

# Pediatric HIV/AIDS Intervention in Constanta, Romania



## About the Cover

Traditional dancers take part in a 2007 ceremony to re-dedicate the Romanian American Children's Centre. The new name, the Romanian Clinical Centre of Excellence, reflects its shift in mission as more and more of its patients move into adulthood and begin families of their own.

In the 1990s, as the AIDS pandemic began to evolve, action against the disease took a much slower course in countries with repressive government regimes where the existence of the disease was hidden. As these regimes crumbled, the true extent of HIV prevalence began to reveal itself. One such country was Romania, which had an estimated 10,000 pediatric HIV cases — but due to a ban on even discussing AIDS that figure may be low. Today it is estimated that there are approximately 5,000 people 21 and under living with HIV. Romania is the only country in the world that has more children with HIV than adults and has the most children with HIV in all of Europe. When access to the pediatric wards in Romania was finally allowed, international NGOs and media were able to shine a light on the horrific conditions for these children, who were often warehoused and lacked access to the most basic HIV care. It became clear that government intervention could not move rapidly enough to save them, and international NGOs and the private sector moved in to attempt to fill the gap.

The story you are about to read has many parts and many contributors. While it starts as a human tragedy, it turns into an instructive reminder of the power that comes when organizations and communities partner for the good of others.

Like me, I think you will come to recognize and admire the tremendous contribution a few people can have on many. Determination not to accept the status quo and the ability to envision HIV-positive children living healthy lives well into adulthood is what surely drove Dr. Rodica Matusa, a pediatrician from Constanta, Romania, to seek help — and her call was answered by a fellow pediatrician from Houston, Texas, Dr. Mark Kline.

Most importantly, this story is about hundreds of children in Romania going from certain death to leading active lives as young adults — some of whom you will meet on the pages that follow. Their future now is filled with hope and promise. But the success of this program does not stop in Romania. It was also the inspiration for the development of a network of Baylor College of Medicine Children's Clinical Centers of Excellence throughout Africa. These outpatient clinics and their satellites are now providing quality care and treatment for more than 70,000 children living with HIV — an initiative unparalleled by any other single organization in the world today.

By documenting our efforts at Abbott and those of others in the developing world, this past decade we have been able to help construct and support the development of model programs that enhance the lives of those in need. And the learning continues. As a health care company — together with our foundation, the Abbott Fund — we understand it is our duty to continually seek ways to provide effective health care solutions. It's a responsibility the people who work at Abbott and the Abbott Fund fully accept personally and professionally.

We are pleased to share this story of hope and triumph in Romania with you and invite you to learn more about our programs and those of our many outstanding partners throughout the world, including the Baylor College of Medicine, by visiting our website at [www.abbott.com/citizenship](http://www.abbott.com/citizenship). Thank you.

**Katherine Pickus**

Divisional Vice President, Global Citizenship and Policy, Abbott

It was more a case of Romania finding me than of me finding it. A fateful meeting in Houston with a handful of Romanian parliamentarians in the autumn of 1995 led to a trip to Romania in February, 1996. At a point in my career when I felt I knew everything there was to know about HIV/AIDS, I witnessed an unfolding tragedy and disease of a magnitude I had never imagined. I knew instantly that my life would never be the same.

From modest beginnings, a children's center ultimately was built and opened in Constanta in 2001. More than 400 Romanian children began highly-active antiretroviral therapy; at the time, probably the largest number of children in treatment for HIV/AIDS in any center worldwide. On Christmas Eve of 2001, I wrote the following from a computer at the Romanian-American Children's Center:

It is bitterly cold and gray outside, with nearly a foot of snow on the ground. But the season cannot shroud the hope that has enveloped Constanta's HIV-infected children and their families. Day after day, they come to the clinic in droves, not for grim pronouncements, but for good news, great news — another kilogram of weight, healing herpes sores, increasing T-cell counts. The prospect of more birthdays, more Christmases to come. And the tears the mothers shed are of joy, not sadness. Being in this place at this moment in time truly is a blessing, and one of the greatest gifts imaginable.

I have described that experience as addictive. By 2003, that addiction had led to the creation of another children's center in Botswana. Lesotho, Swaziland, Malawi and others soon followed. Hundreds of HIV-infected children in care and on treatment became thousands; thousands became tens of thousands. Today, more than 55,000 children are in care for HIV/AIDS across our network of centers.

The next phase in the life of what became known as the Baylor International Pediatric AIDS Initiative will be the creation of a Center for Global Child Health at Baylor College of Medicine and Texas Children's Hospital, tackling major killers of children worldwide — malaria, tuberculosis, diarrheal disease and malnutrition — as well as long-neglected serious and life-threatening diseases of children in the developing world, including cancer and sickle cell anemia. What we have learned over the past decade in rolling out treatment for children with HIV/AIDS will provide a template for all of these new programs.

