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Newsletter

Chagas Disease Clinical
Research Platform



OPTIMIZING THE TOOLS TO IMPROVE THE REALITY OF PEOPLE AFFECTED BY CHAGAS DISEASE

The Chagas Disease Clinical Research Platform was launched in 2009 to address research gaps for this neglected disease which causes up to 14,000 deaths every year, mainly in Latin America. As with other neglected diseases, the resources available to advance research are often limited. Therefore, a space is needed which brings together different people so they can collectively identify barriers and strategies, and pool knowledge, expertise and resources toward common goals.

The Chagas Platform is first and foremost a network of people from throughout the world who share a commitment to improving the life of the people with Chagas disease while ensuring that the disease itself, and those affected by it, remain visible to the world. The Platform is a broad network that includes over 500 members from patient associations, representatives from governments, healthcare professionals, and experts in all aspects of Chagas disease, from drug discovery

to diagnostics, and from clinical research to the social sciences, representing over 150 organizations from 23 countries.

It is a time for reflection on the many lessons learned recently in global health – from unprecedented acceleration of drug development processes, to increased global awareness of the role of structural racism in health outcomes, to renewed understanding of the critical importance of international cooperation to overcome public health challenges. How can these lessons be applied to Chagas to help us achieve the ambitious goals put forth by the WHO to control the disease as a public health problem by 2030?

Progress is being made toward better diagnostic and therapeutic options, as well as for greater visibility for people with Chagas, but many difficult challenges remain. The Chagas Platform will continue to provide a space for interdisciplinary, international, multistakeholder cooperation. ○

Old Rockers Never Die: Benznidazole and Nifurtimox, and the Need to Optimize their Use

María-Jesús Pinazo, DND¹

Old rockers never die. This is what comes to my mind every time I look desperately at the therapeutic options we currently have for treating *T. cruzi* infection and for preventing the progression to Chagas disease for more than six million people who have this infection. These are people living in low- and middle-income countries in Latin America, whose disease burden is considerable for their development. The global costs are estimated to be \$7.2 billion a year, reaching \$189 billion over a lifespan.¹

Taking a very optimistic view, in about a decade we will have new generations of compounds for the effective and safe treatment of *T. cruzi* infections. During this time, we can advance research efforts on parasite-host interaction and apply the knowledge generated to develop better tools to evaluate new pharmacological proposals.

In the meantime, while we wait for results, we continue to rely only on our two old rockers: benznidazole and nifurtimox. Based on the results of clinical trials implemented in the last decade, we know the optimal efficacy of benznidazole. We also know the high rate of adverse effects associated with both benznidazole and nifurtimox in the standard regimens approved for use, which is a major drawback throughout the eight weeks of prescribed treatment. We are witnessing a 20% incompleteness rate of therapeutic regimens.

Aware of this drawback, the scientific community, which is joined by DND's Chagas Program team, is making great efforts to optimize the use of benznidazole and nifurtimox. There are currently some clinical trials at different phases (Phase IIa/IIb/III) in progress (Multibenz, TESEO, BETTY, NuestroBEN, and others) which have recently published results or are in the result analysis stage (BENDITA, Chicamocha), with structures that include different doses and times of use of both drugs.

While we wait for conclusive results that can improve the treatment options and lives of people at risk of suffering from Chagas disease, we must continue to generate evidence both for new uses of benznidazole and nifurtimox and for the identification and development of new therapeutic options. New hits will come. Meanwhile, with the two chords that we have... Long live rock'n'roll! ◊

¹Lee BY, Bacon KM, Bottazzi ME, Hotez PJ. Global economic burden of Chagas disease: a computational simulation model. *Lancet Infect Dis*. 2013 Apr;13(4):342-8. doi: 10.1016/S1473-3099(13)70002-1. Epub 2013 Feb 8. PMID: 23395248



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Implementation of Molecular Biology Techniques for Early Diagnosis of Congenital Syphilis and Chagas in the Context of PAHO/WHO's EMTCT PLUS Program - A Multicentric Study

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Currently available diagnostic tests for congenital Chagas and syphilis are deficient. Diagnosis of congenital Chagas is based on direct parasitological studies at birth, whose sensitivity varies in each site. If negative, a prolonged follow-up of the child is required until two serological tests are performed at 10 months of age, when maternal antibodies disappear. In the case of syphilis, there is no diagnostic method to identify *T. Pallidum*, and all children of mothers with re-active serology and inadequate treatment during pregnancy are assumed to be infected.

