Interprofessional Team Approaches to Chagas Disease Management

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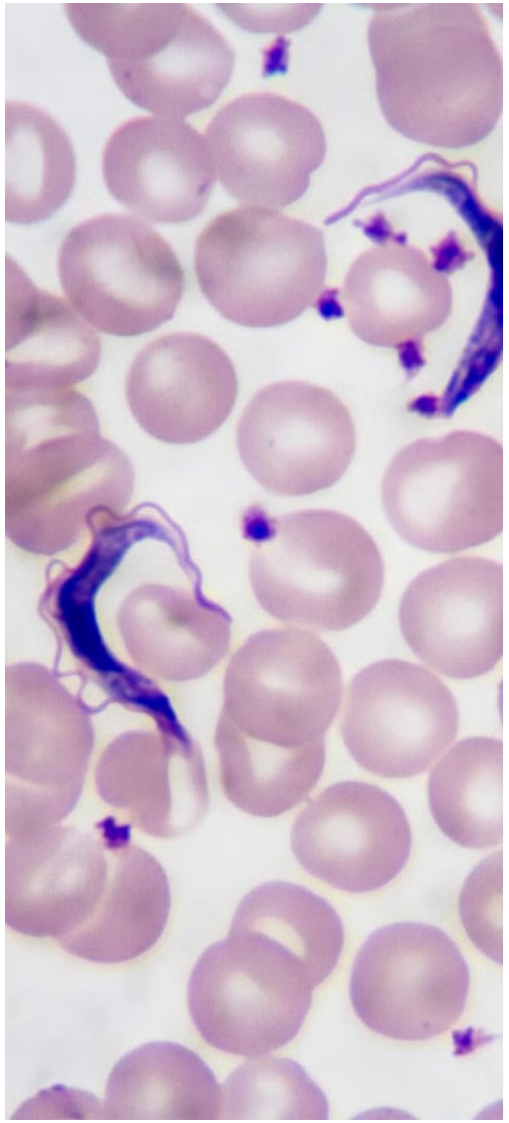
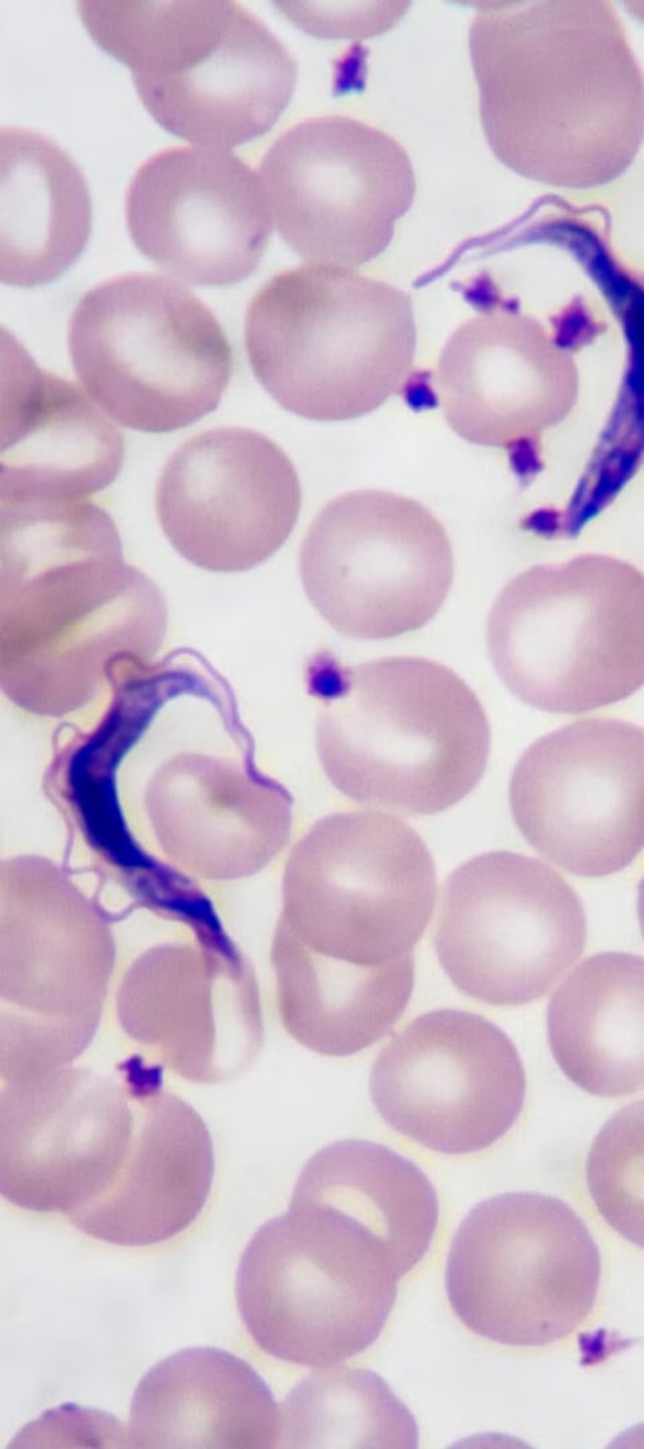




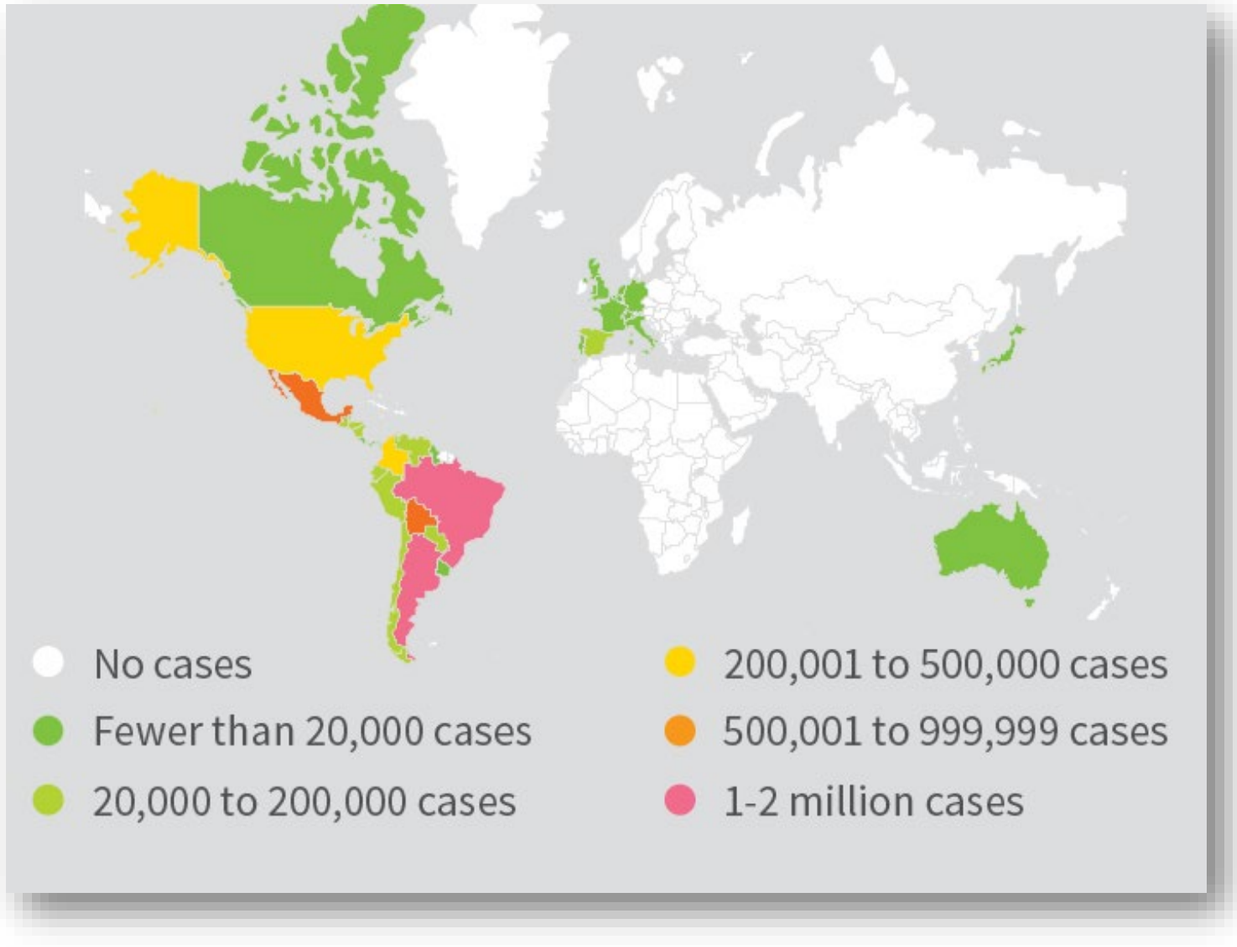
Chagas Disease:

A Quick Overview

- Chagas disease, also known as American trypanosomiasis, is caused by the parasite Trypanosoma cruzi.
- It is typically transmitted to humans through contact with feces of infected triatomine bugs, known as "kissing bugs".

