TRANSFORMING SCIENCE INTO GLOBAL HEALTH SOLUTIONS

Leprosy 2013 – The Problem and the Solutions

Every year, an estimated quarter million people worldwide – mostly in Africa, Asia and Latin America – are diagnosed with leprosy, a cruel disease that leaves its victims maimed, crippled, disfigured and blind, often with terrible quality of life.

It appears that the number of new cases of leprosy has declined over the past 15 or so years, thanks to a new multi-drug treatment that the World Health Organization is providing at no cost. Still, patients frequently neglect the required 6-12 month course of treatments, often because one of the drugs causes severe, stigmatizing skin discoloration during the span of the therapy.

Seeking a better solution, IDRI decided to attack leprosy in two different ways. First, by developing a fast, easy diagnostic test (the current method is inadequate, by *clinical and/or microscopic assessment); and, second, by developing a vaccine that can immunize people against leprosy, while also providing treatment to those who have been exposed to the disease but are not yet showing symptoms.*

The following five thought leaders – several from IDRI and others from around the world – discuss the critical problems that leprosy presents, as well as the essential solutions that can make a real difference in fighting this disease around the world.

Making Sure Another Generation of Children Doesn't Suffer With Leprosy

By Marco Collovati
CEO, OrangeLife / Brazil

Leprosy is a millennial disease, a Biblical one. And its victims have been segregated and discriminated against forever.

People also don't like to talk about it, but leprosy is a very common disease in a number of countries like Brazil.

Even worse, children are the silent victims of leprosy, because adults infect them easily; and a delay in diagnosis can lead to severe and permanent damage, including paralysis of the hands. The solution is to make the eradication of this disease a priority.

I'm especially hopeful about a rapid and accurate diagnostic test we've developed with mobile connectivity. I'm also optimistic about a promising vaccine we've helped create. This, plus serious public health programs, can help us eradicate large numbers of leprosy cases forever.

It's important to personalize our quest against leprosy. If one of our children had this disease, would we do everything in the world to find a cure? The answer, unquestionably, is "yes." And that's why I'm now working passionately and persistently to tackle this ugly and unfortunate global health issue. There is no way I can stand on the sidelines and let another generation of kids suffer like this.

Getting Leprosy Drugs to People in Need Is Critical

By Darrick Carter
Vice President of Adjuvant Technology, IDRI

Leprosy isn't widespread like malaria or TB, but it is debilitating, and there are traumatic repercussions.

It shouldn't be this way, and we can treat this disease. People should not be losing their right to healthy lives to this.

Stopping the spread of leprosy is essential, and we need to make a concerted effort to diagnose it. We have developed a way to rapidly diagnose the disease. And, once we identify affected people, we must treat them so they don't develop irreversible neurological problems. We must also safely immunize everyone in the household who has had contact with leprosy to stop the spread to others.

That said, we don't know where leprosy comes from. In the United States, for example, there are about 100 new cases a year, but only 40 are from people who may have had contact with carriers. There was also a research paper that asserted that armadillos are the host for leprosy. But people are getting leprosy in places that don't have armadillos.

A central problem today is the fact that a lot of leprosy drugs aren't getting to people because of logistics and infrastructure issues.

We have two goals for 2013: making sure that the leprosy diagnostic is launched and used; and developing an effective leprosy vaccine. These are ambitious objectives, but we must deliver in order to help confront leprosy wherever it takes hold.

Cost Cannot Be a Barrier As We Fight Leprosy

By Malcolm Duthie
Senior Scientist, IDRI

Officially, we are told that there are 250,000 cases of leprosy in the world. But I believe that the problem is as large as 1.5 million to 2 million cases.

I also believe that the only way we're going to eradicate this disease is through a vaccine. We need to prevent infection in the first place. If we prevent the infection, we can prevent the disease. In addition, we need earlier diagnosis and earlier treatment. By getting to leprosy proactively and sooner, we can reduce transmission rates.

Cost is a big issue here, however. But I feel strongly that we need to spend money upfront on leprosy research and tools, and, if we do, we'll get benefits for many years to come. The long-term positives of investing like this are pretty clear.

I'm particularly hopeful about a registered diagnostic test for leprosy in Brazil. There is a will to take on leprosy, and a recognized need, too. We just have to get out there in the world and get on with it. This test gives me a good feeling about the progress we can make in 2013 in the fight against leprosy.

2013 and 2014 Are the Tipping Points in the Fight Against Leprosy

By Bill Simmons
President and CEO, American Leprosy Missions

Our dream at American Leprosy Missions is to one day see a world without leprosy. But the state of global leprosy is much more serious than the world recognizes or reports. Indeed, the amount of leprosy far exceeds what's detected on the order of two to three times the annual reported incidents.

The only way to deal with this is by interrupting the transmission of leprosy, which is detectable and treatable. This is the bottom line. Unfortunately, years of research have not uncovered the method of leprosy transmission.

In an effort to dramatically advance the fight against leprosy, American Leprosy Missions has invested energy and money into leprosy vaccine research for more than ten years. The next few years will be exciting, because we're on the edge of a breakthrough. In 2013, we'll see the start of vaccine safety trials; and, in 2014, we'll see trials in an endemic area.

As global experts working in the field of leprosy for more than 100 years, American Leprosy Missions believes that IDRI can help end this disease. We've chosen to invest almost $4 million into leprosy vaccine research because IDRI has the expertise to make our dream a reality.

And, to ensure that the lives of leprosy-affected people are improved, we maintain active funding and development of prevention of disability and rural programs for their benefit. Leprosy affects people, and every person has a right to self-determination and access to care.

The next two years are the tipping points as we try to help communities break the cycle of leprosy transmission. We're excited to stand beside IDRI on the edge of this breakthrough.

Leprosy Has Serious Consequences in Addition to Death

By Steve Reed
Founder, President and Chief Scientific Officer, IDRI

The severity of leprosy is reflected all over the globe – in the Philippines, Ethiopia, Brazil and India, for example.

But, in many respects, it's an ignored problem.

Leprosy's victims often lead lonely and isolated lives, because of the stigma attached to the disease – a stigma that is often affixed to the entire family.

So it's important to remember that this long-term, destructive and debilitating illness has serious consequences in addition to death.

The most important thing we can do is provide new tools, so we can be proactive in detecting and treating the infection early. This would help avoid stigmatization, as well as progression of the disease.

The key barrier is an available diagnostic test that we can implement early on. We have therapeutics now, but they are often administered too late and have to be given for a long time in order to work. A better answer is better treatment of an early infection.

This would be a big improvement, because now we often apply a mass antibiotic to people – whether they're infected or not

I look at 2013 positively. We have better treatments that are getting even better, and we are confronting leprosy in a strong and smart way.