

#### Chagas Disease as a Migrant Health Issue

#### **Chagas Disease ECHO Series**

Colin Forsyth, PhD, MPH



### **Objectives**

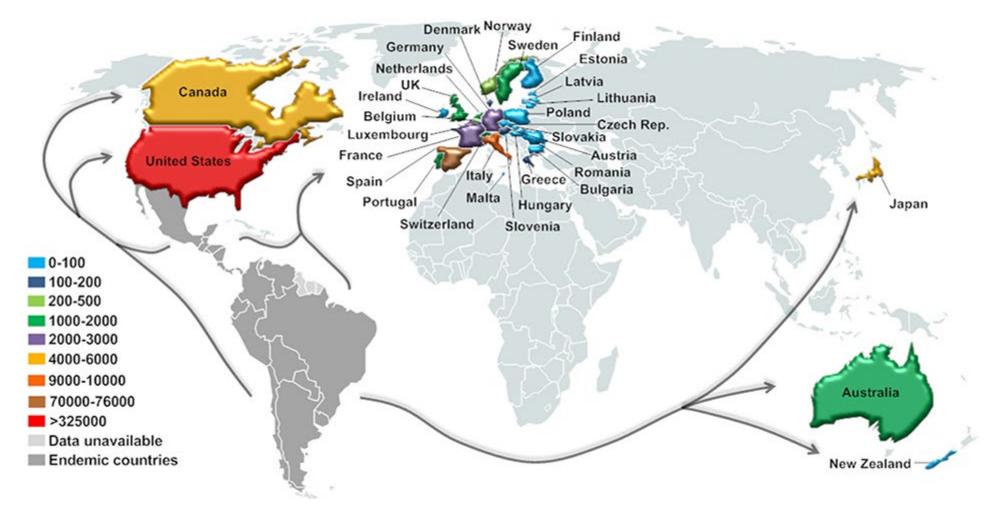
- Establish the reasons why Chagas disease is a challenging global issue
- Explain how Chagas disease impacts groups of people in different ways
- Understand strategies to mitigate problems for migrants from Chagas disease



#### Global Context of Chagas Disease and Migration

#### DNDi

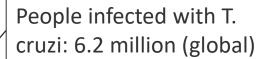
### Chagas disease in non-endemic countries

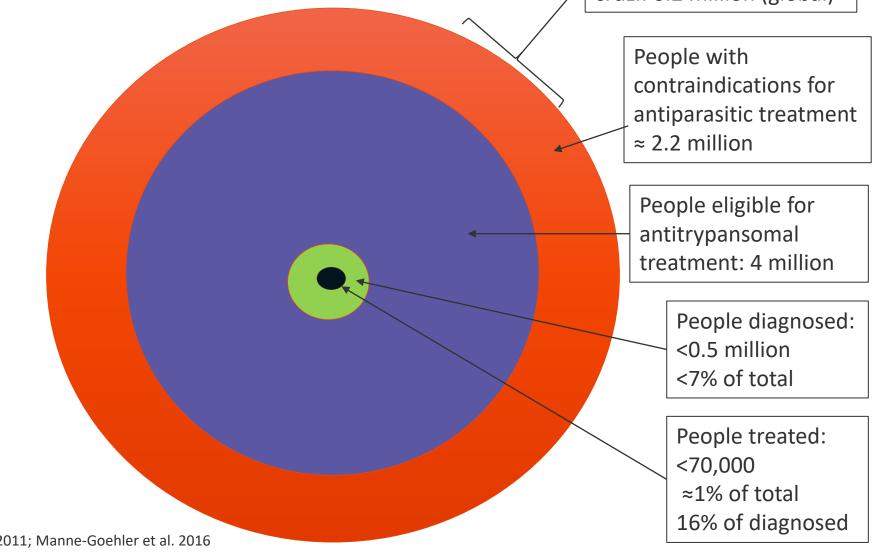


Lidani KCF, Andrade FA, Bavia L, Damasceno FS, Beltrame MH, Messias-Reason IJ, Sandri TL. Chagas Disease: From Discovery to a Worldwide Health Problem. Front Public Health.

#### DNDi

### **Global Neglect of Chagas Disease\***

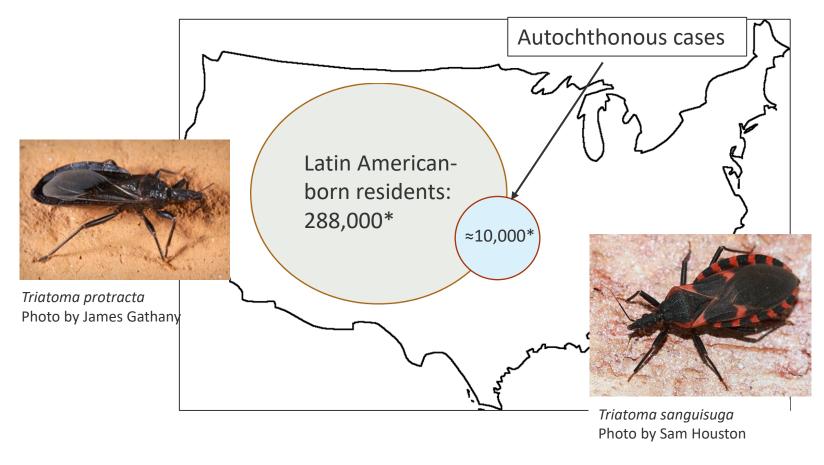




\*Sources: WHO 2015; Basile et al. 2011; Manne-Goehler et al. 2016

DND

## **Current Epidemiological Landscape**



< 1% diagnosed and treated 57,000 people with Chagas cardiomyopathy

\*Irish A, Whitman JD, Clark EH, Marcus R, Bern C. Updated Estimates and Mapping for Prevalence of Chagas Disease among Adults, United States. Emerg Infect Dis. 2022 Jul;28(7):1313-1320.



