

## Chagas disease: Many more stories to tell A dialogue with journalists

Tuesday 13 April 2021

### Executive Summary

#### 1. Objective

Raise awareness among journalists in the Americas regarding the need to report more on Chagas disease; and advocate for its importance on the agenda of the communications media.

#### 2. Speakers

##### Introduction

- **Luis Gerardo Castellanos**, Pan American Health Organization.
- **Chagas disease: from Americas to the World.**  
**Roberto Salvatella**, Pan American Health Organization.

##### Analysis and discussion

- **Why Chagas is not in the media agenda.** **Sebastián Oliel**, Pan American Health Organization.
- **Marcela Dobarro**, Drugs for Neglected Diseases Initiative.
- **How to get in the front page of a newspaper with a little-known topic such as Chagas disease** **Daisy Hernández**, journalist; author of *The Kissing Bug* and professor at Miami University, Ohio.
- **Documenting Chagas disease stories; from rural to urban areas.** **Ana Ferreira**, photographer and documentary creator.
- **Launch of a journalistic contest:** **Carlos Espinal**, Florida International University.

##### Closing remarks

- **Javier Sancho**, Chagas Coalition.

#### 3. Background

##### Roberto Salvatella

- ✓ Chagas disease is a zoonotic disease caused by the *Trypanosoma cruzi* protozoan, which circulates among hematophagous insects of the Triatominae subfamily (commonly known as “kissing bugs” or “conenose bugs”) and in some 150 mammal species, including human beings.

- ✓ The main modes of transmission of *T. cruzi* are vectorial, congenital, via transfusion, and through contaminated food. Transplants of certain organs and laboratory accidents are other modes of transmission.
- ✓ The highest prevalence of the disease was in the 1950s, followed by a decline facilitated by: (a) improving living conditions; (b) rural depopulation; and (c) the start of national programs of vector control.
- ✓ The disease has moved from the rural areas into suburban and urban areas in the Americas, both on the mainland and on islands.
- ✓ Medical consultation is indicated when a person: (a) has lived in an endemic area (i.e., an area with insect vectors); (b) received a blood transfusion prior to the 1990s; or (c) has a mother or grandmother meeting those criteria.

Current estimated statistics on the disease indicate:

6 million people infected
30,000 new vector-transmitted cases a year
8,000 new congenital cases a year
12,000 deaths a year
0.2% prevalence among blood bank donors
17 countries have managed to interrupt the transmission of triatomines throughout their territory or in a level-1 area.
Universal screening of donors is in place in 21 endemic countries.
Only 1% of infected people are adequately diagnosed and treated, due to the disease's lack of clinical signs or to ambiguous symptoms.

**Luis Gerardo Castellanos**

- ✓ America is the only region where the disease is transmitted by insect vector. Thanks to the joint effort of the Pan American Health Organization (PAHO) and its member countries, prevalence has dropped from 200 million people at risk of infection to 65 million currently. However, the persistence of the disease in the Region and its spread beyond the Americas through other modes of transmission are reasons for concern.
- ✓ PAHO has been working to combat the disease for 30 years.
- ✓ Because we have come to fully understand the importance of mother-to-child transmission, over the last five years PAHO and its member countries have been promoting the EMTCT Plus strategy, in which health services provide prenatal consultations for pregnant women that include comprehensive diagnosis and treatment of diseases that are transmitted from mother to child (HIV, hepatitis B, syphilis, and Chagas disease).

- ✓ PAHO provides countries with donated medicines to treat the disease in both pediatric patients and adults.

### **Sebastián Oliel**

- ✓ One of the indications of the general lack of attention to Chagas disease is the number of hits produced by a Google search. While dengue produces 6,220,000 hits and malaria 4,400,000, Chagas disease only produces 619,000.

### **Marcela Dobarro**

- ✓ There are three reasons for the absence of Chagas disease in the media:
  - a) Its relation to poverty. The largest affected group are low-income and rural people.
  - b) Its lack of newsworthiness: it does not fit the logic of the journalism market. The disease is far from the interest of its target audience.
  - c) Its complexity. Since it is not a disease that manifests itself immediately There is inadequate investment in the search for solutions.

