

# Newsletter

## Chagas Disease Clinical Research Platform

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## NEW PATHS TOWARD THE ELIMINATION OF CHAGAS DISEASE DURING THE COVID-19 PANDEMIC

The Chagas Disease Clinical Research Platform has been working since 2009 to overcome the research and development challenges related to this silent disease that kills up to 14,000 people every year around the world, especially in Latin America.

The Chagas Platform members are scientists, scholars, policymakers, representatives of national and international non-governmental organizations, leaders of patient associations and healthcare professionals – more than 150 institutions in total. This diverse network brings together more than 460 professionals from 23 endemic and non-endemic countries.

The COVID-19 pandemic, now widespread in the Americas, reinforces the importance of collaborative research, sharing scientific information at a global level and strengthening local structures to develop accessible treatments

for the populations that are most impacted by the novel coronavirus, as well as by historically neglected diseases. The Chagas Disease Clinical Research Platform operates based on these concepts of flexibility and cooperation, promoting meetings, training, integration of ethical principles and standardization. The network also provides a virtual forum for technical discussions and exchange of experience, seeking to optimize research resources and avoid duplication of efforts.

In one of the hardest years in history for global health, the growing number of research projects related to Chagas disease renews our hope in collaborative work that widens therapeutic possibilities and overcomes longstanding barriers that separate people affected by illness from a safe, effective and affordable drug.



## Summary

# Chagas Platform and the pandemic

Sergio Sosa-Estani, DNDi Latin America

We have written this text amidst one of the greatest pandemics humanity has ever faced. More than 15 million people around the world have been infected by the novel coronavirus, with around 650,000 deaths so far<sup>1</sup>. The Americas are of special concern: afflicted by countless endemic diseases, they have now become the epicenter of COVID-19. At the completion of this newsletter, the region had more than eight million cases of the illness, of which around 350,000 were fatal<sup>2</sup>.

There is still not enough scientific evidence on the SARS-CoV-2 virus propagation capability, nor especially on its association with preexisting infections. While information is limited, it is known that people with heart conditions – which are common among Chagas disease patients – are at greater risk of developing more severe symptoms of COVID-19. Pregnant and puerperal women also deserve attention due to their weakened immune system, especially when it may have been further impacted by other infectious diseases.

In this year's newsletter, the Chagas Platform reaffirms the importance of preventing the congenital transmission of the disease by presenting clinical studies on the efficacy and safety of shorter treatments with benznidazole for women of childbearing age. Such therapeutic alternatives may help reduce the transmission of the disease from mother to child during pregnancy or at childbirth.

The section on access has an article from U.S. researcher Eileen Stillwaggon\*, demonstrating that the preventive treatment of women with Chagas disease can not only prevent the complications of the chronic stage of the disease, but also save the country's healthcare system more than US\$ 400 million. Other contributions to this section include diagnostic strategies, studies of parasitic factors, and collaborations for the standardization of clinical data on Chagas.

A final note: Unitaïd has released a call for proposals aiming at eliminating congenital transmission of Chagas disease in endemic countries in Latin America. This is the first time that the organization – known for its work to provide access to medicines for HIV/Aids, tuberculosis and malaria – has issued a call related exclusively to Chagas. It is a significant step that may encourage other global health institutions to support the development of new diagnostic tools and effective, safe, and affordable treatments of Chagas disease. ◦

<sup>1</sup><https://coronavirus.jhu.edu/map.html> <sup>2</sup><https://ais.paho.org/hip/viz/COVID19Table.asp>

\*With sadness, the Chagas Disease Clinical Research Platform learned of the passing of Eileen Stillwaggon after a long battle with cancer. Among the two books and 31 peer-reviewed articles she published, her work on the economic benefit of maternal and infant screening for Chagas disease in the United States (USA) is an essential piece supporting expanded access to care for affected people. Eileen was a professor at Gettysburg College and the National School of Tropical Medicine at Baylor College of Medicine (USA). She is survived by her husband Larry, three children, two stepchildren, and seven grandchildren.

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# Chagas disease and the market

Andrea Marchiol, Access Manager, DNDi Latin America

Clearly, Chagas disease (CD) and the market are at odds with each other. Neglected diseases do not attract attention, they affect vulnerable populations and are hard to mitigate, and so the market sees them from a distance. Given this very real and unfavorable outlook, it becomes necessary to create convincing strategies that raise the awareness of healthcare systems about how diagnosis and treatment can be significantly relevant from a technical and humane perspective, as well as convenient from the economic aspect.