Since 2010, the Member States of the Pan American Health Organization (PAHO) have committed to promoting the elimination of mother-to-child transmission (EMTCT) of several infections, including congenital syphilis and Chagas. These commitments were renewed and expanded in 2016 with the approval of an Action Plan for 2016-2021 (EMTCT Plus), which seeks to ensure that these infections cease to constitute public health issues in the Americas. In this context, the Parasitology and Chagas Service of the

Ricardo Gutiérrez Children's Hospital in Buenos Aires is managing a prospective, multicenter clinical trial in Argentina, with the purpose of validating the implementation of the polymerase chain reaction (PCR) test for the direct and early diagnosis of congenital syphilis and Chagas in children of infected mothers. For this study, newborns of mothers with untreated Chagas and/or inadequately treated syphilis during pregnancy are enrolled. Newborns are studied by PCR in addition to parasitemia or serology, as appropriate, and then two additional controls are done, at the first month and at 8-10 months of age. The sensitivity of the PCR will then be compared with current diagnostic gold standards (microhematocrit parasitemia in the first months of life or serology at 8-10 months for Chagas and nontreponemal and treponemal test at one year for syphilis).

Currently, the following sites in Argentina have joined the PEDCHAGAS-SiC network study: Hospital Durand (Buenos Aires City), Hospital Argerich (Buenos Aires City), Hospital Lagomaggiore (Mendoza), Hospital Pediátrico Humberto Notti (Mendoza), Hospital CisBanda (Santiago del Estero), Hospital Materno Infantil Dr. Héctor Quintana (Jujuy), Hospital Público Materno Infantil (Salta), and Hospital Regional de Ushuaia (Tierra del Fuego). Four other sites from different regions are in the process of joining the study. So far, 16,772 pregnant women have been tested, and 272 newborns born to mothers with Chagas disease and 57 children of mothers with probable syphilis have been enrolled. The prevalence found was 0.41-4.2% for Chagas, depending on the region, and 0.8-5.2% for syphilis. We are currently in the stage of active enrollment.

This study is registered at clinicaltrials.gov NCT04084379, complies with the EMTCT Plus initiative, and reaffirms the operations of the PEDCHAGAS Pediatric Clinical Trials Network. ◊



A 4-year Follow-up of Children Treated with a New Formulation of Nifurtimox – the CHICO SECURE Clinical Study by the PEDCHAGAS Group

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The efficacy and safety of treating children with Chagas disease with benznidazole and nifurtimox is supported by a significant body of evidence. However, few controlled clinical studies have been conducted in the pediatric population.

Nifurtimox has only been available as a non-divisible 120 mg tablet. The availability of only one dose strength complicates the administration and proper weight-adjusted dosage of the drug, especially for young children. Bayer Pharma started the development of a divisible and dispersible tablet formulation in two dose strengths (30 mg and 120 mg).

For the clinical study, a clinical group, PEDCHAGAS, was set up under the coordination of the Ricardo Gutierrez Children's hospital. The PEDCHAGAS network comprises a group of experts in pediatrics, pharmacology and clinical research with an interest in Chagas disease. A Phase III multicenter clinical trial (NCT02625974) was completed with the enrollment of 330 patients, from 0 to under 18 years old, who were followed up for one year after the end of their treatment in Part 1 of the study (CHICO). Eighteen centers participated in Argentina, three in Bolivia and four in Colombia.

The safety and efficacy of nifurtimox for Chagas disease treatment in pediatric patients have been confirmed. The therapeutic response to treatment with nifurtimox for 60 days compared to historical placebo control measured as seroreduction/seroconversion rate was shown to be superior. PCR was negative in more than 95% of patients at the end of treatment, and remained negative in most of these patients during the 1-year follow-up (<https://doi.org/10.1371/journal.pntd.0008912>).

Based on these results, new nifurtimox dispersible formulations of 120 mg and 30 mg (Lampit) were approved by the US FDA, under the provisions of accelerated approval regulations for the treatment of Chagas disease, in children from birth to less than 18 years of age and weighing at least 2.5 kg. Also, it was recently registered by the Bolivian AGEMED for treatment of Chagas disease. Registry submissions seeking



authorization to market the new nifurtimox formulations are underway in other Latin American countries.

In the second part of the Phase III trial, CHICO SECURE, the patients were followed for three more years. This study part was recently completed, and the results are expected to be presented in 2022.

