Scaling up Access to Chagas Disease

A Partnership Model for Access

Carolina Batista, MD – Geneva Health Forum, April 2016
Since 1999, from ideas to realization ...

1999
First meeting to describe the lack of R&D for neglected diseases
MSF commits the Nobel Peace Prize money to the DND Working Group
JAMA article: ‘Access to essential drugs in poor countries - a Lost Battle?’

July 2003
Creation of DNDi (7 founding members)

2007
First DNDi treatment registered...

2013
10 years of DNDi and 6 treatments made available

James Orbinski, ex-President, MSF Int, 1999
DNDi success is only possible through innovative partnerships

CRITERIA FOR SUCCESS
• Share the same vision
• Mutual understanding
• Involvement throughout the whole process
Chagas disease: An overview

- 6 million cases in Latin America
- Americas: vector transmission. Non-Endemic countries: migration
- Serious long-term complications in 1/3 of infected individuals
- Around 10,000 deaths/year
- Globally the economic burden is around U$ 1 billion
- Less than 1% of infected individuals has access to treatment!
Chagas disease epidemiological numbers

- Number of infected people: 5.7 million
- New cases per year: 38,500
- Population at risk of contracting the disease: 70 million
- Estimated number of infected women in childbearing age: 1.1 million
- Number of children born with the infection from mother-to-child transmission: 8,600
Chagas disease and the Cycle of Poverty

- Disease is both cause and consequence of poverty
- Affects the poorest of the poor
- Patients often live in remote areas
- Socioeconomic burden weighs on family and community
- Marginalized & voiceless patients
Chagas across the globe
Disease going beyond borders

Chagas Disease – Some Challenges

Limited political will

- Denial of Chagas as a public health problem and/or limited resources
- Unknown disease burden
- Invisible “population”, no political voice

Limited tools

- Outdated drugs for treatment
- Long treatment with side-effects and unknown efficacy in chronic cases
- Erratic supply of treatment
- Pediatric formulation only developed recently
- Current diagnostic tools not totally adapted to field realities where access to laboratory is scarce
What do we need for an effective Chagas program?

- Proximity of care to the patients
- Political decision and leadership
- Supervision and Monitoring
- HR Capacity – continued formation

CATALYST
Chagas Access Implementation Project: The Rationale

• Despite some advances in the Chagas landscape in the last years, with more political willingness and evidence around treatment of chronically infected patients, no significant changes in access occurred.

• Major Gaps still remain between the estimates of the number of people living with Chagas disease and those actually diagnosed and receiving treatment.
Chagas Access Implementation Project:

Objective: Demonstrate the feasibility of implementing projects to scale up access in diverse contexts.

- Contribute to the definition of Access models that are applicable to each one of the pilot countries/programs
- Support countries/programs to develop context specific implementation strategies
- Catalyze existing local capacities and translate regional expertise into hands-on operational activities.
- Demonstrate that DNDi partnership model for R&D is also applicable to Access initiatives
Chagas Access Implementation Project: **Selected Pilot Countries/Regions**

- USA
- Mexico
- Colombia
  - Brazil
  - Gran Chaco
The goal of the working group is to mobilize and connect experts on Chagas to advise the Operational Implementation projects and enable policy change for:

• Diagnostics
• Treatment
• Health Economics
• Implementation
• Operational Research
• Advocacy

Members include experts from Argentina, Chile, Brazil and Spain.

The Chagas Consultative Group will ensure that the right questions are asked along the process - from planning to implementation and monitoring its impact.
Colombia: the first pilot country

Some factors & favorable contexts

1. Recent certificate of elimination of Onchocerciasis;
2. Strong social and political movement for access to medicines;
3. Willingness to address issues related to the peace process, such as diseases that primarily affect the population living in areas affected by conflict
Access Plan for Chagas in Colombia: DNDi initial approach for access

Results in 2015:

- Colombian Access Seminar
- Access support team operating in Colombia
- Elaboration of the RoadMap for Chagas
- Evaluation of endemic municipalities to select pilot projects
- Development of Diagnostic Validation Protocol
- Pilot Project proposal
Colombia – Main Outcomes

“Operational Approach”
- Implementation of the Chagas Access Roadmap agreed with the MoH
  - HR availability
  - Training
  - Drug supply/management

Diagnostic Validation Protocol
- Collaboration DNDi-MoH to review national Chagas Protocol

Municipalities selected for pilot project: Mogotes (Santander), San Gil (Santander), Soatá (Boyaca) and Tamara (Casanare).
Preliminary results: Colombia

• Together with the Ministry of Health and local organizations, DNDi conducted a seminar in April 2015, resulting in clear recommendations and agreed commitments.

• The project assisted the development of a comprehensive roadmap for Chagas. The MoH recognized Chagas as a priority disease and provided the political support for the activities.

• DNDi and local stakeholders will work together to demonstrate the feasibility of scaling up access to diagnosis and treatment for Chagas in those areas.

The objective is to evaluate which models are adapted to each context, in order to be replicated in similar settings and improve overall access. Strategies should be developed with the engagement and contribution of all those involved, especially the affected populations.
US Access Implementation Project

Objectives

• Identify and address barriers to access diagnosis and treatment for Chagas patients in the U.S.

• Explore the feasibility of scaling up diagnosis and treatment for Chagas patients

• Support existing treatment providers to document and expand their programs. (Starting with the Chagas Disease Center of Excellence at Olive View-UCLA Medical Center as pilot site).
Mexico Implementation Project
Short term approach

2016-17

Objective
- Lobby government to create in-roads for broader program
- Focus on existing identified patient areas and blood banks (expand to other states outside DF)
- Raise awareness of congenital Chagas

Activities
- Work with MoH and other partners to understand burden of disease, continue to meet with key stakeholders in-country
- Potentially examine blood bank samples for confirmation
- Assess costs associated with treatment and diagnosis timing
- Link stakeholders with online courses
Give neglected patients a voice. They exist and must be heard.

Thank you.
THANK YOU TO ALL OUR PARTNERS & DONORS