### **Daisy Hernández**

- ✓ In her personal experience, media editors were successfully appealed by three strategies that involved emphasizing:
  - a) General novelty: the element of surprise due to the fact that the disease exists but people do not know about it.
  - b) Mother-to-child transmission. This topic has news' impact because it affects newborn children. The social inequality that fosters the disease. Most of those affected in non-endemic countries like the United States are migrants with barriers in terms of language, integration, and access to health care. In this regard, it is important to be very careful not to stigmatize these communities and suggest that "they are bringing the disease."

### **Ana Ferreira**

- ✓ The disease's complexity makes it difficult to represent visually: there are no physicians, no blood, and no deformities. This means the image must center on the person affected and the circumstances surrounding the person.
- ✓ Photography works as a mechanism for reflection and to drive change.

### **Carlos Espinal**

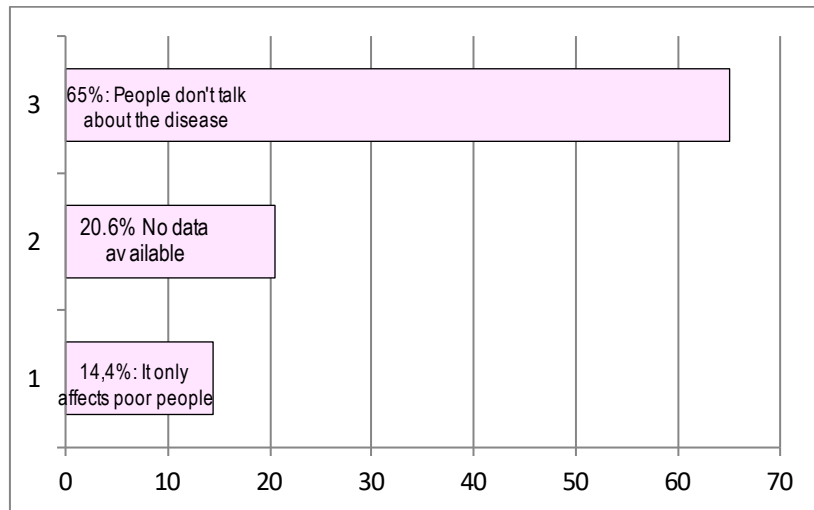
- ✓ Florida International University (FIU), along with its strategic partner, the Inter American Press Association, will issue during the next few months, the rules governing an award of US\$2,500 dollars for journalists who distinguish themselves by publishing on Chagas disease.

### **Contributions by participants**

The activity was organized to include a series of questions during the registration process, to which the 78 participants responded as follows:

### **What difficulties do you think are involved in communicating about Chagas disease?**

Responses fell into three categories:



**Could you share at least three reasons why coverage of Chagas disease in the media is not recurrent and ongoing?**

There was a broad spectrum of responses, including the following:

- There are not many cases, so it does not create concern. There is little information. The patients live in neglected areas.
- Other diseases took center stage: the pandemic began, and the focus changed. There are not enough journalists covering health topics.
- There is little information from the health authorities. COVID takes priority, and journalists don't have data about the disease and how many people is affected
- We do not have data. Knowledge and information are lacking. There is no budget to visit the affected areas
- Because it affects a universe of people not represented in the media. Because it is not of commercial interest.
- It is not popular among readers; there is too much news to cover, and a lack of specialized journalists.
- Because it is a little-known disease, because usually it remains outside the political agenda, and because not many people have the disease.
- Because the disease is not common in developed countries.
- Because there is little available information, but also because of a lack of interest on the part of editors and journalists.

**What do you think journalists and editors need in order to expand and improve coverage of Chagas disease in the media?**

The responses included:

- More training, and access to experts on the subject.
- More information on the part of health authorities.
- Budget, funding.
- More information, and greater knowledge about its impact and those who suffer from it.

- More time and understanding on the part of editors about the importance of communicating this information although it is not a trending topic.
- Whether they be physicians, experts, or patients who have had Chagas disease, it is very difficult to find people who want to talk about it or recognize it.
- Having in-depth knowledge about the disease and ways of contracting it, and improving access to such information for the public.
- More scientific knowledge, physicians who work on the issue, and interest in making the problems known.
- More information and new approaches and/or players, and advances in research on the disease.

**Javier Sancho**

- ✓ The meeting included a diverse group of professionals—not only journalists, but also communicators and creative people.
- ✓ Chagas disease was presented from nontraditional points of view.
- ✓ Greater political commitment is required to increase the prioritization of Chagas disease in the health agendas of the countries