

## 2013–2023 Decade in Review

# Introduction

As we look back over the past decade, we are grateful for the progress we have been able to make in increasing awareness about Chagas Disease and in helping patients access care. We look back in gratitude for the many partners who made that success possible and look forward to even better things in the future. Most of all, we are grateful for the trust placed in us by the patients, providers, and volunteers who work with us to find solutions to this pressing problem.

This report highlights key accomplishments **LASOCHA** has achieved over the past 10 years and provides more in-depth information about our 2023 accomplishments.

It also sets out our goals for 2024, which are:

- fundraising to cover testing supplies and malpractice insurance expenses
- increasing testing and education events
- continuing our data-gathering efforts and using that data to drive policy related to testing protocols in the United States

LASOCHA: Latin American Society of Chagas Jenny Sanchez, RPH – President Rachel Marcus, MD – Medical Director Deborah Guardado, RN – Vice President Graciela Taylor, RN – Secretary

## Ten Years of Fighting Chagas Disease

#### What is Chagas Disease?

Chagas disease is a Neglected Tropical Disease caused by a parasite transmitted by an insect chiefly found in rural areas of Central and South America and Mexico. The infection is lifelong and, if left untreated, can cause life-threatening heart disease, including strokes, heart failure, and lethal heart rhythm problems.

Chagas disease can also be transmitted transplacentally, and the optimal time to treat it is in childhood, when the disease can be cured.

Of the estimated 288,000 individuals living with Chagas disease in the United States, 18,000 live in the Washington, D.C., metropolitan area, which has the highest prevalence of Chagas disease of any locality in the United States.

#### What is LASOCHA's mission?

LASOCHA's mission is to provide access to medical services to the at-risk Latin American community in the metropolitan Washington area, as well as to raise awareness of Chagas disease within the community and within the medical community that serves at-risk patients in the US.

This work covers 3 areas:

-medical services: providing care to those in need
-patient advocacy: raising awareness of Chagas and barriers to care
-research: helping advance the knowledge base about Chagas in the US

### **Medical Services**

In 2013, we began to screen Bolivian immigrants at the Bolivian Mobile Consulate program, launching our treatment and follow up clinic at this time, and making house calls to provide these services.

After connecting with Dr. Robert Gilman at Johns Hopkins in 2015, we became part of the team to support a large-scale seroprevalence study lead by Dr. Yagahira Castro.

Throughout the next 3 years, we helped the team with outreach, testing, performing ECGs and echocardiograms, and linking individuals diagnosed with Chagas disease to appropriate post-study care. We are very grateful to Medstar Primary Care and Tu Familia Clinic for offering us a home for our free follow up clinic.

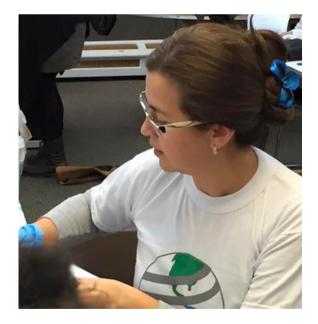
Since that time, we have cared for over 125 people affected by Chagas disease, including those we have identified subsequent to Dr. Castro's study in our ongoing screening program.

We are thrilled to report our newly-launched clinical initiative with the Inova Cares Clinic for Women. To date, approximately 700 pregnant patients have been tested since July, and we provide consultation and cardiac testing for those who have tested positive. We also screen their friends and family.

We are also supporting the initiation of testing at the Virginia Hospital Center OBGYN safety net program, along with a new testing initiative at Mercy Clinic in Gaithersburg, Maryland.

### Current Service Partners

INOVA ICC-W (Inova Cares Clinic-Women) Dr. Adrienne Showler (NIH) Dr. Christina Coyle (Albert Einstein) Medstar WHC Center Clinical Labs Inbios CDC Tu Familia Clinic Virginia Hospital Center OBGYN



#### Research

While we do not have research as a specific goal of LASOCHA, we are aware that data helps to raise awareness.

We provided manpower support to Dr. Yagahira Castro's research program that demonstrated that the Washington, D.C. Metropolitan area was home to the highest risk Immigrant population in the United States (prevalence 3.8%). LASOCHA's contributions included performing all of the cardiac testing for this project.

LASOCHA also sponsored a recent seroprevalence study at Medstar Washington Hospital Center that demonstrated that **16%** of at-risk individuals admitted with certain heart problems had Chagas disease as the cause.

### Research Collaboration

Dr. Robert Gilman (JHU) Medstar WHC Clinical Labs Tu Familia Clinic CDC



A selection of publications can be found on our website under "Provider and Community Outreach" at:

https://lasocha.org/informationfor-physicians/

#### Community/ Provider Awareness and Patient Advocacy

In 2019, LASOCHA President, Jenny Sanchez, served as the Vice President of FindeChagas, –The international federation of people affected by Chagas. Her key contributions included:

-being nominated to be the voice of the federation in the process of WHO recognizing April 14 as World Chagas day and developing its slogan: "Visibility of the disease"

-representing FINDECHAGAS as a member of the International Alliance of Patient's Organizations, which allow people affected by Chagas disease to obtain representation in the WHO assembly

-Participating as a panelist in a WHO webinar about the role disability, stigma, and mental health play in achieving the Neglected Tropical Disease road map targets

-leading the VI Assembly of FINDECHAGAS in April 2022

LASOCHA has also been very active in advocacy directed to the medical community. Through Grand Rounds presentations, other provider education presentations, and contributions to the medical literature, Dr. Marcus and LASOCHA staff have worked to help providers understand how to identify and treat Chagas disease.

We've also provided commentary in local and national news media to help raise awareness about Chagas disease, and provided educational events to the community to raise awareness.

### Community Partners

Bolivian Consulate Guatemalan Consulate Tu Familia Clinic Mercy Clinic Dr. Robert Gilman (JHU)





# 2013-2023 Impact

Chagas Tests	ECGs/ Echos	LASOCHA Followup Clinic Patients
2400+	~240	127
Patients referred to NIH	Grand Rounds Talks	Publication Contributions
18	22	26

Other US/ International Provider Awareness Talks

25/4

# 2023 Impact

Chagas Tests	ECGs/ Echos	LASOCHA Followup Clinic Patients
53/~700 independently/with INOVA ICC-W clinic	28/24	28
	Grand Rounds Talks	Publication Contributions
	4	2

#### Volunteer Hours

277/123 hea;thcare provider/general

## Our 2024 strategy

In the past, LASOCHA has mostly relied on small, one-time donations to cover most costs, and relied on donated rapid test kits from Inbios.

In order to achieve the goals that the organization has set for the coming year, greater community engagement and a larger donor base will both be needed. Also, while there are several small clinics being run on a regular basis, 2024 offers the chance to engage in larger education and testing events. This will be possible through coordination with local health and community organizations.

GOAL	DETAILS
Raise funds to cover costs of educational materials/test supplies/malpractice	LASOCHA will be embarking on its first large-scale fundraising effort in order to fund our expanding activies
Participate in and	We will be working to coordinate with local health
organize large scale	departments and other organizations to offer testing at
testing events (>50	various events. Also, if appropriate, we will also organize
participants)	our own events.
Participate in and	LASOCHA will also be working to coordinate with
organize large scale	providers, facilities, and organizations to offer
education events	educational events for both community members and
(>50 participants)	providers.

## We thank you for your ongoing support of LASOCHA.

#### Acknowledgements

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#### LASOCHA: Latin American

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