The development of a new, divisible tablet formulation of nifurtimox in two different dose strengths will improve dosing accuracy, and consequently safety and adherence to treatment in children of all age groups, especially patients under 2 years of age. Data from the literature suggests that the earlier children are treated with antitrypanosomal drugs, the higher the rate of seroconversion from positive to negative, highlighting the importance of early diagnosis and treatment of Chagas disease. ◦

Considerations on Developing a Multicentric, Long-Term, Prospective Cohort Study for Chagas Disease

Maria Hermoso (Fundação Oswaldo Cruz) and Colin Forsyth (DNDi)

Clinical research in Chagas disease faces several barriers. Although longitudinal studies have yielded some of the most important findings to date regarding the impact of etiological treatment on chronically infected adults, there have been few studies with lengthy follow-up periods, and most of these have focused on a specific geographic area and population. Further, there have been few opportunities for investigators to engage in international collaborative research outside of clinical trials. However, a collaborative, prospective study could provide important evidence to address key questions in Chagas disease regarding biomarkers of disease progression, treatment effectiveness, and clinical outcomes in treated patients. Advantages to international, multicentric collaboration include increased sample size and power, and increased capacity to investigate geographic differences in outcomes.

The Chagas Clinical Research Platform held a workshop on research priorities as part of its 2018 meeting in Santa Cruz, Bolivia. One of the main conclusions of the workshop was the need to urge the creation of a multicentric, long-term cohort study to “confirm effects of drug therapy, validate biomarkers, and better define risk factors for clinical progression.” In 2019 the Drugs for Neglected Diseases *initiative* (DNDi) began exploring the possibility of building a collaborative, multicentric, prospective cohort study. Three separate meetings were held to explore this topic: at the IS-Global Chagas Workshop in Barcelona, in Rio de Janeiro (concurrent with the Meeting of the Brazilian Society of Tropical Medicine), and at the Meeting of the American Society of Tropical Medicine and Hygiene in the United States. These discussions helped develop potential objectives and questions to be addressed through a prospective

cohort study. This effort was put on hold as the COVID-19 pandemic unfolded shortly thereafter.

Sharing data between researchers worldwide is an increasingly important aspect of addressing diseases and developing new therapeutic, diagnostic, and epidemiological approaches. The patient-level meta-analysis of a large number of clinical trials and cohorts can reveal findings that go well beyond the original purpose of the studies that generated the data. Fiocruz is reaffirming its commitment to Open Science practices by encouraging the availability of data and information at each stage of the research process. One of the initiatives is the Institutional Data Repository for Research — Arca Dados, an important element of the institutional policy for management, sharing and opening of research data. Initial experiences aim to bring together members of the Chagas disease research community at Fiocruz to assemble clinical, laboratory and epidemiological data on this collaborative repository to be scaled up to broader research initiatives. A systematic approach for the collection of data and the harmonization of processes and tools also foresees the collection of biological samples within the Fiocruz Biobank Network. Now, Fiocruz, DNDi, and other stakeholders are working together to create the groundwork for a multicentric prospective cohort study with a shared protocol, biobank, and data sharing arrangements, so that key evidence can be available to the Chagas disease research community. The goal is to pilot data collection in a small number of centers in different countries while securing funding to expand. Having this structure in place could eventually enrich our understanding of the long-term clinical impact of existing and future Chagas disease treatments, and help build future science by approaching data sharing as an essential part of the scientific process. ◦

Parameters for Sample Size Estimation in Non-inferiority Trials for New Chagas Disease Treatments

Colin Forsyth (DNDi) and Santiago Perez Llovet (Universidad Católica Argentina – UCA)

In 2021, the Chagas Disease Clinical Research Platform organized a workshop to address a highly relevant question for current clinical research: what are the principal assumptions and acceptable parameters for estimating sample size for clinical studies to evaluate new antiparasitic treatments with a non-inferiority design? This discussion represented a follow-up and an evolution to one of the first workshops of the Platform in 2009.

Investigators from Chagas trials either currently in process or in planning stages met online. Participants represented various institutions, including DNDi; ISGlobal; Oswaldo Cruz Foundation (Fiocruz), Brazil; the National Council of Scientific and Technical Investigations (CONICET), Argentina; The Institute of Clinical and Sanitary Effectiveness (IECS), Argentina; Cardio-infantil Foundation, Colombia; Elea Phoenix Laboratory, S.A., Argentina; Ricardo Gutiérrez Children's Hospital, Argentina; Dr. Mario Fatała Chabén National Institute of Parasitology, Ar-

gentina; Tulane University, United States; University of Calgary, Canada, and the Luxembourg Institute of Health. Experiences with sample size estimation were discussed, considering the challenges in evaluating efficacy through polymerase chain reaction (PCR), the dropout rate due to adverse effects, and the efficacy of current treatments and placebo observed in BENDITA and other recent clinical trials. Participants agreed that non-inferiority designs are appropriate for evaluating the current therapeutic alternatives under investigation and have potential value for exploratory Phase II studies of new chemical entities. Discussions also addressed statistical parameters including power, alpha, the real expected difference between new treatments and the standard regimen, and the non-inferiority margin, considering various scenarios. Another consideration was the urgent necessity of new treatments aligned with the Target Product Profile of 2015, where various stakeholders defined the ideal characteristics for a new treatment for Chagas disease.