Epidemiology

- Chagas disease is considered to be an **emerging disease of importance.**
- Associated with congenital, blood, and organ transplantation transmissions in non-endemic countries.
- **In the U.S., approximately 300,000 individuals are estimated to be infected with *T. cruzi….but this <u>does not</u> include local transmission and is only based on imported case estimations***



https://unitingtocombatntds.org/reports/5th-report/chagas-disease-progress/

Prevalence of Chagas disease in the United States

1

Risk Factors

The prevalence of Chagas disease is higher among persons from Latin America, where the disease is endemic.

2

Geographic Spread

Cases have been reported across the United States with local transmission also occuring in the southern US, particularly in Texas, where it is reportable, and the climate is suitable for the insects that transmit the parasite.

3

Screening Challenges

The lack of routine screening contributes to underreporting, making it difficult to estimate the true prevalence in the country.

Transmission of Chagas disease

1

Insect Vector

The parasite is primarily transmitted to humans through the feces of infected triatomine bugs, also known as "kissing bugs".

2

Non-Vector Transmission

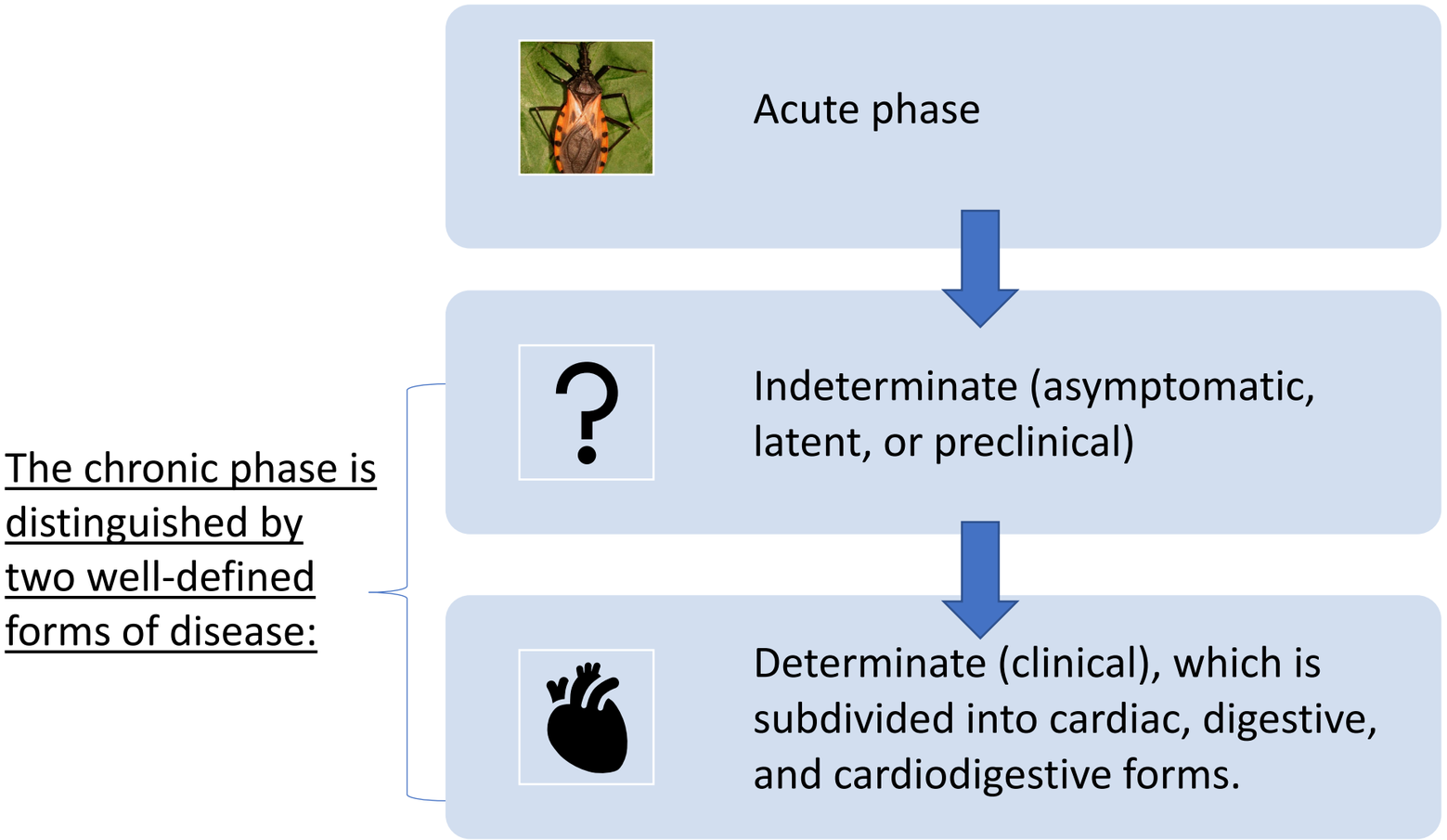
It can also be transmitted through blood transfusion, organ transplantation, and from mother to baby during pregnancy.

3

Other Exposures

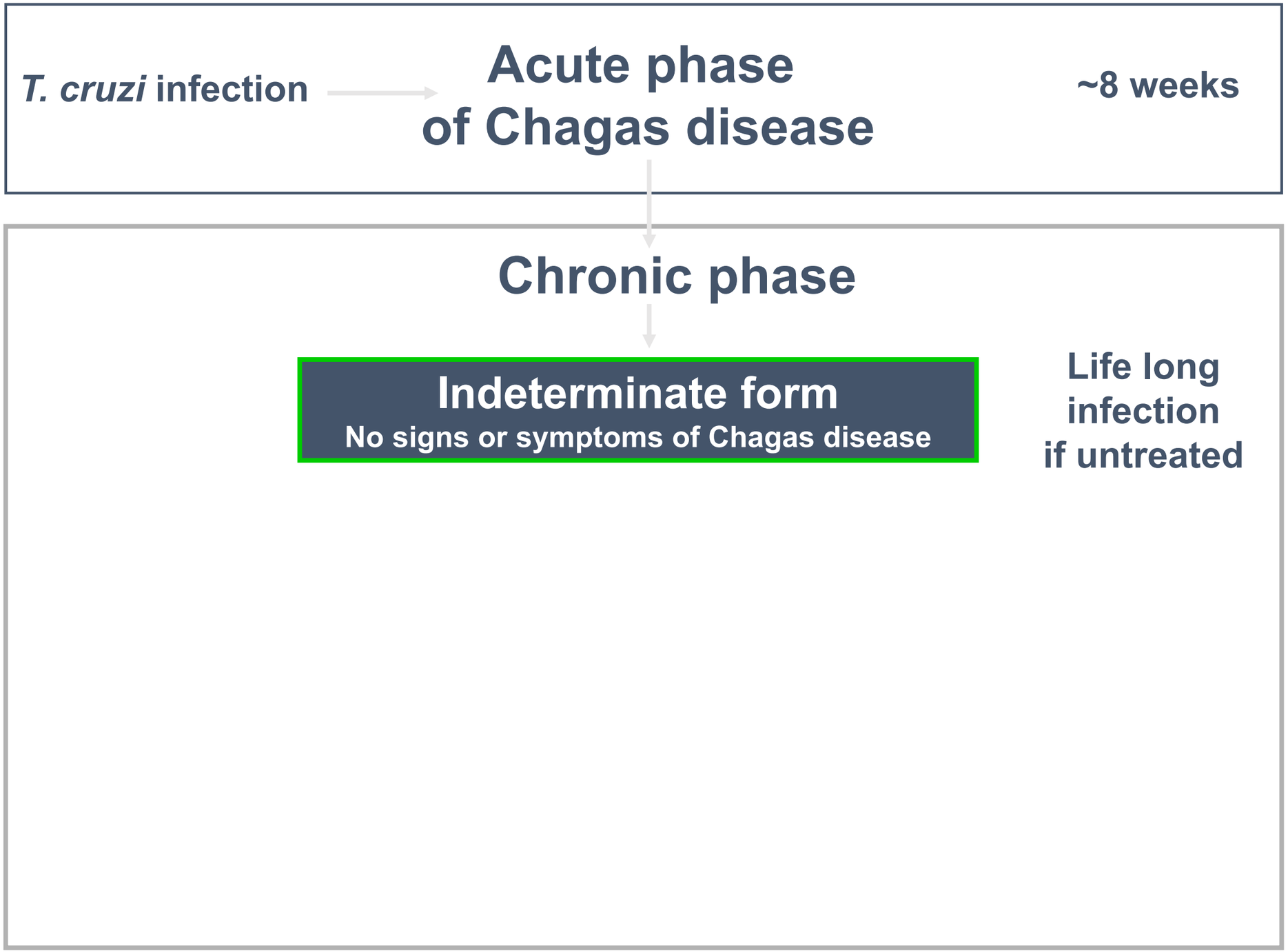
Rare cases have been reported among laboratory workers handling the parasite, and in some cases, through oral transmission via contaminated food or beverages.

