



22nd International Conference on Human Retrovirology:
HTLV and Related Retroviruses
HTLV2026

June 3-6, 2026 | Philadelphia, Pennsylvania, USA

Symposium 8 - Policy/social impact/stigma

Chairs: Goedele Maertens and Carol Rosadas



HTLV in Brazil: recent advances in national policies for surveillance, antenatal care, and elimination of vertical transmission

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Conflicts of interest:

I have no conflicts of interest



Background:

Human T-lymphotropic virus (HTLV) infection remains a **public health challenge** in Brazil.

This study describes key HTLV-related public policy actions led by the Ministry of Health (MoH) in collaboration with states, municipalities, scientists and civil society.

Methods:

We conducted a **descriptive analysis** of official MoH documents on HTLV prevention, surveillance, and clinical management published between 2020 and 2025.



Results

Pregnant women/year
≈ 2.5 million

In 2022, the HTLV Clinical Management Guide was updated, strengthening preventive actions for vertical transmission (VT), including access to cabergoline for pregnant women living with HTLV and infant formula for exposed infants.



Condoms
(internal and external)



Antenatal screening for HTLV
and counseling during
antenatal care



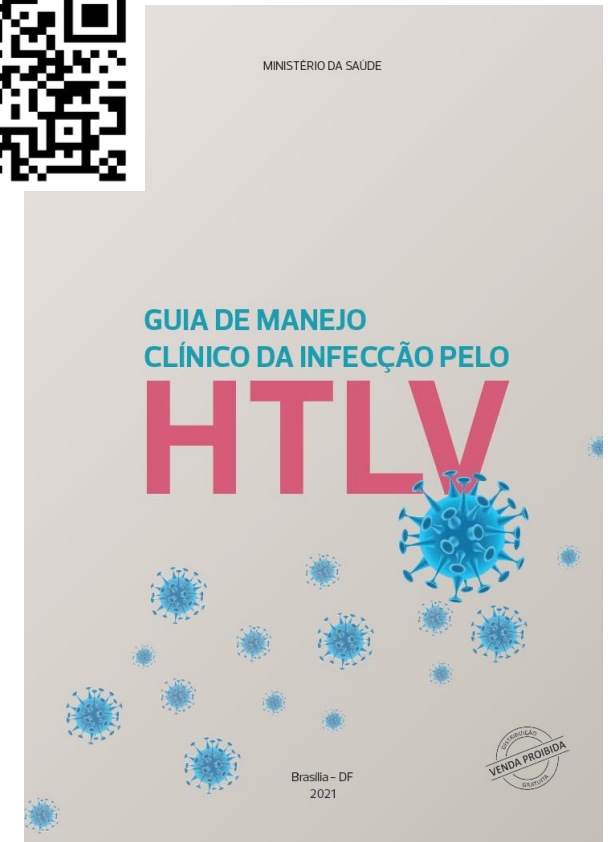
Cabergoline
(lactation
suppression)



Infant Formula
(6 months minimum)



Long-term follow-up in primary and
specialized care and Serological testing for
HTLV-1/2 (at 18 months)



Results

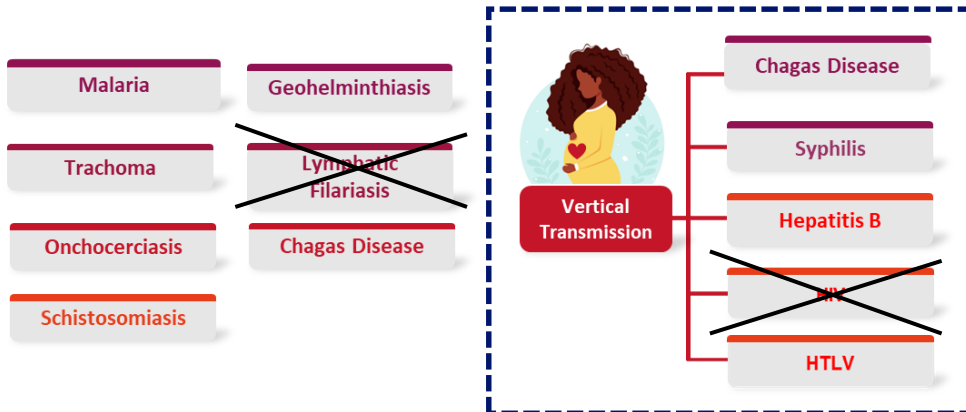
In 2024, HTLV was incorporated into the Healthy Brazil Program, aiming to eliminate Vertical Transmission by 2030.

National government commitment involving not only **health sectors** but **all sectors** that address social determinants.

The aim is to **eliminate those socially determined diseases by 2030**, including vertical transmission infection, like HTLV.



Diseases **expected to be eliminated** as a public health problem by 2030



Luciana Santos, Tedros Adhanom, Adijeane Oliveira de Jesus, Nisia Trindade, Jarbas Barbosa and Budi Gunadi Sadikin
(07th February 2024)

Diseases **expected to reach the WHO and MoH operational targets by 2030**

Tuberculosis Incidence ≤ 10 cases per 100,000 inhabitants	Hepatitis Diagnose 90% of people Treat 80% of people diagnosed	HIV 95% of people living with HIV diagnosed 95% of the people living with HIV on antiretroviral treatment
Leprosy Prevalence < 1 case per 10,000 inhabitants*	Reduce new infections by 90% Reduce mortality by 65%	95% of people living with HIV with suppressed viral load

In 2024, HTLV infection in adults, pregnant women, and exposed children became nationally notifiable.

Estimation: 0.8 - 1.2 million individuals are living with HTLV-1

Establish HTLV as a Notifiable Disease (under implementation)

National surveillance data to better guide public policies and improve the quality of care.

- HTLV
- HTLV in pregnant women
- Exposed children to HTLV

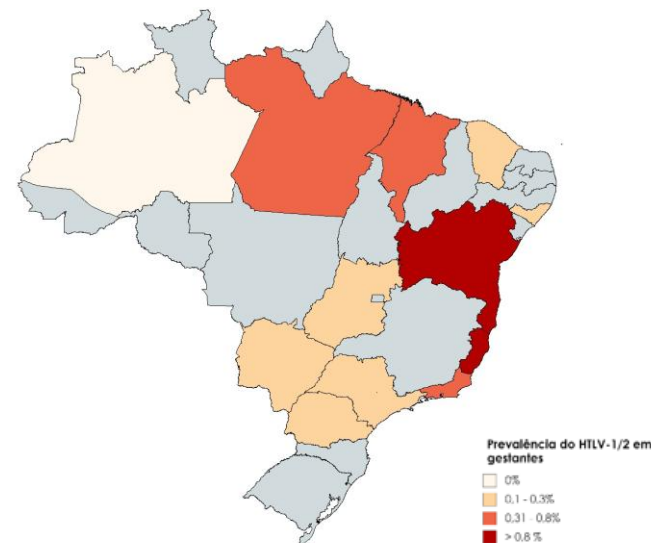
DIÁRIO OFICIAL DA UNIÃO

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Órgão: Ministério da Saúde/Gabinete da Ministra

PORTARIA GM/MS Nº 3.148, DE 6 DE FEVEREIRO DE 2024

Altera o Anexo 1 do Anexo V à Portaria de Consolidação GM/MS nº 4, de 2017, para incluir a infecção pelo vírus Linfotrópico de Células T Humanas -HTLV, da Infecção pelo HTLV em gestante, parturiente ou puérpera e da criança exposta ao risco de transmissão vertical do HTLV na lista nacional de notificação compulsória de doenças, agravos e eventos de Saúde Pública, nos serviços de saúde públicos e privados em todo o território nacional.

