

Chagas Disease: Break the Silence - Time to Treat

Introduction

Chagas disease is a neglected tropical disease (NTD), a parasitic disease endemic in 21 countries in Latin America and that is globalizing in non-endemic regions, like the US where there are an estimated 300,000 cases.¹ Without diagnosis and treatment in the early stage, one in every four Chagas patients develops a fatal symptom of the disease. Access to diagnosis and treatment at the early stage is limited and existing diagnostics and treatments are inadequate.

CHAGAS DISEASE FACTS

- Estimated at risk population: >100 million people
- Estimated infected population: 8-15 million people
- 14,000 Deaths / Year
- Largest parasitic killer in the Americas

Medecins Sans Frontieres/Doctors Without Borders (MSF) and Drugs for Neglected Diseases initiative (DNDi) would like to call the U.S. government's attention to the issues of neglect surrounding Chagas disease and call for political leadership to improve the situation for those suffering from this deadly hidden affliction.

U.S Government Leadership Needed

US Leadership in International Policy

- To support the need for Chagas prevention, treatment and research and development of new tools in the PAHO resolution for elimination of neglected diseases and other poverty-related infections
- To support Chagas Resolution at the World Health Assembly in 2010

US Foreign Policy and Research Priorities

- **Programs**
 - To support disease endemic countries' efforts to not only prevent but also diagnose and treat Chagas disease
 - To raise awareness to Chagas disease as a globalizing disease crossing the boundaries of traditionally endemic regions and to support efforts to educate the medical community and the population at risk as well as increased access and support for US Chagas programs
- **Increased Public Funding for Research & Development**
 - To increase NIH support for early stage research and development of new diagnostics and drugs for Chagas disease. In 2007, \$2.5M of the NIH budget was spent on R&D for new Chagas drugs and diagnostics.²
 - To support USAID late stage research and development and introduction of new diagnostics and drugs in Chagas disease endemic countries. Currently, this is zero.
 - Support for new incentives and funding mechanisms to research and develop needs-based new products for the effective control of neglected tropical diseases, including Chagas disease
- **Regulatory Agency Support**
 - Support efforts for the efficient evaluation and introduction of much needed new tools for controlling Chagas disease
 - FDA neglected disease programs such as the priority review voucher (PRV) system must include Chagas disease
- **Support for Strategies to Strengthen Research Capacity in Disease-Endemic Countries**

¹ Montgomery, Susan P. and Caryn Bern, "An Estimate of the Burden of Chagas Disease in the United States," *Clinical Infectious Diseases* 2009; 49:e52-e54

² Families USA, "The World Can't Wait: More Funding Needed for Research on Neglected Infectious Diseases." December 2008

Neglect of Chagas Disease: What is Urgently Needed?

Improving Access to Treatment With Existing Tools

- **Routine testing and diagnosis of Chagas disease at the primary care level in endemic areas and parts of the world with population movements from endemic areas:** The lack of resources at the primary health care level limits proactive and integrated approaches.
- **Increased access to treatment for children and adults in the primary care system:** Millions of people, especially in rural areas, have neither the opportunity to find out that they are infected nor the possibility of being treated.
- **Integration of vector control with treatment of patients:** Ineffective prevention efforts cause the insect and the disease to reappear and patients to become re-infected.
- **Better data collection to determine the prevalence of Chagas and real requirements for medicines:** The burden of Chagas disease is significantly underestimated in official statistics. Inadequate systems for surveillance and reporting of this disease translate into severe underreporting of new Chagas cases in endemic and non-endemic regions.

Research and Development for Appropriate, Effective Diagnosis and Treatment

- **New diagnostics and treatments urgently needed:** Current treatments consist of two medicines developed more than 30 years ago that have limited efficacy in the chronic phase, toxic side effects, and are not readily accessible to patients due to complicated supply, procurement and drug registration limitations. Simple and affordable diagnostics and tests for cure are needed.
- **Regulatory agency support to accelerate evaluation and approval of new diagnostics and drugs for Chagas disease:** Even the 2 existing treatments are not registered in all relevant countries which limits patient access.
- **Strategies to strengthen coordination of research capacity in disease-endemic countries:** National R&D efforts are too often isolated and could benefit from increased visibility and collaboration.
- **Increased and sustainable public funding for treatment programs as well as research & development:** A recent study reveals that less than 0.5 per cent (\$10M) of all worldwide research and development (R&D) funds were spent on Chagas disease in 2007 and over half of this was spent on basic research.³ Negligible funding has been provided nationally or internationally for diagnosis and treatment programs.

For more information, visit the MSF and DNDi Chagas websites:

MSF: <http://www.chagas-break-the-silence.org/>

DNDi: <http://www.treatchagas.org/>

Doctors Without Borders/Médecins Sans Frontières (MSF) is an international, independent, medical, humanitarian organization that delivers emergency aid in more than 60 countries to victims of armed conflict, epidemics, and natural and man-made disasters. MSF has been working in projects fighting Chagas disease since 1999. Currently, the organisation is working in three districts on the outskirts of Cochabamba, in Bolivia, the country registering the highest Chagas prevalence worldwide.

The Drugs for Neglected Diseases Initiative (DNDi) is an independent, not-for-profit research and development organization that develops treatments for neglected tropical diseases such as leishmaniasis, human African trypanosomiasis, Chagas disease, and malaria. Currently, DNDi has a portfolio of promising Chagas drug development projects. DNDi also works to raise awareness about the need for greater R&D for neglected diseases and strengthens existing research capacity in disease-endemic countries.

³ Moran, Mary, Guzman, Javier et al., "Neglected Disease Research and Development: How Much are We Really Spending?". G-FINDER, 2008.