The table below presents the assumptions and parameters with the values/ranges considered acceptable.

Rate of failure of the standard regimen 12 months after treatment (Comparator)	~20%
Power	Ideally: ≥90% Acceptable: ≥80%
Alpha, one-tailed analysis	≤2.5%
Expected absolute real difference between the experimental arm and the comparator (standard treatment)	Up to 10%
Non-inferiority margin	Up to 20%

These values are considered an approximation, and participants emphasized the need to adapt each study to the epidemiological context and research priorities. Another key emphasis was the need to maintain the important balance between the available resources and the necessity of assuring scientific rigor in the study design to respond adequately to public health questions. Of note, more research is needed to strengthen the evidence base for these recommendations.

New clinical trials are evaluating whether or not shorter regimens of benznidazole are non-inferior to the current standard regimen. A shorter treatment could facilitate adherence to treatment, simplifying the process for healthcare personnel and improving safety for patients. The evidence provided by these new studies will help determine if shorter regimens could be one of the tools for eliminating Chagas disease as a public health problem by 2030, as proposed by the World Health Organization. [○](#)



The Urgent Need to Ensure Sustainability in the Production of Medication for Chagas Disease

Clara Alves, Specialist in Advocacy and Humanitarian Affairs at Doctors Without Borders

first year of life. However, low demand for the pediatric formulation has stalled its development for years. Around 50 years after the adult formulation was discovered, the first easy-to-use pediatric formulation was developed in 2011 by a partnership between the Drugs for Neglected Diseases *initiative* (DNDi) and LAFEPE. In 2018, registration of the pediatric formulation was approved in Argentina for production by ELEA.

For almost two decades, Doctors Without Borders (MSF) has been developing projects to promote access to diagnostics and care for patients with Chagas disease. Our experience has shown that treatment has good results, with cure rates of more than 90% in patients in the chronic stage of the disease treated in Central America. The medication can be administered even in primary care, decentralizing patient care and demystifying the practice of referral for the disease.

However, promoting access necessarily entails ensuring sustainability in the supply of the main drug used for Chagas — benznidazole (BZN). BZN was developed by the pharmaceutical company Roche in the 1960s, but not until 2003 did the Brazilian State Pharmaceutical Laboratory of Pernambuco (LAFEPE) acquire the know-how to produce it. For a long time, it was the only supplier in the world, which created supplier dependency and supply interruption risks. In 2012, Argentina allowed the registration of BZN, produced by the private laboratory ELEA, but it was sold at a higher price. In 2017 MSF paid US\$ 0.21 per BZN pill produced by LAFEPE, while the Pan-American Health Organization paid US\$ 0.47 to ELEA for the same medication¹. For that reason, the alternative did not make strategic sense for patients and health systems.

Buying the pediatric formulation of BZN is even more challenging. It is a known fact that 90% of newborns with the disease can be cured if treated with BZN during their

Another issue was that for a few years, LAFEPE could not attain the certification in good manufacturing practices issued by the Agência Nacional de Vigilância Sanitária (ANVISA). As a result, all purchases of BZN in Brazil were compromised. Even after LAFEPE regularized its certification in 2016, it became abundantly clear that the limited number of producers in the world poses significant risks.

Estimating the demand for the medication is yet another challenge. Due to the invisibility of this disease, neither pharmaceutical companies nor health systems know for sure the number of existing patients with the acute and chronic forms of Chagas disease in the world. This information gap creates disincentives for scaling up production. Treatment sustainability is therefore connected to improved monitoring through reporting and actively searching for patients.

If the disease is to be confronted as a public health issue, through diagnostics and treatment of acute and chronic cases in primary care, it is imperative that more BZN suppliers become available in Brazil and around the world. These urgently needed changes require the collaboration of all agents working to remedy the historic neglect of the disease and its patients. It is crucial that we work towards sustainability in BZN procurement, both in its adult and pediatric formulations, and that more R&D entities get involved in innovating and improving current treatments. [○](#)

¹Chagas Disease: Review of Needs, Neglect, and Obstacles to Treatment Access in Latin America. Disponível em: <https://www.scielo.br/j/rsbmt/a/vDX3W5Vgcw6FDJGRzWVXY3Q/?lang=en>

Paraguay Strengthens Care for Chagas Patients

Vidalia Lesmo,
National Chagas
Program in Paraguay



In 2018, Paraguay obtained a certification for the eradication of intra-household vector transmission of *T. cruzi* by *Triatoma infestans* throughout the country's territory. After obtaining the certificate of **interruption of vector transmission**, the country now faces another challenge: that of achieving similar results in the control of its **current main transmission route: mother-to-child transmission**.

