Neglected Diseases: Forgotten Lives

Confronting SARS

Treating War

Wounded in Iraq
LETTER FROM THE FIELD
FIGHTING SLEEPING SICKNESS IN SUDAN

Darin Portnoy is a family and emergency physician from Gunnison, Colorado. He recently returned from a two-month mission working at a Doctors Without Borders/ Médecins Sans Frontières (MSF) hospital for sleeping sickness in southern Sudan. MSF successfully pushed for the re-introduction of a drug to treat severe cases of this neglected disease, but its future availability remains uncertain.

It is hard to put into words the huge impression that Alison made on me. He was one of the many sleeping sickness patients we treated in Ibba, and his story shows how effective treatment at the right moment can really save a life.

Alison was a 22-year-old man from Mundri County, some seven hours east of our sleeping sickness hospital and treatment center in Ibba. His story began with a gradual change in his behavior nearly four months before we met. At first, Alison's family did not pay much attention to his odd behavior. However, as he became more confused and aggressive, and began to wander off from his family's hut, their concern grew. In desperation, the family put Alison in a separate hut and closed the door so he could not leave. Still, Alison would get out and, finally, the family tied him up for his own protection and theirs.

Family friends who had known another village member with sleeping sickness suggested that Alison be taken to MSF's lab and clinic in Kotobi, a short walk from where they lived. By the time Alison was finally brought to the clinic he was profoundly disoriented and aggressive. He had eaten little and had horrible wounds on his arms and legs from pulling against the ropes used to tie him to a table in his hut.

In Kotobi where MSF tests for sleeping sickness, a local staff member pricked Alison's finger and took some blood for testing. This test came back positive suggesting that Alison had the trypanosome that causes sleeping sickness. He was found to have large lymph nodes on both sides of his neck. To confirm the diagnosis of sleeping sickness, a small needle was placed in one of these nodes and fluid was withdrawn. Trypanosomes were readily visible by microscope and the technician in Kotobi was convinced that Alison had at least Stage 1 sleeping sickness and he strongly suspected that the disease had progressed to Stage 2 (involvement of the nervous system) due to all of Alison's erratic behavior.

To confirm the diagnosis, a lumbar puncture (insertion of a needle to withdraw some of the fluid surrounding the spinal cord) was done on Alison. The test was positive: Alison had an advanced case of sleeping sickness and needed urgent treatment. In Kotobi, this was all explained to Alison's family and his brother was chosen to accompany Alison by truck on the long ride to the hospital in Ibba.

Alison and his brother arrived in the evening after the long, bumpy drive. He was given a blanket, basin, and mosquito netting and told that his treatment with the drug eflornithine (DFMO) would start in the morning.
When I met Alison a few days after he started treatment, his brother was there beside him, encouraging him to eat. An IV was in his arm, delivering the first of the day’s four doses of DFMO.

What I saw happen with Alison, and other patients was amazing. Five to 10% of sleeping sickness patients used to die from melarsoprol, an arsenic-derivative drug we used to give and 30% were not cured by the treatment. The mere ability to treat patients with a well-tolerated, safe, and very effective medication was spectacular. When you coupled this with the patients’ good response to DFMO, it was something to see.

Remarkably, DFMO almost never got to sleeping sickness patients. The drug was developed and used as a cancer drug but was taken off the market in 1995 because it failed to make a profit. Production restarted in 2001 when a cosmetic use for the drug was found—the removal of facial hair in women. It was marketed under the brand name Vaniqa. Under pressure from MSF, and with the involvement of the World Health Organization, a manufacturer was found who promised to provide enough of the medicine to meet global needs for five years. After that, we are not sure what will happen.

Alison’s improvement was gradual, but nonetheless dramatic and I saw him start to respond to our questions and cooperate with the staff, something his brother thought might never be possible. The wounds on his wrists and ankles began to heal as well and his appetite returned.

Alison finished his full two-week course of treatment and preparations were made to get him back home. He still had residual effects of sleeping sickness with periods of confusion, but we expected this to clear in the coming months. I suppose the best part of all was seeing him get back on the truck to return to his home and his family.