So, given the need for a paradigm shift regarding CD patient care, and as the essential process for eliminating Chagas from being a public healthcare problem, DNDi, the Colombian Ministry of Health, its National Institute of Health and departmental secretariats launched an initiative to increase access to diagnosis and treatment of Chagas disease. The Comprehensive Care Roadmap was launched in 2015 in six endemic municipalities in Colombia. Currently, due to satisfactory results regarding improved access to diagnosis and treatment in these pilot municipalities, the departments have been working to expand the roadmap to other municipalities. This situation reveals that it is not only possible to diagnose and treat CD at

the first level of care, but that increasing coverage and extending care from the health system itself is feasible as well.

From the economic standpoint, we have also found that timely diagnosis and treatment hold financial advantages for the healthcare system compared to treating cardiovascular complications caused by CD ten years down the line. An economic analysis and advantage study on the implementation of the Comprehensive Care Roadmap in the six priority municipalities in the country, carried out by DNDi, revealed that the cost of diagnosis and treatment with an antiparasitic efficacy of 80% in an area with 10% seroprevalence (the scenario of the pilot municipalities) could save the healthcare system 4.2 million USD over ten years. Colombia has a total of 126 endemic municipalities that are in the plan for interruption of household transmission of CD.

Governments must participate via their healthcare systems to address the impact on populations affected by neglected diseases. That is why it is our duty to advocate and pressure them to provide a timely response. Otherwise the market will continue to see neglected diseases from a distance. ◦

## Health system savings with the implementation of diagnosis and treatment for CD in endemic municipalities in Colombia



**ERRATA:** This is a revised version of an article that first appeared in August 27, 2020. After a reanalysis of results considering new information, the conclusions changed somewhat. The updated results are presented here.

## Chagas and vertical transmission: the ETMI+ strategy

Marcelo Abril, Mundo Sano

In order to promote the ETMI-Plus strategy of the Pan American Health Organization, Mundo Sano launched, in 2018, two projects: one in Almirante Brown, a municipality near the city of Buenos Aires, and another in the triple frontier region shared by Argentina, Paraguay and Bolivia, in the heart of the South American Chaco.

In Almirante Brown we worked with municipal health authorities to strengthen the capacity of health teams at the first, second and third levels of care, aiming to guarantee access to the diagnosis and treatment of HIV, syphilis, hepatitis B and Chagas disease to all pregnant women in municipal health centers. Furthermore, we promoted the strategy in hospitals dependent on the province of Buenos Aires within the coverage area, so that pregnancies are monitored, newborns are diagnosed and treated for these diseases and mothers can have follow-up appointments after childbirth.

In one and a half years, this project reached over 3500 pregnant women and allowed us to increase our knowledge about these diseases.

In June 2018, a project with the same objectives was launched in the tri-border region between Argentina, Bolivia and Paraguay. Mundo Sano faced this challenge together with the ADeSaR Foundation and carried out coordination with the healthcare systems of the Argentinian province of Salta, Bolivia and Paraguay.

This is an isolated rural area, with very difficult access and limited healthcare services, where ethnic and cultural diversity is an essential part of the landscape.



In order to implement the ETMI-Plus strategy it was necessary to apply an intervention model with periodic intensive actions focusing on pregnant women and their newborns, while strengthening local healthcare sector capacities to make the project sustainable.

Eleven field operations have already been completed, reaching over 1000 pregnant women and around 600 newborns.

While project implementation in Almirante Brown allowed for the detection of a high rate of transmission for congenital syphilis and, subsequently, its reduction by 56%, the high prevalence of Chagas disease among pregnant women stood out in the Chaco area. Thanks to follow-up appointments for each of the women, it was possible, during the first 18 months of work, to diagnose five cases of congenital Chagas, which are guaranteed treatment, as well as eight other previous children of the women who were identified.

Providing the best care for pregnant women and their children, no matter where they are, has been and still is the motivation behind Mundo Sano on its path to ensure that there are "No Babies with Chagas". ◦

## Development of a paediatric formulation of nifurtimox: the Chico-Secure study

Jaime Altcheh, MD, PhD, Parasitología-Chagas, Hospital de Niños Ricardo Gutiérrez, Buenos Aires, Argentina. Collaborating center in Paediatric Chagas disease PAHO/WHO



The efficacy and safety of benznidazole and nifurtimox for the treatment of Chagas disease in children is supported by a significant body of evidence. However, few controlled clinical studies have been conducted in the paediatric population. In recent years, a study at the Ricardo Gutiérrez Children's Hospital laid the groundwork for the development of a paediatric formulation of benznidazole.