The prevalence of HTLV-1/2 infection among pregnant women ranges from 0% to 1.05%, depending on the region and vulnerability. (Around 16,000 pregnant women with HTLV per year)



Higher prevalence among:

- Women
- Black and mixed-race populations
- People with lower levels of education

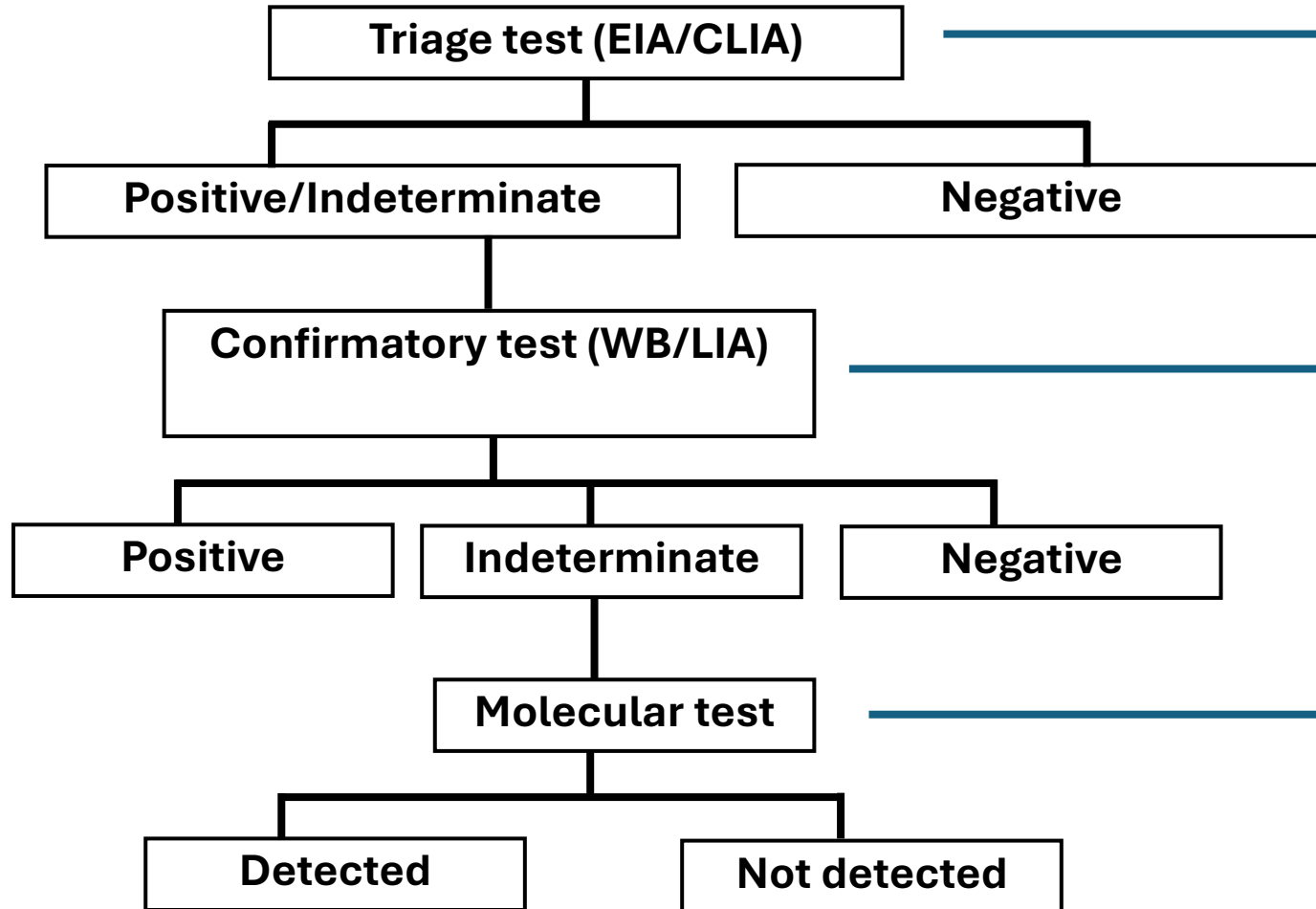
Brasil, 2021; Assone & Casseb, 2024; Rosadas et al 2018, Rosadas & Taylor 2023, Ishak et al 2024

National HTLV prevalence study involving 40,000 pregnant women is ongoing and is expected to conclude by the end of 2026.

Results

In 2024, Universal antenatal HTLV screening was approved.

Pregnant women/year
≈ 2.5 million



Local Laboratories

Challenges:

- High rates of false positive for HTLV
- No rapid test available at the country

47 Surveillance Laboratories

Challenges:

- High cost - R\$260- R\$ 438 (U\$ 48.5 – U\$81.5) per test (50,000 tests/year)
- Laboratories are not so used to perform WB or LIA

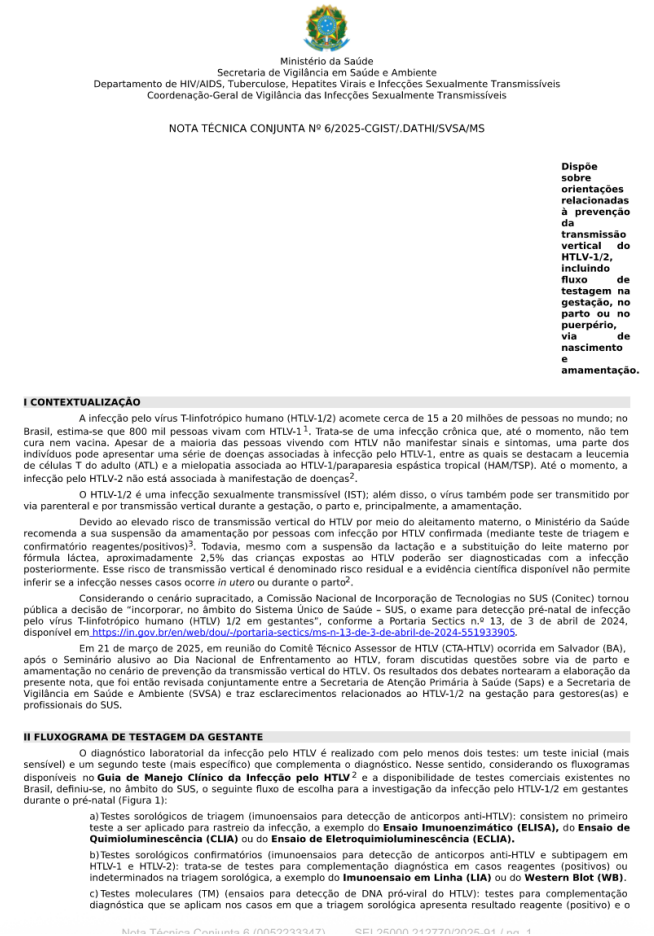
5 National Reference Laboratories

Challenges:

- No commercial molecular kit is available globally.

In 2025, the MoH convened a national meeting with civil society, scientists, health managers, and the HTLV Technical Advisory Committee, resulting in a technical note on testing, mode of delivery, breastfeeding, and follow-up of exposed children.

- HTLV-1/2 **screening** should be performed preferably in the **first trimester** of pregnancy, provided that the full diagnostic flow (screening and confirmatory tests) is available.
- A **reactive screening test alone is not sufficient** to establish diagnosis; confirmatory testing (WB, LIA, and/or molecular tests) is mandatory.
- **Mode of delivery**
 - For pregnant women with **confirmed HTLV-1/2 infection**, elective cesarean section is recommended regardless of clinical manifestations.
 - If **HTLV diagnosis is not yet confirmed, but screening test is reactive** at the time of delivery:
 - Cesarean section is recommended if there are manifestations compatible with ATLL, HAM/TSP, or other HTLV-associated diseases.
 - Otherwise, the mode of delivery should follow standard obstetric indications.



In 2025, the MoH convened a national meeting with civil society, scientists, health managers, and the HTLV Technical Advisory Committee, resulting in a technical note on testing, mode of delivery, breastfeeding, and follow-up of exposed children.

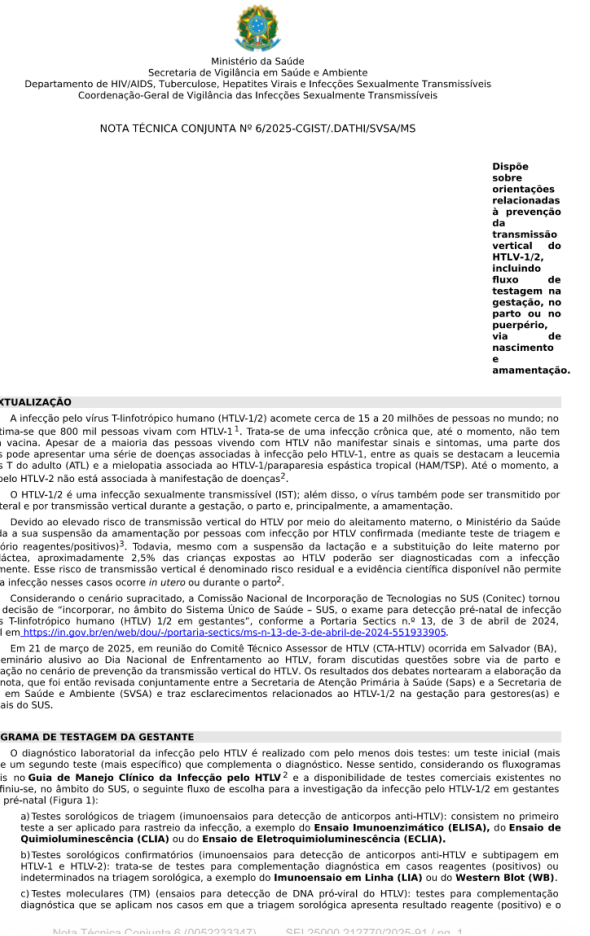
- **Breastfeeding**

- Absolutely **contraindicated** for women with confirmed HTLV-1/2 infection.
- In cases of **inconclusive diagnosis** at delivery, breastfeeding may be temporarily allowed until diagnostic confirmation, but should not exceed 3 months.
- If infection is confirmed, breastfeeding must be immediately suspended, with lactation inhibition using cabergoline and provision of free infant formula.

