30 km from Bucharest. An important part of his work was taking care of children with HIV. Marinescu was head of the local Health Department – a representative of sorts for the Ministry of Health at a county level. Giurgiu was his home. What he saw was a local tragedy.

Many families had seen their children infected in hospitals, but the children in the worst shape were in the orphanages – their disease meant no chance of adoption. And Romania's orphanages were often isolated on the outskirts of cities, where children with HIV lived hard, lonely, abuse-ridden lives.

Almost everyone avoided contact with the HIV-positive. Although the ways the disease could be transmitted were widely communicated through medical workers, television and newspapers, discrimination was everywhere. Especially frightening to people were children with HIV. They were not welcome in kindergartens or schools. People fled when they saw them in the streets.

Marinescu felt compelled to act. "When I visited them for check-ups, the children didn't want to let me go," he recalls. "They called me Daddy, clinging and holding on to my legs with both arms." He'd had his own two children by then, but wanted to adopt the children from the orphanage where he worked. His lawyers warned of the legal complications adoption would entail. So instead he started a foundation called Saint Mary, named in memory of his mother, taking 16 HIV-positive children under its care. "Legally, I became their tutor," he says. "I was poor, but I had a lot of dreams for them." Modest dreams, such as a bigger garden, more food.

Marinescu first housed his children in an isolated ward in the Infectious Disease Hospital in Singureni. A fire forced a move to a small house he built using funds from individual donations. Further donations from local businesses offered basic supplies of food, clothing, fuel for the winter. He visited the children every day, in the morning before going to work or in the afternoon, on his way home. He talked to them and listened to how their day had been.

In the years that followed, other children with HIV came under Marinescu's wing: a young woman who had been found in the street, another with brain damage. There were times when he was caring for as many as 23 children – most of whom are still alive today, some with their own families. Three of the children died. Two were in the final stage of disease when they came under his care, but he still regrets the third, who could still be alive had he not refused to take his medicine.

"When he turned 18, he wanted to live his own life and left the foundation. He also got mixed up with some questionable people, and because of the diseases associated with HIV, he died six months later," Marinescu laments.

While healthcare reforms meant that blood transfusions were handled much more safely, HIV was still spreading. Today there are around 500 new HIV cases in Romania each year, mostly transmitted through sexual intercourse or contaminated needles used with recreational drugs. There are still children born HIV positive, and there is still popular prejudice against them.

Singureni, a small community with just 3,000 inhabitants and little knowledge of HIV, for years opposed the children's presence. The locals protested in schools – if a child with HIV joined, parents moved their children to another class or voiced their fears on local TV shows. Teachers made the children feel so bad about themselves that they stayed home.

One of the worst moments came in 2011, when the mayor of Singureni accused the children of giving HIV to others in the village. The doctor stood up for his orphans. "I know what the mayor would have liked," said Marinescu in a TV interview at the time. "He'd like to have seen them in ghettos. For many years, I tried to teach the people of the village how the disease was transmitted. I did the talking, but I did the listening as well." The incident was debated on national TV and newspapers. The community became divided.

Marinescu's story was not an unusual one. In Constanța, Rodica Mătușa set up her own non-profit NGO – the Speranta Association, meaning 'hope', to care for the HIV-positive orphans she had encountered in her hospital. In 1992, they raised the funds to buy a house and land in the village of Mihail Kogălniceanu, 36 km north of Constanța's main city.

Speranta eventually gained further funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria (through the Romanian Angel Appeal Fund) and became something of a model for similar foundations across Romania. Throughout the 1990s, [foreign aid](#) poured into the country, from governments, from NGOs, from Italy, Japan, the UK and the USA. Foreign aid could provide orphanages with better food and better clothes, but not social integration.

In Singureni, Saint Mary was a small one-man foundation. Its orphans had little, but its limitation became its strength. Its one man had knowledge of the country and system.

Marinescu decided to enrol his children in a school in Giurgiu City, the county capital, where people were more tolerant. During the week, the children stayed in hospital accommodation in the city, which Marinescu had arranged through his connections. When it came to high school, he advised and supported the children to study practical subjects – nursing, computing – that he hoped would enable them to more easily find jobs in later life.

The children's lives went on. In 2002, Romania's government introduced more protection for children with HIV. By law they had the right to education, confidentiality over their HIV status, and disability allowance. Understandably, most of Marinescu's orphans moved away from Singureni as soon as they were able, to start again in the region's other surrounding villages, where no one knew their names or their past.

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On a wall outside Dr Mariana Mărdărescu's office is a panel summing up 25 years of fighting against HIV. Pictures of Hillary Clinton, Madeleine Albright and others who've helped the young Romanian patients with HIV hang from the walls. "Nobody asked how we felt when taking care



of these children," she says. "I'd gone to medical school to save lives, but there I was treating children the same age as my daughter and not knowing if they would survive. When parents asked how long their children would live, I'd just say, 'Let's see.'"