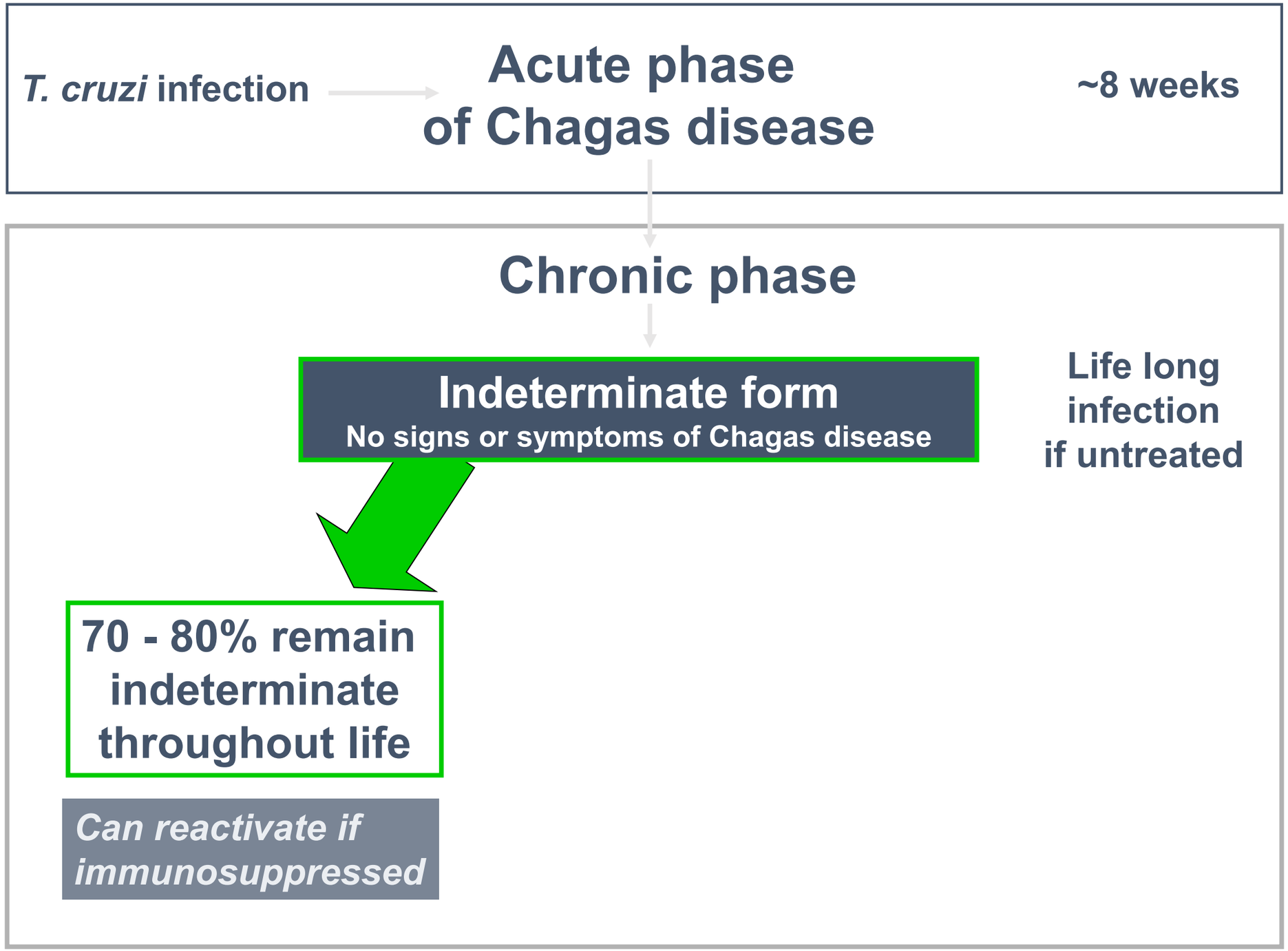
Chagas disease phases:



The chronic phase is distinguished by two well-defined forms of disease:

T. cruzi infection → **Acute phase of Chagas disease** ~8 weeks


T. cruzi infection
Acute phase of Chagas disease
~8 weeks
Chronic phase
Indeterminate form
No signs or symptoms of Chagas disease
Life long infection if untreated


T. cruzi infection
Acute phase of Chagas disease
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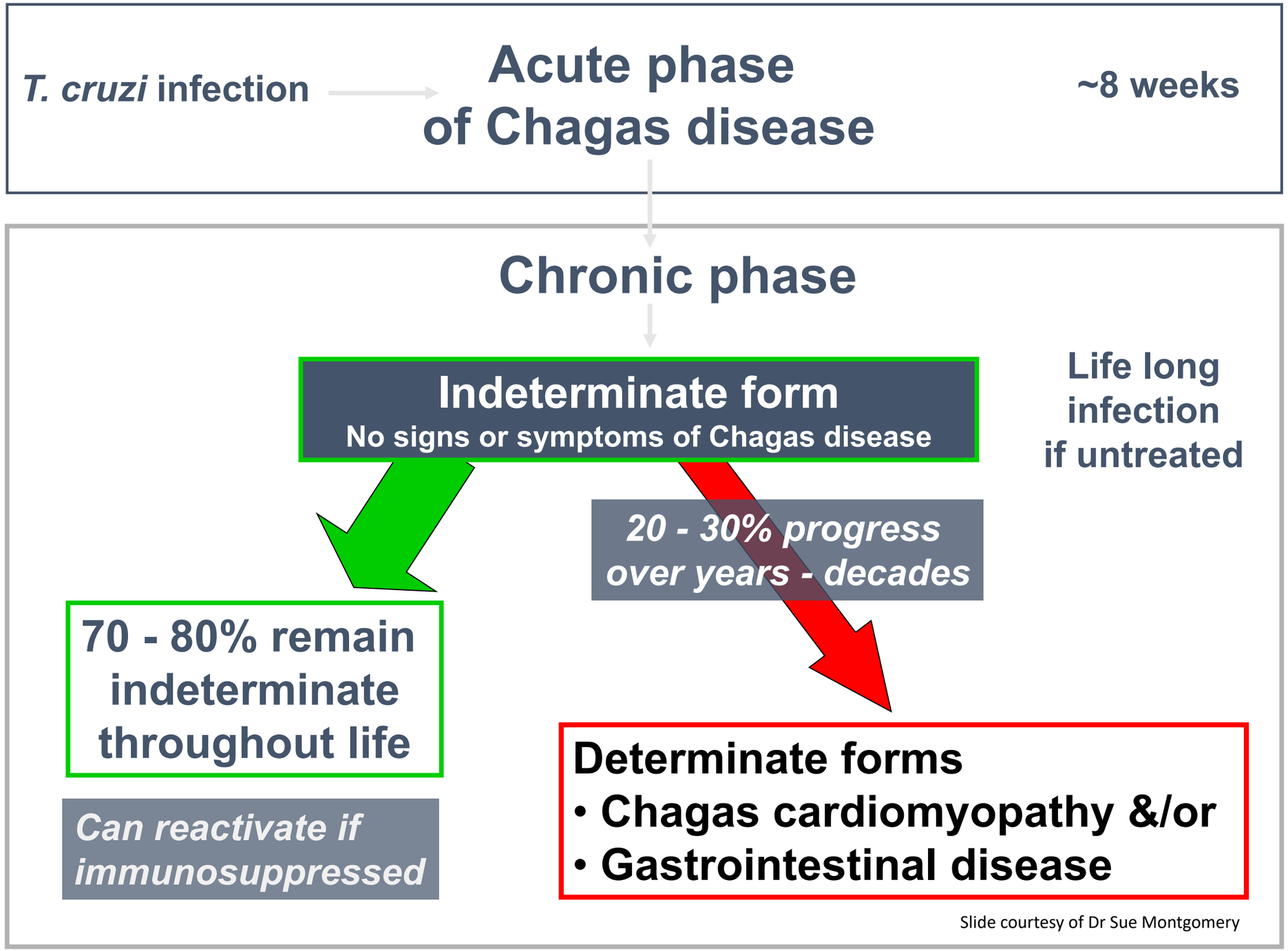
Indeterminate form
No signs or symptoms of Chagas disease
Life long infection if untreated
70 - 80% remain indeterminate throughout life
Can reactivate if immunosuppressed


T. cruzi infection
Acute phase of Chagas disease
~8 weeks
Chronic phase
Indeterminate form
No signs or symptoms of Chagas disease
Life long infection if untreated
20 - 30% progress over years - decades
70 - 80% remain indeterminate throughout life
Can reactivate if immunosuppressed
Determinate forms
• Chagas cardiomyopathy &/or
• Gastrointestinal disease
Slide courtesy of Dr Sue Montgomery

Diagnosis

- Acute infections can be diagnosed by identification of trypomastigotes in blood by microscopy, however parasite levels decrease rapidly within a few months
- Diagnosis of chronic Chagas disease is made by serologic tests for antibody to the parasite.
  - A single test is not sufficiently sensitive and specific to make the diagnosis.
  - Need two or more tests that use different techniques and that detect antibodies to different antigens.
  - CDC can confirm
- Blood donation testing is not recommended for diagnosing Chagas disease