- **Care of HTLV exposed children**

- Infants exposed to HTLV should receive long-term follow-up in primary and specialized care.
- Serological **testing for HTLV-1/2 should be performed from 18 months of age** to confirm or exclude vertical transmission.

Integration between primary care, specialized care, and surveillance services is essential for adequate follow-up of mothers and children.



Results

The MoH is collaborating on prevention, therapeutic and diagnosis strategies.

Prevention:

- Supporting the **PrevINir HTLV-TV** Project to evaluate the use of **Dolutegravir (DTG)** for the **prevention of vertical transmission** of HTLV-1.



Prof. Dra. Maria
Fernanda R. Grassi
(Fiocruz
Bahia/Brazil)

Treatment:

- Supporting the Project designed to evaluate whether the combination of **Tenofovir and Dolutegravir** produces better outcomes on **HTLV treatment** than **Dolutegravir** alone.



Prof. Dr. Carlos
Brites
(UFBA/Brazil)

Diagnosis:

- Support for the **development and validation of rapid immunochromatographic tests**, discussions aimed at **improving the specificity of commercially available tests**, and promotion of the **development of a molecular diagnostic test**.



Researchers,
immunoassay
suppliers and the
national industry

The MoH also supported the development of a distance learning course on HTLV and Vertical Transmission prevention for healthcare professionals.



Curso de atenção integral às pessoas com infecções sexualmente transmissíveis

UFRN / SEDIS / LAIS / NAVI / IFRN / OPAS / MS

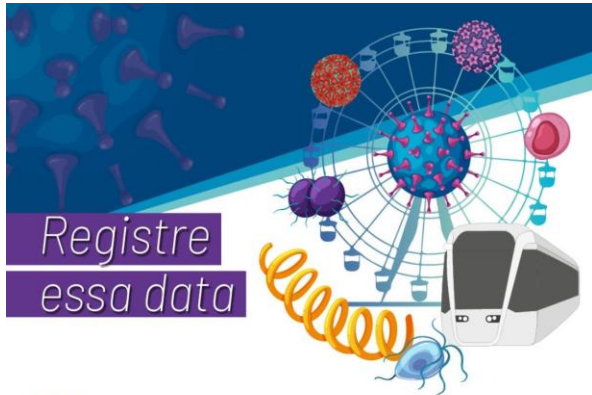
Este curso aborda os principais temas relacionados a atenção integral às pessoas com infecções sexualmente transmissíveis (IST). São eles: Epidemiologia das IST no Brasil e nas Américas, sistema de vigilância epidemiológica no Brasil, vigilância da **Ver mais**

<https://avasus.ufrn.br>



Results

Promotion and supporting of HTLV symposia, local meetings, workshops, summit, conference, national day, international day.



Registre
essa data

XV CONGRESSO DA SOCIEDADE BRASILEIRA DE DST
XVI CONGRESSO BRASILEIRO DE AIDS
XVI CONGRESSO LATINO AMERICANO IST/ HIV / AIDS

3 A 6 JUNHO 2025 | EXPOMAG Rio de Janeiro

www.dst aids2025.com.br



SEMINÁRIO
ALUSIVO AO DIA NACIONAL
DE ENFRENTAMENTO AO HTLV

BAHIANA EXATIA FOLIO SUS+ MINISTÉRIO DA SAÚDE GOVERNO FEDERAL BRASIL



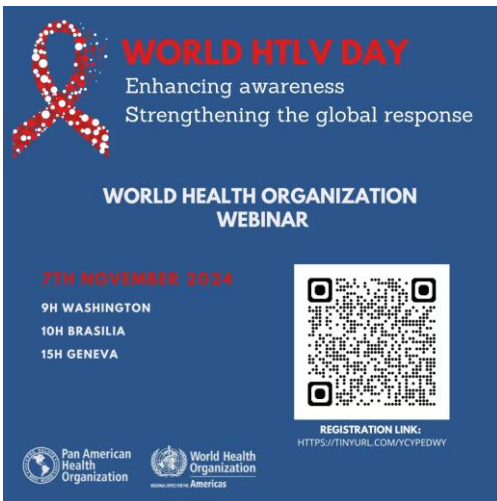
XVII Simpósio
Internacional sobre
HTLV
no Brasil

27 A 29 DE OUTUBRO DE 2025
São Luís - MA - Brasil



XV SIMPÓSIO
INTERNACIONAL SOBRE
HTLV NO BRASIL

8, 9 E 10 DE NOVEMBRO 2022
CAMPO GRANDE - MS



WORLD HTLV DAY
Enhancing awareness
Strengthening the global response

WORLD HEALTH ORGANIZATION
WEBINAR

7TH NOVEMBER 2024
9H WASHINGTON
10H BRASILIA
15H GENEVA

REGISTRATION LINK:
[HTTPS://TINYURL.COM/YCVPEDWY](https://tinyurl.com/YCVPEDWY)

Pan American Health Organization World Health Organization



I SUMMIT DE HTLV
23 de março de 2026
Local: Auditório IMREA Lapa
R. Cuaicurus, 1274 - Água Branca,
São Paulo - SP, 05033-002
Horário: 8h00 às 17h00

Dia Nacional do HTLV

Acompanhe
online acessando:

ERL BAHIANA EXATIA FOLIO SUS+ MINISTÉRIO DA SAÚDE GOVERNO FEDERAL BRASIL

Results

HTLV was incorporated into the Vertical Transmission elimination certification process for states and municipalities, with impact and process targets established in 2025

Brazil adapted the PAHO/WHO framework (impact and process targets) and implemented the **Certification Strategy for states and municipalities ($\geq 100,000$ inhabitants)** for the **Elimination of the Vertical Transmission** or awarded **progressive tiers** (bronze, silver or gold) of good practices, encouraging continuous improvement.

180 municipalities and 10 federal units until 2025 with certification (territories may hold multiple certifications across different infections - HIV, syphilis, Hepatitis B and/or Chagas Disease)

Certification for HTLV Vertical Transmission elimination is under implementation (2025-2026)



GUIA PARA CERTIFICAÇÃO DA
ELIMINAÇÃO DA
TRANSMISSÃO
VERTICAL DE HIV,
SÍFILIS, HEPATITE B
E DOENÇA DE
CHAGAS

Brasília - DF
2024



Results

The certification of states and municipalities was crucial to achieving the elimination of vertical HIV transmission nationwide. If we achieved this for HIV—something that was unimaginable 40 years ago—then we can achieve it for HTLV too!





Conclusion:

Brazil has strengthened HTLV public policies, particularly in surveillance, antenatal screening, clinical management, and Vertical Transmission elimination.

Thank you IRVA for this recognition!





Conclusion:

Brazil has strengthened HTLV public policies, particularly in surveillance, antenatal screening, clinical management, and Vertical Transmission elimination.

....but, as we have seen in this Conference, there is still much work to be done to improve care, strengthen prevention, and achieve the elimination of vertical transmission of HTLV in Brazil. So, we will keep moving forward - and together!

Thank you IRVA for this recognition!



Welcome to Rio de Janeiro/RJ - Brazil



AIDS 2026, the 26th International AIDS Conference







Registration is now open

Register for AIDS 2026 and join thousands of HIV professionals at the world's largest conference on HIV and AIDS.

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Welcome to Belo Horizonte/MG - Brazil



Come and Join us!



XVIII Simpósio Internacional
sobre HTLV no Brasil

HTLV

26 a 28 de outubro de 2027
Belo Horizonte, MG, Brasil



Pre-events start in October 24th 2027

OBRIGADA! THANK YOU!



Pâmela C Gaspar

On behalf of...