My personal journey through the world of HIV/AIDS in Romania and Africa has been both unexpected and unplanned. I have witnessed not only indescribable suffering, but also the resiliency of the human body and spirit. I have seen countless unnecessary deaths, but also the rebirth of families and whole communities, thanks to the advent of lifesaving treatment. As a specialist in pediatric infectious diseases, I view HIV/AIDS as the greatest challenge of my generation. It has been the professional privilege of a lifetime to have the opportunity to contribute in even a small way to blunting the effects of this epidemic scourge.

**Mark W. Kline, M.D.**

Professor and Chairman  
Department of Pediatrics  
Baylor College of Medicine  
Physician-in-Chief  
Texas Children's Hospital  
President  
Baylor International Pediatric AIDS Initiative



## A Country in Trouble

Romania became a communist country as of the termination of the monarchy and occupation by the Soviets in 1947. The country remained under direct military and economic control of the Soviet Union until the late 1950s, when Soviet troops began a negotiated retreat and Nicolae Ceausescu took control. A short period of economic well-being and openness in the late 1960s and through the early 1970s was followed by increasing national debt. To achieve the goal of excising the country of the influence of the International Monetary Fund and

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Above: With little protection from cold or hunger, this haunting image captures the plight of the many Romanian children living in poverty when Dr. Mark Kline first visited the country in 1996.

World Bank and ridding it of its foreign debt of \$10 billion, Ceausescu initiated a project of total reimbursement, imposing policies that exhausted the Romanian economy. The Romanian people were left on the brink of starvation with desperate shortages of food, fuel and other essentials. Extreme poverty, combined with diminishing personal and political freedoms, led to the overthrow of Ceausescu in the Romanian Revolution of December 1989.

### A Dangerous Climate

Under the Ceausescu regime, all forms of family planning — including contraception — were banned. This, coupled with abject poverty, led to higher percentages of children



Catalin and Andrei are part of the Flower House "family", where children with HIV live in a home environment, free of stigma or discrimination. Andrei (right), serves as a role model for the younger boys and was the first to leave Flower House to work and live on his own.



who were abandoned, institutionalized and neglected. Universal precautions to stem the spread of disease were largely ignored. Transfusions of unscreened blood coupled with the denial of the existence of any risks of HIV transmission in Romania fostered a climate that allowed the unhindered spread of the disease.

The epicenter of the disease was in Constanta, the second largest city in the country. Constanta is a harbor city by the Black Sea where workers from all over the country had converged, often living transient lives in unclean and unsafe conditions. Many people, including sex workers, sold their blood to make money — not knowing it was infected with HIV. And because no blood-screening programs were in place, the infected blood was not detected. Children then received transfusions of infected adult blood for medical procedures; there were also claims that some children received adult blood to make them stronger. This practice was allegedly happening in some of the larger state-run children homes. Thus, HIV took a particularly hard toll on children in Romania, with an estimated 3,748 children having died of AIDS by September 2006.

During the late 1980s — the early years of the epidemic — Constanta found itself totally unprepared for dealing with thousands of pediatric AIDS cases. The response to the crisis was neither structured nor sustained; it was an emergency response that involved leadership of dedicated people and support from western countries. There was a clear dichotomy in perceptions: while the Romanian Ministry of Health denied the gravity of the situation and simply waited for the patients to die, the civil society, funneled by the support of international volunteers and donors, started to work in partnership with the hospital ward.

But because civil society was so effectively undermined during the Communist period in Romania, it took more than 10 years following the revolution of 1989 for people living with HIV/AIDS to organize themselves at a national level and demand changes to the health care system.

## Snapshot: Romania in 1989 - 2009



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22.2 million citizens

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69 years:  
male life expectancy

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76 years:  
female life expectancy

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U.S. \$12,200  
GDP per capita (PPP)

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25% population below  
poverty line

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1.9 physicians per  
1,000 people





## March 1988

Eighty-eight newborns die by unexplained causes in just one month. The situation is classified as medical malpractice.



## May 1989

More than 200 sick children from orphanages are sent to the pediatric ward at Municipal Hospital; a specially isolated area in the hospital basement, where “nobody entered with the exception of a few professionals from the pediatric ward, dressed like astronauts” — whose entrance was protected by a freshly constructed wall to block the view from the street. Mortality rate is high and new cases are diagnosed every other day. Due to the long-standing policy of state secrecy in these kinds of matters, there is no way of knowing how many children have HIV or have already died of AIDS at this time. Estimates range from 7,000 to 10,000 infected in the 1980s. What is known is that Romania was then, and remains, the only country in the world that has more children than adults living with HIV.



## February 1990

With the fall of Ceausescu in December 1989, international press and NGOs are allowed into Romania, and reports of the pediatric HIV epidemic begin to surface. Many companies, hospital officials, foundations and volunteers get their first look at the plight of Romanian children in general and, more specifically, those living with HIV. Romanians — including health officials — start to talk about these children and AIDS for the first time, but public discussion remains limited.