Nifurtimox was only available as a 120 mg tablet. The availability of only one dose strength required the tablets to be broken, complicating the administration and proper dosage of the drug, especially in young children. The pharmaceutical company Bayer started the development of a 30 mg dividable and dispersible tablet formulation and planned a trial program to register nifurtimox in the United States. Thus a Phase 3 clinical trial was initiated, requiring the development of patient recruitment capacity within the context of a multicenter clinical trial following the highest quality standards of care, clinical practice and research (NCT02625974).

From the R. Gutiérrez Children's Hospital in Buenos Aires and PAHO/WHO collaborating center in paediatric Chagas disease, the multicenter network for the study of paediatric Chagas disease, PEDChagas, was organized with Bayer's

support. The network is composed of a group of experts in paediatrics, pharmacology and clinical research with interest in Chagas disease. Fifteen centers in Argentina, three in Bolivia and four in Colombia joined PEDChagas. In the Phase 3 trial, a total of 330 children from 0 to 18 years old were enrolled and followed up for one year. The efficacy and safety of 30 vs 60 days of nifurtimox treatment were compared. As the clinical endpoint, the therapeutic response was evaluated by measuring the reduction of optical density by conventional serology and parasitemia by direct methods and *T. cruzi* PCR. An excellent therapeutic response was observed, with a seroreduction/seroconversion rate higher than the historical published placebo control and a negativization via parasitological methods higher than 96% at one year after end of treatment. Nifurtimox was well tolerated, with a rate of drug-related adverse events of 27.9%, not exceeding that previously reported in the literature.

The study is currently continuing with a 4-year post-treatment follow-up that will allow the study's efficacy and safety data to be reinforced. The development of a new paediatric formulation will improve dosing accuracy, safety and adherence to treatment in children of all age groups, especially patients under 2 years of age. ◦



Mundo Sano

No Babies with Chagas

[www.youtube.com/watch?v=RnuHnaMktM8](https://www.youtube.com/watch?v=RnuHnaMktM8)

To learn more about the Triple Frontier Project

[www.youtube.com/watch?v=yK9mclXlzJ8](https://www.youtube.com/watch?v=yK9mclXlzJ8)



## Short benznidazole treatment before pregnancy: the BETTY trial

Maria Luisa Cafferata, (IECS)\* and Pierre Buekens, (Tulane University)\*\*

Retrospective studies suggest that women treated at a young age do not transmit *Trypanosoma cruzi* when pregnant later in life. The current treatment with benznidazole reduces the parasitic load before pregnancy, but side effects limit its use. A shorter, low-dose benznidazole treatment might reduce the side effects and increase compliance, but its efficacy to reduce *T. cruzi* parasitic load has not yet been established.

The BETTY trial is testing a new short and low-dose benznidazole treatment to prevent congenital transmission of *Trypanosoma cruzi*. The trial enrolls women in reproductive age during the postpartum period to reduce the parasitic load before their next pregnancy. The trial is funded by the US National Institutes of Health (NIH R01HD095857) and registered in ClinicalTrials.gov (Identifier: NCT03672487). DNDi is providing technical and scientific advice.

BETTY is a double-blind, non-inferiority, randomized controlled trial comparing a shorter 30-day treatment with 150mg/day of benznidazole (30d/150mg) vs a standard 60-day treatment with 300 mg/day of benznidazole (60d/300mg). We are recruiting previously untreated *T. cruzi* seropositive women with a live birth during the postpartum period in Argentina, randomizing them at six months postpartum (to avoid potential side effects that may interfere with breastfeeding), and following up with them for 10 months post-treatment. Our first aim is to measure the effect of the preconceptional treatment with benznidazole 30d/150mg compared to 60d/300mg on the parasitic load, measured by the frequency of positive PCR (primary outcome) and by real-time quantitative PCR, immediately and

10 months after treatment. Our second aim is to compare the frequency of adverse events leading to treatment interruption. We plan to enroll 600 *T. cruzi* seropositive women in four public health facilities in 24 months, in three endemic provinces in northern Argentina (Chaco, Santiago del Estero, and Tucumán).