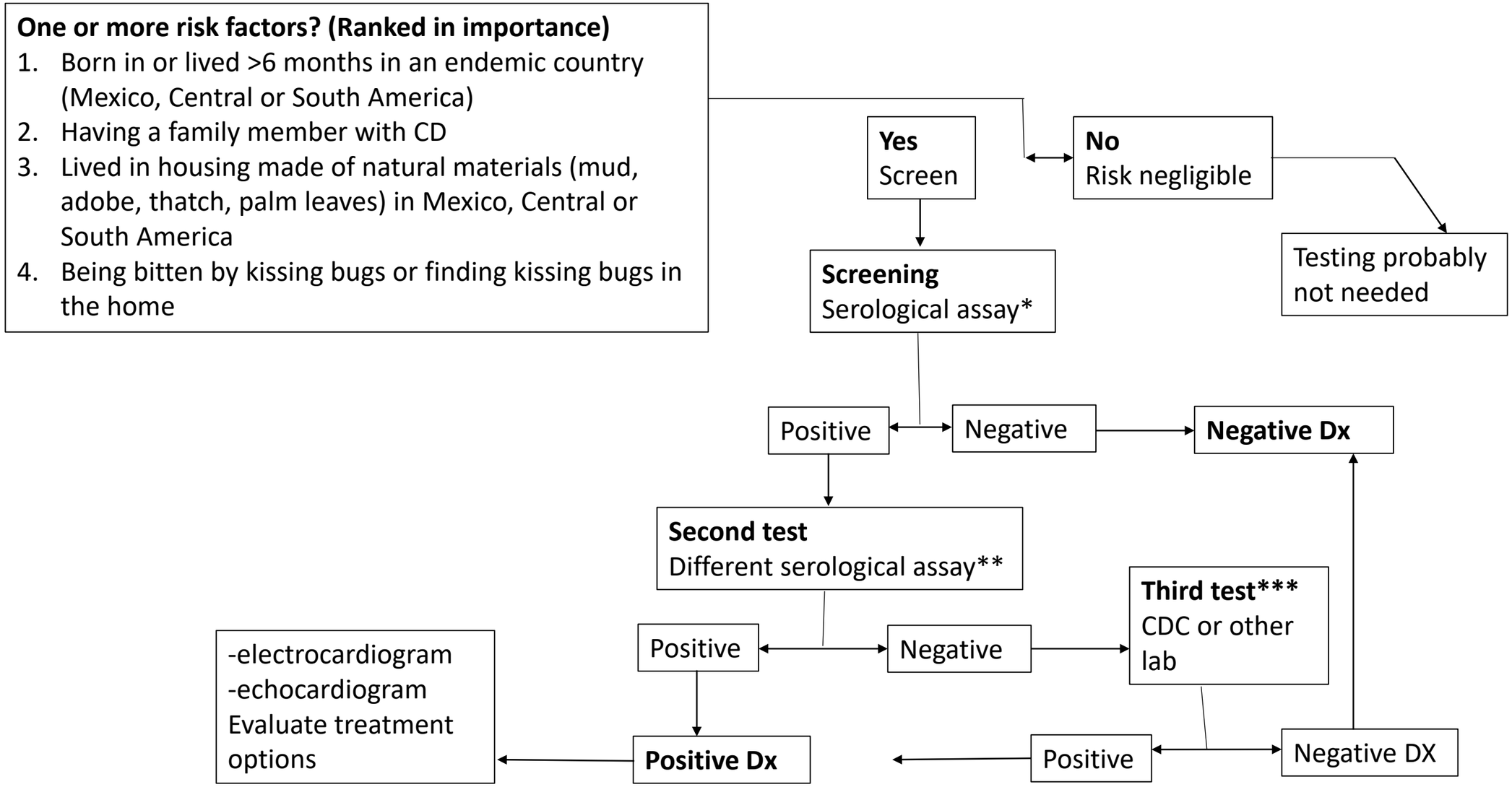
Treatment

- If eligible, can be treated with anti-parasitic medications
  - FDA approval for Benznidazole ages 2-12 years
  - FDA approval for Nifurtimox 0-18 years
  - Low cost or free for uninsured
- Lifelong regular cardiology checks
- No test for cure
- Approved for use in children and is affordable
- Patient needs monitoring, especially for side effects

Who to screen for Chagas Disease (Humans)???

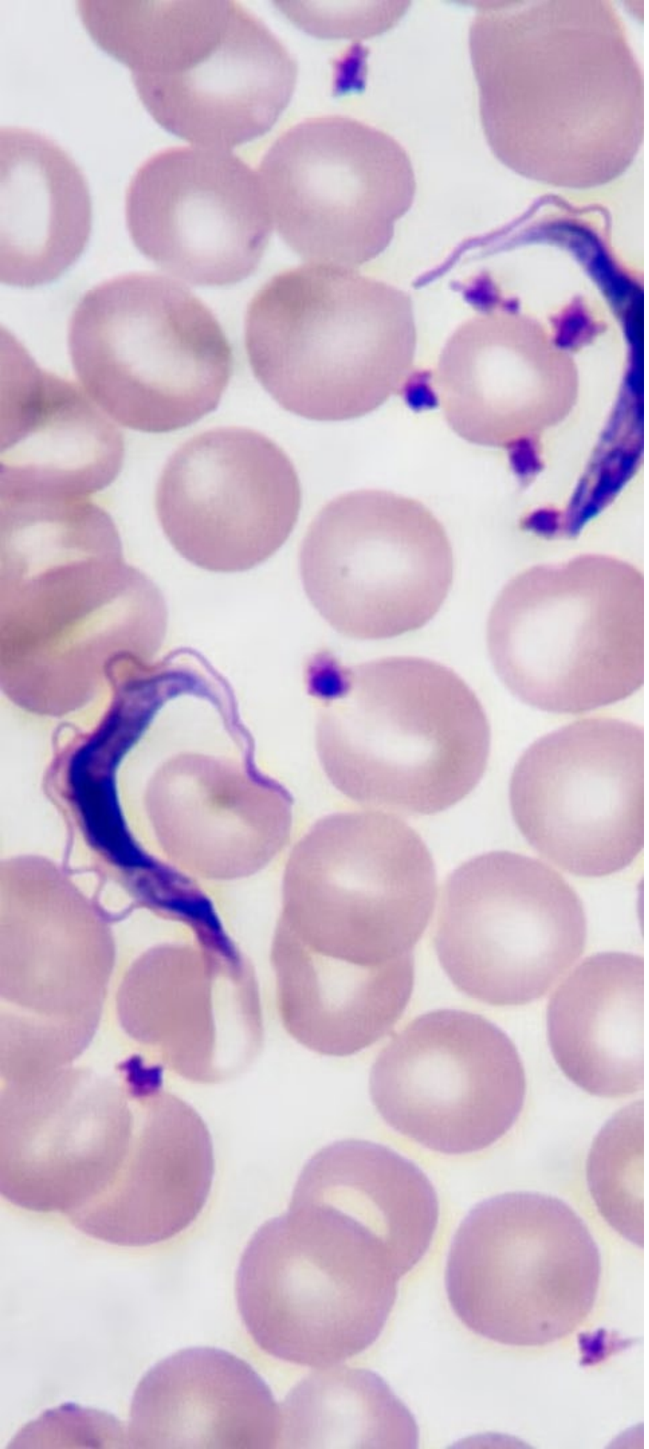
- Any first-generation or second-generation Latino/as
- Newborns or children of seropositive women
- Family members of affected patients with Chagas disease
- Blood and organ donors
- First-generation Latino/as with unexplained cardiomyopathy, stroke, arrhythmias, or abnormal electrocardiograms
- First-generation Latino/as at increased risk of Chagas reactivation (e.g. HIV, transplant recipients)
- Pregnant women having lived in endemic areas
- History of living in poverty or substandard living conditions in areas with triatomine activity
- Recognition of kissing bugs
- People with Chagas positive dogs?

Forsyth, C. J., Manne-Goehler, J., Bern, C., Whitman, J., Hochberg, N. S., Edwards, M., ... & Meymandi, S. (2022). Recommendations for screening and diagnosis of Chagas disease in the United States. *The*



Forsyth CJ, Manne-Goehler J, Bern C, Whitman J, Hochberg NS, Edwards M, Marcus R, Beatty NL, Castro-Sesquen YE, Coyle C, Stigler Granados P, Hamer D, Maguire JH, Gilman RH, Meymandi S. Recommendations for Screening and Diagnosis of Chagas Disease in the United States. J Infect Dis. 2022 May 4;225(9):1601-1610. doi: 10.1093/infdis/jiab513.

It takes a village…



Chagas Disease Management in the United States

Chagas disease management in the United States requires a collaborative, multi-disciplinary approach that acknowledges the complexity of factors influencing its spread, diagnosis, treatment, and prevention.

There are a lot of collaborators and resources….