## **Chagas Disease: Main Risk Factors**

- Having been born or lived >6 months in mainland Latin America
  - Excluding the Caribbean
- Having lived in housing made of adobe, mud, or thatch in rural Latin America
- Having a family member with Chagas disease
- Finding kissing bugs living in the home





#### Studies on Prevalence of Chagas Disease in Latin American-born Populations in the U.S.

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



# Prevalence of Chronic Comorbidities among People Living with T. cruzi Infection in Los Angeles

- Cross-sectional study of 221 patients at the Center of Excellence for Chagas Disease at Olive View-UCLA Medical Center
- >50% had 2 or more chronic comorbidities
- Most common
  - hypertension 43%
  - obesity 40%
  - hyperlipidemia 31%
  - diabetes mellitus 20%





#### Chagas Disease as a Migrant Health Issue

- Migration and risk of Chagas disease
  - Migrants from Chagas-endemic countries were often exposed to risk of Chagas disease due to socioeconomic conditions
  - Access to healthcare in host countries is often precarious
  - Migration exposes people to additional health risks; more research is needed to determine any relationship with *T. cruzi* exposure
- Studies of *T. cruzi* infection along migration routes
  - 79/392 migrants at Mexico/Guatemala border reported seeing triatomines at places they slept during travel, and 12 were seropositive for *T. cruzi* (Conners et al 2017)
  - Half of 120 Central American migrants in Mexico reported being bitten and 20% had serological evidence of *T. cruzi* (Montes-Rincon et al 2018)



#### DNDi

1. Based on the information below, which of the following individuals would you expect to have the lowest risk of Chagas disease?

A. Lucia, a 21 year old university student from Brazil.

B. Wilson, a 47 year-old welder who grew up in a rural area of Puerto Rico.

C. Cintia, a 35 year old Spanish teacher from Argentina.

D. Mario, a 2 year-old born in the U.S. whose mother is from Bolivia.

E. Ariana, a 28 year old pregnant nurse from Bogota, Colombia.

# What can happen when this disease goes unrecognized?



Alyse Wheelock, MD



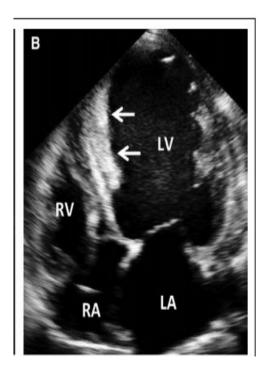
What can happen when this disease goes unrecognized?

- 42 y/o previously healthy woman from El Salvador
- Reported history of stroke in 2014 in El Salvador
- Works at McDonalds and unable to take time off for appointments

- In May 2019, she had sudden-onset complete Broca's aphasia and right-sided weakness while at home with family
- Rushed to Emergency Department