## 1990 – 1992

Through the hospital, connections were made with many international NGOs and private donors, helping to address the critical needs of the rising number of infected children, including basic medication (since specific HIV medication was not yet available), clothing, food, education and developmental stimulation, housing for the abandoned children in family-type houses, terminal care, etc. A valuable lesson was learned thanks to all these efforts: that AIDS does not necessarily equal death, given the potential for treatment and recovery.





## 1992 – 1994

The pediatric ward of the Municipal Hospital operates in a one-room day clinic, caring for hospitalized children with AIDS.

Treatment is only available for opportunistic infections, and wasting syndrome is addressed mainly with proper nutrition but little medication. Many children with AIDS are residents of the hospital, simply because they remain rejected by other state programs, and private family homes are full. The conditions in the hospital are terrible, as facilities have not been renovated or properly maintained since the 1970s. Romanian authorities begin to publicly acknowledge that HIV/AIDS is a problem of the entire society, and a national AIDS program is launched. It will take another three years to establish regional HIV centers with support from the World Health Organization (WHO).



## 1995

AZT (zidovudine) is the first AIDS drug approved for use in Romania — five years after it became available in the United States.



## 1996 – 1997

After introducing herself at an international medical meeting, Dr. Rodica Matusa invites Dr. Mark Kline, Houston-based Baylor College of Medicine professor of Pediatric Infectious Diseases, to visit the children at the local Constanta hospital where she worked as the director of pediatrics. Dr. Kline remembers, “At that point in my career, I thought I had seen everything... I really thought I knew everything there was to know about pediatric HIV, but I realized at that point that this disease was having a terrible impact on children in poor countries. I could not get it out of my mind.” Dr. Kline decided after that life-changing visit to commit himself to helping to care for and treat the children with HIV/AIDS in Constanta. He set up a program with his colleagues from the Baylor College of Medicine to train the doctors and nurses in Constanta so they could provide the best care possible for their pediatric patients.



## 1998 – 1999

The arrival of Dr. Kline and the team from Baylor began a new chapter in the lives of children with HIV in Constanta. However, challenges still exist in the rest of the country. In 1998 the Romanian National AIDS Commission moved forward slowly, elaborating its strategies and country recommendations; for example, it set the standards for triple therapy, but without being able to ensure it continuously. Only about 200 of Constanta's 1,000 children known to be living with HIV/AIDS had access to the so-called protease inhibitor medicines.

Rodica is one of the social mothers at the Baylor complex (Flower House and the Baylor Habitat house), who provides ongoing emotional and moral support as the children grow into adulthood.







## A New Chapter

It became increasingly obvious to the hospital staff that they were fighting an impossible battle, treating the explosion of pediatric HIV cases in a one-room, makeshift clinic. The lack of medication, training, space and staff — as well as consistent supply of medications — was becoming more overwhelming by the day. Yet, in spite of high death tolls and lack of medication, more than 1,000 children with HIV/AIDS were known to still be alive in Constanta. These children needed medication and long-term care, and could not wait

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Above: Children with HIV/AIDS were initially evaluated and treated in a hospital staff office that was turned into a makeshift one-room clinic. The Baylor team, seen here on one of their first visits, quickly realized the significant challenges they would face in trying to care for their young patients.

for the Romanian government to coordinate a sustained national response. Dr. Mark Kline saw that an immediate response was necessary, and in 2000 formed the Baylor International Pediatric AIDS Initiative. Its goal was to implement a sustained program of pediatric HIV treatment in countries with limited resources, and Romania was to be the first country to be part of the initiative.

One of the first priorities was to get needed antiretroviral therapies to the children in a clean and safe environment; however, there was neither a sustainable infrastructure in place to receive the drugs and properly administer them, nor





Left: A group of young patients wait restlessly for a first glimpse of the newly renovated HIV clinic. The clinic represents the first real hope for children of the region to live full and healthy lives despite their HIV status.

Bottom Left: Dr. Mark Kline and Executive Director Ana-Maria Schweitzer are seen dedicating the Baylor-Habitat House in 2007. The house provides individual apartments for former occupants of the Flower House, who have grown into adulthood and are ready to leave their “family.”

Bottom Right: Catalin is one of the adolescents from the Flower House who proudly volunteered his time to work on the construction of the Baylor-Habitat House.

the trained staff to oversee the full-time and comprehensive treatment program.

### **The Romanian-American Children’s Center**

Drs. Matusa and Kline wanted not only to provide children with medicine as needed, but also a place where children could be treated in clean, modern facilities, and where healthier, abandoned children could be taken out of the hospital and given a proper home, education and love. This would involve not only changes to physical structures, but also building a multidisciplinary team of trained professionals who could handle the children’s physical as well as psychological needs.

Dr. Kline’s vision was to construct a state-of-the-art, stand-alone pediatric outpatient clinic in Constanta that would be readily accessible to pediatric HIV/AIDS patients and their families and/or caregivers. His dream started to take form when the Municipal Hospital provided Baylor with an abandoned orphanage that was in great disrepair for the new pediatric AIDS clinic. Next, Dr. Kline had to find funders for this nearly \$1 million dollar facility.

