Chagas disease: Breaking the silence

Explaining Chagas disease through the stories of patients in Latin America.

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Although Chagas disease was discovered more than a century ago, it remains a major public health challenge. Chagas disease affects approximately six million people, mainly in Latin America. Yet, less than 1% of affected individuals receive proper anti-parasitic treatment, and current tools to fight the disease are outdated and inadequate.

Like other neglected tropical diseases, Chagas disease often affects poor and marginalized communities.

The disease can be silent for decades until it may become fatal, leading to severe cardiovascular and gastrointestinal complications in up to 30% of patients - the second leading cause of chronic heart failure in Latin America.

Chagas disease has been coined a “silent and silenced disease,” not only because it progresses slowly, often without symptoms, but also because it affects deprived people who have no political voice or access to healthcare.

Yet, for the first time in history, the global community officially celebrated World Chagas Disease Day in April 2020 to raise awareness of people living with the disease, and the resources needed to move toward elimination.

- Chagas disease is often associated with poverty in rural areas and impoverished housing infested with triatomine bugs, known as “kissing bugs”.

- A doctor uses blood samples to perform rapid diagnostic tests for Chagas disease. The cell phones help to monitor the time needed to get the test results.

- Carmen Cecilia Acuña lives in a very old and deteriorated house in Soata, Colombia. Her house is made of mud and the roof is made of cane, a haven for triatomine bugs. When the municipality inspected her house, it found more than 60 triatomine bugs. They fumigated the house and tested the entire family. Carmen was the only one to be tested positive for Chagas disease.

- Six years ago, Blanca Mayoli Mene started losing her breath. The doctor told her it could be a respiratory infection or something in her breast. Two years ago, she was tested for Chagas disease and the result was positive. The disease is affecting her heart. Blanca has four children and only one was tested. She fears her other children may also be infected but because the health center is so far she has not been able to test her other children yet.
The Oswaldo Cruz Foundation, known as Fiocruz, is a scientific institution for research and development in biological sciences in Rio de Janeiro, Brazil. It is one of the world’s main public health research institutions. Novartis works with Fiocruz on research into neglected tropical diseases such as Chagas disease and leprosy.

Albert Einstein (center right) stands beside Carlos Chagas (center left). Chagas, a Brazilian scientist, hygienist and infectiologist (1879-1934), became aware of large blood-sucking insects, which lived in local dwellings and bit people during their sleep, usually in the face. When dissecting these bugs, Chagas found numerous trypanosomes in their hindgut. He named them Trypanosoma cruzi in honor of his mentor, the Brazilian physician and bacteriologist Oswaldo Cruz (1872-1917). Chagas described the new discovered infectious disease, its parasite, vector, host, clinical manifestation, and epidemiology.

Fredy Ernesto Montero, aged 70, is a retired TV actor. While donating blood when he was 19, he learned he had Chagas disease. He didn’t have any symptoms then and was referred to Fiocruz, where he has since been treated. Today, he suffers from hypertension and arrhythmias (an irregular rhythm of the heart) and his quality of life has been affected. Cardiac rehabilitation helps him to live better with the disease.

Nilda Ribeiro dos Santos, aged 65, exercises in the Chagas disease cardiac rehabilitation center in Rio de Janeiro. She had first symptoms of Chagas disease when she was still undiagnosed; today Nilda suffers from Chagas heart failure. Patients might have mild symptoms similar to a flu during the acute phase but could develop more severe manifestations of the disease later on. During the chronic phase, the disease mainly affects the heart, leading to cardiac disorders in up to 30% of patients. Chagas cardiomyopathy results in the majority of morbidity and mortality in Chagas disease patients.

Doctors Fernanda Sardinha (left) and Andrea Silvestre (right) lead a cardiac rehabilitation session with Edivan da Silva, aged 40. A few years ago, Edivan collapsed with a sustained ventricular tachycardia (fast abnormal heart rate) due to Chagas disease and now has an implantable cardiac defibrillator. The disease affected him deeply, he stopped going out, he can no longer run or play football and he had to quit his job as a carpenter.

Ricardo Pereira Lopes, aged 78, is the oldest patient in the Chagas disease cardiac rehabilitation center. He was 65 when he was diagnosed but he believes he was infected while he was growing up in Lassance, a rural area of Minas Gerais, in Brazil. Lassance is where Carlos Chagas discovered his first case of Chagas disease.

The Chagas disease cardiac rehabilitation center at the National Institute of Infectious diseases (INI) in Brazil is the world’s first cardiac rehabilitation unit for Chagas disease patients. From left to right: Aline Xavier (physiotherapist), Fernanda Bomfim (nursing technician), Ruth Camila (receptionist), Erica Maciel (nurse), Aline Nunes (physiotherapy student), Maria Aparecida da Silva (cleaner), Fernanda Sardinha (Chagas disease doctor), Rosane Dalila (nursing technician).
Chagas Disease

Novartis is committed to reimagining the fight against Chagas Disease and advocating for an integrated, end-to-end care approach.

Learn More

See how Chagas disease impacts the lives of people and their families. #NovartisGlobalHealth

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List of links present in page

- https://www.novartis.com/tags/category/access-healthcare
- https://www.novartis.com/diseases/chagas-disease