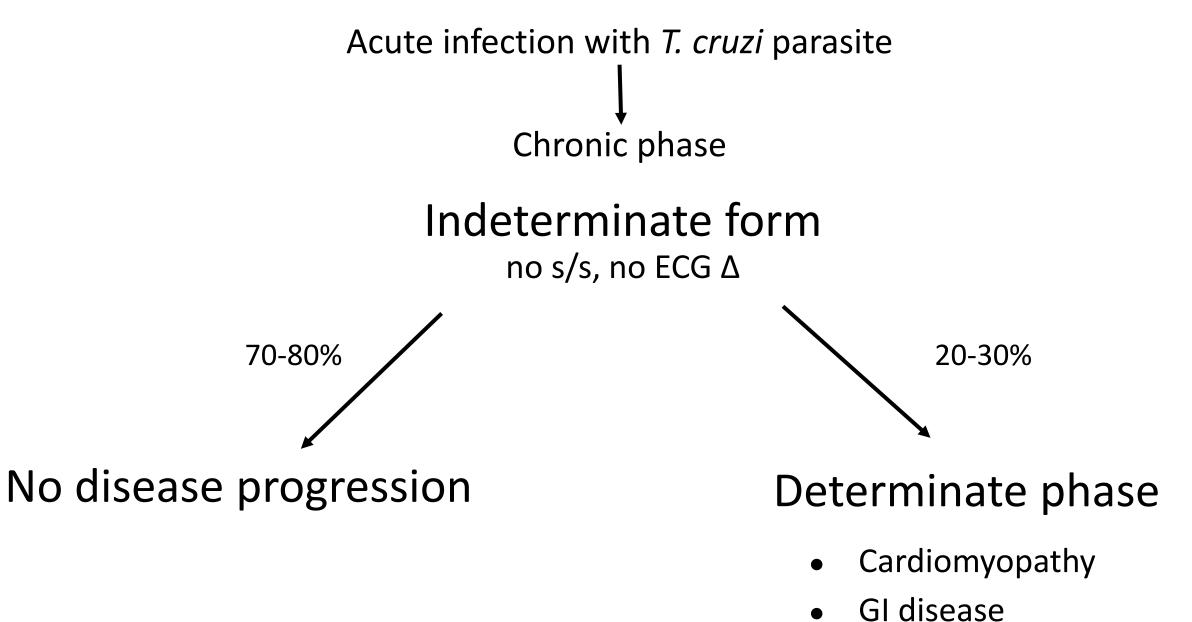
## Imaging showed

- Left MCA stroke leading to Broca's aphasia
- TTE: normal EF of 55%, LV apical aneurysm and akinesis of inferolateral and anterolateral wall with associated thrombus



## Work-up reveals positive *T. cruzi* serologies

- Received acute rehab with physical/occupational therapy
- Started on anticoagulation
- Evaluated in Infectious Diseases clinic not initiated on anti-parasitic treatment
- Some speech difficulties persist but right-sided weakness is nearly completely resolved



Carmo, Circulation 2018



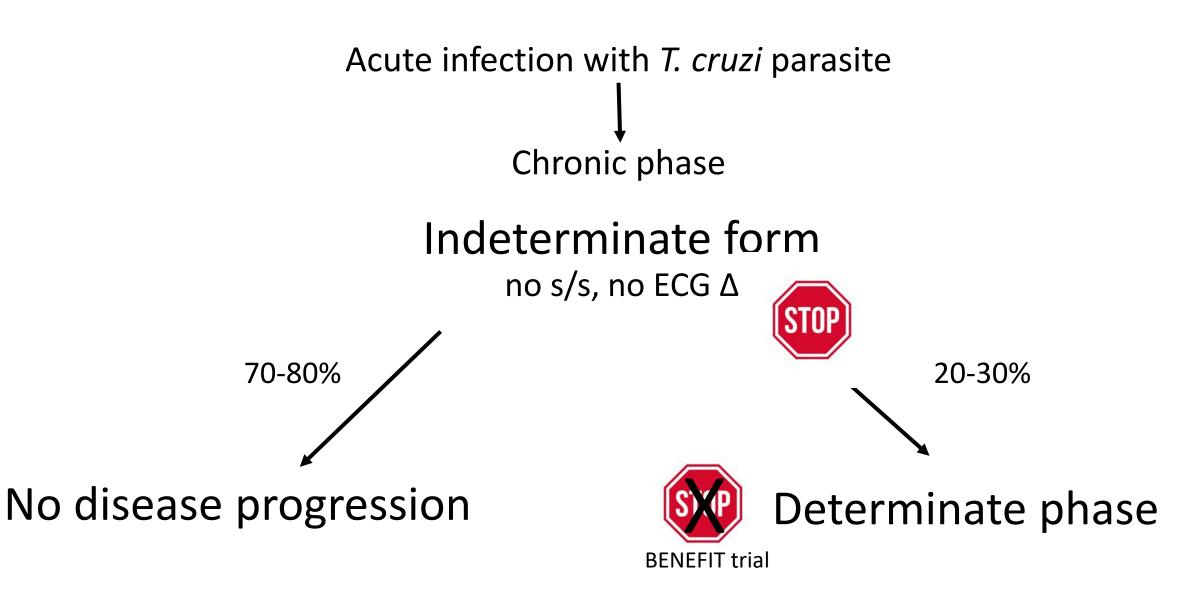
#### Aneurysms



#### Myocardial Abnormalities

#### Thromboembolism

#### Carmo, Circulation 2018



Carmo, *Circulation* 2018 Morillo et al, *NEJM*, 2015 What objective findings could be found in a US resident affected by Chagas disease who has not returned to his country of birth (El Salvador) in >20 years?

- A. Right bundle branch block on electrocardiogram
- B. Left ventricular apical aneurysm associated with thrombus and embolic stroke
- C. No ECG or echocardiogram abnormalities
- D. Any of the above



#### 2 Barriers to Care Impacting Migrants with Chagas Disease

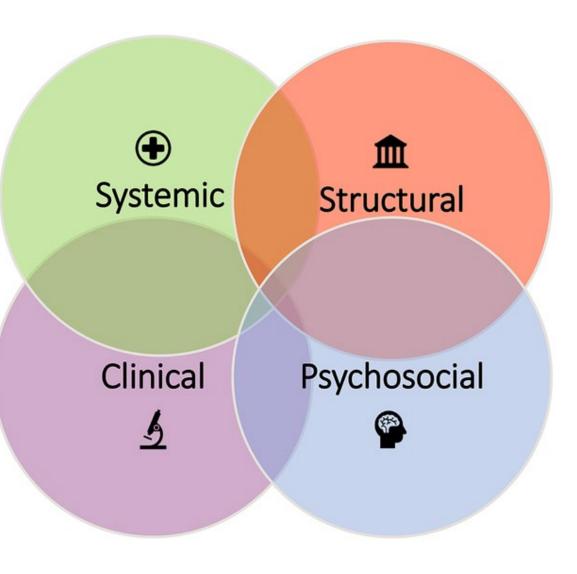
### DNDi

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### Multidimensional Barriers to Diagnosis and Treatment of Chagas Disease

