

Chagas in the United States: Increasing Prevalence, Continued Neglect

Chagas disease has traditionally been characterized as a Latin American phenomenon, endemic only to the 21 countries south of the United States border. However, recent studies have shown that the prevalence of Chagas disease outside of Latin America is increasing in large part due to population flows, and Chagas disease is becoming an important global health issue.^[1]

Caryn Bern and Sue Montgomery of CDC estimate that there are 300,167 individuals infected with Chagas disease living in the US.^[2] This is more than six times the estimated prevalence of Chagas in Spain (47,743),^[3] the country with the next highest population of Latin American immigrants.

Modes of Transmission in the US

Chagas is primarily transmitted by large, blood-sucking insects widely known as “kissing bugs,” but can also be transmitted congenitally, through blood and organ transplants. According to Bern and Montgomery, “the US cannot be classified as an area of nonendemicity for Chagas in the same sense as Europe or Asia” due to the fact that eleven Chagas-carrying triatomine species live in the US. Although the likelihood of vector-borne transmission is rare due to modern housing conditions and lower efficiency of vectors, there have been seven reported cases of autochthonous Chagas disease in the US.^[4]

In January 2007, the US began routinely screening blood donations for Chagas disease, and organ donation screening has now begun in some areas. According to the American Red Cross, 1 in 30,000 blood donations nationwide – and roughly 1 in 300 donations from Latin Americans in Southern California – continue to test positive for Chagas disease, even though donations from individuals with a known history of Chagas disease are not accepted.^[5]

CDC estimates of the prevalence of Chagas disease are based on demographic data, not actual diagnoses. This raises the question: of the more than 300,000 people who are estimated to be infected with Chagas disease in the US, how many have been – or will be – diagnosed? Testing for Chagas disease is not routine in the US, and the populations most at risk often do not have access to healthcare.

Most people infected with Chagas disease have no signs or symptoms to indicate infection in the early phases of the disease. Twenty to thirty years after the initial infection, however, up to 30% of patients will experience the often deadly complications of the chronic stages of the disease.

A Case of Neglect

Maira Gutierrez, an El Salvador native and 29-year US resident, was diagnosed with Chagas disease by the Red Cross in 1997 after donating blood. At the time, the Red Cross was conducting exploratory screening of the disease (routine blood screening for Chagas was not implemented in the US until 2007).^[6] In the following years, Gutierrez repeatedly sought treatment without success – the doctors she contacted either did not know of Chagas disease or did not know how to treat it. Despite suffering from heart palpitations, Gutierrez gave up her search.

In 2007, a decade later, her sister called frantically to tell her that there was a story on the evening news about the opening of the Center of Excellence for Chagas Disease, at Olive View-UCLA Medical Center in Los Angeles County. Gutierrez subsequently underwent treatment for Chagas disease at the Center, but she still doesn't know if she's cured, because no definitive "test of cure" currently exists.

The American Red Cross now refers blood donors who test positive for Chagas to the Olive View-UCLA Center of Excellence for Chagas Disease for treatment – still the only center of its kind in the US. The Center has implemented one of the only programs in the country that proactively screens at-risk individuals for Chagas disease through outreach programs in Hispanic communities in the Los Angeles area.

Health Practitioners Unfamiliar with Chagas

Even when patients are diagnosed, health care providers in the US are largely unaware of Chagas disease and are unfamiliar with treatment protocols. Dr. Meymandi, director of the Center of Excellence for Chagas Disease, is often referred Chagas patients from around the country because of a lack of knowledge in the wider medical community.

In 2007, CDC published practical recommendations for the evaluation and treatment of Chagas disease in the US^[7] in an effort to address the lack of knowledge and standardization in this area, but more education and training in the healthcare community is needed to ensure adequate surveillance, diagnosis and treatment of Chagas disease in the US.