One of the first funders, The Sisters of Charity of the Incarnate Word, based in Houston, had read a feature story in the *Houston Chronicle* about Dr. Kline’s efforts. The sisters were

deeply moved by the story and called Dr. Kline to ask how they could help.

The second major funder to join, the Abbott Fund, learned about the Baylor program through a medical association and offered its support. Both the Sisters of Charity and the Abbott Fund provided grants to renovate the clinic, and the Abbott Fund pledged to pay ongoing operating expenses. The new clinic was scheduled to open in the spring of 2001, but there was an immediate and critical missing piece — there was no reliable and steady source of antiretroviral medication, as government supplies still were unreliable. Abbott agreed to donate enough of these drugs to treat opportunistic infections to care for 500 children for their lifetime. Through Dr. Kline’s advocacy, other companies, including BMS, Roche and Merck followed suit.

In April 2001, the new Romanian-American Children’s Center was dedicated in the presence of everyone from the Minister of Health, to the Mayor of Constanta, to two of the future pediatric clinic’s patients speaking at the opening ceremony. The new, modern building included ample waiting space; a play corner; several well equipped offices for doctors, psychologists and social workers; a small library for professionals as well as a conference room for training and meetings with patients and parents; and just as

importantly, a pharmacy stocked with AIDS medications from several companies. More than 600 patients were being served almost as soon as the doors opened in this warm and welcoming facility adorned with artwork from children at the Texas Children's Hospital (affiliated with Baylor) back in Houston.

In an effort to replicate the high standards at the Houston-based Baylor College of Medicine, one of the leading medical schools in the world, the Baylor team set up an electronic system that monitored patient evaluations and the dispensing of medication. They trained their Romanian colleagues to use the system as part of their daily activities. This helped ensure ongoing quality care as well as transparency and accountability for donors, thus encouraging long-term support. The Romanian Ministry of Health began providing the rest of the needed medications, funneling these into the newly established clinic pharmacy. Thus, the children now had medication from two sources, private and governmental. Constanta became the only city in Romania that did not experience treatment interruptions due to the existing drug-purchasing process, which included time-consuming auctions and the collection of approvals.

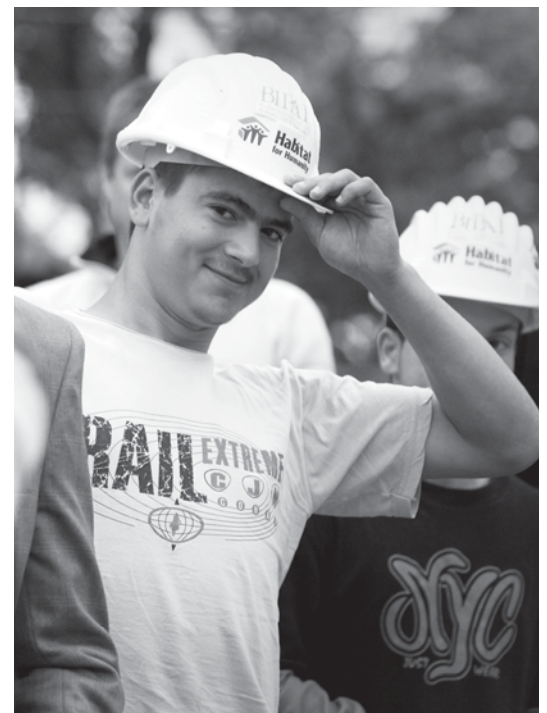
As the children of Constanta finally had access to ongoing highly active antiretroviral therapy (HAART), their life expectancy changed dramatically. In a few years, the mortality rate dropped to less than 1% per year and the hospitalization rates decreased by 90%. "In just three years, the Center has

decreased the mortality rate of children living with HIV/AIDS in Constanta from 15% to 3%, proving that it is possible to provide first-rate pediatric care and treatment in a resource-limited setting," said Dr. Mark Kline.

With the Center functioning smoothly, the need to ensure proper care for the children who remained in the hospital as well as those who were unable to visit the Center became even more apparent. The next step was to integrate mobile and home-based care programs for the 200 families who were unable to visit the clinic. The Abbott Fund responded with a long-term commitment to support these programs, and provided staff training and resources to sustain management systems. Not wanting to ignore those children who needed to be hospitalized, the Abbott Fund also supported the renovation of the Pediatrics Ward at the Infectious Diseases Hospital in Constanta, resulting in these children receiving a continuum of quality care between the clinic and the hospital.

### The Flower House

The ongoing problem of children with HIV being abandoned and living in hospitals continued through the 1990s. By the year 2000, most abandoned children in Constanta had been moved into relatively small 10-to-12-child family-type homes supported by various international NGOs. However, some children remained hospitalized or were returned from group homes to the already overcrowded Municipal Hospital. State institutions were not prepared or equipped to deal



with these sick children, and other private facilities were also overcrowded.

