

e-Newsletter:

N. 1, April 2020

# UPDATES ON CHAGAS DISEASE IN THE US



This newsletter provides updates on selected activities related to Chagas disease care and treatment in the United States (U.S.) and is intended for individuals interested in the U.S. situation.

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#### Collaborative Initiatives between UCSF and Fundación Mundo Sano: Efforts to Develop and Disseminate Clinical, Diagnostic, and Epidemiological Information to Clinicians who Manage Patients with Chagas Disease in the U.S.

Provided by: Caryn Bern – [caryn.bern2@ucsf.edu](mailto:caryn.bern2@ucsf.edu)

### Highlighted Publications

Forsyth C, Meymandi S, Moss I, Cone J, Cohen R, Batista C. Proposed multidimensional framework for understanding Chagas disease healthcare barriers in the United States. *PLoS Negl Trop Dis*. 2019. [doi:10.1371/journal.pntd.0007447](https://doi.org/10.1371/journal.pntd.0007447)

Carlier Y, Altcheh J, Angheben A, et al. Congenital Chagas disease: Updated recommendations for prevention, diagnosis, treatment, and follow-up of newborns and siblings, girls, women of childbearing age, and pregnant women. *PLoS Negl Trop Dis*. 2019. [doi:10.1371/journal.pntd.0007694](https://doi.org/10.1371/journal.pntd.0007694)

Whitman JD, Bulman CA, Gunderson EL, et al. Chagas disease serological test performance in U.S. blood donor specimens. *J Clin Microbiol*. 2019. [doi:10.1128/JCM.01217-19](https://doi.org/10.1128/JCM.01217-19)

Pan American Health Organization. Guidelines for the diagnosis and treatment of Chagas disease. Washington, D.C.: [PAHO; 2019.](#)

Lynn MK, Bossak BH, Sandifer PA, Watson A, Nolan MS. Contemporary autochthonous human Chagas disease in the USA. *Acta Trop*. 2020. [doi:10.1016/j.actatropica.2020.105361](https://doi.org/10.1016/j.actatropica.2020.105361)

Pinazo MJ, Pereiro A, Herazo R, et al. Interventions to bring comprehensive care to people with Chagas disease: Experiences in Bolivia, Argentina and Colombia. *Acta Trop*. 2020. [doi:10.1016/j.actatropica.2019.105290](https://doi.org/10.1016/j.actatropica.2019.105290)

### Other Sources of Information

**Chagas Texas Taskforce Monthly Newsletter Facebook & Twitter**

**Chagas Disease in the United States Video**

## Screening for *Trypanosoma cruzi* in the United States

### Educating U.S. Healthcare Providers on Chagas: the Texas Chagas Taskforce and the Chagas ECHO Project

Paula Stigler Granados - [psgranados@txstate.edu](mailto:psgranados@txstate.edu)

In 2015, the Centers for Disease Control prioritized the education of U.S. healthcare providers on Chagas Disease. As a result, cooperative agreements were created between the CDC and three U.S. academic institutions to develop outreach programs targeting this population. Having both local and imported cases reported, Texas was an obvious place to open up dialogue with local physicians and others regarding how best to manage this neglected and relatively unknown disease. Led by Dr. Paula Stigler Granados from Texas State University, the Texas Chagas Taskforce was soon formed. This multi-disciplinary group pulled together experts from across the entire state to discuss current and relevant research, as well as strategize how best to disseminate important information and trainings to healthcare providers. One activity that was a result of these efforts was the formation of a tele-mentoring program on Chagas disease via an already established learning platform called ECHO. These monthly interactive online sessions provide continuing education credit, as well as case based discussions with Chagas disease experts across the country. Another important activity that came about as a result of the Taskforce's efforts is the pilot program for screening newborns in Texas. This program will help us to better understand and estimate the prevalence of Chagas disease in Texas and the potential for congenital transmission.