List of Possible Collaborators and Partners

- Healthcare Providers
- Public Health Agencies
- Vector Control Agencies
- Research Institutions and Scientists
- Non-Governmental Organizations (NGOs) and Advocacy Groups
- Pharmaceutical Companies
- Veterinary and Animal Health Professionals
- Academic Institutions and Educators
- Governmental Health Policy Makers
- International Health Organizations (e.g., WHO, PAHO)
- Community Leaders and Advocates
- At-Risk Communities and Patient Advocacy Groups
- Others??

Challenges in our work (the village)

- **Reaching out to busy Physicians and their networks:** requires aligning with the already packed schedules of physicians and ensuring that the information about Chagas disease reaches them effectively.

- **Lack of awareness about a neglected disease:** Overcoming the lack of awareness about Chagas disease, classified as a neglected disease, is an ongoing obstacle.

- **Populations most affected are often uninsured or use non-traditional ways of accessing healthcare or do not have access:** The disparity in access to healthcare complicates the management of Chagas disease.

- **Navigating a complex disease that has multiple barriers such as standard diagnostics and easy to recognize symptoms:** Understanding other diseases with similar barriers could provide insights into effective strategies

Successes in our work (the village)

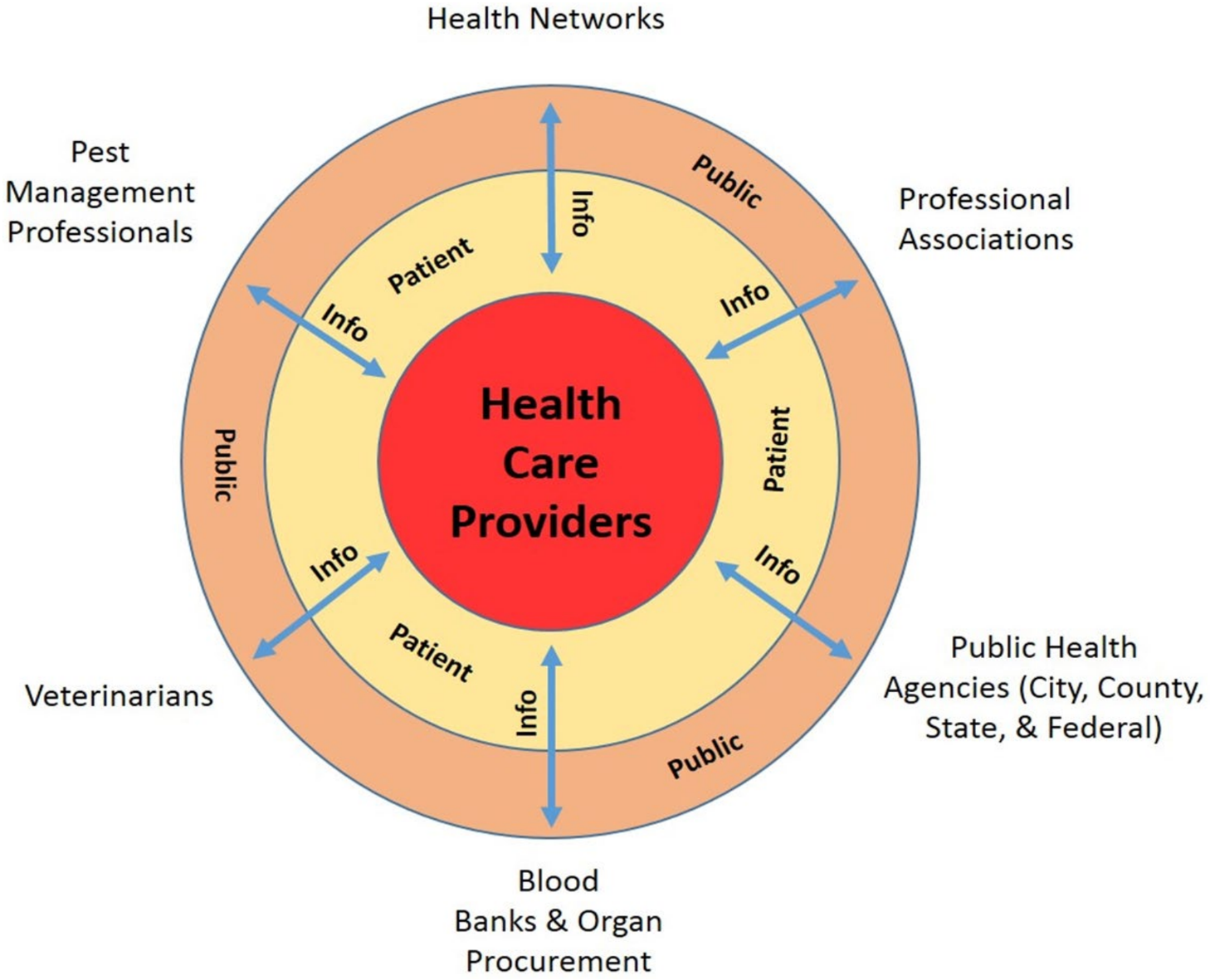
Developing collaborative networks:

Establishing a broad network of existing groups already working in the field of Chagas disease – e.g.Texas Chagas Taskforce, USCN

Integrating new partners into the network – e.g. Clinical Directors Network (CDN), UTHealth ECHO, AHEC

This collaboration has facilitated the sharing of best practices, resources, and research findings, fostering a more cohesive and coordinated approach to addressing the challenges of Chagas disease.

Chagas Taskforce Model for Collaborative Education and Outreach



Successes in our work

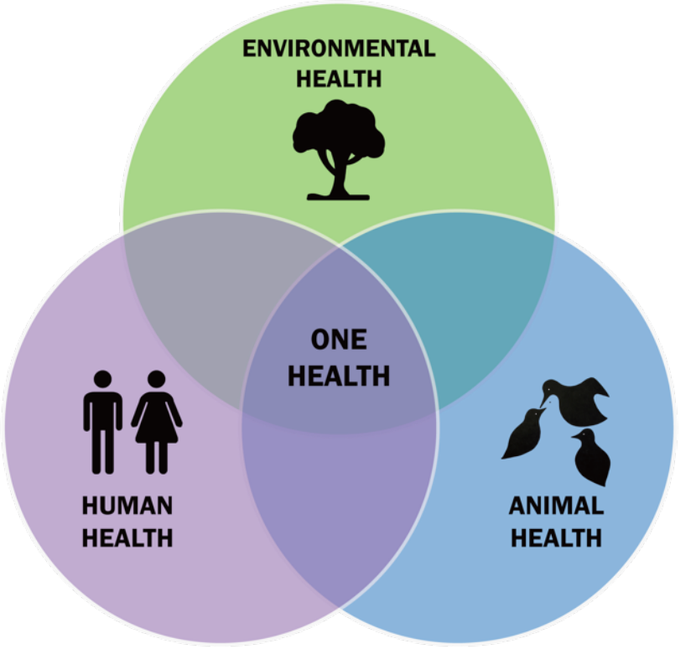
Creation of the ECHO series

- Utilizing a One Health Approach to increase collaborations and networks

Development of a CHW curriculum and training materials

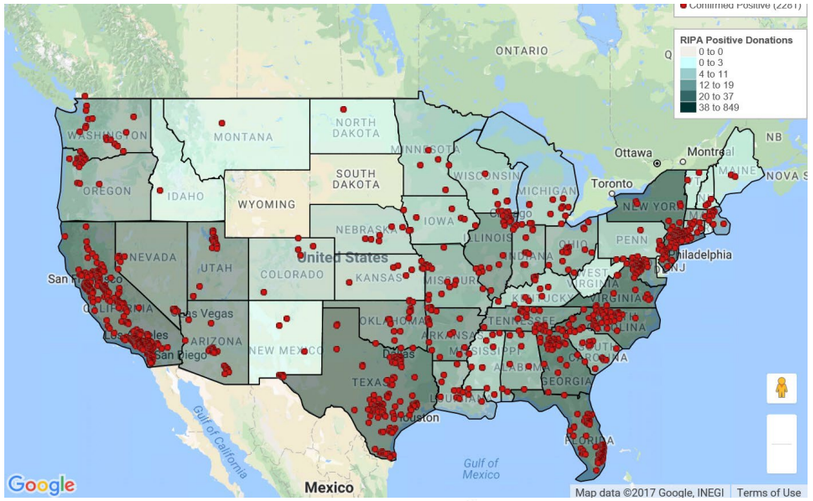
- Assist with patient navigation, community awareness, stigma reduction and outreach to most at-risk communities

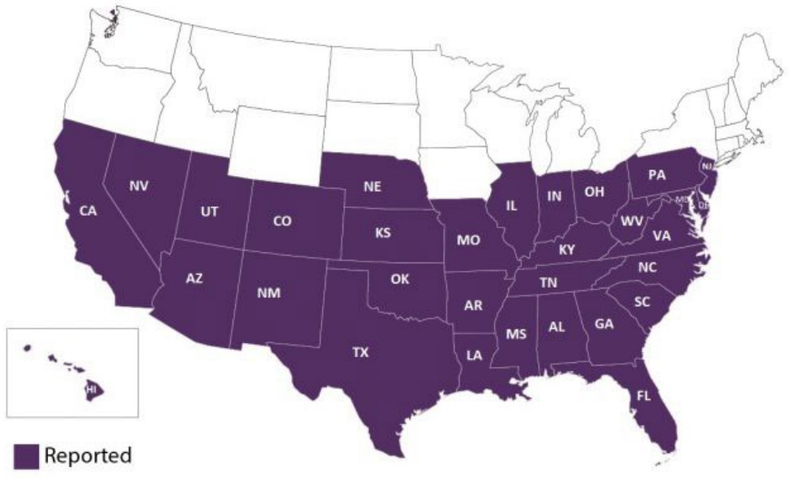
Other Successes?