Two weeks of treatment with DFMO saves lives but the disease can still recur and patients must return at six, twelve, and 24 months to have a repeat lumbar puncture to be certain that the trypanosome has been eradicated from the body. While Alison’s story is unique, his situation is not. South Sudan is in the midst of a sleeping sickness epidemic. Each month, the MSF team in Ibba screens more than 2,000 people and treats at least 150 patients with the disease and the numbers show no sign of falling.
The past three decades have brought unprecedented medical advances and considerable improvements in health to some parts of the world, but this “health revolution” has left most of the world’s population behind. Every year, more than 14 million people die from treatable infectious diseases. They are dying because medicines are too expensive, no longer produced, increasingly ineffective, highly toxic, or are non-existent.

Despite this dire situation, little money goes into research and development (R&D) for newer and better treatments targeting neglected diseases including malaria, kala azar, sleeping sickness, and tuberculosis.

In our more than 30 years of work in the field, Doctors Without Borders/ Médecins Sans Frontières (MSF) has witnessed first-hand how the lack of effective drugs for infectious diseases increases suffering and destroys lives. For example, until quite recently, patients suffering from sleeping sickness had to undergo painful treatment with an arsenic-based medicine because more effective treatment was unavailable.

In many regions such as southeast Asia and East Africa, chloroquine, once hailed as a “wonder drug” against malaria, now fails to cure it because of the development of resistance, leading to millions of needless deaths each year (see page 8). And while most people in the industrialized world think that tuberculosis (TB) was eradicated along with smallpox years ago, it continues to kill two million people a year—almost all of whom live in poor countries. For people suffering from these diseases and others like them, the future looks bleak.

WHY ARE SOME DISEASES NEGLECTED?
Infectious diseases primarily affect the poor—97% of deaths from these diseases occur in developing countries. Pharmaceutical companies argue that developing drugs for diseases affecting the poor is an investment that will not pay off, so they focus their attention on other diseases—including non-life-

GETTING DRUGS FOR NEGLECTED DISEASES ON THE MARKET
The Drugs for Neglected Diseases Initiative (DNDi) was created by MSF and partners to improve the quality of life and health of people suffering from neglected diseases by using an alternative model to develop new drugs or new formulations of existing drugs for people suffering from sleeping sickness, kala azar, and Chagas’ disease. In this model, a variety of players, predominantly from the public sector, will not only develop drugs but also collaborate to raise awareness about the need to research and develop drugs for neglected diseases, and build R&D capacity in disease-endemic countries. Key partners include the World Health Organization and public research institutions in Malaysia, India and Brazil.

The initiative will be launched formally in July 2003 in Geneva. The DNDi will coordinate drug R&D projects in collaboration with the public sector, the pharmaceutical industry, and other relevant partners. MSF plans to contribute a share of its annual budget to DNDi’s start-up costs for at least five years. For more on the DNDi, see the Access Campaign’s web site: www.accessmed-msf.org.
threatening conditions such as male pattern baldness, erectile dysfunction, and obsessive shopping—that will guarantee the highest financial return. Statistics show where the priorities lie:

¥ Of the 1,393 new drugs approved between 1975 and 1999, only 16 (or just over 1%) were specifically developed for tropical diseases and tuberculosis, diseases that account for 11.4% of the global disease burden.

¥ Ninety percent of the world’s health R&D is devoted to conditions that affect just 10% of the world’s population.

This “market failure” has been compounded by a failure of public policy—both in wealthy countries like the US and within disease-endemic countries—to promote needs-driven R&D. “Drug development cannot be left to the private sector alone,” said Bernard Pécoul, MD, director of MSF’s Campaign for Access to Essential Medicines. “No amount of market tinkering will stimulate drug companies to invest in drug development for patients with kala azar and sleeping sickness in Sudan, Congo or India, who are too poor to ever represent a viable market, so we need governments to step in and set priorities based on global health needs.”

As part of our Campaign for Access to Essential Medicines, MSF is advocating for increased R&D for neglected diseases in a number of ways. We are pushing for a clear commitment from governments and private industry to tackle the problem. To demonstrate a practical solution, the organization has been a driving force behind the creation of the Drugs for Neglected Diseases Initiative (DNDi) (see page 4). DNDi is a needs-driven, not-for-profit drug development initiative focused on sleeping sickness, kala azar, and Chagas’ disease. MSF has also published articles in medical journals and released an independent report on the crisis in R&D for neglected diseases entitled *Fatal Imbalance* to stimulate debate among the medical and scientific community as well as policy-makers and opinion leaders. To access these articles or to download a copy of the report, please visit [www.accessmed-msf.org](http://www.accessmed-msf.org).