Chagas disease (CD) is an endemic disease in Paraguay, with a prevalence of 1.5-2% in blood banks and 5% in pregnant women, so it is estimated that about 400 children are born with the infection every year. However, access to diagnosis and treatment has historically been very low. In this context, one of the barriers facing our health systems, and which negatively impacts the health of patients, is healthcare providers' lack of knowledge on patient management.

To address this gap, in collaboration with ISGlobal's Chagas Initiative, we have developed our first Chagas disease management guidelines, the *Management Guide for Adult Patients with Chagas Disease* and the *Practical Guide for the Management of Congenital Chagas Transmission and Recent Chronic Childhood Chagas*, aiming to provide our healthcare teams with standardized technical tools based on scientific evidence. Published in 2021, they provide guidelines for healthcare and vector control teams on the prevention, control and surveillance of the disease, improving care through

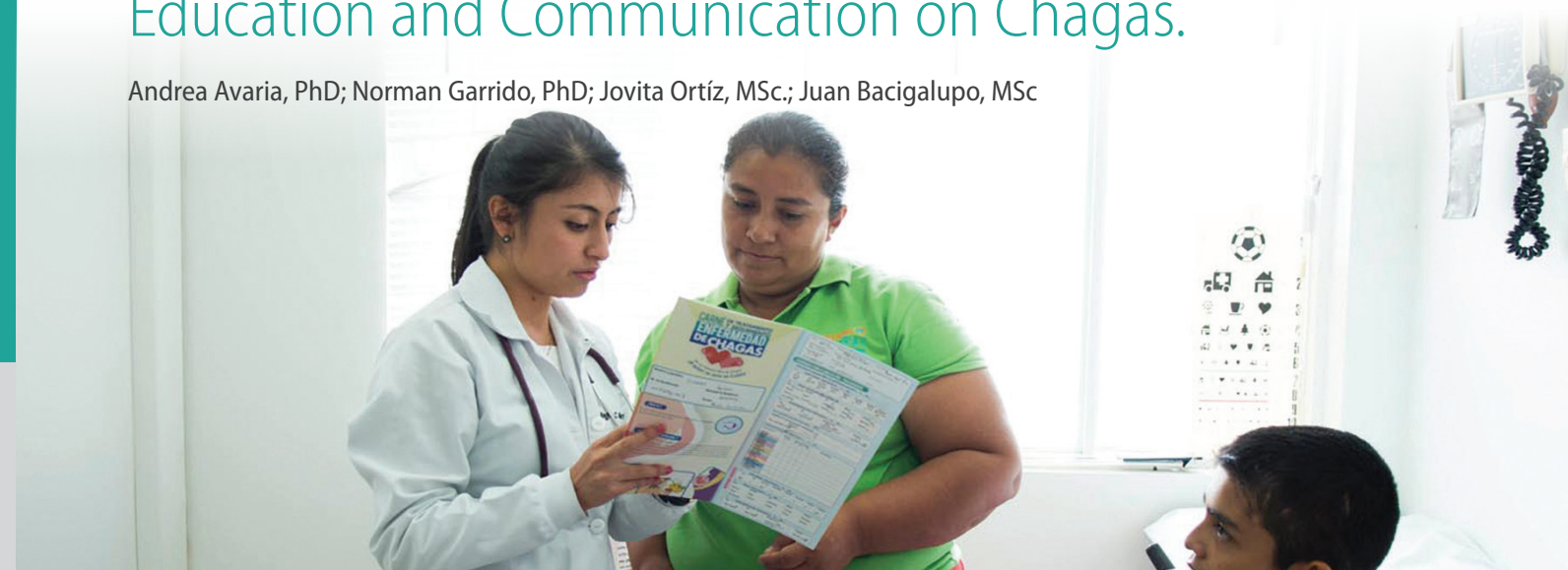
the implementation of a protocol-driven, comprehensive care model for patients with CD, helping to reduce the appearance and transmission of the disease. In addition, they define technical guidelines for epidemiological surveillance, early diagnosis, management and timely treatment of people infected with the etiological agent (*Trypanosoma cruzi*), helping to improve the quality of life of our affected patients and contributing to the progressive control and elimination of the transmission of this disease.

The clinical guidelines play an important role as a support tool and help in the daily clinical practice of healthcare providers, who need to rely on simple information that is appropriate to the problem, applicable to real-life patients, easy to understand and accessible at the patient point of care. Their use guarantees that patients can receive standard diagnoses and/or management regardless of the attending physician or their location.