Project ECHO®

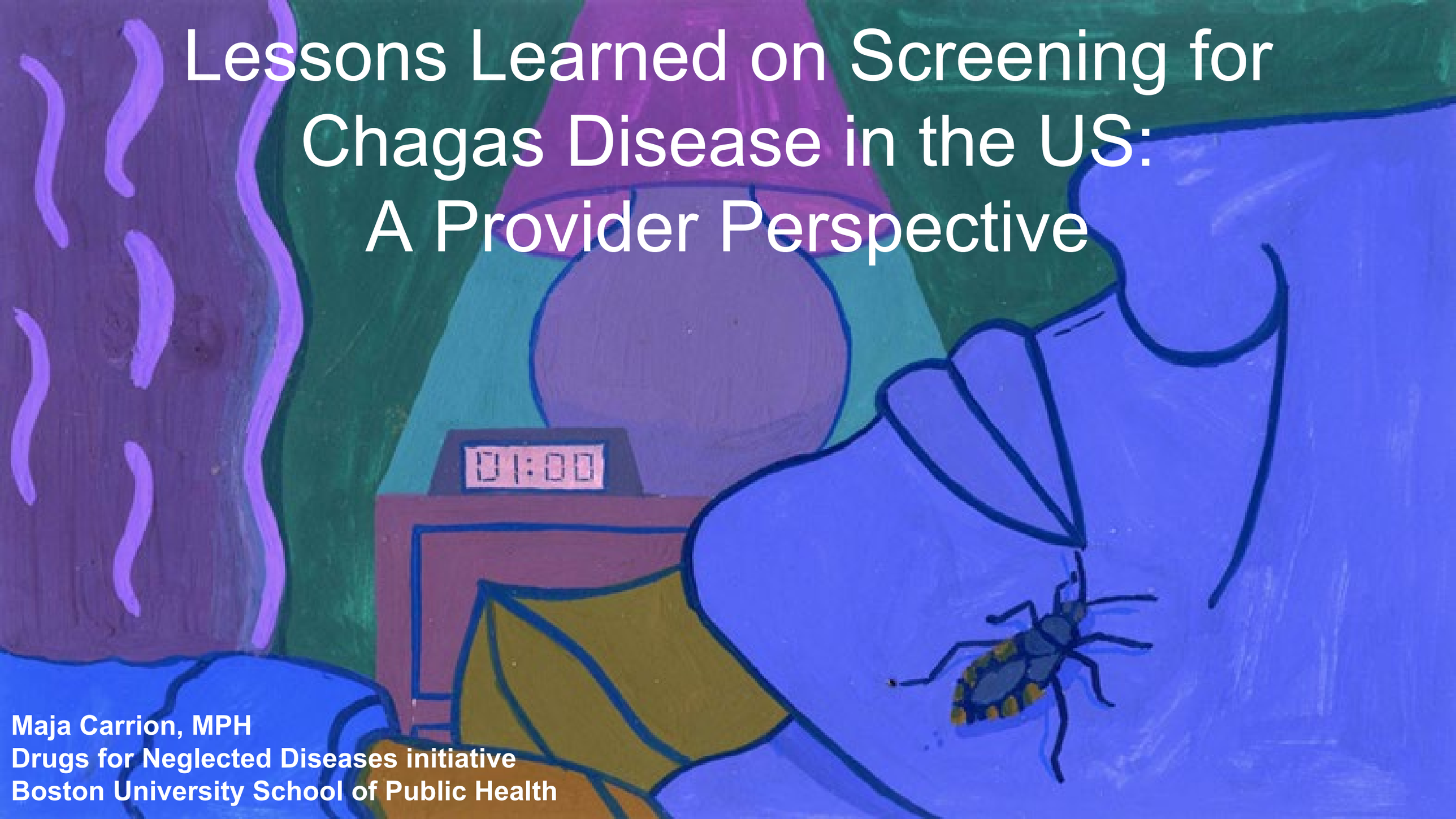
Collaboration is Key





- Chagas disease vectors are found in nearly 30 states of the U.S
- People living with Chagas disease can be found across the entire U.S.
- Collaborations with key partners help to build awareness and surveillance
- Using a One Health approach can help raise awareness about the disease and its vector

Lessons Learned on Screening for Chagas Disease in the US: A Provider Perspective



Maja Carrion, MPH
Drugs for Neglected Diseases initiative
Boston University School of Public Health

Screening Programs Results

Studies on Prevalence of Chagas Disease in Latin American-born Populations in the U.S. (2010-2020)*

Study	Population	prevalence (%)
Castro et al. 2020 (20)	1,514 people in the greater Washington, DC metropolitan area (community screening program)	3.8
Hernandez et al. 2019 (19)	189 relatives of 86 previously diagnosed patients with CD	7.4
Manne-Goehler et. al. 2019 (21)	5,125 people from endemic regions screened in primary care setting in East Boston	1.0
Meymandi et al. 2017 (14)	4,755 Latin American-born residents of Los Angeles (community screening program)	1.2
Traina et al. 2017(16)	327 hospital patients with electrocardiogram abnormalities	5.2
Park et al. 2017 (17)	80 patients with pacemakers	7.5
Traina et al. 2015 (15)	135 hospital patients with nonischemic cardiomyopathy	19.0
Kapelusznik et al. 2013 (18)	39 hospital patients with nonischemic cardiomyopathy	13.0

Source: U.S. Chagas Diagnostic Working Group 2021

Barriers to Screening (based on literature/experience)

- Lack of physician awareness/ knowledge
- Limited guidelines about who to screen and how
- Confusion about which tests to use
- Patient barriers/fears

INSECT: Implementing Novel Strategies for Education and Chagas Testing

- Improve knowledge and awareness among healthcare providers
  - Focus groups and in-depth interviews about how they learn best
- Evaluate Strong Hearts program
  - Initiative started in 2018 to increase testing at East Boston Neighborhood Health Center (EBNHC)
  - Focus groups and in-depth interviews with providers at EBNHC
- Roll out screening programs in other sites in the USA
  - Locally, regionally, nationally
- Improve community knowledge and awareness
- Improve department of public health buy-in

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CDC
CENTERS FOR DISEASE CONTROL AND PREVENTION

Qualitative Data Gathering

Group Interview Dates and Participants

Participant	Date	Profession	Specialty	State
1	6/21/21	MD	GIM	MA
2		MD	FM	FL
3		MD	FM	FL
4	8/4/21	MD	PEDS ID	MA
5		MD	FM	MA
6		MD	GIM	CA
7	9/1/21	MD	PEDS	MA
8	10/6/21	MD	FM	CA
9		MD	FM	CA
10		MD	FM	MA
11		MD	FM	CA
12	10/18/21	MD	ID	NY
13		MD	FM	MA
14		MD	UC	CA
15	10/27/21	RN	GIM	MA
16		RN	OB/GYN	MA
17	11/8/21	PA	EM	CA
18		PA	EM	CA
19	11/17/21	MD	PEDS	MA
20	12/14/21	MD	OB/GYN	MA
21		MD	GIM	CA
22		MD	ID	MA
23		MD	GIM	MA
24	12/16/21	NP	GIM	NY
25		NP	FM	NY

GIM = General Internal Medicine; FM = Family Medicine; PEDS ID = Pediatric Infectious Disease; PEDS = Pediatrics;
ID = Infectious Disease; UC = Urgent Care; OB/GYN = Obstetrics/Gynecology; EM = Emergency Medicine

In-Depth Interview Dates and Participants

Participant	Date	Profession	Specialty
1	4/5/21	MD	ID
2	4/9/21	MD	ID
3	4/15/21	PharmD	ID
4	4/20/21	MD	ID
5	6/29/21	MBA	Lab Mgmt
6	7/2/21	MD	GIM
7	8/19/21	MD	GIM
8	8/20/21	MD	FM
9	8/25/21	NP	OB/GYN
10	11/8/21	MD	FM
11	11/10/21	MSW	-
12	11/23/21	MD	GIM
13	11/23/21	MD	FM
14	12/1/21	MD	GIM
15	12/10/21	MD	OB/GYN
16	12/17/21	NP	FM
17	1/10/22	NP	FM
18	1/14/22	MD	FM
19	1/21/22	NP	FM

MD = Medical Doctor; PharmD = Pharmacist;
MBA = Master's in Business Administration;
NP = Nurse Practitioner; MSW = Master's in Social Work;
ID = Infectious Disease; Lab Mgmt = Laboratory Management;
GIM = General Internal Medicine; FM = Family Medicine;
OB/GYN = Obstetrics/Gynecology

Case-Studies and Workflow Integration:
How to Encourage Primary Care Providers to Screen for Chagas Disease

Malwina N. Carrion[1], Taylor Paiva[2], Madolyn Dauphinais[3], Alyse Wheelock[3], Daniel L. Bourque[4], Davidson H. Hamer[2], Natasha S. Hochberg[4]
[1]Boston University, Boston, MA, USA, [2]Boston University School of Public Health, Boston, MA, USA, [3]Boston Medical Center, Boston, MA, USA, [4]Boston University School of Medicine, Boston, MA, USA

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INTRODUCTION

Chagas disease is a parasitic infection that affects roughly 8-10 million people worldwide. While often asymptomatic, it can cause significant morbidity and mortality, particularly if left untreated. In the United States (US), Chagas primarily affects Latinx immigrants and their children.