We identify seropositive mothers through at least one positive or indeterminate test. If the mother is eligible and consents, we collect maternal blood to verify *T. cruzi* seropositivity via an additional IHA and ELISA. Mothers are confirmed as seropositive if they are positive for both tests.

Seropositive mothers are visited at home 4-8 weeks postpartum and are invited to participate in the trial, pending informed consent. Before treatment, we perform EKG, echocardiogram, and chest X-ray. We also perform a complete blood count (CBC), kidney function tests and liver function tests before treatment and at least once during treatment. During treatment, contraceptive methods are provided. We monitor participants weekly for side effects and adherence. We collect dried blood spots to measure benznidazole blood levels during the first 30 days of treatment. We collect blood for *T. cruzi* PCR immediately before treatment, at end of treatment (30 and 60 days), and 10 months after treatment.

We hope that the BETTY results help to facilitate the treatment of *T. cruzi* infected women of reproductive age. If treatment with benznidazole 30d/150mg is not inferior to the 60d/300mg course and causes fewer side effects, it would be easier to treat *T. cruzi* infection before pregnancy. ◦

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## Chagas Express XXI:

active search for chronic cases mobilizes the population to talk about Chagas in Brazilian endemic areas

Tania C. Araujo-Jorge, Erik J. Costa, Nancy D. Costa, Roberto R Ferreira, Jonathan G. Oliveira, Thallyta M. Vieira and Luciana R. Garzoni

The decision to make the notification of chronic Chagas disease mandatory in Brazil is a major victory for the movement led by associations of people affected by the disease. As a consequence of this outcome, we now have the challenge of locating and making chronic patients visible, to guarantee comprehensive care and the right to health.

The Chagas Express XXI, a social technology for the active search of people with Chagas disease and health promotion at the local level, was first tested in Brazil in July 2019. It was developed by researchers and students at Fiocruz and by affected people who work with the Rio Chagas Association.

The Chagas Express XXI provides fun, interactive activities on Chagas disease organized in an exhibition in the form of an imaginary train, alluding to the train car where Carlos Chagas discovered *T. cruzi* in 1909. The technology aims to: (1) promote health with joy; (2) encourage the creation of new associations of people affected by Chagas disease, amplifying their voice and visibility; (3) publicize the new Brazilian Clinical Protocol and Therapeutic Guidelines for Chagas disease (PCDT-Chagas), encouraging access to diagnosis; (4) recreate Chagas' discovery with residents of endemic areas; (5) resume the campaign for treatment and disseminate therapeutic innovations; (6) actively search for chronic cases, refer them to primary care and support the organization of local lines of care; and (7) bring hope for people affected by chronic Chagas disease,

based on their own voices and on the dissemination of innovations for facing the disease.

The Chagas Express XXI is configured in the format of a train station as entrance and exit, followed by a set of six "cars" forming an imaginary train with several fun activities. Identified at the station, participants are introduced to the exhibition and follow the thematic cars: (1) ASSOCIATIONS: to get to know FINDECHAGAS and its associations, their struggle and organization; (2) INNOVATIONS & LABORATORY: to learn about the tools for the diagnosis and treatment of Chagas disease; (3) DISCOVERIES & PLAY: to enter a giant blood vessel and discover biopsychosocial determinants of the disease; (4) HOME & ENVIRONMENT: to learn about the risks in different environments, the diversity of transmitting insects and reservoir animals, and the necessary cautions in and around the home, discovering through art the socio-environmental determinants of the disease; (5) WELL-BEING: with self-massage, music, dance, aromatherapy and other integrative health practices to exercise self-care; (6) YOUR VOICE: to interact with the team, talk about your experience at Express and get involved. More details: @expressoChagas.

The social debt with Chagas disease patients needs to be redeemed through a strong partnership between public entities and organized civil society. The educational material developed for the Chagas Express XXI is available for free to be replicated and/or adapted. ◦





## Assessing *Trypanosoma cruzi* phylogeography to improve serological diagnosis of maternal and congenital infection

Claudia Herrera and Eric Dumonteil, Department of Tropical Medicine School of Public Health and Tropical Medicine Tulane University, New Orleans, USA

The development of new serological tests for the diagnosis of *T. cruzi* infection, especially in pregnant women, is currently a major critical need and research priority to overcome the limitations of current tests. In Latin America congenital transmission occurs in an average of 5% of approximately 1 million infected women, and in the United States it is estimated that 63–315 babies acquire *T. cruzi* infection congenitally every year, but most infections go undetected and untreated. Babies can be treated and cured if there is an early diagnosis of the disease.

