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Partnerships, Action and Education Bring Focus to a Neglected Disease: Buruli Ulcer

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Among the world's array of medical ills that attract little attention or resources, Buruli ulcer may well be the most neglected of neglected diseases. Although it's found in tropical and subtropical regions worldwide, it's barely known in developed countries and little research is done on it. It is primarily associated with bodies of water like rivers and ponds, but its mechanism of transmission is unknown. More than half its victims are children. There is nothing close to a preventive vaccine for it and the number of people afflicted is unclear. One reason its prevalence is uncertain is that in some countries it's not even considered a reportable disease.



A child gets treatment for buruli ulcer at a clinic. Photo credit: MAP International USA

But Buruli ulcer (BU) is clearly present in at least 30 countries worldwide, particularly in West Africa. The World Health Organization (WHO) estimates that it has affected more than 35,300 people in Cote d'Ivoire, 15,500 in Ghana, 10,800 in Benin. Buruli ulcer cases have been reported in parts of Australia, Brazil, New Guinea, Malaysia and Mexico. It was prevalent enough in Uganda's Buruli County in the 1960s that it acquired that region's name.

"Buruli is caused by infection with *Mycobacterium ulcerans*, an organism related to the bacterium that causes tuberculosis and leprosy," notes Julien Ake, M.D., West Africa regional director for MAP International, the nonprofit international medical-assistance organization, which is leading a concerted effort against Buruli ulcer in Cote d'Ivoire.

"The first signs of infection with the BU bacterium appear to be somewhat benign – usually development of painless nodules, or swellings, in the skin," Ake says. "If they are allowed to progress, they can lead to the formation of large ulcerations in the skin, most often on the arms and legs, sometimes on the trunk – leading to disfiguring scarring from the skin lesions. If treatment is delayed, the disease can result in irreversible bone attacks, loss of organs like eyes and genitals, amputation of limbs, restriction of joint movement and long-term disability."

The tragedy of Buruli ulcer is that in its early stages – when the nodules first appear – it can be easily and effectively treated with antibiotics. Because it seems benign and so often afflicts people in poor, remote areas, it often doesn't get dealt with as it should. Once it has reached an advanced stage, there are few happy outcomes.



Photo credit: MAP International USA

Treatment involves a long course of antibiotic injections and surgery to cut out diseased tissue, often requiring two to three months of hospitalization. The process imposes an economic and logistical burden that makes its victims reluctant to seek care until the disease is well-advanced and can't be ignored. Health specialists speak in terms of "prevention of disability" and work to shorten its course and minimize deformities.

Targeting Buruli Ulcer

MAP International is perhaps best-known for its work providing more than \$250 million each year in medical supplies for relief and development programs around the world. But it also has a strong commitment to preventing disease and promoting health in underserved regions, often working with partner organizations like the World Health Organization (WHO) and nongovernmental organizations (NGOs) like the American Leprosy Missions (ALM).



Community health care workers get training. Photo credit: MAP International USA

MAP emphasizes a "Total Health" concept that focuses on helping individuals, families and communities work together to improve their physical, social and economic well being. In line with this, the organization has trained nearly 2,000 community health care workers over the past five years in countries as diverse as Bolivia, Ecuador, Kenya and Cote d'Ivoire.

MAP's efforts in Cote d'Ivoire against Guinea worm and helminth-borne diseases are illustrative. In 1999, it began working in Cote d'Ivoire with the Carter Center, UNICEF and other partners in the Carter organization's campaign to eradicate the parasitical Guinea worm disease in countries throughout Africa and Asia. Over seven years, a program of education and preventive measures reduced the disease's prevalence in Cote d'Ivoire by 99 percent. No cases of the disease have been reported in the country since 2007.

In 2007 MAP launched a campaign to eradicate soil-transmitted helminth-borne diseases (such as roundworm and tapeworm) after the Pasteur Institute of Cote d'Ivoire published a study concluding that 37 percent of the children in the country's capital, Abidjan, were infected with helminths.

Working as part of the Ivoirian Ministry of Health National Program for Pupil and Student Health, MAP staff visit schools in and around Abidjan twice a year. There, they provide children with anti-parasitic medications that protect them for six months. Additionally, they work with communities to develop clean water sources — installing water filters, repairing broken water hand pumps, drilling new wells and setting up community water committees to sustain access to clean water.

"In line with these experiences, in 2002 we decided to work on another neglected disease, Buruli ulcer," notes Jodi Allison, MAP's director of corporate relations. "Our office in Cote d'Ivoire saw this as a problematic disease that wasn't being dealt with. We thought, 'We're good at health education and health program development. We have trained people on the ground there. This is something we can do.'"