Primary care providers (PCPs) are the first, and sometimes only, point of contact in the US healthcare system for many vulnerable populations. But PCPs have a myriad of health concerns to address with their patients and are often unaware of the risk of Chagas disease among their patients.

METHODS

To better understand how to convince PCPs to screen for Chagas, we asked them about their motivation, attitudes and preferences towards professional educational activities, and to identify current barriers to screening for Chagas in their clinics. We spoke with 43 PCPs in total.

We conducted group interviews with 24 PCPs in four different states who serve at-risk populations but do not currently screen for Chagas disease as part of routine care.

We also conducted 19 in-depth interviews with PCPs who currently screen for Chagas disease regularly at a community health center in Boston, MA.

Location	# of Participants	Roles
Massachusetts	31	22 MDs, 4 NPs, 5 Other*
New York	3	1 MD, 1 NP, 1 PA
California	7	5 MDs, 2 PAs
Florida	2	2 MDs

MD = Medical Doctor; NP = Nurse Practitioner; PA = Physician's Assistant, Other = 2 nurses, 1 pharmacist, 1 social worker, 1 laboratory manager

How to convince **primary care providers** to screen for **Chagas disease**?

Case-based learning, workflow **integration**, and **national screening guidelines**.

NOT Twitter!

Take a picture to **visit** our **website for resources and materials!**

@ChagasBoston

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This work is supported by a grant from the U.S. Centers for Disease Control and Prevention (CDC)

RESULTS

PCPs from group interviews were interested in learning more about Chagas disease and cited case-based learning as the most engaging and effective way to cover new material. However, 88.4% (38/43) mentioned that the many issues they must cover in a visit means that Chagas screening could only work if it was integrated into their workflow.

Having the screening test as part of an order set with other routine tests (27/43; 63%) or being prompted by a reminder in the electronic medical record (15/43; 35%) were mentioned as effective tools.

Many PCPs reported that official guidelines from either the CDC or their respective professional organizations/associations mattered to them. While neither the CDC nor any professional organization/association based in the US currently has official screening guidelines, 72% (31/43) of PCPs reported that this would either encourage them to start screening or help them to prioritize screening in their visits.

One surprising result was that social media is rarely used by PCPs for professional activities (3/43; 7%).

DISCUSSION

Based on our interviews, it seems that a systematic approach is necessary to improve screening for Chagas disease in the US. It is not enough to raise awareness among providers; they must be supported by workflow integration and encouragement from professional organizations.

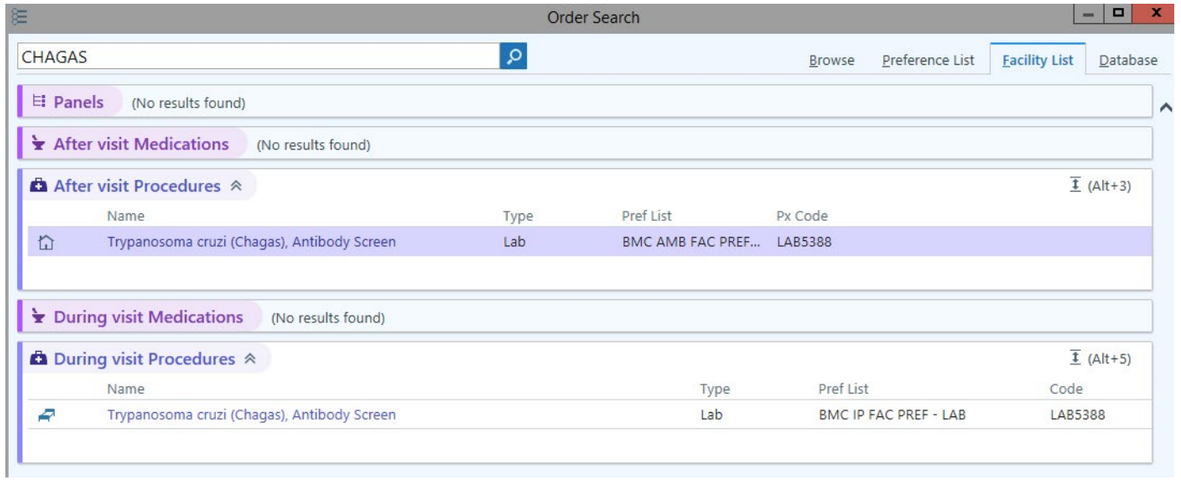
Furthermore, recent literature and anecdotes have pointed to social media as a useful tool for spreading information and education to healthcare providers, but this was not what our project found. Additional studies should be done examining whether there is a difference in social media usage among provider specialties or if this finding is consistent throughout.

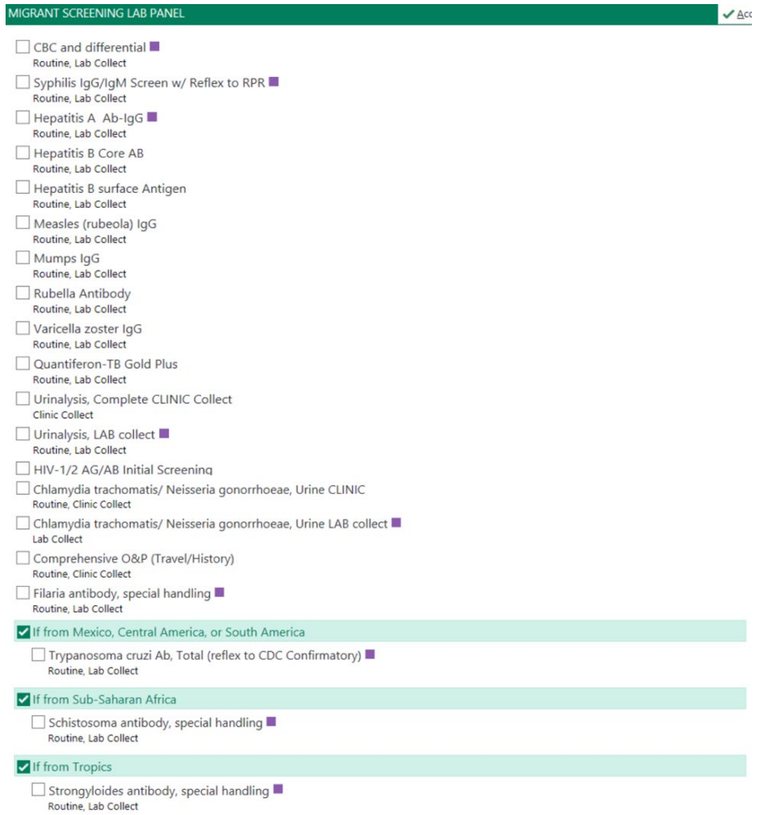
What doesn’t work?

- Trying to force champions
- Focusing on background, biology, epidemiology
- Assuming any level of knowledge or interest
- Social media?

What does work?