The diagnosis of chronic infection with *T. cruzi*, including maternal and congenital cases, relies principally on serological tests to detect antibodies against the parasite, but there is no gold standard. Thus, the World Health Organization recommends the use of at least two tests for a reliable diagnosis, and additional tests need to be performed in case of discordance between the first two. Cases of individuals who are seronegative with conventional tests, but seropositive with alternative tests or parasite-positive have been reported. This situation makes the diagnosis of *T. cruzi* infection challenging and costly, and can delay medical care of congenital transmission cases. Although significant improvements have been achieved in recent years, the specificity and sensitivity of available tests remain somewhat overestimated. Part of the discordances may be attributed to the large genetic and antigenic diversity of *T. cruzi*, which has been divided into seven discrete typing units (DTUs), TcI–TcVI and Tcbat. Indeed, a major weakness is

that current serological tests are based on a very limited set of parasite antigens, mostly from strains originating in Brazil or Argentina, and do not reflect the entire range of diversity of parasite strains and DTUs across the continent.

Also problematic is our insufficient understanding of the phylogeography of *T. cruzi* DTUs, their possible relationship with congenital transmission, the clinical features of the disease and patient prognosis, and drug resistance. Recent studies are challenging the current hypotheses on DTU geographic distribution and biological properties. Thus, the identification of *T. cruzi* DTUs from infected mothers and congenital cases has become a critical point to understand the epidemiology of congenital Chagas disease and to improve prevention and patient care. Molecular DTU identification has been classically based on ribosomal genes due to their extensive use in phylogenetic studies, and more recently on multilocus sequence typing (MLST) using sequences from single-copy genes. However, the sensitivity of these methods remains limited for a successful genotyping in patient samples, mostly due to the difficulty of detecting low amounts of parasite DNA in small volumes of blood. New methods based on multiplex real-time PCR have been proposed to simplify the genotyping process, but they are not more sensitive than conventional PCR. A next-generation sequencing (NGS) and metabarcoding approach has been tested to assess the multiclonality of infection in clinical samples, which may be promising. ◦

## Chagas disease in the US: saving lives and money

Eileen Stillwaggon, National School of Tropical Medicine, Baylor College of Medicine, Houston, TX, USA

Lifetime societal savings, implementation costs, benefit-cost ratio		
Universal Chagas screening, 4 million US births per year - Maternal prevalence, 0.16%		
Per birth-year cohort	\$ 60 screening cost per birth	\$ 8 screening cost per birth
Savings	\$ 420 million	\$ 632 million
Implementation costs	\$ 278.6 million	\$ 70.6 million
<b>Benefit-cost ratio</b>	<b>1.5</b>	<b>8.9</b>

Chagas disease causes serious, even fatal, cardiac and gastrointestinal injury in 30% of the persons infected. About 5.7 million people in Latin America are infected, and 400,000 Latin Americans abroad. Due to vector control in endemic areas and blood screening, congenital transmissions comprise an increasing share (1/4) of new cases, with about 9,000 infections per year in Latin America and several hundred in the US and Europe. Benznidazole is highly effective in treating infants and effective in treating adolescents and young adults. Treating women before pregnancy reduces the risk of congenital transmission, and early diagnosis and treatment can prevent severe complications of the chronic stage of Chagas. In the US, pregnant women are the best access point for diagnosing and treating entire families. Hispanics have the lowest access to regular health care, and many face the risk of arbitrary arrest by seeking care. Delivery is the most likely time for contact with the healthcare system because 99.95% of Hispanic women give birth in hospital.

Pregnant women and newborns are already screened for a wide variety of genetic conditions and congenitally transmitted diseases, including syphilis, HIV, and in some states toxoplasmosis, rubella, and cytomegalovirus. Adding a Chagas screening during pregnancy or at delivery would increase

the cost by a trivial amount. Screening and treatment costs are much lower than the lifetime costs of undiagnosed or late-diagnosed Chagas, including costs of care and loss of productivity from illness and premature mortality. Even as a standalone test, at current screening costs, universal screening could result in more than \$400 million in lifetime savings per birth-year cohort (all US births in one year). The estimated prevalence of Chagas in US women of childbearing age is 0.16%, and mother-to-child transmission is estimated to be 1–5%. A congenital Chagas screening program in the US would be cost-saving for all levels of maternal prevalence above 0.06% and all rates of congenital transmission greater than 0.001% compared to no screening program.