Public support is crucial to create political goodwill. Therefore, to raise public awareness about this crisis, we are touring the US and Europe with the Access to Essential Medicines Expo, a traveling exhibit that informs visitors about the treatment barriers facing people with neglected diseases. And MSF is advocating at the international level for governments to commit to increased resources, appropriate national policies, and a global framework of needs-driven R&D, which will ensure that advances in science and medicine contribute to alleviating suffering and meeting critical medical needs in the developing world.
Imagine a five-year-old girl living in a small village in sub-Saharan Africa. Feverish, she begins to shake and vomits up her breakfast. The girl’s head hurts and she’s getting weaker. She starts to cough and can’t eat. Her mother takes her to a health post later that day and the doctor diagnoses malaria. She is given the drug chloroquine to take for three days. This happens to her maybe six times a year. Unfortunately, there is a good chance that the medicine she’s been given doesn’t even work due to drug resistance. Tragically, drugs do exist that can effectively treat malaria, but they are much more expensive than chloroquine, and their use is being blocked in many countries.

**ADVOCATING FOR MORE EFFECTIVE TREATMENT**

Doctors Without Borders/Médecins Sans Frontières (MSF) is now pushing endemic countries, donors, and those involved in malaria treatment to support the use of the most effective treatment for drug-resistant malaria, artemisinin-containing combination therapy (ACT), which is recommended by the World Health Organization. Older antimalarials such as chloroquine and sulfadoxine-pyrimethamine (SP) no longer work in many parts of the world because of the development of resistance. Artemisinin has been used in Chinese traditional medicines for thousands of years. It has become a common treatment in Asia during the past 30 years where malaria resistance to older drugs is high. When used in combination with another drug, artemisinin derivatives appear to slow the development of resistance to the second drug. To date, no resistance to artemisinin drugs has been reported.

In many areas of Africa, resistance levels to more common treatments are extreme. MSF teams have found chloroquine resistance rates of 78-85% in Bandundu, Democratic Republic of Congo and 87% in Mbarara, Uganda. But nowhere has resistance been higher than in Burundi which was struck by a major malaria epidemic in 2000-2001. MSF teams diagnosed and treated malaria in the hard-hit provinces of Kayanza, Ngozi, Karuzi, and Cankuzo and during a six-month period treated more than 1.2 million patients. The epidemic is estimated to have affected nearly three million people in Burundi and resulted in thousands of deaths. Those contracting malaria were treated with ineffective medicines—because chloroquine was Burundi’s first-line treatment. “In parts of Africa, giving patients chloroquine is equivalent to giving them sugar pills” said Nicolas de Torrenté, executive director of MSF-USA.

During the course of the epidemic, MSF teams carried out several resistance studies and found that resistance to chloroquine in Burundi was as high as 90% in some areas, and resistance to SP was up to 63% in some regions. The World Health Organization recommends changing treatment protocols when resistance to first-line drugs reaches 25%. After strong advocacy efforts by MSF, the Burundi government decided in late 2002 to revise the national protocol so that ACT would be first-line treatment. This decision should take
effect in July 2003. However, MSF is still watching the situation closely.

OVERCOMING BARRIERS

Now integrating ACT into all of its medical projects, MSF is fighting to make better malaria treatments a priority at the international level by pushing for policy change and increased funding. In addition to Burundi, other countries are also planning to make ACT first-line therapy. A key barrier to switching to ACT is that it costs ten to twenty times as much as the currently used antimalarials. MSF estimates countries with high resistance to current malaria treatments (Burundi, Kenya, Rwanda, Tanzania and Uganda) would need to spend $19 million to change to ACT—a sum too high for them to pay without donor help.