Forsyth C, Meymandi S, Moss I, Cone J, Cohen R, et al. (2019) Proposed multidimensional framework for understanding Chagas disease healthcare barriers in the United States. PLOS Neglected Tropical Diseases 13(9): e0007447. https://doi.org/10.1371/journal.pntd.0007447





DNDi

# 86% of 2,677 Latin American-born residents of Los Angeles had never heard of Chagas disease (Sanchez et al. 2014)

It's a fatal disease, and yet you don't hear anything about it, it's like a phantom disease that is killing people but nobody knows it exists, until they tell you you have it. You always hear about diabetes, cancer, but [Chagas] disease is something that's never heard anywhere, not even in the media.

-Sara, 60, El Salvador

The majority of doctors in the United States don't know what Chagas is. I've gone to two cardiologists... and I had to show the doctor on Google what Chagas is.

-Omar, 41, El Salvador



What are the Main Difficulties or Concerns in Seeing a Doctor for Chagas Disease from Patients' Point of View?

- Not having a source of transportation
- Difficulty in getting time off from work
- Lack of insurance coverage
- Financial resources
- Bureaucracy/delays in the health system
- Having services close to home

Before I couldn't go [to the doctor], because I didn't know how to drive. I had to wait for someone to take me; I depended on someone giving me a ride as a favor. And then I didn't have money to pay for the appointment or the ride, or sometimes for lack of time, and I've had to neglect other tasks so I could go to the doctor. -Renata, 36, Mexico

Forsyth CJ, Hernandez S, Flores CA, Roman MF, Nieto JM, Marquez G, Sequeira J, Sequeira H, Meymandi SK. "You Don't Have a Normal Life": Coping with Chagas Disease in Los Angeles, California. Med Anthropol. 2021 Aug-Sep;40(6):525-540.

Forsyth CJ, Hernandez S, Flores CA, et al. "It's Like a Phantom Disease": Patient Perspectives on Access to Treatment for Chagas Disease in the United States. *Am J Trop Med Hyg*. 2018;98(3):735-741. doi:10.4269/ajtmh.17-0691

# What is the most difficult part of adjusting to life in the United States?

#### Top responses

- 1. The language (n=30, 60%)
- 2. Being far from family (n=13, 26%)
- 3. Finding/keeping jobs (n=13, 26%)

Well when you get here you go about in fear, if you don't have papers here. Also language, well you know that if you don't speak the language you feel afraid and that frustrates you in the beginning.

-Roberto, 39, El Salvador

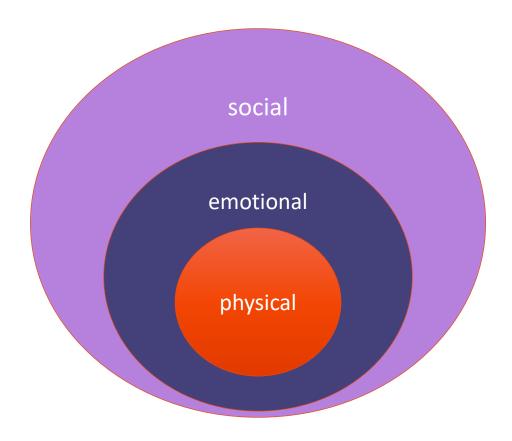
That was the most difficult part, the jobs. I started to get jobs here and there, and worked and worked. And then [the doctors] found out I had this Chagas disease and I had to stop working because I didn't have time to go to work. I was spending all my time in the hospital.

-Carlota, 64, Guatemala



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#### Dimensions of Disease





# Key challenges in organizing Chagas disease care for migrant communities in the United States

- Heterogeneous population
  - Differential responses to testing and treatment?
  - Strategies around information, education and communication need to be adaptable (e.g., different terms for kissing bugs)
- Availability of insurance coverage
- Linguistic differences
- Fear of accessing healthcare
- Inability to get time off from work
- Transportation challenges
- Mobility
- Preferring not to know
- Preferring to stay under the radar



	California	Texas	Florida	New York
Estimated burden of CD, (US ranking) [42]	70,860 (1)	36,977 (2)	18,096 (3)	17,403 (4)
Latino population, millions Pew Research Center [43, 44]	15.2	10.7	5.0	3.7
As % of state pop.	39.0	38.2	24.0	19.0
% foreign born	36.0	30.0	48.0	39.0
Chagas reportable?	No	Yes	No	No
Local vectors [4]	T. leticularia T. rubida T. protracta P. hirsuta	T. leticularia T. sanguisuga T. rubida T. protracta T. gerstaeckeri T. indictiva T. neotomae T. recurva	T. leticularia T. sanguisuga T. rubrofasciata	None
Medicaid expansion? [45]	Adopted	Not adopted	Not adopted	Adopted
% uninsured Henry J. Kaiser Family Foundation 2018b [83]	8	15	12	6
Patients treated [46]	111	40	15	35
Key epidemiological studies	Meymandi et al. 2017 [47]	Garcia et al. 2015 [6]	Leiby et al. 2002 [48]	Kapelusznik et a 2013 [49]

Table 1 Public health indicators for Chagas disease in the highest-prevalence US states

Forsyth, C.J., Stigler Granados, P., Pacheco, G.J. *et al.* Current Gaps and Needs for Increasing Access to Healthcare for People with Chagas Disease in the USA. *Curr Trop Med Rep* **6**, 13–22 (2019). https://doi.org/10.1007/s40475-019-0170-1

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2. Which of the following areas would not represent a key difference between Florida and California that could impact programs for Chagas disease?