Mayra Aragon



Alisson Bigolin



Carmen S. B. Domingues



Jair Brandão



José Boullosa A. Neto



Cláudia G. Siqueira



Romina S. M. de Oliveira



Carolina Rosadas



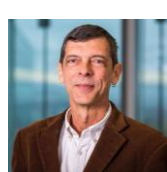
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From Invisibility to Public Policy: Integrating HTLV into Brazil's Vertical Transmission Elimination Certification Process

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Secretariat for Health and Environmental Surveillance – SVSA / Ministry of Health of Brazil - MoH

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Conflicts of interest

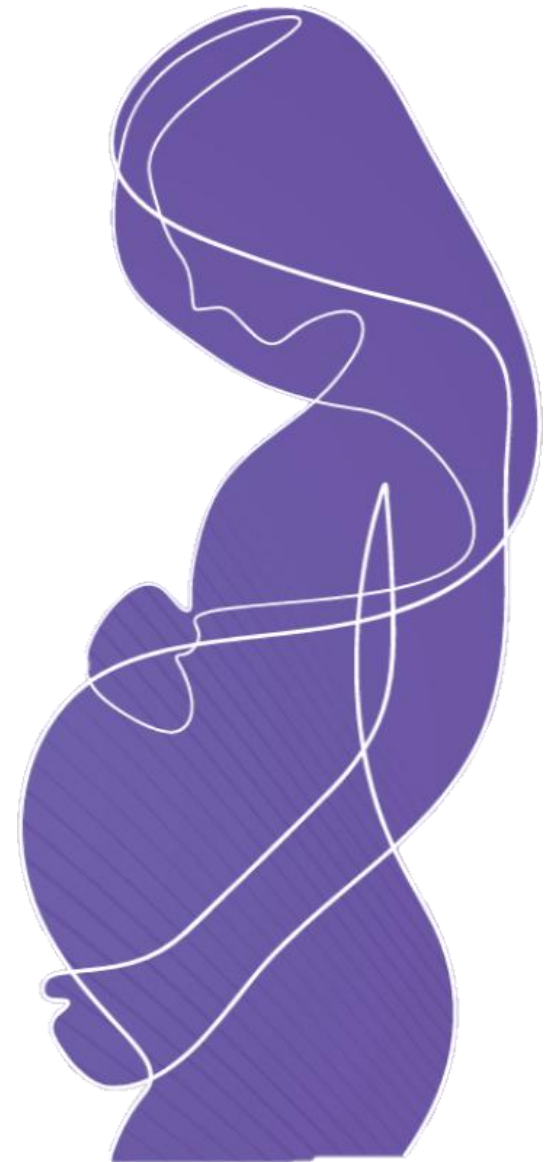
I have no conflicts of interest

Background

In Brazil, the Certification of Municipalities and States for Elimination of Mother-to-Child Transmission of HIV, Syphilis, Hepatitis B and Chagas Disease occurs in municipalities $\geq 100,000$ inhabitants and Federal Units and includes the possibility for the bronze, silver or gold tiers certification in “the path to elimination” (180 municipalities and 10 federal units).

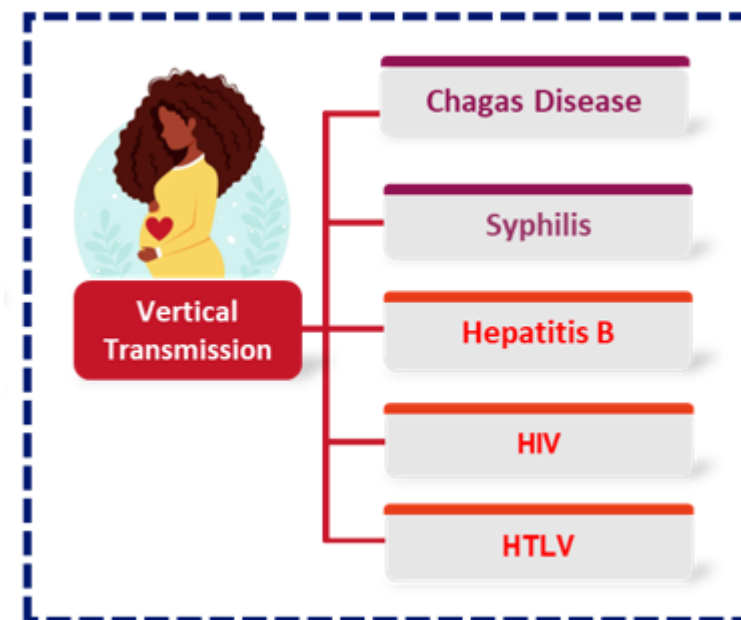
Encourage, support, and recognize the local efforts to elimination of MTCT

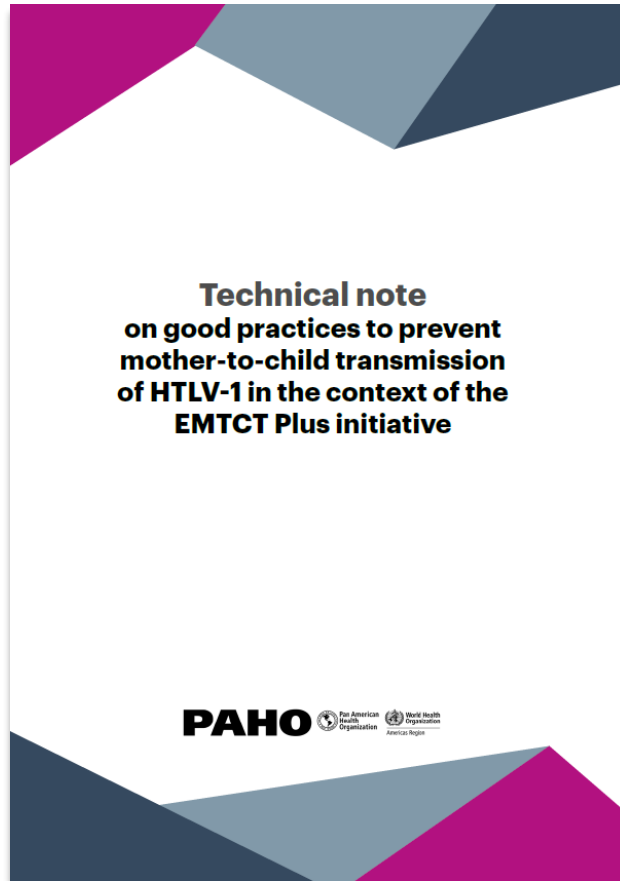
Brazil will incorporate HTLV into the vertical transmission elimination certification process from 2026.



Methods

Descriptive policy and governance analysis of normative documents, technical notes, and governance instruments of the Unified Health System (SUS)





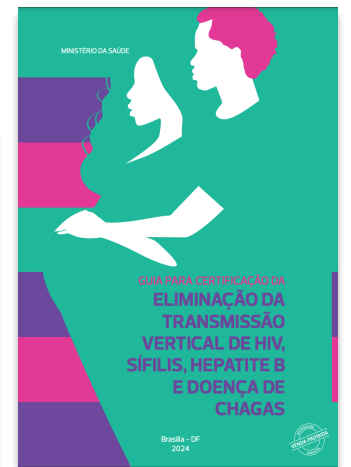
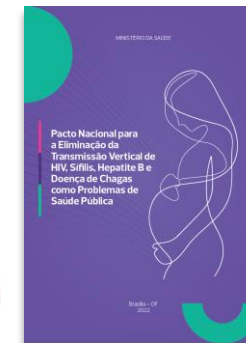
Impact target [interim target]

<5% of HTLV-1 mother-to-child
transmission rate

Programmatic objectives [interim targets]

- >95% coverage of HTLV-1 antenatal screening
- >90% coverage of core interventions (90% of pregnant women living with HTLV-1 informed about their options on infant feeding and nutrition and receive necessary support consistent with the decision made; i.e., replacement feeding with properly prepared infant formula, short-term breastfeeding, thermal treatment of breast milk)
- >90% coverage of HTLV-1 testing in infants born to HTLV-1 seropositive mothers, according to the current national algorithms

- Brazil validated impact and process indicators adapted from PAHO good public practices
- Deliberations of the Brazilian HTLV Technical Advisory Committee



Impact targets – Elimination and tiers

Impact target	Elimination	Parameters			Assessment period
		Gold	Silver	Bronze	
1) Incidence rate of HIV-infected children due to mother-to-child transmission	≤ 0.5 case per 1,000 Live Births (LBs)	≤ 1.0 case per 1,000 LBs	≤ 1.5 cases per 1,000 LBs	≤ 2.0 cases per 1,000 LBs	At least for one year (last full year)
2) Rate of mother-to-child transmission of HIV (public and private sectors)	≤ 2%	≤ 2%	≤ 2%	≤ 2%	
3) Incidence rate of congenital syphilis	≤ 0.5 case per 1,000 LBs	≤ 2.5 cases per 1,000 LBs	≤ 5.0 cases per 1,000 LBs	≤ 7.5 cases per 1,000 LBs	
4) Hepatitis B surface antigen (HBsAg) prevalence in children ≤5 years old	≤ 1.0 case per 1,000 ≤5-year-old birth	≤ 1.0 case per 1,000 ≤5-year-old birth	≤ 2.0 cases per 1,000 ≤5-year-old birth	≤ 3.0 cases per 1,000 ≤5-year-old birth	
5) Coverage of etiological treatment for children aged 0 to 3 years diagnosed with <i>T. cruzi</i> infection	≥ 90%	≥ 90%	≥ 70%	15% increase in coverage compared to the previous baseline year	At least for two years (last two full years)
6) Incidence rate of acute Chagas disease among women in child-bearing age	≤ 0.5 case per 100,000 women in child-bearing age	≤ 1.0 case per 100,000 women in child-bearing age	≤ 1.5 cases per 100,000 women in child-bearing age	≤ 2.0 cases per 100,000 women in child-bearing age	
7) HTLV vertical transmission rate	≤ 5%	≤ 5%	≤ 5%	≤ 5%	At least for one year (last full year)
8) Incidence rate of vertical transmission of HTLV	≤ 0.5 case per 1,000 Live Births (LBs)	≤ 1.0 case per 1,000 LBs	≤ 1.5 cases per 1,000 LBs	≤ 2.0 cases per 1,000 LBs	At least for one year (last full year)