For further information, please visit: <https://wp.uthscsa.edu/echo/echo-programs/chagas-disease/>



## Diagnostic Considerations for *Trypanosoma cruzi* Infection in High-risk U.S. Populations

### Addressing Gaps in Screening and Diagnosis of Chagas Disease in the United States

Colin Forsyth, *Drugs for Neglected Diseases initiative* – [cforsyth@dndi.org](mailto:cforsyth@dndi.org)

The Rethinking Chagas Workshop highlighted several gaps in screening and diagnosis of Chagas disease in the U.S. Most cases are identified through blood donor screening. Before its discontinuation in February 2020, the AABB Chagas Biovigilance Network reported 2462 *T. cruzi*-positive donations from 2007-2019, representing <1% of estimated U.S. cases. Detection of seropositive donors declined from 321 annually from 2007-2011, to 107 annually from 2011-2019. Screening via the healthcare system is necessary to identify more patients, but is not widely available due to low provider awareness,

Chagas disease's long asymptomatic phase, and limited availability of tests. Of four FDA-cleared tests for clinical use, one is not in production and another lacks a U.S. distributor. Only one is a point-of-care test. Workshop participants discussed the limited data on these tests' performance in U.S. populations. Another important concern was a lack of clear, consistent processes for diagnostic confirmation, given heterogeneity among major laboratories and between state health departments.

Participants agreed on three key actions to improve diagnostic processes in the United States: 1) perform further research on the performance of the FDA-cleared tests; 2) increase the availability of diagnostic tools by working with manufacturers to strengthen distribution; and 3) clarify diagnostic processes. The following year, with support from DNDi, several clinicians and investigators organized a working group to draft evidence-based diagnostic recommendations. The aim is to create a tool for providers that facilitates identifying patients at risk and coordinating testing, a necessary step to increasing access to appropriate care for this neglected disease.

## **Catalyzing the Development of Priority Diagnostics for Chagas Disease: A Meeting on Diagnostics Related to Chagas Disease**

David Hamer – [dhamer@bu.edu](mailto:dhamer@bu.edu)

In May of 2019, a meeting titled *Catalyzing the Development of Priority Diagnostics for Chagas Disease* was held to discuss existing gaps in the initial diagnosis of Chagas disease. Currently available diagnostic tests were reviewed during the meeting and gaps in care related to diagnostics for patients with chronic Chagas disease, as well as the lack of testing to assess treatment response in the United States were highlighted. Overall, participants at this meeting emphasized the need for more NIH funding to optimize existing diagnostics and to research new diagnostics for Chagas disease. A summary of major topics of discussion is included below.

Challenges to testing remain in part due to a complex testing algorithm that requires performance of multiple serologic assays prior to confirmation of disease. A simplification of this algorithm is needed to quickly and easily identify patients with chronic disease.

Differences in discrete typing units related to disease in Central America and Mexico versus South America raise concerns about how these differences impact the sensitivity and specificity of testing. Future testing must account for these differences in *Trypanosoma cruzi*.

Prognostic markers that can predict which patients are likely to develop cardiac or gastrointestinal complications from Chagas disease are needed.

A lack of testing to assess response to treatment in the United States is a major gap in care. In Europe, PCR is frequently used to help guide response to treatment, but limitations with sensitivity of this method and restrictions surrounding its use for patients with chronic disease within the United States make this approach impractical.

## **Treatment Programs for Chagas Disease in the United States**

### **The Center of Excellence for Chagas Disease based at Olive View-UCLA Medical Center: An Update on Recent Activities**

Sheba Meymandi – [chagas@dhs.lacounty.gov](mailto:chagas@dhs.lacounty.gov)

Established in 2007, the Center of Excellence for Chagas Disease based at Olive View-UCLA Medical Center has continuously worked to increase Chagas disease screening in patients within the United States. Historically, patients were not treated until they were symptomatic, which the treatment center recognized was too late to prevent complications. As a result, they started screening patients with heart failure and eventually expanded to the general community through collaboration with local nurses and churches for health screenings. Through this work, they have screened over 10,000 patients and have identified communities in which there is likely significant prevalence of disease. The Center of

Excellence for Chagas Disease based at Olive View-UCLA Medical Center treats anyone who has screened positive and serves as the referral center for the Department of Health Services for Los Angeles County and the American Red Cross blood bank.

The center is trying to spread the message that early screening, diagnosis and treatment is key to decreasing complications. In addition to the medical benefits, screening can also have humanitarian and economic benefits due to prevention of the morbidity and mortality associated with heart failure. With the program's success, they have directed a great deal of attention towards increasing awareness and involvement of providers, public health departments and other interested parties across the United States. For example, Chagas disease is now reportable to the Department of Public Health in Los Angeles County. The treatment center is currently focused on increasing awareness among primary care physicians so that patients may be treated as quickly as possible, especially since treatment is readily available in the United States.