- Short, focused messaging
- Shareable resources
  - also useful for political/policy motivation
- Integration into workflow
  - EMR screening panels, alerts (maybe)
- Including as part of another risk group
  - Recently arrived im/migrant screening
- Official recommendations, guidelines, and policies
  - Professional associations
  - CDC
- Capitalizing on enthusiasm
  - Identify organic champions





Testing Recommendations

The Journal of Infectious Diseases

MAJOR ARTICLE

Recommendations for Screening and Diagnosis of Chagas Disease in the United States

Colin J. Forsyth,[1] Jennifer Manne-Goehler,[2] Caryn Bern,[3] Jeffrey Whitman,[4] Natasha S. Hochberg,[5,6,7] Morven Edwards,[8] Rachel Marcus,[9,10] Norman L. Beatty,[11] Yagahira E. Castro-Sesquen,[12] Christina Coyle,[13] Paula Stigler Granados,[14] Davidson Hamer,[5,15] James H. Maguire,[2] Robert H. Gilman,[12] and Sheba Meymandi[16]; US Chagas Diagnostic Working Group

There is a need for formal CDC guidelines

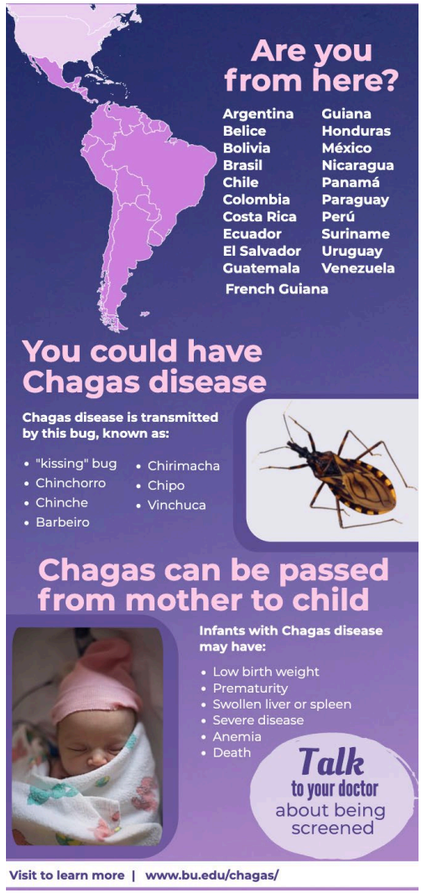
Table 2. Recommendations for Screening and Diagnosis of Chagas Disease in the United States

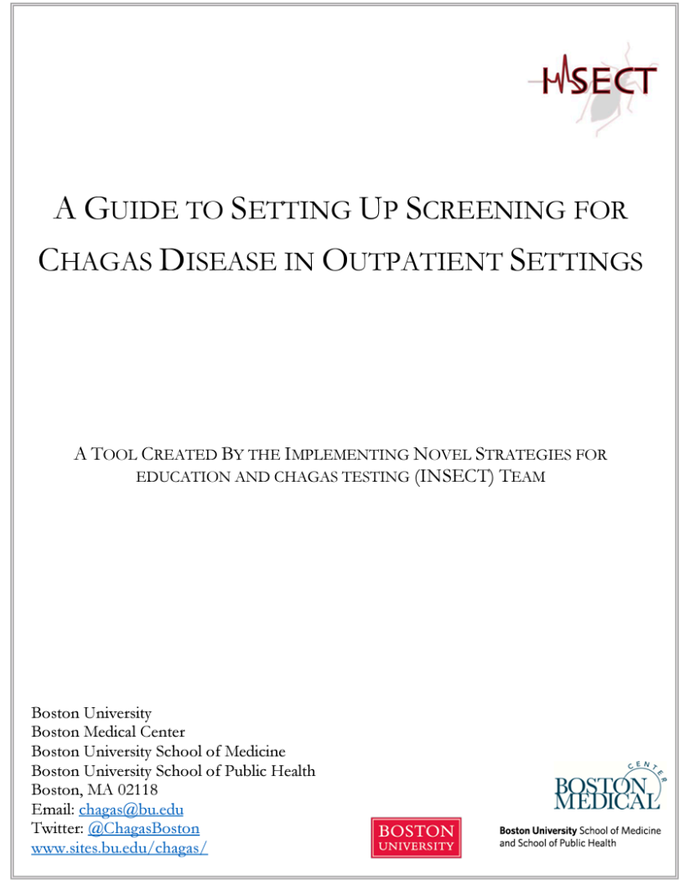
Recommendation	Strength	Quality of Evidence
Who should be screened for Chagas disease in the United States?		
People who were born or lived for a prolonged period (> 6 mo) in areas of Mexico, Central or South America with endemic Chagas disease	Strong	Low
Close (first-degree) relatives of people previously diagnosed with Chagas disease	Strong	Low
People with entomologically confirmed or highly suspected exposure (bites and/or triatomines/kissing bugs found in the home), in states with known presence of triatomine species capable of transmitting *Trypanosoma cruzi*	Conditional	Low
Travelers with confirmed exposure to triatomines or associated risk factors in regions of Latin America where Chagas disease is endemic	Conditional	Low
Women of childbearing age who have lived in a region of Mexico, South or Central America with endemic Chagas disease	Strong	Moderate
Which clinical conditions warrant diagnostic testing for Chagas disease in people from endemic countries of Latin America?		
Electrocardiogram abnormalities suggestive of infection, even in the absence of symptoms. These include first-degree atrioventricular block, premature ventricular contractions, atrial fibrillation, right bundle branch block, left anterior fascicular block, bifascicular block, and low voltage QRS	Strong	Low
Bradyarrhythmias and tachyarrhythmias	Strong	Low
Regional wall motion abnormalities (particularly basal inferolateral, apical aneurysm)	Strong	Low
Thromboembolic phenomenon	Strong	Low
Congestive heart failure and/or a reduced ejection fraction	Strong	Low
Megacolon/megaesophagus	Strong	Low

And more research…

A great resource

- https://sites.bu.edu/chagas/ - Boston Chagas group website
  - posters, postcards, handbook, training, consultations/support





Case Discussions

Case #1 - Letter from a Blood Bank

- The patient, a 32-year-old male, living in South Texas, originally from Mexico, moved to the US at the age of 2 and decided to participate for the first time in a blood drive in his community.

- Four weeks later, he received a letter from the Blood Donation center, informing him that he had tested positive for Chagas disease. The letter advised him to consult with his doctor for further information and also mentioned that he would be unable to donate blood again in the future.

- Upon receiving the letter, he immediately looked up Chagas disease online to educate himself about the condition and its implications for his health.

Potential Next Steps

- **Scenario 1 - Goes to urgent care with the letter and asks to be tested:** In this scenario, the patient takes proactive steps to address the positive test by seeking immediate testing and consultation at an urgent care facility.
- **Scenario 2- Schedules with his PC provider for an appointment in 3 weeks:** The patient opts for a planned approach, scheduling an appointment with his primary care provider in three weeks to address the test results and discuss further steps.
- **Scenario 3 - Disregards the letter because he doesn't have insurance:** Unfortunately, due to the lack of insurance, the patient dismisses the importance of the letter, potentially forgoing crucial follow-up testing and medical advice.

Next Steps and Test Results

- If Scenario 1 is followed and the second test is positive:
  - Refer the individual to an infectious disease specialist for confirmatory testing and treatment options.
  - Involve the local health department or CDC for guidance on further management.

- If Scenario 2 is followed and the second test is positive:
  - Promptly collaborate with infectious disease specialists or Chagas disease experts for confirmatory testing and initiation of treatment.
  - Consider referral to other relevant healthcare professionals as part of a comprehensive care plan.

- If the second test yields inconclusive results in either scenario:
  - Conduct further testing in consultation with infectious disease specialists or relevant healthcare professionals experienced in Chagas disease diagnosis to determine the appropriate course of action.

Negative vs. Positive Result

- After receiving the initial test results, it's crucial to discuss the potential outcomes for both negative and positive results.
- In the case of a positive result, confirmatory testing is essential to validate the diagnosis. Exploring treatment options in the event of confirmation is important for establishing immediate care.

Confirmation and Treatment

- Confirmatory Testing: Involves coordination with the health department, CDC, and a designated physician to ensure an accurate diagnosis.
- Treatment Options: Identifying a physician experienced in Chagas disease for expert guidance on required therapy, and long-term care.
- Support for Family Members: Delving into the potential risk and **testing options for family members**

Rural vs. Urban Considerations

Differences in living environment impact access to healthcare, support systems, and disease awareness. Understanding regional disparities is crucial for tailored interventions and resource allocation.

Case #2: Family Case with a Pregnant Mom

- 26-year-old pregnant woman tests positive
- Recently moved to a new city and visited a new clinic to receive routine care. Clinic was actively screening women with a history of travel or residence in Latin America.
- Patient was born in the U.S., but mother and father are from El Salvador. Patient lives with her mother, grandmother and sister. She has two other children ages 8 and 5.
- Patient reports some travel to El Salvador to visit family, but not in the las 8 years.

- **What are the next steps? Who should be involved?**

Case #2: Family Case with a Pregnant Mom

Next steps

- test baby when born
- test other kids and family members
- treat mom (when?)

Results

- Baby negative at birth, whats next?
- Grandma was positive (age 65) needs further assessment, other kids negative and sister negative

Who should be involved? adult ID, OB GYN, PED ID, anyone else? (e.g. cardiologist, GI specialist)

Case #2: Family Case with a Pregnant Mom

What's next?

Newborn Baby
The newborn baby has been confirmed as healthy and tested negative for Chagas disease through PCR testing at birth. What should happen next? Who is involved in this process?

Grandmother
The grandmother, aged 65, has tested positive for Chagas disease and requires further assessment due to underlying health problems. What should happen next and who is involved in the process?

Other Children and Sister
All other children of the mother have tested negative for Chagas disease

Case #3: Cardiac patient

52 year old male presents to ER with chest pain

EKG abnormal and shows a RBB

Patient originally from Argentina, but lived in the U.S. for 20+ years

Whats next???

Conclusions

- Community Awareness is important, however without Health care provider awareness it is difficult to move forward
- Sensitive populations require special considerations
- Screenings and Treatment options need to be increased

What do you think are the most critical needs to improve screening and treatment in the U.S.?

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