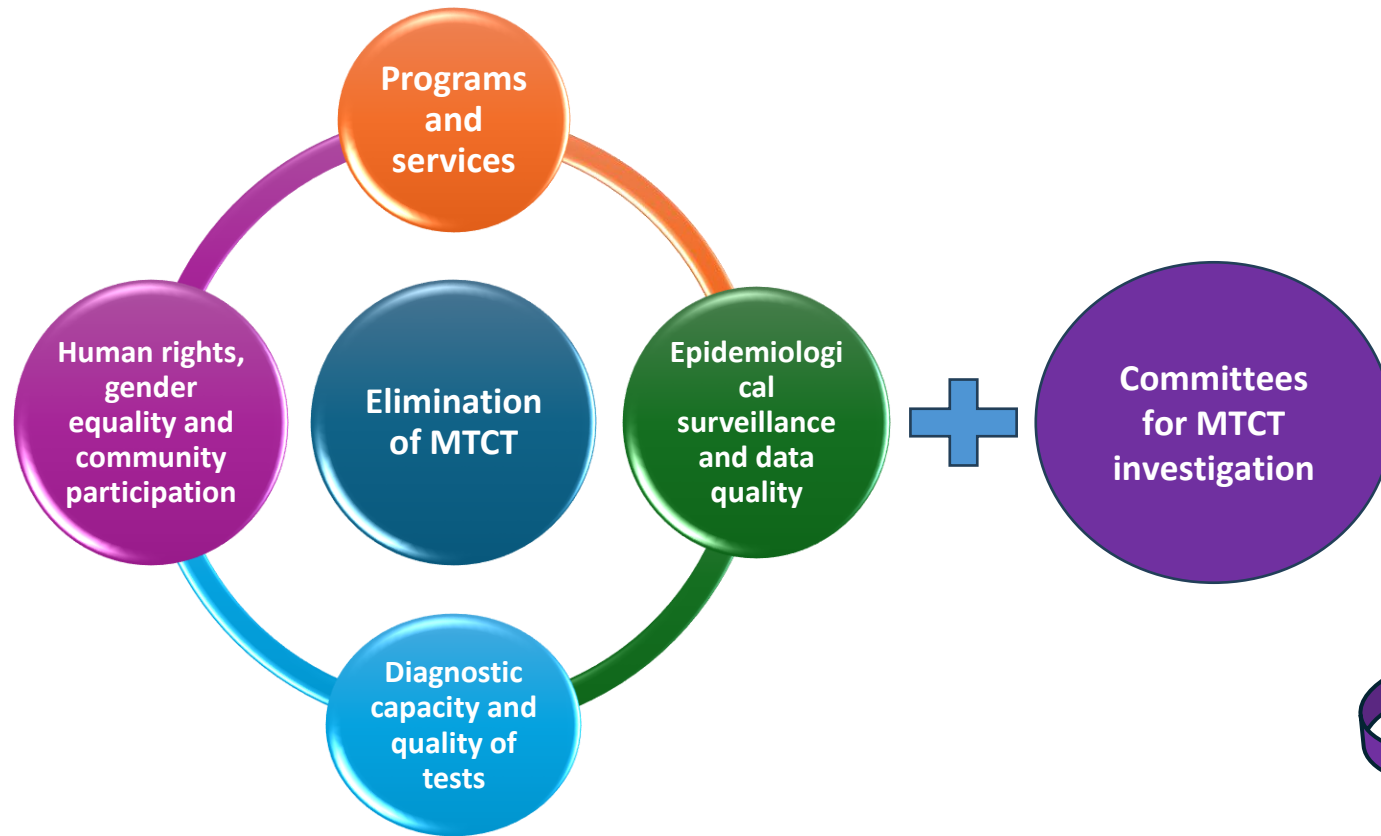
Process targets– Elimination and tiers

Process target	Elimination	Parameters		
		Gold	Silver	Bronze
1) Minimum coverage of 4 (four) prenatal care visits	≥ 95%	≥ 95%	≥ 90%	≥ 90%
2) Coverage for pregnant women who underwent at least one HIV test	≥ 95%	≥ 95%	≥ 90%	≥ 90%
3) Coverage for pregnant women living with HIV using antiretroviral therapy	≥ 95%	≥ 95%	≥ 90%	≥ 90%
4) Coverage for pregnant women who underwent at least one syphilis test	≥ 95%	≥ 95%	≥ 90%	≥ 90%
5) Coverage for pregnant women adequately treated for syphilis	≥ 95%	≥ 95%	≥ 90%	≥ 90%
6) Coverage for pregnant women who underwent at least one HBV	≥ 90%	≥ 85%	≥ 80%	≥ 70%
7) Coverage for Hepatitis B vaccine in children (up to 30 days after birth)	≥ 95%	≥ 90%	≥ 80%	≥ 70%
8) Coverage for three doses of Hepatitis B vaccine (infant vaccination)	≥ 95%	≥ 90%	≥ 85%	≥ 80%
9) Coverage of pregnant women with screening tests for Chagas disease	≥ 90%	≥ 85%	≥ 70%	15% increase in coverage compared to the previous year.
10) Testing coverage for diagnosis of children ≤ 1 year old exposed to <i>T. cruzi</i> through vertical transmission	≥ 90%	≥ 85%	≥ 70%	15% increase in coverage compared to the previous year.
11) Coverage of etiological treatment for Chagas disease in women of childbearing age	≥ 90%	≥ 85%	≥ 70%	15% increase in coverage compared to the previous year.
9) Coverage of pregnant women with at least one HTLV test	≥ 95%	≥ 80%	≥ 50%	Implemented screening
10) Coverage of infant formula provision for HTLV exposed children	≥90%	≥80%	≥70%	≥60%
11) Testing coverage among HTLV exposed children aged ≥18 months	≥90%	≥85%	≥80%	≥50%

Pilot implementation

Integration into existing certification evaluation structure

- Municipalities and Federal Units validation processes
- 2026 pilot project to test indicator measurement and data flows



National Validation Team

National Validation Committee

Elimination of Mother-to-Child Transmission Certification Ceremony





Conclusion

- Integrating HTLV into Brazil's certification process of vertical transmission elimination makes the infection visible, measurable, and accountable.
- This strategy aligns with the Healthy Brazil Program goal to eliminate HTLV vertical transmission as a public health problem by 2030 and offers a replicable model for endemic countries.



Authors – brazilian team



Mayra Aragon



Cristiano Francisco



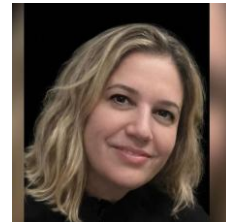
Carmen S. B. Domingues



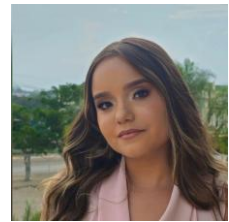
Adjijane Oliveira de J.



Aranaí Guarabyra



Ariane de Matos



Juliana Moreno



Rayone Souto



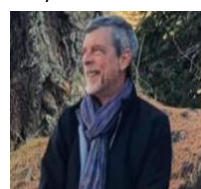
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Aparecida Moraes



Pamela Gaspar



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**Obrigada!
Thank you!**

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Welcome to Rio de Janeiro - Brazil



AIDS 2026, the 26th International AIDS Conference



≡ AIDS 2026 MENU ▾



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The HTLV Brazil Health Education Initiative:

Multiple strategies for science communication and health education on HTLV and associated diseases

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Angélica Miranda³, Tânia Fonseca⁴, Christian Reis⁵, Evânia Galindo⁵,
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² Ministry of Health of Brazil

³ Federal University of Espírito Santo

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⁵ Fiocruz Pernambuco

⁶ Fiocruz Bahia



DEBILIDADE E INTELIGÊNCIAS

Why awareness matters



Low public awareness



Stigma



Delayed diagnosis



Missed opportunities
for prevention and care

Our challenge

Transform scientific knowledge into accessible and engaging communication strategies, connecting science to people.



Development of a
multimodal communication
initiative on **HTLV**.