## **East Boston: The Role of Patient Care Navigation in the Care of Chagas Disease Patients**

*Julia Koehler – [julia.koehler@childrens.harvard.edu](mailto:julia.koehler@childrens.harvard.edu)*

Clinicians devoted to their patients from Latin America, and determined to provide the best possible care for them, began screening for Chagas disease at the East Boston Neighborhood Health Center in March of 2017. Infectious Disease specialists at Boston Medical Center, the health center's major academic referral center, had previously declared their determination to care for patients with Chagas disease. One to two patients each month received this diagnosis, yet far fewer patients were appearing in the Infectious Disease clinic for evaluation and treatment.

Once the Strong Hearts project's coordinator was able to begin her patient care navigation work, she found that an inability to communicate in English with the Infectious Disease clinic's scheduling staff, fear to ask one's boss for time off from work, fear to leave one's neighborhood and venture into unknown and possibly hostile spaces, fear of ICE and lack of insurance were reasons patients could not attend Infectious Disease clinic appointments. Some of these barriers were quickly remedied by the clinic, e.g. schedulers made phone calls in the patients' language, but others were not easily removed.

For over a year, Strong Hearts had no care navigator. Recently, with stable funding, a full-time project coordinator has begun to focus on enabling patients already diagnosed with Chagas disease to access specialty care. He accompanies patients through every step of the process at which they need support.

Most patients would benefit from an assigned care navigator by their medical center. Until all patients receive systemic support to attend our hospitals, which are only marginally accessible to the poor and powerless, the Strong Hearts navigator will hopefully make a path with his work. As summarized by the poet Antonio Machado: Traveler, it is your footsteps that make the path and nothing else; Traveler, there is no path, you make the path by walking.

## **LASOCHA: Screening and Treating LA Immigrants with Chagas, Raising Awareness of Chagas**

*Rachel Marcus and Jenny Sanchez – [doctorchagas@gmail.com](mailto:doctorchagas@gmail.com)*

Since partnering with Drs. Yagahira Castro and Robert Gilman on the seroprevalence study of Chagas in Latin American immigrants to the DC area (ending in Sep 2018), we have established a multi-site follow up clinic to provide basic cardiac testing to seropositive individuals, and antiparasitic therapy to those for whom it is appropriate. We have treated 5 individuals in the past 2 years, and have recently seen our 71<sup>st</sup> patient in follow up clinic. We have continued our screening efforts: in the past 18 months we have screened an additional 150 individuals, 24 of whom tested positive on rapid testing. During that time period Jenny Sanchez has been appointed Vice President of FindeChagas, and will be travelling to Geneva in the next month to help organize World Chagas Day materials. Rachel has also given over 15 talks to medical groups including Cardiology and OBGYN grand rounds, webinars, national meetings, and served on the writing committee for the World Heart Federation Chagas disease Roadmap and co-authored the chapter on Echocardiography in Chagas Disease for the ASE textbook. We are gearing up

to increase the volume of screening with a goal of screening 1000 more individuals in the next year, and are revamping and expanding our educational materials and website.

For further information, please visit [lasocha.org](http://lasocha.org)



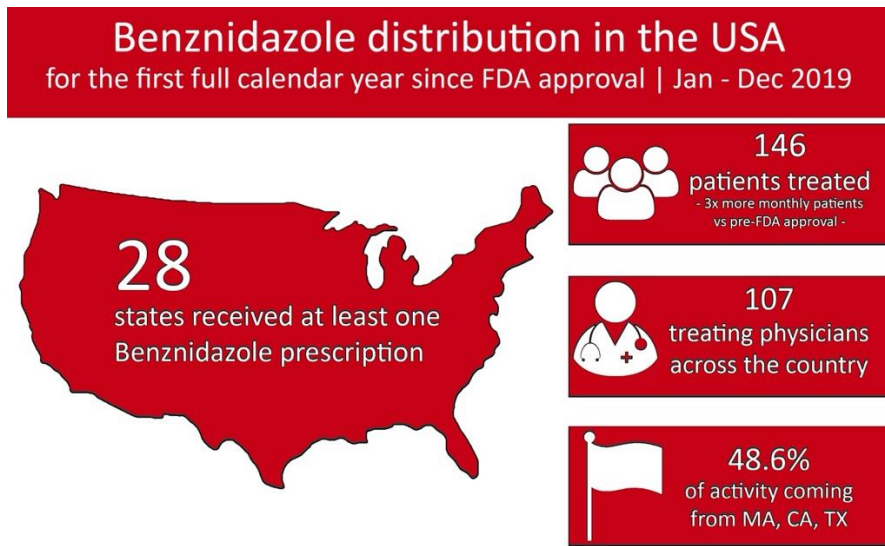
## **Benznidazole Distribution in the United States**