New point-of-care tests reduce screening costs from \$60 to \$8 per birth, at which cost universal screening is cost-saving for prevalence as low as 0.008% of pregnant women. New diagnostics are being introduced to test for multiple conditions with one blood draw, reducing costs even further. The implementation of universal screening with a point-of-care test would cost \$70.6 million. The lifetime benefit of reduced morbidity and mortality for mothers and infants is almost 9 times the screening cost for each birth-year cohort (see table). Reaching additional family members multiplies those benefits. ◦

## Parasitic factors involved in congenital Chagas disease

Alejandro Gabriel Schijman, PhD, Laboratorio de Biología Molecular de la Enfermedad de Chagas, INGEBI - CONICET, Argentina

Transmission of *T. cruzi* infection from an infected mother to her fetus, causative of congenital Chagas disease (CoCD), represents around 25% of new cases of Chagas disease per year. Roughly 5% of chronically infected women transmit the parasite to their offspring; thus, approximately 9000 infants with CoCD are born in Latin America every year. Since CoCD can be repeated at each pregnancy and pass from one generation to another, it can perpetuate and expand CD in time. Most newborns with CoCD are asymptomatic at birth, making diagnosis highly unlikely without specific testing. A proportion of CoCD newborns display higher frequencies of low birth weight, prematurity, and low Apgar scores. Trypanocidal treatment in early life is highly successful, but if untreated, ≈30% progress to the life-threatening cardiac and/or digestive chronic stages of CD.

The transmission and severity of CoCD depend on complex interactions between the infecting parasite strains present in the maternal bloodstream with: (i) the maternal immune system, whose responses depend on genetic and environmental factors, (ii) the responses of the placenta, and (iii) the fetal immune system displaying responses that can be modulated by maternal and environmental factors, and its own genetic background.

To infect the fetus, the parasite present in maternal blood must cross the first placental barrier, the trophoblast in the intervillous space, to reach the fetal capillaries. This invasion of the placental tissue may be facilitated after week 20 of pregnancy

due to the physiological metabolic adaptation of the placenta. A higher infection capacity of certain *T. cruzi* strains to placental tissues has been described in murine experimental models, human placental explants and a placenta-derived epithelial cell line (BeWo), indicating a role of parasite genotype in tropism toward the placenta which might contribute to congenital transmission. In murine models, different *T. cruzi* strains provoke different profiles of placental gene expression in response to infection. Strains more able to survive in the deleterious placental environment could be more prone to cause CoCD. To date, all *T. cruzi* discrete typing units except Tc IV have been observed in CoCD human cases, with different geographical distributions, and recent investigations suggest that particular *T. cruzi* haplotypes are preferentially congenitally transmitted.

The strains' virulence and capacity to limit immune responses may create parasite-driven immune deficiency with increased parasitemia. The maternal parasite load slightly increases during the second and third trimesters of pregnancy, and pregnant women who transmit CoCD display higher parasitemia than those who do not. This points to a central role of parasite burden as a risk factor of CoCD. Etiological treatment of girls and women of reproductive age is thus a key strategy to decrease parasitemia and consequently the risk of CoCD transmission.

Questions regarding the role of parasite diversity, host genetics and immune responses deserve further investigation to shed light on the mechanisms leading to congenital transmission. ◦

## Chagas collaboration to aggregate and standardise data

Infectious Diseases Data Observatory (IDDO)

The Infectious Diseases Data Observatory (IDDO) and the Drugs for Neglected Diseases *initiative* (DND*i*) recently launched a new global Chagas scientific collaboration. The data platform will collate and standardise clinical data to accelerate better treatments for people worldwide with Chagas disease.

There is a wealth of clinical data on Chagas, but large-scale analyses have not been possible due to variations in the data or differing study designs. The new platform aims to address this by amalgamating and standardising available individual patient data (IPD) to allow for more statistically powerful, in-depth analyses. This will help produce a stronger evidence base to direct new strategies and treatments.

According to Professor Philippe Guérin, Director of IDDO, “Currently, large volumes of treatment data exist, but making comparisons of efficacy between drugs, regimens and regions is almost impossible from publications. This collaboration with DND*i* will improve outcomes for patients with Chagas by ensuring that all future scientific research is based on the most complete aggregation of the existing evidence.”