Reaching



PLHTLV
People living
with HTLV



Families
Support and information
for loved ones



**Healthcare
professionals**
Knowledge and tools
for better care



**Broader
community**
Awareness and
prevention for all

The HTLV Brazil Initiative

Starting with @htlvbrasil



Evidence-based information

Reliable and up-to-date scientific content.



Science communication

Translating research into clear and accessible messages.



Connecting science to people

Engaging the community and empowering lives.

From Instagram to multimodal communication and health education strategies for HTLV



Collaborative network involving Fiocruz, the Brazilian Ministry of Health, State Health Departments, partner institutions and people living with HTLV (PVHTLV).

Communication tools developed:



Books and educational materials



Viraldo Mascot
for health education and science outreach



Podcast
HTL ... O quê?



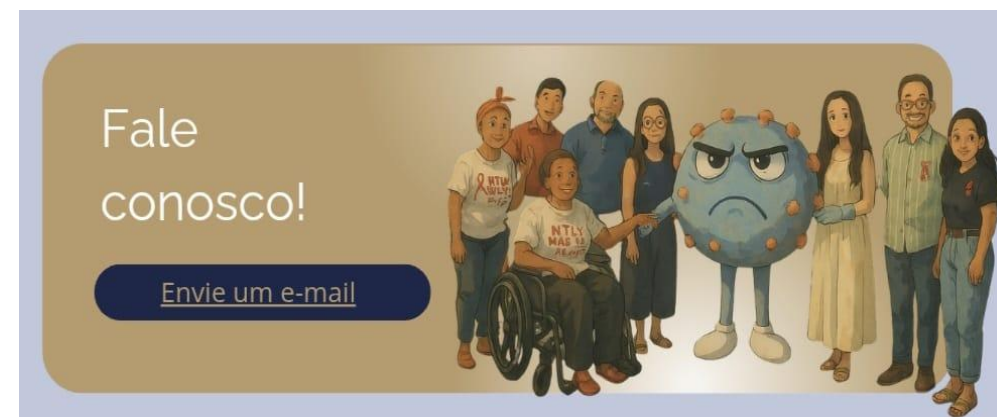
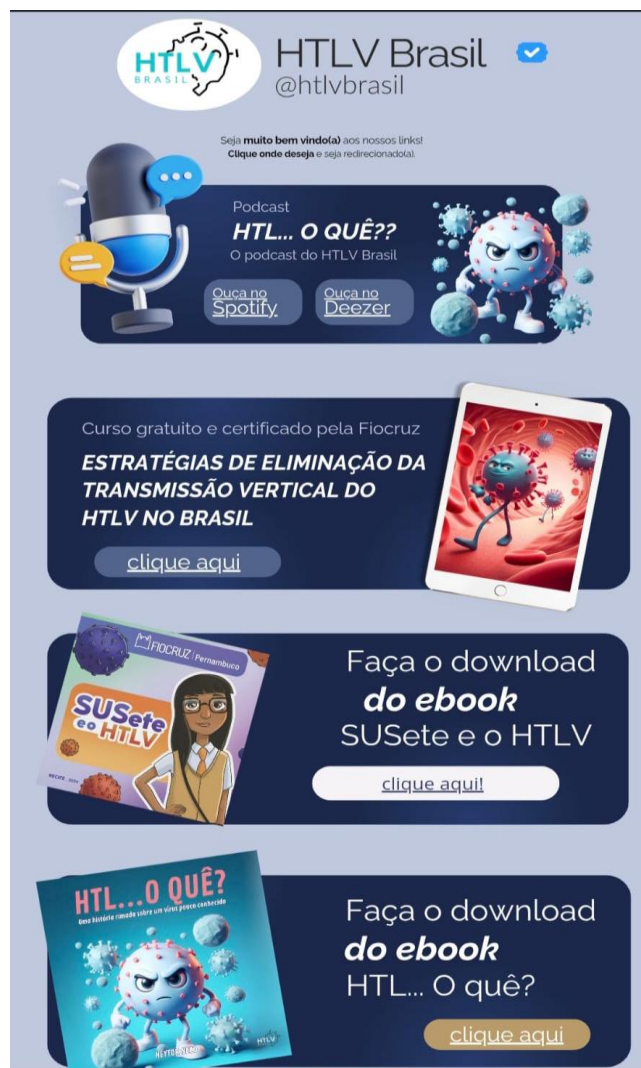
Board game



Online course



HTLV Brasil



- Support network connecting researchers, health services and People Living with HTLV

Results

Educational products



Results

Viraldo across Brazil

Science outreach and community engagement activities (2024–2025)

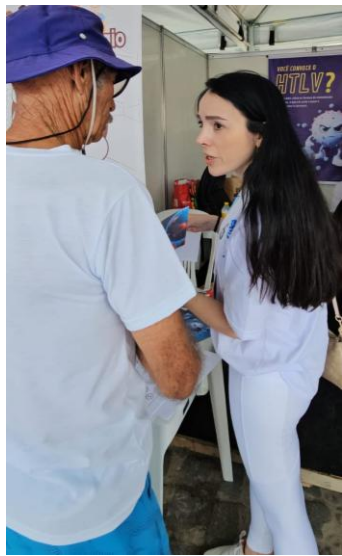


Activities included:

- Science fairs
- Public engagement events
- Health education workshops
- National awareness campaigns

Recife and Olinda's Giant Carnival Puppets, Pernambuco, Brazil





📍 Recife, Pernambuco
Science Fair- Fiocruz
pra Você 2024

Results

HTLV: Coming Out of Invisibility - Ministry of Health Workshop 2024



Brazilian Scientific Society Annual Meeting 2025





📍 São Paulo, SP
HTLV WORLD DAY, 2024



Paulista Avenue

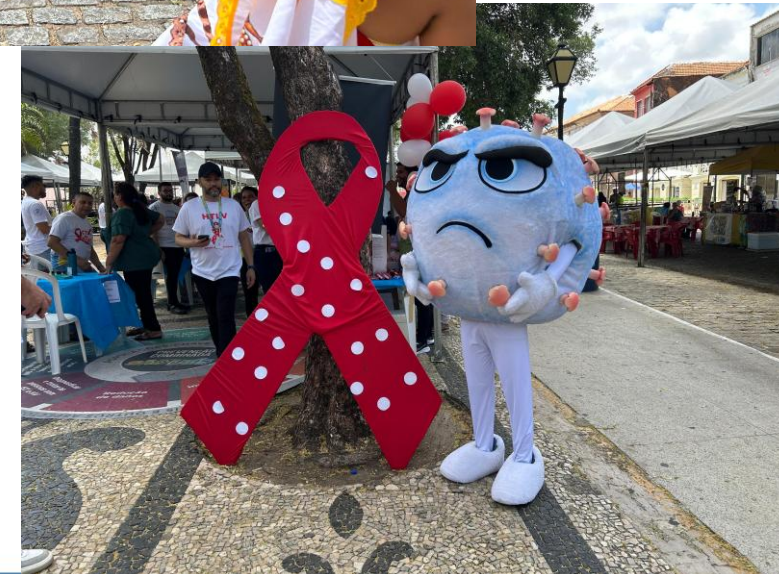
📍 Salvador, BA
NATIONAL HTLV DAY, 2025



XVII International Symposium HTLV – Maranhão
*Science outreach with the State Health
Department, 2025*



📍 São Luís, MA



Results



PODCAST
HTL... O QUÊ?



HTL
O QUÊ?
O PODCAST DO @HTLVBRASIL



Results

FIOCRUZ | Pernambuco



Online course for HTLV vertical transmission prevention

National training strategy developed by the HTLV Brazil Initiative

The screenshot shows the course interface with a purple header. On the left, a vertical banner reads 'CERTIFICAÇÃO DA ELIMINAÇÃO DA TRANSMISSÃO VERTICAL DO HIV, SÍFILIS E HTLV, E SELOS DE BOAS PRÁTICAS' next to a line drawing of a fetus. Below this is a video of a woman speaking at a podium. The main content area has a blue header with the text 'CURSO Estratégias de eliminação da transmissão vertical do HTLV no Brasil' and a cartoon virus character. Below the header, it says 'Módulo 1 | Aula 1' and 'Introdução ao HTLV: Histórico, Transmissão, Aspectos Virais, Epidemiologia e Prevenção da Transmissão'. A sidebar on the left lists 'Aula 1' and 'Aula 2'. A box on the right lists 'Objetivos de aprendizagem' with bullet points: 'Conhecer os aspectos históricos', 'Compreender as formas de transmissão', 'Entender as características e propagação do vírus', and 'Conhecer as formas de prevenção'. At the bottom right of the box is a video of a woman speaking.