Although there has been reluctance to support ACT from major international aid agencies including the US Agency for International Development (USAID), some donor organizations have signaled their support. Earlier this year, the Global Fund to Fight AIDS, Tuberculosis and Malaria announced grants to Zambia and Zanzibar to implement ACT. “When Zambia first decided to change its national protocol to more effective malaria treatment, some donors opposed this more expensive choice,” said Dr Jean-Marie Kindermans from MSF. With its decision to grant Zambia and Zanzibar money, the Global Fund has given a very positive sign that it endorses the use of more effective malaria treatment. By financing malaria treatment programs that include ACT, the Global Fund and other donors can play a crucial role in ensuring that all people who need it, including the poorest and most vulnerable, have access to effective malaria treatment. But in the meantime, the clock is ticking. People who should be receiving good treatment are slipping away, one fever at a time.

Based on material written by Anastasia Warpinski, MSF International, that first appeared in the 2002 MSF International Activity.

Malaria is spread by mosquitoes already infected with a parasite. When an infected mosquito bites a human, it transfers the parasite into the person’s bloodstream, where it multiplies and causes illness or death. When another mosquito bites the person, the disease is passed along to others, and the cycle continues.

Various attempts to eradicate the disease have failed and malaria remains a daily, deadly threat to 40% of the world’s population. Approximately 300 to 500 million people contract the disease each year and one to two million die, many of them children. In fact, every 30 seconds, a child dies of malaria.

Those that survive can experience stunted physical and mental development, poor education performance and greater susceptibility to other diseases.
Frustrated by the lack of medicines accessible to patients with infectious diseases in many of the countries in which we work, MSF decided to take to the streets – literally. Last March, MSF launched the Access EXPO, an interactive traveling exhibit designed to raise awareness about neglected diseases and promote the research and development (R&D) of appropriate treatments.

The EXPO is housed inside a 48-foot tractor-trailer. So far, we have visited dozens of cities in 19 states, reaching more than 12,000 enthusiastic visitors. At the same time, identical versions of the truck have traveled throughout Europe. This spring, it will make several stops as we approach Washington, DC, where we will conclude the tour on the National Mall, directly in front of the Capitol.

The Access EXPO introduces the public to five infectious diseases: sleeping sickness, kala azar, tuberculosis, HIV/AIDS, and malaria. Upon entering the exhibit, visitors spin the “Wheel of Misfortune” and receive a card with a brief scenario describing the life of a person living with one of these diseases. As they walk through the exhibit, people learn about their assigned disease, read first-hand testimony from people living with it, and find out more about who is affected, where they live, and what their extremely limited treatment options are. Finally, in a mock “clinic” at the end of the EXPO, doctors and nurses who have worked with MSF give a medical consultation to all the visitors about “their” disease and answer any questions they may have.

**THE PUBLIC’s RESPONSE**

The response of visitors has been remarkable. Almost all signed our petition calling on the US government and the Pharmaceutical Research and Manufacturers of America (PhRMA) to undertake more R&D of treatments for neglected diseases. As with the refugee camp exhibit that came to the United States in 2000, visitors appreciated the direct contact with MSF field volunteers. In total, 91 MSF field workers – doctors, nurses, logistics, and administrators – volunteered their time at the EXPO. Interestingly, the two most neglected diseases, kala azar and sleeping sickness, generated the most questions and interest among the public.

The EXPO’s initial audience was public health advocates, medical professionals and students, as well as a general adult population. The 2002 tour included 18 university campuses – with Harvard Medical School, Johns Hopkins School of Nursing, Columbia’s School of Public Health, and the National TB Center in Newark, NJ, scheduled stops in 2003. Additional film screenings and lectures enabled us to explore the issues more deeply – with many medical students vowing to lobby for neglected diseases to appear on their curriculum, some of them learning about these diseases for the first time.

We also found that younger visitors really enjoyed the EXPO despite its serious subject matter. One 12-year-old girl in New York chose to go through the exhibit five times so that she could learn about each of the diseases. Two sisters, both under age 12, returned with their mother to the EXPO for a second day to take notes about what they had learned the day before. Due to this enthusiastic response, we developed a youth component to the program. In May, we will visit New Rochelle High School near New York City, after students asked us to bring it there. At every stop, we will schedule tours for school groups. We have produced a booklet targeted at middle and high school children called *It’s a Different World Without Medicines*. It provides a comprehensive background to the issues raised in the EXPO, and can be used in the classroom, along with suggested lesson plans and classroom exercises, all available from MSF.

In Washington, we are inviting members of Congress to visit the EXPO, and hope to gain their support. The vast majority of new medicines are researched and developed in the US – and our positive reception as we have traveled the US shows us that the plight of millions of people in developing countries dying from lack of treatment is indeed a concern for many Americans.

