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## An Everyday Struggle for Breath; Childhood Asthma Project Reaches Out in Harlem

By Richard Perez-Pena

NEW YORK —For Sadi Fofana, nights were the worst. Days were tough, too, for a child whose asthma forced him to pause for air several times on the climb to his family's sixth-floor walk-up, a cramped home plagued by dust, vermin and drafts.

But harder still were the nights on a musty mattress, lying next to a jagged hole in the wall that allowed roaches, rats and mice the run of the apartment, on 116th Street near Seventh Avenue in Harlem. At night, as his wheezing and coughing grew worse, he would rouse his mother, Fatoumata Makadji, and tell her that he could not breathe. She would bundle him off to the emergency room -- six times in three months last year -- and sacrifice sleep and school in search of relief.

"I would cough so bad, ooh, it feels like I'm going to throw up," said Sadi, 7. "Sometimes I couldn't breathe so bad I thought I might die."

It is hard to conceive, now, as he bounds about his living room, conversing with a visitor and taunting his little sister, Tata, that this is the same boy. Sadi, a second grader, still has asthma. He still lives in circumstances most Americans would consider abject. But thanks to an ambitious project by Harlem Hospital Center and Harlem



Children's Zone, conditions in his home are much improved, his asthma is under control for the first time in years, and he has not seen an emergency room in eight months.

After living with fear of death, of bed, of those stairs, of missing the school he enjoys, Sadi says, "The only thing I'm afraid of now is the medicine, because some of that medicine tastes nasty."

The goals of the asthma project are nothing short of extraordinary -- to test every child in a 24-block area of central Harlem, more than 2,000 of them, identify those with asthma, and then mount a full-scale assault on the disease in each asthmatic child's home. Experts say there have been no more than one or two other attempts anywhere in the country at intervening so deeply into the lives of so many asthmatic children.

Members of a 12-person team from the hospital become a regular part of the families' lives for months. They see to a wide range of physical changes in the homes to reduce exposure to elements that contribute to asthma -- from training families to clean house to replacing old furniture to eliminating pests -- and make sure the children are receiving proper medical care.

"I'm not sure we understood just how big this was when we decided to do it," said Dr. Vincent Hutchinson, an allergist at Harlem Hospital and medical director of the project. "But we knew how important it is to intervene at an early age, because asthma is a progressive disease. The earlier you treat it and get it under control, the less severe it gets later on."

So far, the team has visited the homes of 168 children, about one-

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third of the 500 or so asthmatic children they plan to reach. How effective the program will be is anyone's guess, as even the team acknowledges. In fact, one of the questions they hope to answer is how well this kind of intensive intervention works.

Among the findings has been that one in four school-age children in central Harlem have asthma, one of the highest rates ever documented in this country. Many experts say they think that testing every child in East Harlem or parts of the South Bronx would reveal rates as high, if not higher.

Asthma, a chronic inflammation and constriction of the airways, afflicts an estimated 17 million Americans, and kills more than 5,000 every year. Among children, it is a leading cause of absenteeism and emergency room visits.

The causes of the disease are poorly understood. But several studies have established that environmental factors like dust, pollen and air pollution can trigger attacks. Some severe triggers are more prevalent in poor, urban neighborhoods, including the feces of cockroaches and dust mites, cigarette smoke, mold, diesel exhaust and the dander of animals like household pets and rodents.

After nearly a year of work, the Fofanas, immigrants from Mali in western Africa, are one of the successes of the Harlem project, and their story exemplifies the methods the team uses.

Some families the project encounters have no health care; the team usually manages to enroll the children, at least, in some form of

government-sponsored insurance. The Fofana children already had health care, but that was no guarantee of good care.

Mandingo is the native language of Ms. Makadji and her husband, Belinke Fofana, and they understand French, but after nine years in the United States, their English remains limited. For years, Ms. Makadji has taken her children to a doctor with whom she has no language in common, and they often communicated in impromptu sign language.

Since last summer, Daouda Diarrassouba, a community worker with the asthma project, has gone with her on doctor visits. Mr. Diarrassouba, who is from Ivory Coast, speaks English, French and a variant of Mandingo. He fields questions in English and repeats them in French, Ms. Makadji replies in Mandingo, and he translates the answers into English.

"We were confused about how to use the medicine and when to use the medicine," Ms. Makadji said. "We found out we did a lot of it wrong."

That, the project workers say, is a depressingly common problem. Parents get the dose or timing wrong, or do not use a spacer, a plastic tube that helps people inhale asthma medication. And there are more serious errors, like simply failing to provide needed medication every day.

"It's very difficult in a busy clinic setting to do proper education, and many regimens for asthma medication are complex," Dr. Stephen Nicholas, director of pediatrics at Harlem Hospital, said.