Course highlights



Strategies for the elimination of mother-to-child HTLV transmission



Educational materials integrated into the training modules



6,000+ participants enrolled



5,000+ additional places opened due to demand



Results



Online course for HTLV vertical transmission prevention

Aligned with Brazil's goal to eliminate mother-to-child transmission by 2030



Supports the aim of the Healthy Brazil Program to eliminate mother-to-child transmission by 2030



Available on Campus Virtual Fiocruz

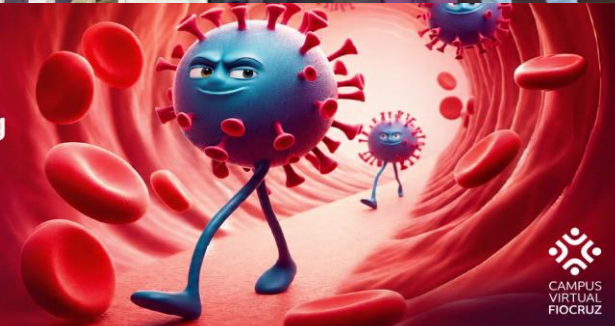


Free of charge



ONLINE COURSE

Strategies for Eliminating Mother-to-Child Transmission of HTLV in Brazil



100% online asynchronous

45 hours of workload

3 modules divided into 11 lessons



CAMPUS VIRTUAL FIOCRUZ

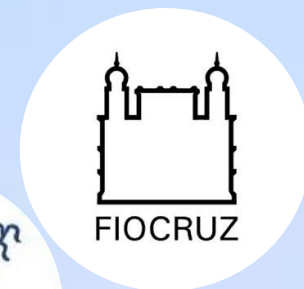


Conclusions

- **A Brazilian differential: a network based collaborative model:**
 - *Ministry of Health and State Health Departments,*
 - *Fiocruz Units,*
 - *Partner Instituciones*
 - *PLHTLV*
- **Supporting HTLV elimination efforts**
- **The HTLV response in Brazil shows that coordinated action is highly effective, it strengthened national capacity to adress HTLV, particulary in preventing vertical transmission and improving care**



Come and Join us!



XVIII Simpósio Internacional sobre HTLV no Brasil

HTLV

26 a 28 de outubro de 2027
Belo Horizonte, MG, Brasil

Pre-events start in October 24th 2027

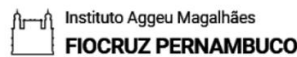




Thank you!

Obrigada!

clarice.lins@fiocruz.br



A community-based partnership to assess knowledge about HTLV-1 and ATLL and perceptions about research among an at-risk population in Philadelphia

Sean P. Reilly, MD
Sidney Kimmel Comprehensive Cancer Center at
Thomas Jefferson University Hospital

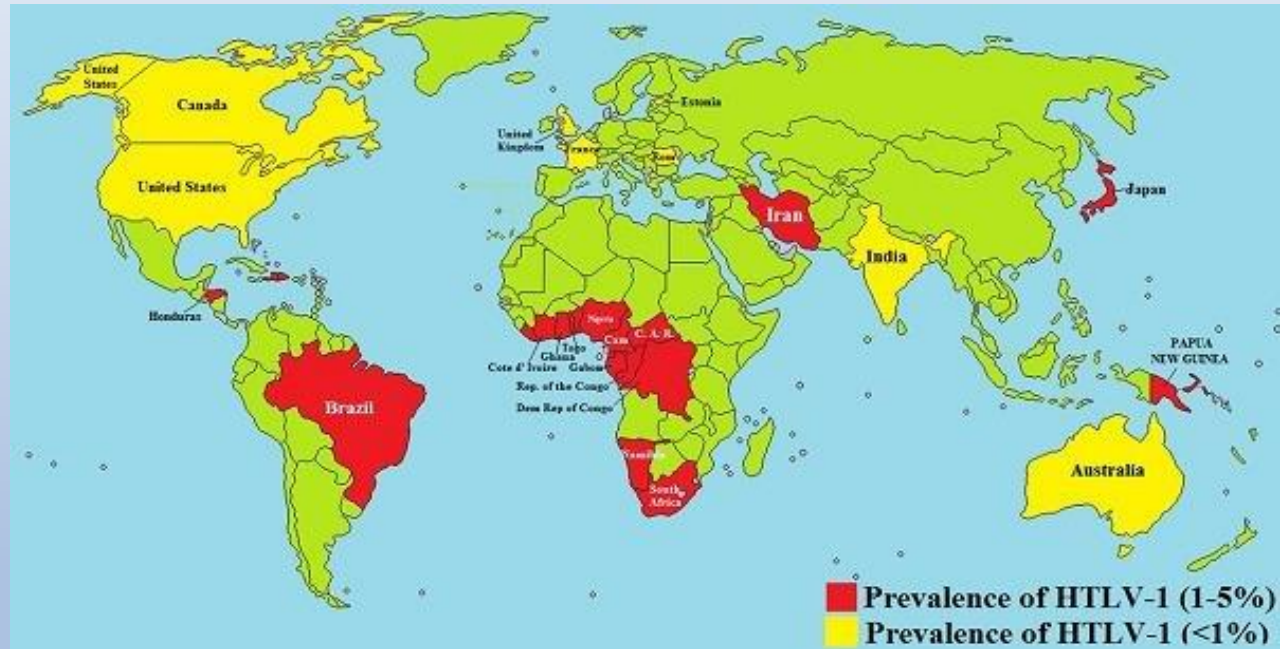
In collaboration with the African American Cultural Alliance of North America (ACANA)

Conflicts of interest

I have no conflicts of interest

Background

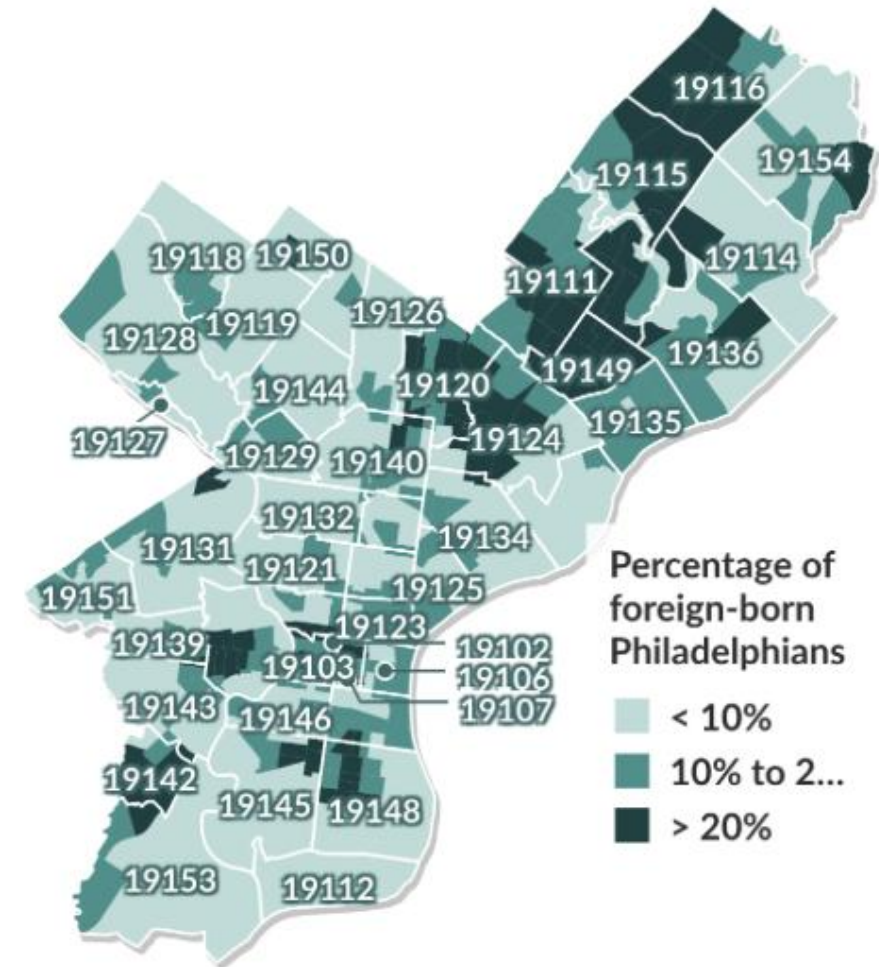
- HTLV-1 has a heterogeneous distribution, even within countries in which it is endemic
- Prevalence in the United States is poorly characterized, estimated at <1% primarily based on blood donor data
- Cities such as Miami and New York City have shown increased prevalence levels based on immigration trends



Fani, M et al. 2019 *Journal of cellular physiology*

Philadelphia: A City of Immigrants

- 1.6 million people
 - 600,000 African or African–American heritage
 - 30,000 Caribbean heritage
- Gaps:
 - No data for HTLV-1 incidence or prevalence in African and Caribbean communities
 - No data community's awareness of HTLV-1 or ATLL