We encourage you to join us on the final leg of the tour (see page 9 for a listing of upcoming tour dates and locations). And if you haven’t done so already, please sign the enclosed petition and send it to us before May 8th so that we can deliver it in Washington or sign it on our web site.

Stephanie Davies, Director of Public Education
SIGN OUR PETITION URGING THE PRESIDENT AND PHARMACEUTICAL INDUSTRY TO DO MORE TO INCREASE ACCESS TO ESSENTIAL MEDICINES

More than 14 million people in developing countries die every year from treatable, infectious diseases. They are dying because medicines are too expensive, no longer produced, increasingly ineffective, highly toxic, or are non-existent. Most new medicines are researched and developed in the United States in public and private research institutions.

You can sign the petition by visiting our web site: www.doctorswithoutborders.org or if you prefer, you can sign and send the petition cards found in this issue.

If you sign before May 14, 2003, Doctors Without Borders/Médecins Sans Frontières (MSF) will deliver your petition along with thousands of others when the Access EXPO visits Washington, DC.

For more information about MSF and our Access to Essential Medicines Campaign, visit our web site or contact us.

FUTURE ACCESS EXPO DATES

The NJ Medical School
National Tuberculosis Center
University of Medicine and Dentistry of New Jersey, Newark, NJ
May 1 — May 2

New Rochelle High School
New Rochelle, NY
May 7 — May 10

National Mall,
Washington, DC
May 14 — 18

Check our web site to find out about related events at the tour stops.

GOT PILLS? Millions Don’t. Join the Campaign! Visit our web site to find out how to order these T-shirt and help us spread the word.

LET’S GET HUMAN ABOUT MEDICINES
Teachers: Visit our web site to order this magazine and related materials for your classroom.

Above:
ABDUCTED VOLUNTEER’S BIRTHDAY REMEMBERED

Doctors Without Borders/Médecins Sans Frontières (MSF) offices worldwide marked the 33rd birthday of kidnapped volunteer, Arjan Erkel, by holding events on March 9 and 10 urging his immediate release. Dressed in T-shirts bearing Arjan’s image, MSF-USA staff, returned volunteers and supporters gathered in front of New York’s Public Library to hand out birthday cake and ask passers-by to sign the petition calling for his release. In Los Angeles, West Coast staff and volunteers also collected hundreds of signatures in just two hours.

Erkel was kidnapped by three gunmen in the Russian republic of Dagestan on August 12, 2002. Since then, there has been no word about his condition or whereabouts. More than 300,000 petitions have been delivered in Moscow calling on Russian President Putin and the Chairman of the Dagestani State Council to do everything possible to secure his release.

To add your name to the petition calling for Arjan’s immediate release, visit our web site: www.doctorswithoutborders.org

MSF USA BOARD ELECTS NEW OFFICERS

In November 2002, MSF-USA’s Board of Directors named Carol Etherington the new President of the Doctors Without Borders Association. Etherington works as an Assistant Professor of Community Health at Vanderbilt University School of Nursing in Nashville. Trained as a psychiatric nurse, she has worked extensively with traumatized populations in community and post-disaster settings. Etherington has served on the board since 1998.

The board also elected Darin Portnoy to the post of Vice President. Portnoy first started volunteering as a doctor with MSF in 1997. He joined the board in 2001.

NEW YORK OFFICE IS MOVING

The New York office of Doctors Without Borders/Médecins Sans Frontières (MSF) is moving to a new midtown Manhattan location. In addition to providing needed working space the new office has been designed to accommodate public events. Starting on Monday, June 2, 2003, you can find us at our new address:

Doctors Without Borders/Médecins Sans Frontières
333 Seventh Avenue (between 28th and 29th Streets)
2nd Floor
New York, NY 10001-5004

The telephone and fax numbers will remain the same:

Tel.: 212-679-6800
Fax: 212-679-7016

SUBSCRIBE TO NEW EMAIL NEWSLETTER

Find out the latest news on MSF’s projects around the world in Doctors Without Borders new monthly email newsletter. Every month subscribers receive updates on the latest events, opinion pieces on aspects of humanitarian aid and colorful stories about volunteers real experiences on the medical frontlines. Sign up to receive the newsletter by visiting our web site: www.doctorswithoutborders.org

Above:
Staff of MSF-USA carry out a petition drive in Manhattan on Arjan’s birthday, ’03.