Ten such children became the subject of concern at the Baylor clinic. An appeal from Baylor to the Abbott Fund led to the purchase and renovation of Flower House, a small group home. The ten children were finally free from hospital walls and had a home with caring adults (social mothers and fathers around the clock) who looked after their basic needs as well as their health and social development.

The little village, just outside of Constanta, where the children lived was touched by the presence of “a house that is primarily distinguished by the Texas flag hanging from the second-floor balcony.” The community learned to accept them, and children were visited by friends and families — all coming together at anniversaries, holidays and other special occasions.

### Beginning a Dialogue

Working with the same patients year after year — including those living in the Flower House and other group homes — meant assistance with much more than their medical condition. One challenge was helping the children attend normal schools in the neighborhoods where they lived. Initially, many children were not sent to school due to their ill health or expectancy of imminent death. There was still

also a great deal of misinformation and stigma about HIV in the community. This, in fact, was the case for several of the children living in the Flower House.

As needed, a team of psychologists from the Center would begin a program of educating everyone at each school, starting with sessions for teachers and school principals and then meetings with parents and children. Sometimes they were successful and the children were able to attend the school; other times they had to move to another school that was more receptive. Four of the children at the Flower House were initially denied entry into their local school. After the Baylor team intervened with a strong education and advocacy effort, the situation was turned around and the children were warmly welcomed into the school. This program came to the attention of the School Inspectorate and triggered the development of a strong collaboration to educate teachers and pupils across the region to talk about HIV.

Another key component of the Baylor program was to address the psychosocial needs of children, parents and/or caregivers. The outreach frequently focused on the parents, which often proved as intensive as working with the children. Diagnosis disclosure and helping parents regain hope or assisting them through the grieving process were some of the issues that the team dealt with. As most parents needed support, they learned to lean on each other in support group



Left: Many parents at the Baylor clinic were initially afraid to disclose or discuss their children's HIV status. Parent and family support groups became instrumental in bringing these issues out into the open and helping participants deal with them.



meetings. A real network of parents arose, and they met regularly with the clinic doctors in order to find out news about the therapy, to ask questions, and to find out about hope for a vaccine and for the future of their children.

If good progress was made in regard to school acceptance and community support, the same could not be said about access to medical services outside the clinic. Paradoxically, the system that denied the mere existence of AIDS for so many years was forced to treat people with AIDS, since those who began to live longer on ARV therapy experienced complications and required consultations from oncologists, tuberculosis specialists, surgeons, psychiatrists, etc.

The unspoken belief by the local medical community was that all AIDS problems should be solved by the Children's Center and the Municipal Hospital (specifically, the Infectious Diseases Hospital), since AIDS was a "special" problem, which needed "special resources." In fact, most situations were solved through personal professional relationships among physicians, but the problems lingered for years and were sustained by the system itself.

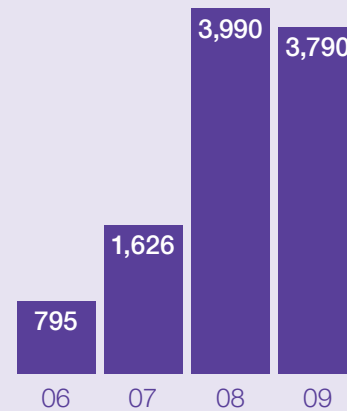
For example, the laws written in 2002 regarding HIV prevention measures and protection for HIV-infected persons lacked clear implementation measures, sanctions and control mechanisms. Therefore, they did not provide protection from discrimination for the infected patients and their families. This is demonstrated by the fact that in 2004 the National Council Against Discrimination took action on only one HIV-related discrimination case.

From 2001 through 2006, the Center developed many programs, evolving to meet the needs of its clients. All the programs kept in mind the intricate connection between the clinic and the community, and all the services were delivered to both simultaneously from the very beginning.

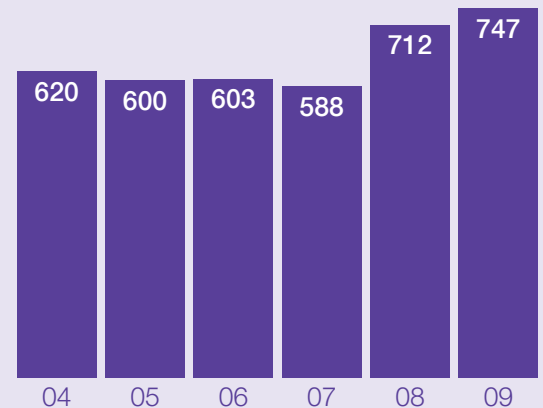
However, the next set of challenges lay ahead. The original group of children treated at the clinic were not only surviving, but also thriving and slowly growing into young adults.