- a) Availability of insurance coverage for people at risk of T. cruzi Infection
- b) Presence of vector species in the natural environment
- c) Proportion of Latin American-born population from Chagas-endemic countries
- d) State government posture and rhetoric toward provision of healthcare for migrants

3. Which of the following is NOT a major barrier affecting access to diagnosis and treatment of Chagas disease for Latin American migrants in the U.S.?

- a) Linguistic diferences between people at risk and healthcare personnel.
- b) Low awarenss of what Chagas disease is among people at risk.
- c) Limited testing options.
- d) Difficulties in getting time off from work.
- e) All of the above are barriers

# Supporting individuals through Chagas disease care

- 35yo woman from rural El Salvador, moved to US in 2010, found to be *T. cruzi* positive in 2018
- Single mom of 2 children aged 6 and 12 years
- Works preparing food carts for commercial airplanes
- EKG revealed sinus bradycardia, TTE was normal
- Offered anti-parasitic treatment in Infectious Diseases clinic (60 day course of benznidazole)

# Neglected disease = neglected treatment options

- Visits on day 1, 15\*, 30, 37\*, 45\*, 60 of benznidazole therapy
  - \*Telemedicine visits led by pharmacist protocol developed by Alejandra Salazar, PharmD
- Adverse effects: mild pruritic rash on arms, daytime fatigue, nausea with vomiting x 3
- Adjunct medications prescribed: hydrocortisone 1% cream, meclizine 25mg prior to benznidazole dose

## Follow-up

- Continues to follow once a year in ID clinic continues to be asymptomatic and has a normal EKG
- Children were screened (negative)



3 Strategies to Improve Access to Testing and Treatment of Chagas disease in Migrant Communities



## Center of Excellence for Chagas Disease (CECD)



- Founded in 2007: 1<sup>st</sup> US center to provide comprehensive care for Chagas disease
- Located within Olive View-UCLA Medical Center, a safety-net facility in Los Angeles, California
- Sources of patients
  - Community-based screening program
  - Referrals from Red Cross
  - Screening of Olive View patients (obstetrics, cardiology)
  - Patient family member referrals
  - Inquiries from patients and providers in L.A.
- over 8,000 screened, over 300 treated
- volunteer-driven

CECD Patient population by the numbers			
Mean years lived in US	21.2		
% living below federal poverty line	63.4		
% with < high school diploma	60.0		
% reliant on Medical, MyHealthLA	72.3		



One or more risk factors? (Ranked in importance)

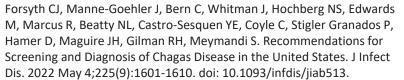
- Born in or lived >6 months in an endemic country (Mexico, Central or South America)
- 2. Having a family member with CD
- Lived in housing made of natural materials (mud, adobe, thatch, palm leaves) in Mexico, Central or South America
- 4. Being bitten by kissing bugs or finding kissing bugs in the home