The guidelines have been a very valuable tool in Paraguay, especially for primary healthcare providers located in rural areas, where they have considerably simplified the diagnosis and treatment process, improving access to people with CD. These reference tools must be implemented by healthcare providers throughout the country's territory. These documents have been developed by consensus among all the services involved, following the latest recommendations provided in the Pan American Health Organization's guidelines. [◦](#)

ChaoChagasChile: From Research to the Development of Strategies for Information, Education and Communication on Chagas.

Andrea Avaria, PhD; Norman Garrido, PhD; Jovita Ortiz, MSc.; Juan Bacigalupo, MSc



“Chagas and Challenges for Chile Today: Diversity, Migration, Territory and Access to Rights. A qualitative approach to the dynamics of Chagas disease care in the Tarapacá, Atacama and Metropolitan regions” is an applied qualitative research project that aims to dig deeper into the realities of national and migrant healthcare service users and treatment teams at different healthcare levels in three regions in Chile. The research process was developed in response to the research question: What experiences and meanings of Chagas disease are generated by healthcare users — Chilean and migrant, men and women — and of the healthcare teams providing treatment in the current process of Chagas diagnosis, care, and monitoring in the Tarapacá, Atacama and Metropolitan regions of Chile? The answers to this question have helped improve people's health through evidence, insights, concrete information, education, and communication (IEC) proposals, and recommendations to improve the implementation of the National Plan for Chagas Disease, considering subjective aspects underlying healthcare processes.

Using qualitative analysis based on Grounded Social Theory, we identified resistance, obstacles and opportunities in the healthcare teams and the population in relation to Chagas. Additionally, we have made progress in understanding health-Chagas disease-care processes from the perspective of the affected population and general users — both Chilean nationals and migrants — as well as healthcare providers, with the aim of improving the quality and opportunity of healthcare services for people affected by Chagas through incorporating the different actors' perspectives and territorial particularities.

The main results of the initial open and thematic coding reflect the diagnosis, follow-up and treatment experiences

of Chilean and foreign pregnant women. These results highlight the general need to educate the population considering gender, class and territory in order to strengthen access and adherence to healthcare by providing good services and through recognition of the complexities implied by a diagnosis such as Chagas (stress, fear, prejudice), as well as the need to generate improvements in providing information about the healthcare process. We are also making progress in understanding the meaning of Chagas for women and their modes of resistance to it. Blood donors describe their experience of going to the donation site and receiving their *diagnosis by chance*, and also relate the ways diagnosis is provided. Information and communication is reiterated as a critical element in this group. For their part, healthcare teams represent people with Chagas disease with culturally defined stereotypes which carry their own meanings, which intersect both the conditions of migrants (a series of constructions and related stereotypes) and social class, as well as territorial constructs (rurality and borders, among others).

The execution of the project has contributed qualitative research capabilities to healthcare teams, with a focus on understanding the coherence and transcendence of the results to produce relevant educational strategies.

Based on qualitative evidence and the needs arising from the process, IEC materials have been developed, aimed at pregnant women, blood donors, migrants, the general public, and healthcare teams. Through the resulting collaboratively developed products — videos, infographics and a self-learning course — we have reconceived and recast from where and how Chagas is approached in Chile today (www.chaochagaschile.cl). [◦](#)

Making Information on Chagas Disease Accessible: The iChagas App

Andrea Marchiol and Rafael Herazo (DNDi)



There is a fairly clear consensus that one of the greatest access barriers to the diagnosis and treatment of Chagas disease is healthcare providers' lack of knowledge about the clinical-epidemiological management of the disease. This barrier is transversal throughout the region, affecting all countries, and over-powering most health systems, which must search, identify, diagnose, assess, treat and monitor Chagas patients.

Despite ongoing efforts in the region, initiatives to strengthen the technical capacity of healthcare providers in the different health systems have been limited and insufficient. Initiatives such as in-person and online training, discussions of clinical cases, and virtual courses have borne fruit in certain aspects, but the ongoing rotation of healthcare providers requires a continuous and updated on-the-job training, which is difficult to maintain