Bern and Montgomery also estimate that every year 63 to 315 babies may be born with Chagas disease. Despite the fact that these levels are in the range of other congenital conditions that appear in the American College of Genetics' recommended newborn screening panel, screening for congenital transmission of Chagas disease is rarely conducted, suggesting a lack of awareness among obstetricians and gynecologists. To date, no congenital cases have been recorded in the US.

Furthermore, Bern and Montgomery conservatively project that up to 45,000 cases of heart disease could be attributed to the disease, in many cases without the patients or their healthcare providers ever realizing the cause.^[8]

The healthcare community's lack of awareness may contribute to an increased burden on the healthcare system from patients with serious heart complications caused by Chagas, who may require aggressive treatments such as defibrillators or heart transplants. These complications are in large part preventable if the disease is treated early.

Treatment Access in the US

The drugs that currently exist to treat Chagas disease (nifurtimox and benznidazole) are accessible in the US only under special CDC and FDA protocols. These protocols are more cumbersome for benznidazole, the first line treatment for most countries in Latin America. While neither of the two treatments are ideal (both have limited data proving efficacy in the chronic phase, and both have significant side effects), these medicines can slow or prevent progression of the disease if treatment occurs early on.

According to Dr. Meymandi, "We can get [benznidazole], but it is a very laborious process through the FDA. Hopefully at the end of this year the CDC will have access to the newer agent, benznidazole."

Dr. Meymandi adds, "the difference in terms of the treatments is that benznidazole is a shorter course, it's two months, with a better side effect profile. Nifurtimox, which we have easier access to in the US, is a three-month course, and the side effect profile is pretty abysmal. It is like giving chemotherapy. Major side effects are nausea, vomiting, memory loss, you develop neuropathies, and the list goes on."

US Global Health Policies Neglect Chagas

Though more than 100 million people are at risk for Chagas in the Americas, the disease is often neglected in US global health and neglected disease policies and programs for disease control. For example, neglected disease programs such as the President's NTD Initiative and the FDA's priority review voucher (PRV) system do not include Chagas. In 2007, less than \$2.5 million of the federal^[9] budget was spent on research and development (R&D) for new Chagas drugs and diagnostics, a negligible amount for a disease affecting over 8 million people.^[10]

President Obama's five-year Global Health Initiative could change this dynamic by including Chagas disease control measures in its NTD control policy, including support for increasing surveillance, diagnosis, treatment programs; investment in R&D of new drugs and diagnostics; regulatory agency support; and measures to strengthen research capacity in disease-endemic countries. Increased attention is also needed to improve the situation for those living with Chagas disease in the US.

US leadership is needed to ensure Chagas disease is appropriately addressed in international policies (WHO and PAHO), which should reflect the urgent needs for prevention, treatment and

development of new diagnostics and medicines. Over the long term, the emphasis must be on working with our Latin American neighbors to control the disease.

With the Chagas disease burden concentrated in marginalized populations, Chagas patients do not have the political clout necessary to move this silent disease out of the shadows. DNDi's Chagas campaign aims to raise awareness about this important public health issue, push for policy changes and encourage R&D investments that will make a difference for Chagas patients in the future.

References

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9. This includes Center for Disease Control, Department of Defense, National Institutes of Health and United States Agency for International Development.
10. Families USA, "The World Can't Wait: More Funding Needed for Research on Neglected Infectious Diseases." December 2008

The Drugs for Neglected Diseases initiative (DNDi) is an independent, not-for-profit product development partnership (PDP) working to research and develop new and improved treatments for deadly neglected diseases such as leishmaniasis, sleeping sickness, Chagas disease, and malaria. DNDi's cost-effective, patient-driven model for drug research is proving to be a viable alternative for patients long neglected by market-driven drug development priorities. DNDi is currently the only PDP with a portfolio of Chagas-specific drug development projects.

On the 100th anniversary of the discovery of Chagas disease, DNDi has launched a campaign to raise awareness about this neglected disease and to address the urgent need for new treatments.

For more information on DNDi's Chagas campaign "Wake Up. Time to Treat Chagas Disease!" please visit www.treatchagas.org.



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