A Venture of Partnerships

Early on in its Buruli ulcer program, MAP established a strong partnership with the American Leprosy Missions. "ALM's involvement with Buruli ulcer goes back a dozen years," says Jim Oehrig, ALM's chief program officer.

"A member of our board of directors, Dr. Wayne Meyers, was a missionary in the Congo — what was then Zaire — and is often called 'the father of Buruli ulcer work.' He insisted that we should use our leprosy expertise on Buruli, since leprosy and Buruli are often found in the same places, are 'first cousins' in epidemiological terms and are treated with some of the same medicines and prevention of disability techniques.

"Many leprosy organizations are active in Buruli ulcer work for these reasons. When MAP said it was going to take on Buruli ulcer, we were anxious to partner with them." Oehrig adds that ALM is not an implementing organization. Rather it supports MAP with funding and regular provision of technical assistance, capacity building and program design geared to WHO guidelines. ALM was able to attract additional financial support for the project from other organizations, including Leprosy Mission Ireland and Irish Aid. These funds, when combined with MAP resources, totaled some \$1.3 million.

More recently, an important partnership was established with the Abbott Fund, the philanthropic organization of Abbott Laboratories. Abbott had been associated with MAP for more than two decades, donating medicines and supplies for MAP's international medicines program. MAP's Jodi Allison happened to be meeting with Abbott Fund officials in 2010 — a time when the Abbott organization was considering a new focus on neglected diseases. She mentioned MAP's Buruli ulcer initiative.

“It was serendipitous,” says Jeff Richardson, vice president of the Abbott Fund. “MAP was a longtime partner that we not only trust, but that is well regarded throughout the international health community. We researched Buruli ulcer and saw a huge need.” Since the partnership began in 2010, the Abbott Fund has committed grants totaling more than \$550,000 through 2013.

Buruli Ulcer Gaining Traction

Descriptions of cases in Africa that were clearly Buruli ulcer date back more than 100 years. Sir Albert Cook, a British physician working in Uganda, described a BU-like skin ulcer disease in 1897. The disease was described definitively in 1948 — by physicians in Australia. Despite the location, it’s not a significant problem in Australia. The 1948 Australian work was based on six cases and, in 2006, the country reported only 72 cumulative cases.

In fact, Buruli ulcer’s significant spread came some 30 years after that. While cases of BU had been reported in several sub-Saharan African countries before 1980 (including Congo, Gabon, Ghana and Uganda), after 1980 its incidence increased dramatically in Benin, Cote d’Ivoire and Ghana. And it was reported for the first time in other countries in the region.

Multinational Attention

Internationally, concern about Buruli ulcer followed its emergence. In 1998, WHO convened an international conference on the disease in the Cote d’Ivoire city of Yamoussoukro, from which the Global Buruli Ulcer Initiative (GBUI) was launched. It’s a partnership of WHO, member nations, NGOs and academic and research institutions, including MAP, the American Leprosy Missions, Médecins Sans Frontières (Doctors Without Borders), the Raoul Follereau Institute and about a dozen other organizations based in Africa, Europe and the United States.

Since then, GBUI has been continuing its emphasis on preventing, controlling and treating the disease. In 2004, the World Health Assembly (WHA), WHO’s decision-making body, adopted a resolution urging improved surveillance, control and research on BU. In 2012, WHA included BU in its report on “Accelerating to Overcome the Global Impact of Neglected Tropical Diseases.”

A Network of Buruli Ulcer Research

The 15 partners in the GBUI research network range from the Armed Forces Institute and Michigan State University in the United States and the Swiss Tropical and Public Health Institute in Europe to the Noguchi Memorial Institute for Medical Research in Ghana and the Pasteur Institute of Guyana in French Guyana.

Understanding of the disease is advancing steadily, albeit gradually. In the past five years, for example, researchers have published more than 120 articles on aspects of Buruli in the online Public Library of Science’s journal *Neglected Tropical Diseases*. In 2008, a team of 17 scientists working in Belgium, the United States, Ghana and Portugal announced that they had isolated *Mycobacterium ulcerans* in an aquatic insect from an endemic area of Benin and cultivated it in a pure culture. The study lent support to the belief that the BU bacterium is transmitted to humans from aquatic environments. In 2009, a team based in Switzerland and Ghana announced that it had sequenced *M. ulcerans*’ genome.

“Progress has been made, but many, many unknowns remain about Buruli ulcer,” notes Kinglsey Asiedu, M.D., GBUI’s coordinator, based at WHO’s Department of Communicable Diseases. “The disease is being pursued on a number of fronts but answers are still far off.”