## Snapshot: Constanta

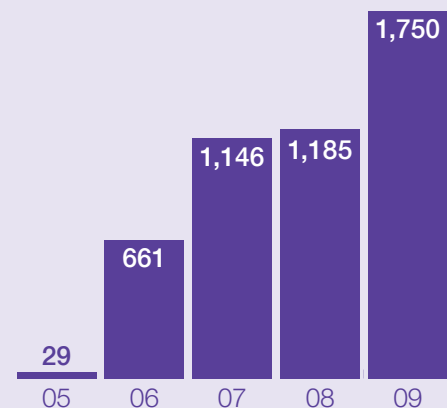
Persons Receiving Counseling and Testing



Persons Receiving Care and Treatment



Number of Health Care Workers Trained or Re-trained





## A Full Life

The flexibility allowed by Baylor and the Abbott Fund in the design and management of programs for the Romanian-American Children's Center was a distinctive feature that usually is not possible in a state-run program. Because of this flexibility and the direct contact with parents and children, the programs were shaped to directly respond to their needs. This proved particularly valuable as the original cohort of children treated at the Center became adolescents and young adults.

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Above: The Flower House opened in 2001 and accommodated 10 HIV positive children who had been orphans or abandoned due to their diagnosis. Most of them were aged 8-10 and had been living in hospitals for years.

In an interview with Dr. Kline, he marveled that "the transformation (of the children) has been remarkable. These little, stunted children, in some cases 10- or 11-year-olds that looked like 3- or 4-year-old children have grown tall and strong. They look perfectly healthy. Some have graduated school. Many of them are in job training. Some of them are living independently. Many of them are married. We had about 10 pregnancies and births from girls cared for at our clinic...fortunately none of the babies are infected... they can all look forward to a very full life."

### **New Challenges**

Because of their uninterrupted HAART medication and consistent medical care, the children enjoyed good health

Flower House residents Gratian and Elena, take part in vocational training workshops that help them build independent living skills.







Left: Children at Flower House live in a family environment where they are accepted and given love and affection.

and normal physical development. And while the disease remained important in their lives, it was no longer the central focus. Instead, the normal challenges and problems that affect many adolescents occupied their minds. As most young people their age in Romania, their focus was on relationships, peer acceptance and finding their identity. Some of them coped better with this transition than others.

The content of the medical and psychosocial programs had to evolve rapidly to meet the patients' emerging needs; initially the diagnosis disclosure and acceptance of the diagnosis was the focus, but in time new topics arose. These included changes of the body in adolescence, love and relationships, sexuality and self-esteem. As the patients grew, the parents also had to be supported to accept the fact that the time had come to let them become more independent and taste life by themselves. This was a challenge too, but it turned into an individual lesson for each family.

A big, and somehow unexpected problem as the children grew up, was adherence to their HIV medications. It is difficult to consider that these young adults would forget or neglect to take the drugs that were responsible for their good health. However, recent Baylor data shows that 90% of all patients that have detectable viral loads at the Center in Constanta have difficulties in adhering to treatment.

Counselors also needed to learn to deal with these young adults as one half of a couple. Child psychologists and social workers had to make a shift in their attitudes and objectives by focusing on the couple rather than the individual,

sometimes including couples where only one or both were HIV-infected. The whole interdisciplinary team had to learn to be comfortable with this shift and adjust its methods of work, since couple counseling brings on issues like disclosure of diagnosis to the partner, prevention of infection of partner, pregnancies (planned or unwanted), achieving financial independence, facing loss, etc.

Unfortunately, rates of unwanted pregnancies and transmission of HIV infection show that in some cases, prevention programs have failed. Baylor Black Sea Foundation's internal reports show that that in 2007 there were 36 unwanted pregnancies, and during the first ten months of 2008 there were 27 pregnancies. In 2008, seven persons had positive seroconversion while they were part of an HIV-discordant couple.

Transition to adulthood brought focus on other problems as well: learning how to find and keep a job, empowering patients to overcome their own fears and pursue their dreams, and convincing patients to follow difficult treatments and to stay in the care of the clinic, despite geographic mobility that might come along with new jobs and families.

More and more it was understood that some of the failures of the HIV-infected patients were not due to defects of character but to handicaps in the community, including high levels of stigma and violations of human rights (such as bearing children or sexual freedom), insufficient prevention and risk-reducing education for non-infected youth, ineffective screening systems in the wider community as well as lack of communication between institutions that should provide referrals and protection.

## A New Focus

In January 2007 the Romanian American Children's Center (RACC) reported 485 patients in its care. The difference between HIV-infected children and HIV-infected adults had become more and more unclear, with some patients from the Center being transitioned to the adult ward at the Infectious Diseases Hospital of Constanta (IDHC) and others wanting to remain in the care of the Center despite having reached adult age. While some of the psychosocial services could be transitioned in the hospital setting, the overall Center programs were not available for the more than 800 combined patients in Constanta.