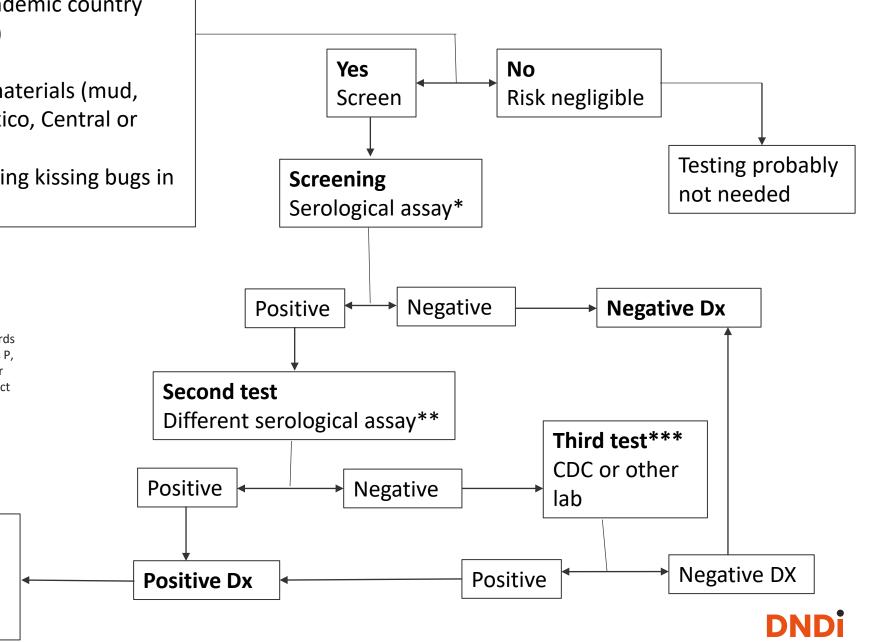
-electrocardiogram

Evaluate treatment

-echocardiogram

options





Recommended Actions	Dimensions Impacted			
Incorporate routine screening, diagnosis and treatment of CD into primary healthcare programs, including those serving vulnerable populations regardless of insurance and/or immigration status.		Â	(P)	4
Facilitate regulatory approval of diagnostic and therapeutic tools.	$\bullet$	ß		
Incorporate CD knowledge and treatment guidelines into medical school curricula; promote continuing education on CD treatment guidelines for providers in areas with heavy CD burdens.		4		
Develop affordable medications that are safe and effective in all phases of the disease.	5	lacksquare	<b>(P)</b>	血
Explore means of reducing side effects and maximizing efficacy in benznidazole and nifurtimox	5	$\bullet$	(P)	血
Create simplified diagnostic procedures which minimize discordant or inconclusive results.	4	lacksquare		
Develop an accurate test of cure which can be implemented immediately after treatment.	4	lacksquare	( <sup>2</sup>	
Identify biomarkers which reliably predict disease progression.	4	lacksquare		
Create programs offering free or low-cost services, including transportation.	血	lacksquare	<b>P</b>	
Provide CD healthcare in environments where patients feel safe from harassment, discrimination or persecution due to their ethnicity, CD diagnosis, or immigration status.	Â	(P)		
Link CD programs to other community-based services for immigrants and other vulnerable groups affected by CD.	<b>m</b>			
Integrate mental health services into CD healthcare at the point of diagnosis	(P)			
Support the development of patient groups and associations.	<b>P</b>		Â	
Develop public campaigns that raise awareness of CD, counter misconceptions, and reduce stigmatization and fear.	(P)		Â	
Legend:: 🕀 = Systemic, 🏦 = Structural, 🍄 = Psychosocial, 🛃 = Clinical				

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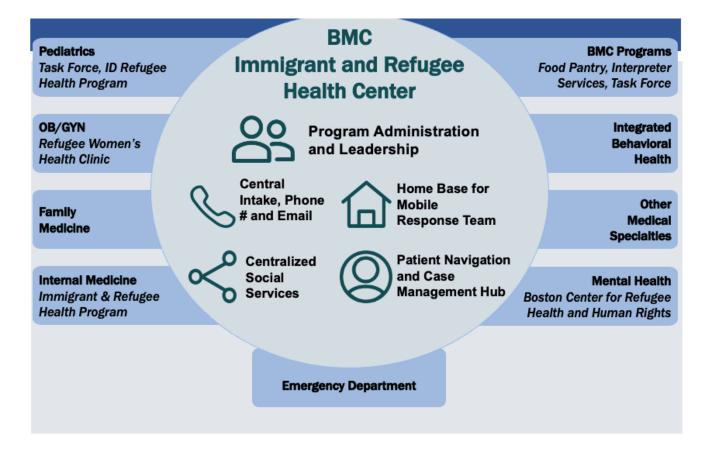
Ingredients to increasing access to testing and treatment in migrant communities

- Screening/testing in safe places (churches, community centers)
- Incorporation of rapid tests
- Integration of Chagas testing and treatment with other key primary healthcare needs (e.g. diabetes, hypertension, depression) – example of University of Florida
- Use of mobile clinics
- Use of telemedicine in certain situations (example of La Plata, Argentina)
- Bilateral collaborations (e.g. Bolivia-Barcelona Chagas Platform)



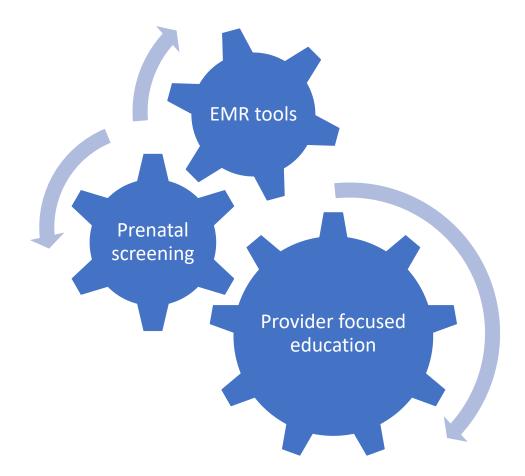
Integrating Chagas disease services into existing primary care for refugees/immigrants/migrants at BMC

### **Boston Medical Center Context**



do not speak English as their primary language

# Chagas disease screening efforts



### Team effort, including:

Natasha Hochberg, MD, David Hamer, MD, Daniel Bourque, MD, Katherine Reifler, MD (Infectious Diseases) Sarah Kimball, MD (Immigrant and Refugee Health Center) Former team members: Alejandra Salazar, PharmD, Maja Carrion, MPH "Clinic champions" recruited from primary care clincs Many others!