'Let's see' turned into children who had been expected to die within a few years living to see 30 and beyond. Mărdărescu now heads HIV surveillance and control at Matei Balș, the largest infectious-disease hospital in the country, in Bucharest. According to her reports, 20,146 people have been registered as HIV-positive since 1985, with 12,866 still alive, 65 per cent of whom were infected as children before 1990.

"The fact that so many of them are alive today makes me think they'll reach 60," says Mărdărescu, "because HIV is now a chronic disease."

The first treatments began in 1995. Today, 90 per cent of the HIV drugs available in the world are available in Romania. Marinescu's orphans remember how hard it was to take the medicine when they were just eight or nine years old. At first, they were given powdered drugs, then syrups because they were too young for the pills. As adults, many are on special treatment plans, taking two to five pills a day, with regular check-ups every three to six months, depending on their physical and mental state.

The challenge now, Mărdărescu says, is to create a combined-dose treatment that combines many drugs in a single pill, is easy to take and doesn't take a toll on the patients' physical appearance. This is vital because even with access to treatment, many patients abandon their treatment over time. "Some of them see it as a routine; others get to a state where they feel stuck and refuse the treatment, either for some time or for ever," she says.

"We call them therapeutically aged. We offer the possibility of



treatment, but some drop out in favour of [enjoying] their day-to-day lives, which they want to be the same as the lives of others."

Things can only change if the patient agrees to work with a psychologist, says Mărdărescu, adding that after treatment is stopped, the results of their blood tests get worse and the illnesses associated with HIV can eventually kill them.

This is a legacy of the years when access to drugs was difficult. Even with the legal reforms of 2002, and later 2004, which provided further rights including a disability pension and food allowances, Romania was still a country in the process of rebuilding. Local health authorities were unprepared for the changes that swept in and the scale of the problem. The government would promise access to drugs, but hospitals and pharmacies wouldn't be stocked, sometimes for weeks, playing havoc with attempts to keep patients on their regimens.

On the positive side, Romanians with HIV are entitled to disability allowance of around €250 a month from the government, possibly more depending on health status and whether they need a full-time carer. But this creates something of a dilemma if they want to work. Start working and their disability allowance is cut in accordance with their working hours – and, outside of the major cities, wages in Romania are low. Giurgiu, for example, is one of the poorest cities in the country. And for the types of jobs available to HIV-positive orphans, the average monthly pay is around €200. Many living with HIV, though, struggle to work a full eight-hour day.

When they turned 18, most of Marinescu's orphans banded together to rent places of their own. Some of them have their own families now. Roxana has a four-year-old girl who's now in kindergarten. Ileana has two children. A third young woman moved to Spain and has one child. "She calls me frequently to let me know how she's doing," says

Marinescu with delight.

Roxana is talkative, with a big smile and perfect teeth. She's happy to have a family of her own. "I did some research and did everything I needed to prevent my little girl from getting the virus," she tells me. "Because I did everything the right way, my little girl isn't ill. I was able to give birth in Giurgiu, my hometown, by C-section. The doctors know what they have to do when dealing with an HIV-positive pregnant woman, so I wasn't afraid at all. The day after the C-section I already started taking care of my baby. I knew I couldn't breastfeed her, but I wanted to take care of her myself... When you grow up without parents, things are different. I didn't need anyone to help me."

Roxana is determined to tell her little girl about her illness. "When she turns 10 or 11, I'll tell her the truth about myself. I won't hide it from her, it doesn't make any sense. She'll find out anyway. I've read a lot on the subject, enough to understand it myself and be able to speak to others about it."

Marinescu taught his children not to hide who they are. Yet candour comes at a price, so many are understandably still reluctant. Cristina says they avoid having their pictures taken, because of years of traumatic experiences being pointed at in the street. "Things haven't changed that much in the way HIV is perceived," she says. "We avoid having too much exposure."

Like the other orphans, Cristina's biggest wish is to find a job. She's a good seamstress and would like to work in a protected factory – sheltered workshops financed through European Union funds or foreign aid that provide a stepping stone for people that need social support, such as Roma people or the unemployed. Other HIV orphans have benefited from similar models. The Speranta Association, for instance, has established two farms where its children, now young adults, are

working or training. "They've tried to get jobs in the city, but you know how it is," says Rodica Mătuşa. "Either people found out they were HIV-positive or they just didn't manage to find work, so we had to do something to help them make a life for themselves." The farms and their workers support themselves using 60 per cent of what they produce, selling the rest. One farm, named Speranta after the Association, grows vegetables and livestock, while the other, ARICO (Aripi pentru Copii, or Wings for Children), produces flowers.

The challenge for Marinescu's orphans is to find such a future for themselves. But no matter what their path, they know they always have a home. Many come back and work as volunteers in the centre where Marinescu once took care of them. They come together often, celebrate birthdays together, comfort and help each other in every way they can. Marinescu continues to help his adopted children with food, advice, medical treatment, even wedding dresses. The doctor gave them a family that kept them alive as [children](#), and a bond that helps keep them alive as adults.

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