This led to the decision to transition from a child-only to a family program that welcomes HIV-positive adults and children. Dr. Kline said, "We are choosing to expand our own range of services to accommodate the entire age range from infancy to adulthood. We will continue to provide medical and psychosocial services to these individuals, but we're also going to tackle issues like housing and job training, education and subjects surrounding marriage and family."

To reflect this new, more broad-based and comprehensive approach, the Romanian American Children's Center was renamed the Romanian Clinical Center of Excellence in December 2007. The Center of Excellence now provides all needed services under the same roof, including programs in infectious diseases, pulmonary diseases, gynecology and dental care; psychosocial and vocational counseling, social assistance, family planning and support groups; and education for healthy independent living. The Center also

continues to educate and train health professionals and develop a new research department. Drug supplies will be sustained by the Ministry of Health and donations from Abbott for all infectious diseases, while the Abbott Fund and other private donors support the rest of the program.

Much energy has been invested in developing relationships with local authorities and hospitals in order to broaden the results and programs beyond the Center, as well as to promote this model of care at the national level. Therefore, anyone in Constanta receiving care for HIV now receives quality care. Trainings, educational meetings and debates, as well as exchanges of good practices have also been integrated into the program.

## Changes at Flower House

The Flower House, once a haven for abandoned sick children, became restrictive for the needs of growing adolescents. While it was clear that these vulnerable adolescents would need some form of ongoing support, it was also clear that living in a bedroom with two or three colleagues was providing neither the intimacy nor the conditions to encourage independent living. A unique partnership with Habitat for Humanity, supported by the Abbott Fund, allowed for the building of the Baylor-Abbott Fund Habitat House, containing three individual apartments. The two facilities (Flower House and Baylor Habitat House) now provide more independence, and the people who live there contribute to its upkeep while receiving continued medical and psychosocial support from Baylor. Thus the support system transitioned from a program that was totally responsible for the children to a partially supportive one.



Left: As the Baylor clinic patients grow into adulthood, their medical and psychosocial needs evolve. This nurse is offering family planning guidance to a female patient.

## Moving Into the Future

The impact of Baylor's interventions will not be sustainable unless prevention, testing and treatment are delivered together and in an integrated manner. Delivering education, prevention and treatment only to those with HIV does little to protect the general population. So Baylor, in partnership with county hospitals and with the School Inspectorate (through a special volunteer initiative focused on behavioral change and HIV education), helped to establish rapid voluntary counseling and testing for the general population in two counties.

Baylor also used its results and influence to demonstrate the need for change in standards of care and promotion of human rights for the HIV-infected. In 2008, Baylor Romania became involved in national and local campaigns to fight discriminatory HIV testing before employment and discrimination in medical settings.



Left: Dr. Kline embraces Marius, one of the first Baylor clinic patients and Flower House residents. Seeing Marius and other patients thrive and grow into adulthood is enormously gratifying for all those involved in the Romania program.

Bottom: Nesjivan Septar, a nurse, is greeted happily by children during a visit to the Flower House.



## THE PARTICIPANTS



### **Mark W. Kline**

Mark W. Kline, MD, President, Baylor International Pediatric AIDS Initiative. Dr. Kline is professor of Pediatrics, chief of Retrovirology, director of the AIDS International Training and Research Program, and director of the Baylor-CDC Global AIDS Technical Assistance Project, all at Baylor College of Medicine. He also serves as president of the Baylor International Pediatric AIDS Initiative. Dr. Kline is a graduate of Trinity University and the Baylor College of Medicine. He trained in pediatrics at the Baylor College of Medicine, where he also served as chief resident. Dr. Kline is board-certified in pediatrics and infectious diseases. He has served on the Executive Committee for Infectious Diseases of the American Academy of Pediatrics, and as chair of that organization's Committee on Pediatric AIDS. He is a fellow of the Infectious Diseases Society of America and a member of the Society for Pediatric Research and the American Pediatric Society.

Dr. Kline is active in the education and training of medical students, residents, and postdoctoral fellows, and has been the recipient of several teaching awards. He has authored more than 240 scientific papers and textbook chapters. He has given more than 300 national and international presentations on topics in pediatric infectious diseases.



### **Rodica Matusa**

Rodica Matusa graduated from the Faculty of Medicine in Cluj-Napoca and earned a doctor's degree in AIDS. She worked as a specialist doctor at the Clinic Hospital for Infectious Diseases in Constanta and published many research papers. Since 1991 she has headed the Speranta (Hope) Association in Constanta, dedicated to the prevention of HIV/AIDS and to providing assistance to infected persons.

In 2005, Dr. Matusa retired from being Executive Director of the Black Sea Foundation, but continues to be active working with numerous HIV/AIDS organizations and being a member of various local boards in Romania.



### **Ana-Maria Schweitzer**

Ana-Maria Schweitzer, MA, has been the Executive Director of the Baylor Black Sea Foundation, which oversees the Baylor Center of Excellence in Romania, since 2005. She first joined the Baylor program as a staff psychologist in 1999.