Right page:
MSF donated 40 boxes of protection equipment to help control the SARS outbreak in Hong Kong, China, ’03.
CONFRONTING
SARS

In response to the outbreak of a deadly respiratory disease, Doctors Without Borders/Médecins Sans Frontières (MSF) has organized teams in Vietnam and Hong Kong to help contain the illness. The newly identified virus known as Severe Acute Respiratory Syndrome (SARS) is now recognized as an international epidemic that has already killed more than one hundred people and infected a thousand worldwide.

A six-person team working in Hanoi, Vietnam, one of the hardest hit countries, has set up an isolation wing for 100 patients in the Bach Mai Hospital. MSF has flown in antibiotics and antiviral treatments. Medical volunteers are also providing training in isolation and protection techniques for the local medical staff and psychological support to staff and patients. “MSF has a great deal of experience in the isolation of diseases,” said William Claus, who set up the emergency wing in Hanoi for MSF, “and our presence has been important for the local hospital staff, many of whom are understandably apprehensive about treating this mysterious illness.”

In Hong Kong, MSF has donated 40 boxes of various protection materials to the Hospital Authority to support medical staff treating patients with SARS in Hong Kong. The protection items include goggles, caps, protection gowns and masks. MSF has also organized a team of medical volunteers to conduct educational seminars on SARS and its prevention to various community groups.

MSF continues to monitor the situation closely as little information about the spread of the disease is available.

IN MEMORIAM

Dr. Carlo Urbani, an Italian doctor and president of MSF-Italy, who was the first person to identify SARS and alert health officials, died of the illness on March 29th in Bangkok. Carlo death was the most coherent and eloquent epilogue his life could produce, said Nicoletta Dentico, one of his colleagues at MSF-Italy. He is survived by his wife and three children.
TREATING WAR WOUNDED IN IRAQ

Doctors Without Borders/Médecins Sans Frontières (MSF) now has more than 40 international aid workers based in Iraq and surrounding countries to assist civilians caught in the conflict. The increase in staff follows the April 11th release of MSF aid workers François Calas and Ibrahim Younis who were detained for nine days by Iraqi authorities. Before they were taken, Calas and Younis had been part of a six-person team providing support to the medical staff of the 250-bed al Kindi general hospital in northeast Baghdad.

ASSESSING NEEDS AND RESTOCKING SUPPLIES
MSF is now assessing the immediate health needs of the people in Baghdad and determining where it can be most effective in providing assistance to overburdened hospitals. “There could be surgical needs for weeks,” said Koen Henckaerts, MD, Director of Operations for MSF and one of the newly arrived aid workers. Shrapnel and bullet wounds will need to be closed once the risk of infection subsides and broken bones will need to be reset. MSF is also concerned that people with chronic health conditions such as diabetes and kidney failure may be at risk due to the country’s current vacuum of medical care.

Recent spates of looting and chaos have left the city’s hospitals short of both staff and supplies. Quantities of critical items such as anesthetics, transfusion sets and painkillers are dwindling. Hospital staff have also indicated that unless quick action is taken the lack of clean water and food could cause outbreaks of diseases such as dysentery, cholera, and typhoid among the already weakened population—especially children. In response, MSF has already shipped medicines, surgical kits for 300 operations, a kit for treating 150 wounded, and supplies for blood transfusions.

MSF is also conducting needs assessments in Basra, Al Qut, Karballah and Northern Iraq, in view of providing emergency medical care in other areas of the country. It is prepositioning supplies and expatriate staff at a number of locations in neighbouring countries. These teams are equipped with nutritional and water/sanitation supplies including high-energy biscuits, therapeutic milk, water purifying systems that provide water for 10,000 people per week, blankets, tents and sheeting.

SPEAKING OUT AT THE UN
Here in the US, on April 9th, Nicolas de Torrenté, executive director of MSF-USA, briefed the United Nations Security Council on the initial team’s experience in Baghdad and the dire situation facing Iraqi civilians. He stressed the need for relief efforts to be independent and urged the US and UK forces not to use humanitarian aid as a tool to advance their military and political goals.