*Martin Manfredi – [mmanfredi@exeltis.com](mailto:mmanfredi@exeltis.com)*

2019 marks the first full calendar year since the FDA approval of benznidazole tablets. Throughout the year, benznidazole was dispensed to 146 patients across 28 states. On average, a total of 12 patients were treated on a monthly basis, which represents three times more patients treated versus pre-FDA approval dispenses.

In addition, a total of 107 physicians prescribed benznidazole at least once. The vast majority of activity can be traced to the states of California, Texas, and Massachusetts, encompassing 48.6% of all the treatments dispensed.

This is the first glimpse of information for a full calendar year since FDA approval of benznidazole. Access to treatment is one of the fundamental barriers in regards to Chagas disease in the United States. This information highlights an evident improvement in this matter, and serves as the baseline in which to build upon.



**Collaborative Initiatives between UCSF and Fundación Mundo Sano: Efforts to Support Treatment of Chagas Disease in the U.S.**

Caryn Bern – [caryn.bern2@ucsf.edu](mailto:caryn.bern2@ucsf.edu)

Professor Caryn Bern provided advice to Mundo Sano and Exeltis on improvement of the website information available to providers seeking to prescribe benznidazole. The information pamphlet “Important items to address before prescribing Benznidazole in the USA” was prepared and is now available in English and Spanish on the Mundo Sano website.

For further information, please visit: <https://www.mundosano.org/en/chagas-usa/>

**Collaborative Initiatives between UCSF and Fundación Mundo Sano: Efforts to Develop and Disseminate Clinical, Diagnostic, and Epidemiological Information to Clinicians who Manage Patients with Chagas Disease in the U.S.**

Caryn Bern – [caryn.bern2@ucsf.edu](mailto:caryn.bern2@ucsf.edu)

Approximately 45 U.S. medical practitioners from 16 different states have signed on to the U.S. Chagas Disease Providers’ Network. The network has the following aims: (1) To facilitate local/regional referral of patients seeking a provider for diagnosis and management of Chagas disease; (2) To act as a platform for treating physicians to seek input or advice on diagnosis, drug treatment and management of Chagas disease from knowledgeable practitioners; and (3) To disseminate information about Chagas disease diagnosis, treatment and management in the U.S., including new recommendations, CME and other resources.

To join the network contact Dr. Caryn Bern: [Caryn.Bern2@ucsf.edu](mailto:Caryn.Bern2@ucsf.edu)

**Highlighted Publications**

Forsyth C, Meymandi S, Moss I, Cone J, Cohen R, Batista C. Proposed multidimensional framework for understanding Chagas disease healthcare barriers in the United States. *PLoS Negl Trop Dis*. 2019. [doi:10.1371/journal.pntd.0007447](https://doi.org/10.1371/journal.pntd.0007447)

This analysis used a combined approach of a literature review on Chagas disease healthcare access and the experience of the Center of Excellence for Chagas Disease at Olive View-UCLA Medical Center (CECD) to describe barriers to Chagas disease diagnosis and treatment in the United States. Overall 34 barriers were identified and grouped into 4 overlapping dimensions which included clinical, structural,

systemic and psychosocial groupings. Using these dimensions, the authors proposed a multidimensional framework to explain the low numbers of people who are tested and treated and to serve as a potential basis for organizing a public health response.