# Provider education

- Multi-departmental educational programs launched in 2019
  - Took inspiration from Strong Hearts program at East Boston Neighborhood Health Center
  - Grand rounds for Internal Medicine, Family Medicine, Pediatrics, sessions for OB/midwife groups, Immigrant and Refugee Health Center, Residency noon conferences, etc.
- INSECT program: Implementing Novel Strategies for Education and Chagas Testing (supported by the CDC)



# EMR (Epic) tools

- Migrant screening order panel
- Reflex confirmatory testing
- Prenatal testing panel

#### MIGRANT SCREENING LAB PANEL

CBC and differential

Routine, Lab Collect

Syphilis IgG/IgM Screen w/ Reflex to RPR Routine, Lab Collect

Hepatitis A Ab-IgG Routine, Lab Collect

Hepatitis B Core AB Routine, Lab Collect

Hepatitis B surface Antigen Routine, Lab Collect

Measles (rubeola) IgG Routine, Lab Collect

Mumps IgG

Routine, Lab Collect

Rubella Antibody

Routine, Lab Collect

Varicella zoster IgG Routine, Lab Collect

Quantiferon-TB Gold Plus

Routine, Lab Collect

Urinalysis, Complete CLINIC Collect Clinic Collect

🗌 Urinalysis, LAB collect 🔳

Routine, Lab Collect

HIV-1/2 AG/AB Initial Screening

Chlamydia trachomatis/ Neisseria gonorrhoeae, Urine CLINIC Routine, Clinic Collect

Chlamydia trachomatis/ Neisseria gonorrhoeae, Urine LAB collect

Comprehensive O&P (Travel/History) Routine, Clinic Collect

Filaria antibody, special handling Routine, Lab Collect

#### ✓ If from Mexico, Central America, or South America

Trypanosoma cruzi Ab, Total (reflex to CDC Confirmatory)
Routine, Lab Collect

#### ✓ If from Sub-Saharan Africa

Schistosoma antibody, special handling Routine, Lab Collect

#### If from Tropics

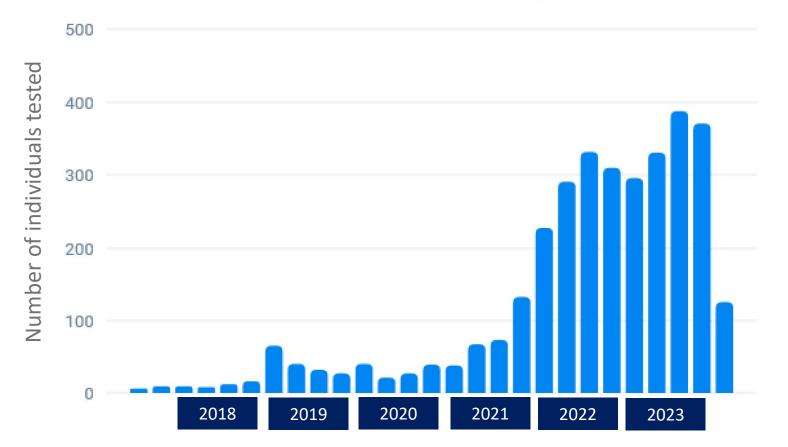
Strongyloides antibody, special handling Routine, Lab Collect

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### **Chagas Disease Screening**

Between 8/2/2017 and 2/1/2024 by quarter



Which of the following is NOT essential to establishing a Chagas disease screening program within a primary care setting serving patients from endemic areas?

- A. Insurance coverage or other payment structure for testing
- B. Established connections for referring patients to specialty care within infectious diseases and cardiology clinics
- C. Access to a Biosafety Level 3 laboratory
- D. Provider awareness of Chagas disease



### The Global Refugee Crisis: Implications for *T. cruzi* transmission and epidemiology



### **Global Refugee Crisis**

- 100 million displaced people and refugees 1.2% of global population (UNHCR 2022)
  - Growing global political insecurity and instability
  - Increase in repressive regimes
  - Climate change
- 7.7 million Venezuelan refugees and migrants, mostly in Latin American countries
  - >250,000 Venezuelans crossed US-Mexico border in 2023 (Center for Strategic and International Studies)
- 1 million displaced Central Americans (UNHCR)
  - Violence (gangs)
  - Extortion
  - Poverty and food insecurity
- Social and political crisis in Haiti
  - 146,000 crossings reported at US-Mexico border 2020-2023
- Africa: 30 million displaced people
  - Democratic Republic of the Congo, Ethiopia, Central African Republic, South Sudan and Nigeria
  - Civil conflicts, human rights abuses, insecurity
- Ukraine
- Syria

US Customs and Border Protection reports of border crossings by "extracontinental" migrants

100,000 50,000 

Source: Reuters, Dec. 11, 2023

• China • Extracontinental

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#### **Common Western Hemisphere Migration Routes for African Migrants**

Source: Migration Policy Institute (MPI) compilation based on fieldwork conducted by the authors, discussed in Caitlyn Yates, "As More Migrants from Africa and Asia Arrive in Latin America, Governments Seek Orderly and Controlled Pathways," *Migration Information Source*, October 22, 2019.