Challenges in the Present

Hope for research breakthroughs in the future notwithstanding, MAP’s BU program in the present focuses on planning, education, improvements in therapeutic resources, diligence by staff in the field and collaboration with partners.

“Our first step,” says Aubin Yao, program director of MAP Cote d’Ivoire, “was a pilot project integrating Buruli ulcer control activities into Cote d’Ivoire’s existing health system. Focusing on an endemic health district, we developed partnerships with ALM, WHO, the Cote d’Ivoire Ministry of Health and the Pasteur Institute of Cote d’Ivoire. We worked to strengthen the capacities of health facilities for controlling the disease, of communities for early case detection and referral, and of health professionals for addressing the problem.”

As a result, the number of cases reported in the pilot district increased ten-fold. The proportion of cases reported at the disease’s earliest stage jumped from 20 percent to 65 percent. In 2007 the program was scaled up to cover eight endemic health districts encompassing some 2.3 million inhabitants in about 700 villages.

“A significant part of the effort has involved education,” Yao notes. “We’ve worked with the health district management teams to reinforce their abilities in management of control activities. We’ve trained nearly 1,200 community volunteers and 1,000 school teachers in early case detection and referral. We’ve trained health professionals in case detection and management, including prevention of disabilities, surveillance and reporting. We’ve provided training in Buruli ulcer surgical treatment to surgeons at the referral hospitals in the targeted endemic districts.”

The project has involved close consultation with the Ministry of Health to establish a strategic plan for a national program and national policies and creation of case management guidebooks and training modules for health professionals and community volunteers. At the other end of the spectrum, equipment and training materials have been provided to rural clinics and district hospitals. ALM funding has enabled construction of Buruli-dedicated wards at hospitals in Abidjan and Taabo, some 185 km/115 miles to the north as well as training in BU awareness for community healthcare workers, teachers and lay church workers. Abbott Fund grants have underwritten equipment as diverse as motorbikes for community volunteers and cell phones, computers, software

and GPS technology to support surveillance and reporting.

A Daunting Challenge Grounded in Poverty and Geography

“The people most at risk for contracting Buruli ulcer are poor and live in remote areas,” notes Ake, MAP’s West Africa director. “They are often too poor to pay for transportation to go to the district hospital. There is a serious lack of medical personnel. Often, in areas where we don’t work, the health professionals don’t know how to deal with BU. The disease is still an emerging one and it is not taught in medical schools.”

A big problem is the time required for a swab test performed in a rural clinic or district hospital to be processed by the Pasteur Institute in Abidjan, the only laboratory in the country able to perform the analysis. By the time results are returned, the patient is likely to have gone home and is difficult to locate. Then, there’s the nature of its progression.

“Since Buruli ulcer’s early stages involve painless nodules, or swellings, they’re often not taken seriously,” Ake says. “Patients ignore it, until it becomes a serious issue – and difficult to treat. Part of it is a hope that it will go away rather than turn out to be a disease with a potential for disfigurement.

The current treatments for advanced cases require lengthy hospital stays, often several months, during which family members need to stay with the patient. The result is both extended family separation and serious economic impact.

Future Needs and Challenges

“Clearly,” says WHO’s Asiedu, “Buruli ulcer work faces a number of urgent challenges. We need oral medications that can be given by health workers in remote areas rather than relying on injections that must be given in hospitals. We need the capability to diagnose the disease much more quickly in the field. We need to understand how people get infected.”

MAP is seeking to help other nations — most notably Ghana and Liberia — come to grips with Buruli ulcer disease. MAP’s initiative in Ghana, begun in 2008, follows the strategies developed for Cote d’Ivoire. In a partnership with Ghana Health Services and ALM, the program is targeting several endemic districts with promising results.

In Liberia, the situation is more complex. Still establishing a presence in the country, MAP is working in partnership with the Ministry of Health and Social Welfare of Liberia, WHO, ALM, the Institute of Tropical Medicine in Antwerp, Belgium and Emory University in the United States.

A major issue in Liberia, notes ALM’s Oehrig, is that while it’s clear Buruli is a problem in the country, there are no statistics. “There’s plenty of anecdotal evidence,” he says, “but officially Liberia’s Buruli ulcer count is zero. Our mission for 2012 is to conduct a detailed survey to get an accurate picture of the problem.”

Adds MAP’s Allison: “The lack of information in Liberia underscores how challenging this effort is. In Cote d’Ivoire, we’re working in eight health districts and Buruli ulcer is endemic in about 60 health districts. The good news is that detection in the early stage has increased significantly where we are working. This means we’re having an impact.”

By Ralph Fuller