Scaling up Access to Care for People with Chagas Disease: Lessons Learned in Endemic and Non Endemic Countries

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DNDi success is only possible through innovative partnerships

Over 160 partnerships worldwide

CRITERIA FOR SUCCESS
- Share the same vision
- Mutual understanding
- Involvement throughout the whole process

Universities & Research Institutes
- PDPs
- Int. Org. & NGOs
- Pharmaceutical companies
- Biotechs
- CROs
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 Access Implementation Project: Rationale

- Despite recent advances in the Chagas landscape (increasing political resolve, growing scientific evidence, inter institutional collaboration) *no significant improvement in access has occurred.*

- Major Gaps still remain between estimates of the number of people living with Chagas disease and those actually diagnosed and receiving treatment.
  - Over 99% of Chagas disease patients worldwide are undiagnosed
Objective: Demonstrate the *feasibility* of implementing projects to *scale up access* in diverse contexts.

Develop access models tailored to the pilot regions/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 elements of the DNDi partnership model for R&D are also applicable to access initiatives, while developing new components/strategies to meet the particular changes of access programs.

Generate and create evidence related to implementation and access programs.
Chagas Access Implementation Project: Selected Pilot Countries/Regions
Consultative Group for Chagas Access Projects

The goal of the working group is to mobilize and connect experts on Chagas to advise on implementation projects and enable policy change for:

- Diagnostics
- Treatment
- Health Economics
- Implementation
- Operational Research
- Advocacy & Communications
- IEC
- Set up tools to measure the impact of program

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

Mission/vision: The Chagas Consultative Group will ensure that the right questions are asked during the process—from planning to implementation and monitoring of impacts.
Colombia: the first pilot country

Precursors to implementation:

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 the conflict.
### Principal Barriers to Access and Treatment for Chagas Disease in Colombia

#### Diagnostic
- Long delays for diagnostic confirmation
- Lack of risk-based screening tool
- Lack of supplies and equipment
- Not available in primary care
- Delays in sending samples to regional or national labs
- No screening in prenatal care; low coverage in endemic areas

#### Medication
- Delays in importation
- Delays in distribution from national to regional level
- Delays in distribution from regional to municipal level
- Lack of accurate estimates
- Irregular supply

#### Treatment
- Distance between rural patients and health centers
- Numerous patient visits required
- Low awareness of CD among physicians and patients
- Bureaucratic delays in authorizing treatment
- Side effects from medication

#### Systemic
- Lack of goals and measurement of treatment coverage
- Clinical guidelines not widely distributed
- Varying guidelines for CD among insurers
- Lack of clearly defined targets for diagnosis and treatment

#### Effect:
- 60% of positive screening tests don’t receive confirmatory test
- 1.2% of at-risk population screened
- 0.3-0.4% of estimated cases have been treated

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1. Marchiol et al. 2016, unpublished manuscript
2. Cucunubâ et al. 2016, publication pending
Colombia 2015 Seminar: Towards the Elimination of Barriers to Access and Treatment for Chagas Disease

• Creation of Patient-Centered Roadmap
• Update of official Chagas treatment guidelines
• Simplify diagnosis and move to the primary care level
• Creation of a national entity to manage critical drugs/supplies
• Ramp up Chagas disease training/education of healthcare personnel
• Empower communities to carry out diagnosis and treatment
• Registration of antitrypanosomal drugs
• MoH recognized Chagas as an important public health problem

Bogotá, April 2015

Organizers
• Colombian Ministry of Health and Social Protection
  • National Institute of Health
  • Chagas Network
  • Drugs for Neglected Diseases initiative (DNDi)

Participants
• Patient groups
• Chagas experts
• Public health officials
Access Plan for Chagas in Colombia: DNDi initial approach

Results in 2015:

- Access Seminar – April
- Access support team operating in Colombia
- Elaboration of a Patient-Centered Roadmap for Chagas
- Evaluation of endemic municipalities for inclusion in pilot projects
- Development of a simplified diagnostic protocol
- Pilot project proposal – 4 municipalities
The Patient-Centered Roadmap for Chagas Disease

- Greatly simplifies diagnosis and treatment process
- Increases role of primary care
- Outlines steps for diagnosis, etiological treatment, management of side effects, and care of chronic complications
Anticipated Outcomes - Colombia

• Increased coverage of the at-risk population
• More patients diagnosed and treated
• Decrease of the economic and social cost of the disease
• Increased collaborative efforts toward the elimination of Chagas disease as a public health problem
• Capacity building of local health workers
• Increased public awareness towards the disease
Next Steps

• Gather data on pilot program, 2016-2017
• Evaluate the impact of the pilot program in Colombia; determine what works and what to refine
• Apply lessons learned from the pilot programs and national efforts to increase treatment access in Colombia & other countries

Give neglected patients a voice. They exist and must be heard.

Thank you.