### DNDi

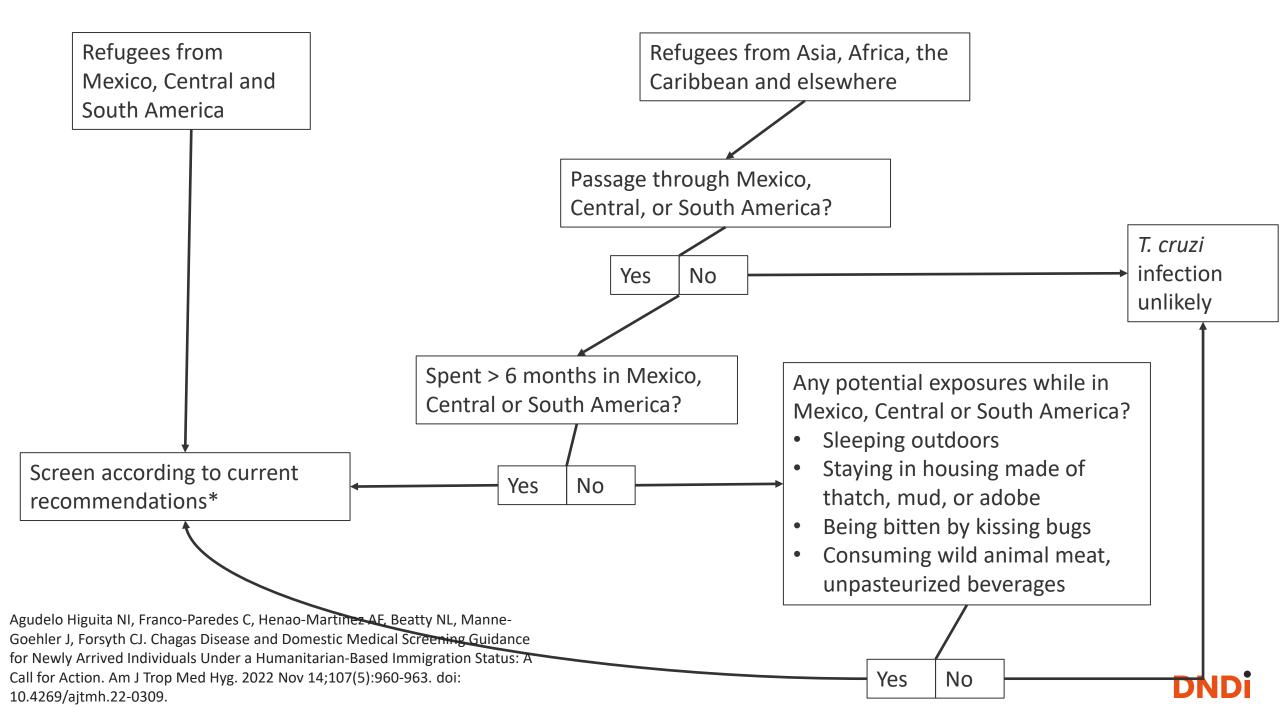
### Are current migration routes causing risk of exposure to T. cruzi?

### • Potential risk factors:

- Due to conditions including forced detention and border camps, many non-Latin American migrants and refugees are spending >6 months in endemic areas
- Living in camps or substandard housing susceptible to triatomine infestation
- Sleeping outdoors in areas where triatomines are in the environment
- Consumption of food contaminated by triatomines
- More research needed!
- Migration routes contribute to numerous deaths, illnesses and injuries



Source: NY Times, January 5, 2024



# 4. Which of the following factors would NOT pose a potential risk of T. cruzi exposure to people from Asia, Africa, Europe, and the Caribbean on transcontintental migration routes through Latin America to the United States?

- a) Sleeping outdoors or in camps in areas where triatomines might be present.
- b) Consuming foods that might be contaminated by triatomines.
- c) Spending several months or more in an endemic country, whether due to waiting for authorization to cross the border or as a result of exploitation by human smugglers.
- d) Having lived in their home countries in housing made of natural materials such as adobe or wood.

### Where are you from? Complex migration histories and Chagas disease risk

# Where are you from?

- Healthy 28yo woman, born in Haiti
- Fleeing rising violence, economic instability, left Haiti in 2019:
  - Moved to Chile in 2019 for 3 months
  - Sao Paolo, Brazil for 3.5 years
  - By bus and foot: Brazil → Bolivia → Peru → Ecuador → Columbia → Panama → Costa Rica → Nicaragua → Honduras → Guatemala → Mexico → Texas → arrived to aunt's house in Massachusetts in 2022
- When she arrived with husband, she was 37 weeks pregnant



**Common Western Hemisphere Migration Routes for African Migrants** 

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# Prenatal infectious disease screening

- CBC with differential, HIV, syphilis, hepatitis B, GC/CT PCR, quantiferon gold, rubella and varicella serologies
- And *T. cruzi* serologies which returned positive from both commercial screen and CDC confirmatory testing

## Connection to care

- Seen in ID clinic
- Plan for initiation of treatment once no longer breastfeeding
- Referred to Immigrant and Refugee Health Center for primary care
- Has had frequent phone contact with case management/ social workers but missed in-person appointments – currently living in shelter ~1.5 hours away by public transportation

# Chagas disease as a migrant health issue

- Global neglect of people affected by Chagas disease extends into the US
- Barriers to care shape the full continuum of Chagas disease care from diagnosis to treatment
- Multiple methods to improve access to testing and treatment that can be tailored according to context
- The current global crisis of displacement and common routes of migration carry new and poorly understood transmission risks

# Thank You



- f facebook.com/dndi.org
- youtube.com/dndiconnect
- 🔰 twitter.com/dndi
- instagram.com/drugsforneglecteddiseasesinitiative
- in linkedin.com/company/dndi