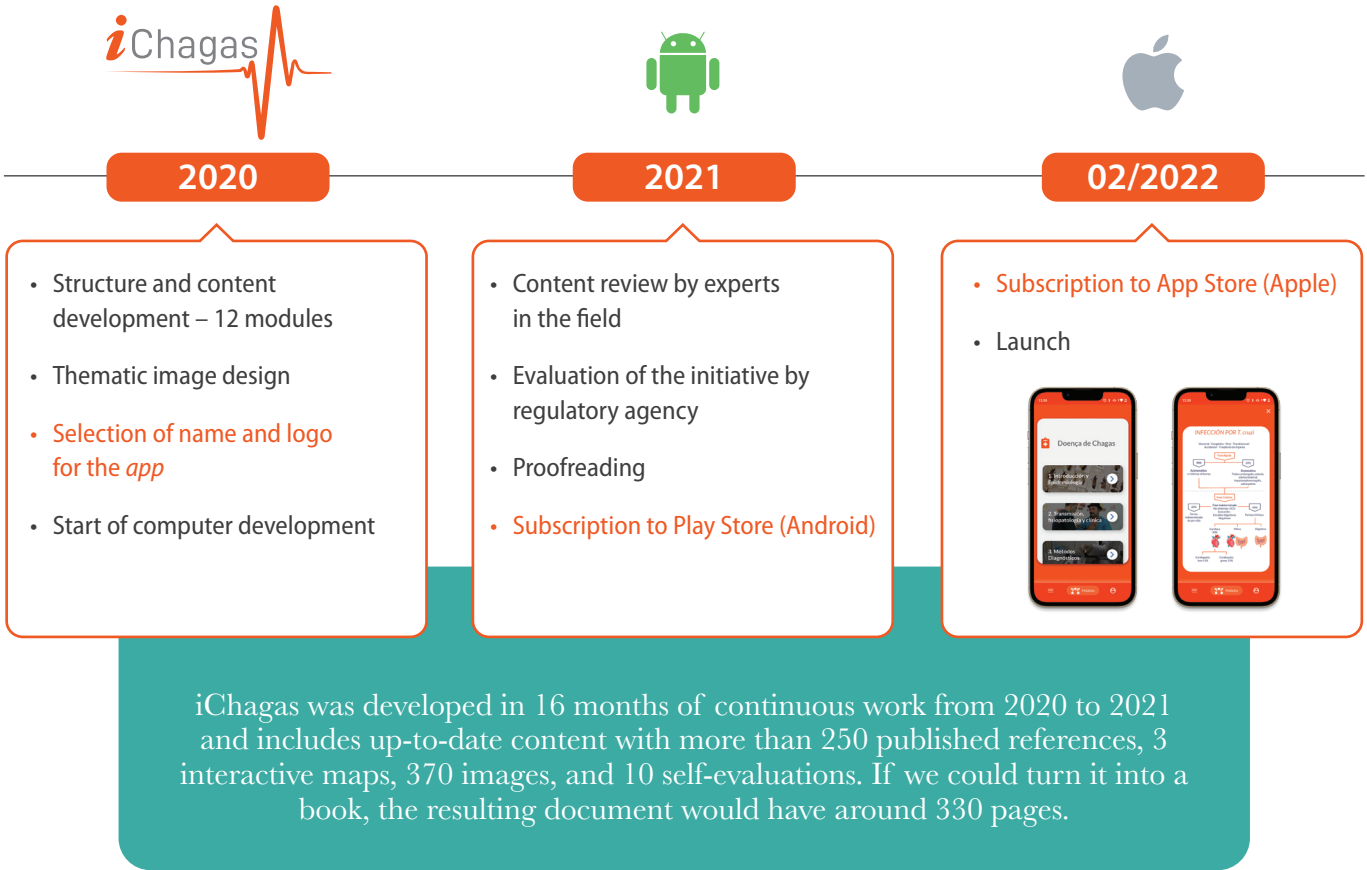
over time. In addition, healthcare providers who serve the primary care network are usually far from the urban centers where this type of training is carried out, and the distance prevents them from easily accessing training and/or refresher courses.

Responding to these issues, DNDi, in partnership with experts from the region, has developed the iChagas app for mobile phones and tablets, aiming to provide updated information on Chagas disease to healthcare providers. Our app is free to download and is available on both the Apple App Store and the Android Google Play Store. It can be accessed online or offline in case of connection issues.

The iChagas app contains more than ten modules that seek to cover all the complexity of Chagas disease. Core modules on