"And there's often a very clear component of denial. It's a difficult thing to accept that your child has a chronic illness, and part of our job is to make sure they do accept it."

Sadi shares a tiny bedroom with his parents and two younger sisters, Tata, 5, and Fatima, 2, who also has asthma, though it is not as severe as Sadi's. Two cousins sleep in the apartment's other bedroom. His father is a street vendor who sells African masks, working long hours and often traveling to other cities.

Their apartment was, simply, a dust trap. Even today, in its much-improved state, the rugs and aging furniture make it a far from ideal environment for an asthmatic.

The asthma project hired a professional cleaning service to scour the apartment, and bought the family a vacuum cleaner with a particle filter, and air filters. With some families, it becomes a matter of simply teaching them how to clean house.

The team persuaded the Fofanas to discard a filthy living room rug, but the family insisted on replacing it, against advice, with a somewhat newer one. They provided bunk beds so the children could sleep up, away from the floor, where dust collects, and gave them special mattresses and sheets that resist allergens. They hired handy-men to patch gaping holes in the Fofanas' bedroom, kitchen and living room walls.

They brought in exterminators no fewer than five times, and Ms. Makadji considers it a major achievement to have only the

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occasional sighting of roaches and mice, with no rats. They saw to the repair of a broken window that allowed cold air, another asthma trigger, to cut through the apartment.

As with many families, the asthma project tried to persuade the landlord to make improvements and, later, helped the family take the landlord to housing court.

"The landlords are crucial, like you really can't just clean the pests in one apartment, because they'll come back unless you address the whole building," said Yvonne Prader, a social worker with the project. "But the landlords usually resist our efforts. They delay and figure the tenants will give up, and most of these tenants do."

Ms. Makadji said of their court case, "My husband said, 'Forget it; I'm going to look for another apartment.'"

The asthma team helped there, too, putting the Fofanas on the waiting list for public housing that would be better and cheaper than the \$850 a month they pay now. They are trying to persuade the city's Housing Authority to move the family up on the waiting list, based on medical need.

The Harlem project grew out of the work of Harlem Children's Zone, a nonprofit group whose mission is to blanket the area bounded by 123rd Street, 116th Street and Fifth and Eighth Avenues, with services for the poor, like parenting classes and help in finding jobs and housing.

"The last major area we hadn't tried was health care," said

Geoffrey Canada, president of Harlem Children's Zone.

In 2001, Mr. Canada and Dr. Nicholas met at a breakfast held by the Robin Hood Foundation, a philanthropy. "I said, 'Hey, I've been wanting to talk to you about asthma,'" Mr. Canada said. "And he said, 'Hey, I've been wanting to talk with you about asthma.'"

They teamed up and devised a project, with help from Columbia University's Mailman School of Public Health, the city's Department of Health and Mental Hygiene, and T. Berry Brazelton, the child development expert.

The hospital won a grant from the Robin Hood Foundation to carry out the effort, which has a budget of \$650,000 this year.

Team members say the greatest challenges they face are not the pests or the dust, but the fraught, often chaotic lives of the families they meet -- conditions illustrated on a recent day by the team's visits to homes where their intervention has barely begun.

Six-year-old Jahmere Parkinson, a first grader with asthma, lives on 124th Street near Mount Morris Park, in a two-bedroom apartment occupied by seven members of his extended family. Three of them -- his parents and grandmother -- smoke.

"My husband and I usually smoke when the kids aren't around, and we're trying to work out a plan to quit," said Jahmere's mother, Monique Woods-Parkinson. "My mom, that's another matter."

She acknowledged that of late,

Jahmere had not taken the medicine he is supposed to have every day.

There is no sink in the family's kitchen. They wash their food and dishes in the bathtub, where the faucet never shuts off completely, in a bathroom rife with cockroaches, with big holes in the walls that let mice come and go.

In the bedroom, peeling plaster and dark mold stains mark the ceiling, and duct tape covers holes in the walls to keep rodents out. A layer of diesel soot covers the windowsill facing the bus stop outside. Piles of random clutter -- havens for dust and pests -- mark various parts of the apartment.

Nearby, on Seventh Avenue near 124th Street, live Leonor Martinez, 9, and her brother Darrol Mejia, 6, who both have asthma. These days, eight people live in their tiny one-bedroom apartment, including their mother, Rosalina Calderon. Two couches, two beds and a dresser cram the small living room, with a makeshift curtain creating a suggestion of privacy around the beds.

Mold marks the living room walls, and signs of roach infestation are everywhere. There are persistent leaks under the kitchen and bathroom sinks. The refrigerator does not work. Many of the kitchen cabinets have no doors.

"We hope we can get these children and these families to where Sadi and his family are," Dr. Hutchinson said. "We hope to do that for all of them."