The Baylor program provides a unique model of care for medical, psychological and social needs of HIV positive patients, including many long-term survivors that have become young adults. This has resulted in the Center of Excellence evolving from a HIV-AIDS clinic providing services to children into a family-centered clinic serving children and adults with a wide range of medical needs and prevention services – all ensuring a continuity of care in accordance with changing needs of patients, their families and the local community. Ana-Maria strives to create a balance among prevention, testing, care services and patient advocacy.



### **The Sisters of Charity of the Incarnate Word**

The Sisters of Charity of the Incarnate Word are religious women serving within the Church as signs of God's presence in the world.

Entrusted as they are with the mission of embodying the love of the Incarnate Word, they bear in mind that, whatever the form of their ministry, it is by means of their own lives that they witness most convincingly to the presence of Jesus Christ. They share their gifts in ministries of prayer, healing and education.

Based in Houston, Texas, they directly serve those in need in areas such as El Salvador, Guatemala, Ireland, Kenya, Romania and the United States.



### **Baylor College of Medicine**

Baylor College of Medicine in Houston, the only private medical school in the Greater Southwest, is recognized as a premier academic health science center and is known for excellence in education, research and patient care.

For 2009, *U.S. News & World Report* ranked BCM 13th overall among the nation's top medical schools for research and 7th for primary care. BCM is also listed 13th among all United States medical schools for National Institutes of Health funding, and No. 2 in the nation for federal funding of research and development in the biological sciences at universities and colleges by the National Science Foundation.

Located in the Texas Medical Center, Baylor College of Medicine has affiliations with eight teaching hospitals, each known for medical excellence.

The college has total research support of \$302 million, with \$241 million from federal sources, and more than 90 research and patient-care centers and units. Currently, BCM trains more than 3,000 medical, graduate, nurse anesthesia, and physician assistant students, as well as residents and post-doctoral fellows.



### **Baylor International Pediatric AIDS Initiative**

The Baylor College of Medicine International Pediatric AIDS Initiative was established in 1996 by Dr. Mark W. Kline, professor of Pediatrics at Baylor College of Medicine, to foster international HIV/AIDS prevention, care and treatment, health professional education and clinical research. It has rapidly grown to become the world's largest university-based program, dedicated to improving the health and lives of HIV-infected children. The mission of the Baylor College of Medicine International Pediatric AIDS Initiative (BIPAI) and its affiliated non-government organizations in Romania, Botswana, Lesotho, Swaziland, Malawi, Uganda, Kenya and Tanzania is to conduct a program of high quality, high impact and highly ethical pediatric and family HIV/AIDS care and treatment, health professional training and clinical research.



### **The Abbott Fund**

Established in 1951, the Abbott Fund is a private 501(c)3 not-for-profit organization in the state of Illinois and is funded solely by Abbott, a global broad-based health care company. The Abbott Fund's vision is to create healthier global communities worldwide. Its approach is to support programs that are results-driven and to make a lasting impact on people's lives. Much of its philanthropy aims to improve health care services for the poor, marginalized and underserved.

The Abbott Fund supports and partners with a broad range of organizations, including community-based charities, academic institutions, medical and health professional associations, international relief agencies and not-for-profit organizations. Many of these programs are helping to create solutions to address the global health needs shaping our world today. Where appropriate, these programs are also able to benefit from Abbott's health and technical expertise, leadership and products. Major areas of program funding include: Access to Health Care, Science and Medical Innovation and Community Vitality.

### **BIPAI network looks after HIV-affected children**

[http://www.bcm.edu/findings/vol4/is2/06feb\\_n1.html](http://www.bcm.edu/findings/vol4/is2/06feb_n1.html)

### **A global view makes a difference**

[http://www.bcm.edu/findings/vol1/is7/03july\\_m.htm](http://www.bcm.edu/findings/vol1/is7/03july_m.htm)

### **Treating HIV's youngest victims around the world**

[http://www.bcm.edu/findings/vol3/is2/05feb\\_n1.htm](http://www.bcm.edu/findings/vol3/is2/05feb_n1.htm)

### ***The Tiny Faces of AIDS***

<http://www.bcm.edu/solutions/v2i1/tinyfaces.html>

### **BIPAI's pediatric AIDS center in Romania grows up**

<http://www.bcm.edu/news/item.cfm?newsID=1026>

### **Center for AIDS Research, March 2002, Volume 5, Issue 1**

<http://www.bcm.edu/cfar/?PMID=2701>

### **Dr. Mark Kline and the Baylor International Pediatric AIDS Initiative**

[http://www.medangel.org/kline\\_bipai/kline\\_bipai.shtml](http://www.medangel.org/kline_bipai/kline_bipai.shtml)

### ***Mortality Rate for Romanian Children with HIV in Constanta Drops Significantly; Hundreds Receive Care and Treatment at Children's Center***

<http://baylorids.org/newsreleases/release19.shtml>