“This project is gathering key knowledge with partners in the scientific community around a common purpose to advance clinical research in a way that has never been done before,” says Dr Sergio Sosa-Estani, Head of the Chagas Clinical programme at DND*i*.

The Chagas Scientific Advisory Committee (SAC) recently met for the first time to shape the platform's key aims and objectives. Members of the committee come from across the Chagas research and clinical community and have expertise in clinical practice, drug and vaccine development, policy and global health advocacy. Countries represented include Argentina, Brazil, Colombia, the United States and Spain – encompassing endemic regions and areas such as North America where cases of the disease are increasing.

Dr María Jesús Pinazo, SAC member, said: “Through the Chagas platform, the key players that exist at the international level will have the opportunity to meet and align strategies to improve the control of Chagas at a global level. The prioritisation of actions can only be based on a critical reading of homogenised and updated data.”

“The research needs confronting Chagas are complex and bigger than any single player can address on their own,” explains Dr Sheba Meymandi, SAC Chair. “However, there is strength in numbers. By pooling information and resources, we can gain insights into some of the major questions confronting us today, and that will translate into better care for the patients we see.”

The platform will shortly be making its research agenda open to the community for feedback. The research agenda will set out and prioritise the key questions that can be addressed using a data platform. Anyone who is interested in contributing data can contact the team at [chagas@iddo.org](mailto:chagas@iddo.org). ◦

### Chagas disease:

[www.iddo.org/research-themes/chagas-disease](http://www.iddo.org/research-themes/chagas-disease)

### Sign-up for to receive news on the platform's progress.

[iddo.us2.list-manage.com/subscribe?u=fd49ccbd5a59ea957607de1&id=04f4ad3433](http://iddo.us2.list-manage.com/subscribe?u=fd49ccbd5a59ea957607de1&id=04f4ad3433)



# April 14<sup>th</sup>: World Chagas Disease Day

Elvira Idalia Hernández Cuevas, FINDECHAGAS

In May 2019, the World Health Organization designated a specific day to remember that Chagas disease is a very real, worldwide health problem, in response to a request by FINDECHAGAS and institutions dedicated to the investigation and care of Chagas disease, and with Dr. Pedro Albajar Viñas' invaluable support. For this reason, every April 14th, humanitarian associations of people affected by the disease throughout the world, who are part of FINDECHAGAS, will be able to say, "Look at us. Here we are, affected by Chagas."

Having a specific day raises a series of personal questions: Is it possible to change the way the disease and those affected by it are perceived, and to find the best way to care for them? Is it possible to guarantee the right to health? Many governments do not take the severity and consequences of this disease seriously, putting the health of working people at risk, and if these people are unable to work or happen to die they leave behind families with young children to fend for themselves. More comprehensive preventive and informative programs are an urgent need of the affected population or those at risk of contracting Chagas. Everyone hopes to see careful and consistent efforts by governments to reduce or eradicate this disease, to achieve key objectives in prevention, diagnosis, treatment and follow-up.

Someone with Chagas or who has a family member afflicted with the disease deals with uncertainty and worries on a daily basis, because they can never be sure that the illness is gone.

The doctor never discharges them or tells them when they will be cured. They don't choose to get infected. The person's life and that of their family instantly changes when they hear the words, "You have Chagas", "Your child was born with Chagas", "Your dearest family member has Chagas".

For women who transmit congenital Chagas to their newborns at birth, feelings of sadness, helplessness, guilt, and others are difficult to overcome and it may take a while for them to understand or at least treat this condition. It doesn't suffice to hear, "We will give the child medication and s/he will be fine" and other words that sound empty at that moment, because all we want is to save the life of the child we love. Many of us say, "I wish it had been me instead of my child."

As a mother it is difficult to have a child with Chagas disease, but it is even more difficult to have failed at preventing transmission in the first place. And whose obligation is it to prevent Chagas? Who has the necessary infrastructure to carry out prevention programs? Who is trained to make a timely diagnosis, treat, and follow-up the affected person? The healthcare sector of each and every government has the capacity and obligation to do so.

FINDECHAGAS is a non-profit organization in which people with big hearts provide support and information to those who request it. Let's raise awareness about the importance of Chagas disease. Support FINDECHAGAS by sharing the material that is published on our communication channels. ◦

## DNDi

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