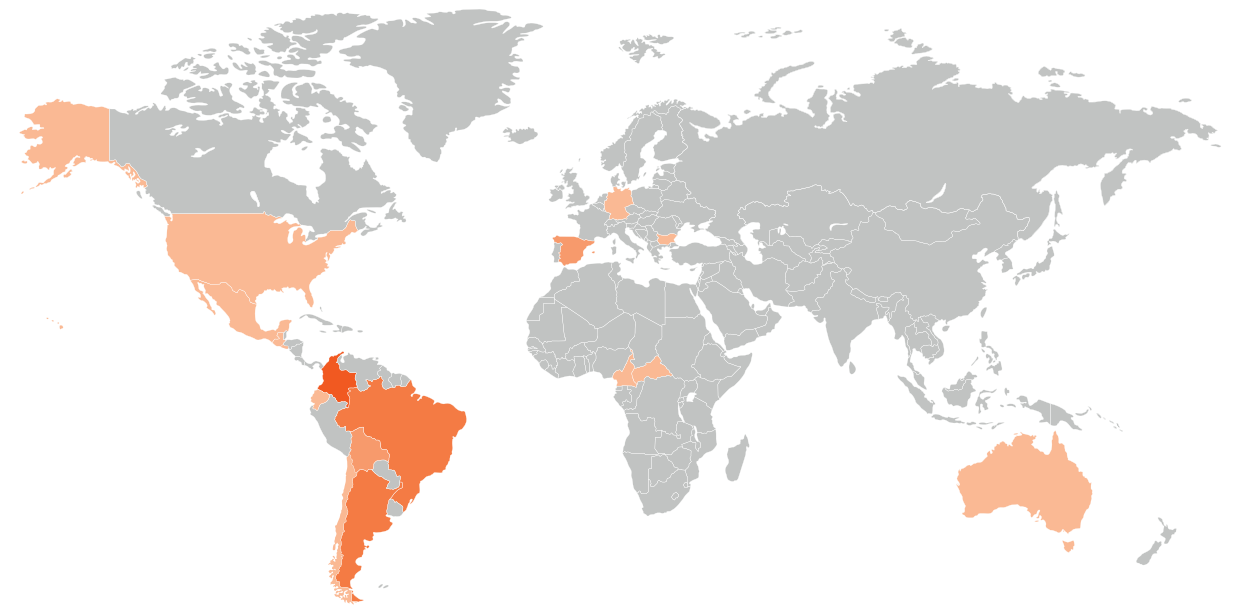
epidemiology, history of the disease, natural evolution, transmission mechanisms, and diagnosis link to a series of other modules that delve deeper into the clinical aspects, including complications and special situations, concluding with the social, political, and promotion and prevention aspects involved in a coordinated and comprehensive response to this disease.

Equally important is recognizing our patients and those who still do not know they have the disease, and therefore have not had access to appropriate care. For this reason, we dedicate the iChagas app to all those who still await the improvements to lives and communities that the best science and innovation can one day make possible. ◯



iChagas has been downloaded by different professional profiles in 16 countries.

We are working on greater outreach to expand the use of the app in all regions.



Reflections on World Chagas Day, April 2022

Elvira Idalia Hernández Cuevas,
FINDECHAGAS President

Associations are collectives of people and are created for the common good of others. The strength of an association is driven by the self-interest of its associates and the objectives they have in common. FINDECHAGAS is a federation made up of associations from several countries around the world whose main objective is to help those affected by Chagas disease.

Through the Federation, the associations that constitute it promote joint initiatives benefitting those affected by the disease. One example is their representation before the Member States, the World Health Assembly and the World Health Organization to request the approval of World Chagas Disease Day, designated to be celebrated on April 14th of each year. According to experts, health-related world days generate greater visibility for diseases and have a positive influence in the promotion of public policies benefitting those affected and their families, in addition to increasing social awareness among the general population.

Since the first celebration of World Chagas Day in April 2020, FINDECHAGAS has asked the ministries of health of the countries affected by Chagas for greater visibility of the disease and increased access to treatment. In 2021, the Federation requested comprehensive and universal care, as COVID-19 affected the operation of health services for Chagas disease, partially interrupting routine services, which poses a threat to the health of people with Chagas disease.

Now, in 2022, we at FINDECHAGAS have resumed our requests and are again addressing the governments of the world with the topic “Help us know how many we are and where we are.” Our hope is for governments to listen to us and develop health programs that reveal the exact number of people affected by Chagas in the world who need treatment, and who have the right to receive diagnosis and access to healthcare, treatment and follow-up for Chagas disease. This is the only way to control and reduce this condition which lacks timely and appropriate care and causes so much suffering and death year after year — the birth of children with Chagas, children of mothers with Chagas; people of working age who are unable to work because of the disease; families that lose a father or mother, leaving orphaned and unprotected children. These and other social problems are generated when governments are blind to people’s needs and do not allocate resources for Chagas care. This is why the associations that make up FINDECHAGAS will continue to speak out until we are heard.

I want to conclude with this sentence that I hope will foster reflection among readers and those interested in the issue of Chagas: “Those affected by Chagas do not have vacation or take holidays; they carry the disease in their bodies and in their hearts 24 hours a day, 365 days a year.” ◯

DNDi

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Alerta!