Carlier Y, Altcheh J, Angheben A, et al. Congenital Chagas disease: Updated recommendations for prevention, diagnosis, treatment, and follow-up of newborns and siblings, girls, women of childbearing age, and pregnant women. *PLoS Negl Trop Dis*. 2019. [doi:10.1371/journal.pntd.0007694](https://doi.org/10.1371/journal.pntd.0007694)

This publication provides a summary of the WHO Technical Group recommendations on “Prevention and Control of Congenital Transmission and Case Management of Congenital Infections with *Trypanosoma cruzi*”. These recommendations include populations to be targeted for intervention and diagnosis of Chagas disease in both women and neonates, as well as the treatment of infected neonates, infants, girls or adults. In addition, the summary discusses considerations regarding follow-up, family members and recommendations for healthcare systems and public health organizations.

Whitman JD, Bulman CA, Gunderson EL, et al. Chagas disease serological test performance in U.S. blood donor specimens. *J Clin Microbiol*. 2019. [doi:10.1128/JCM.01217-19](https://doi.org/10.1128/JCM.01217-19)

This study compared the four FDA-cleared IgG serological assays (three enzyme-linked immunosorbent assays (ELISAs) – Hemagen, Ortho and Wiener) and the one rapid test (InBios). Through testing of 500 seropositive and 300 seronegative blood donor samples, this study provided evidence to improve laboratory diagnosis of Chagas disease in the United States. Specimens with a known country of origin were grouped into regions and the four assays were compared using two different comparators (blood donation and consensus) and a latent class analysis.

Pan American Health Organization. Guidelines for the diagnosis and treatment of Chagas disease. Washington, D.C.: [PAHO: 2019](https://www.paho.org/en/2019).

The 2018 Pan American Health Organization Guidelines offer evidence-based clinical practice guidelines that characterize recommendations for the diagnosis and treatment of Chagas Disease in both adult and pediatric patients. Recommendations were developed using systematic reviews and primary studies, which were then graded by an expert panel on Chagas disease and peer evaluated according to subject area and methodology.

Lynn MK, Bossak BH, Sandifer PA, Watson A, Nolan MS. Contemporary autochthonous human Chagas disease in the USA. *Acta Trop*. 2020. [doi:10.1016/j.actatropica.2020.105361](https://doi.org/10.1016/j.actatropica.2020.105361)

This analysis provides a systematic review of the literature and public health department reports to evaluate suspected or confirmed cases of locally acquired Chagas disease in the United States. This study found 76 cases, indicating the disease burden and risk of locally acquired disease in the United States is higher than previously recognized.

Pinazo MJ, Pereiro A, Herazo R, et al. Interventions to bring comprehensive care to people with Chagas disease: Experiences in Bolivia, Argentina and Colombia. *Acta Trop*. 2020. [doi:10.1016/j.actatropica.2019.105290](https://doi.org/10.1016/j.actatropica.2019.105290)

This article describes three projects focused on increasing access to diagnosis and treatment of Chagas disease through primary healthcare facilities in Bolivia, Argentina and Colombia. It highlights different models that allow for successful integration of these Chagas related practices into the primary healthcare system, as well as important lessons learned from these projects.

## Other Sources of Information

### Chagas Texas Taskforce Monthly Newsletter, Facebook & Twitter

To subscribe to the monthly Chagas Taskforce newsletter, send an email to [PSGranados@txstate.edu](mailto:PSGranados@txstate.edu) and you will be added to the list. Also, connect through social media [@TexasChagas](https://www.facebook.com/TexasChagas) on Facebook and [@ChagasTexas](https://twitter.com/ChagasTexas) on Twitter. You can send photos of bugs to be identified or get connected to experts across the country on Chagas disease to answer questions.



## Chagas Disease in the United States Video

This video discusses triatomines and information about Chagas disease that can be shared with patients and providers. Presented by the Texas Chagas Taskforce and UTHealth School of Public Health in San Antonio.

To watch the video, please visit: <https://www.youtube.com/watch?v=R01YQhI5PIw&t=86s>

## Acknowledgements

We acknowledge that we are living in unprecedented times during the ongoing global coronavirus pandemic and hope that you are all safe and well. During these challenging times, it remains important to continue working on the many ongoing Chagas disease initiatives that will ultimately have a large impact on the care of these patients.

This newsletter is a followup activity to the 2018 *Rethinking Chagas: Reshaping the Agenda for Chagas Disease in the United States* workshop held by the Harvard T.H. Chan School of Public Health and supported by [Fundacion Mundo Sano](#). We appreciate the contributions of the many individuals who provided text and materials for the newsletter.