© 2024 The Pew Charitable Trusts

HTLV-1 In Our Community

- Objectives:
 - Gauge knowledge on HTLV-1 and ATLL among African and Caribbean immigrants in Philadelphia
 - Determine willingness of community to participate in future HTLV-1 related efforts
- African Cultural Alliance of North America (ACANA)
 - Large cultural group including both African and Caribbean immigrants in Philadelphia



Methods

- In partnership with ACANA, an informational session was arranged at a monthly ACANA meeting, conducted by Zoom
- All participants took a survey before (pre-) and after (post-test) the survey to capture baseline and change in knowledge on a 5-point Likert scale
- Discussion was held with community afterwards

I have heard of Human T-cell Lymphotropic Virus -1 (HTLV-1)

I know how HTLV-1 spreads

I know of ways to prevent HTLV-1 transmission

I know where HTLV-1 is most common in the world

I know of the screening tests for HTLV-1

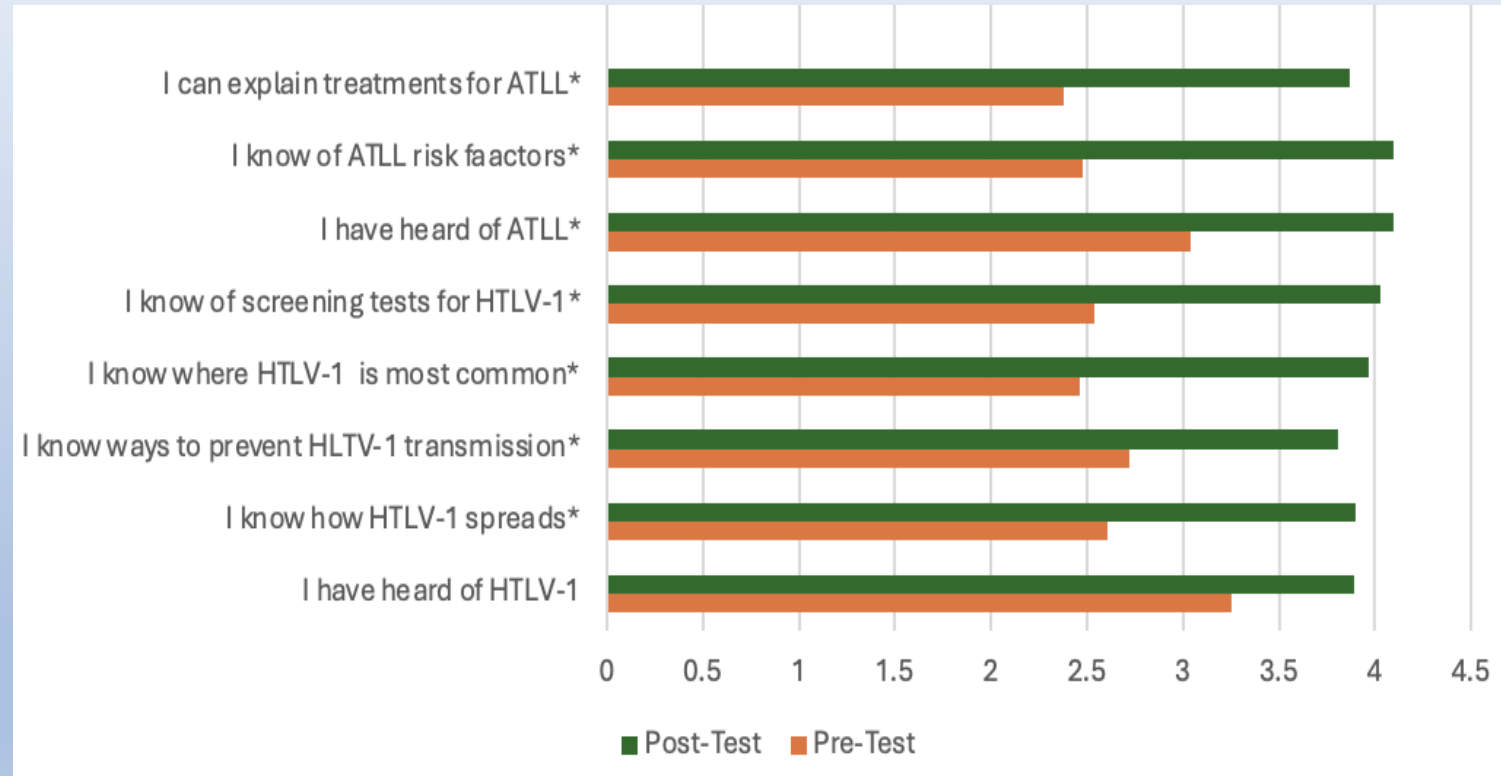
I have heard of Adult T-cell Leukemia/Lymphoma (ATLL)

I know of ATLL risk factors

I am aware of treatments for ATLL

Results

- 54 participants present across two sessions
- 1st Session:
 - 25 via zoom, 8 in person
 - 4 pre-tests, 11 post-tests completed
- 2nd Session:
 - 21 present, all in person
 - 21 pre-tests, 20 post-tests completed



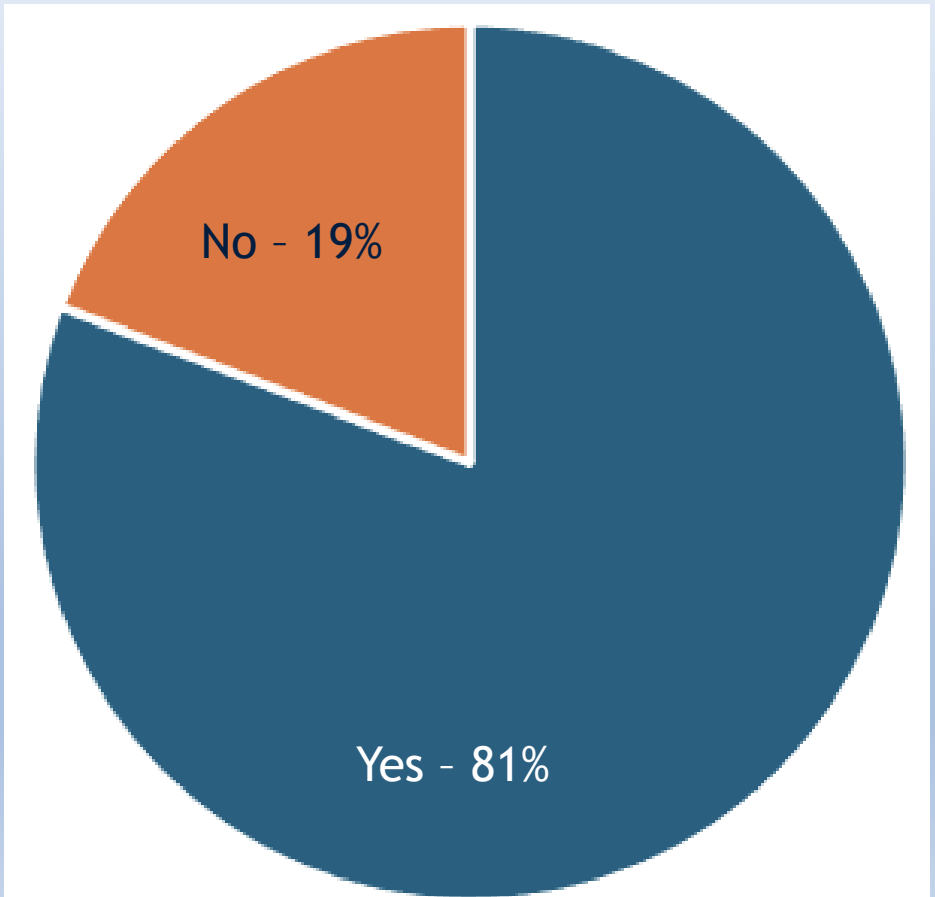
Results

Question	Pre Test Mean (SD)	Pre-Test Quartile Range	Post-Test Mean (SD)	Post-Test Quartile Range	P-value
I have heard of HTLV-1	3.25 (1.59)	1.75-5.00	3.89 (1.37)	3.25-5.00	0.119
I know how HTLV-1 spreads	2.61 (1.27)	1.50-3.00	3.90 (1.26)	3.00-5.00	<0.001
I know of ways to prevent HTLV-1 transmission	2.72 (1.45)	1.25-3.75	3.81 (1.24)	3.00-5.00	0.007
I know where HTLV-1 is most common	2.46 (1.32)	1.00-3.00	3.97 (1.30)	3.00-5.00	<0.001
I know of screening tests for HTLV-1	2.54 (1.25)	1.00-3.00	4.03 (1.07)	3.00-5.00	<0.001
I have heard of ATLL	3.04 (1.27)	2.00-4.00	4.10 (1.02)	4.00-5.00	0.002
I know of ATLL risk factors	2.48 (1.16)	1.00-3.00	4.10 (1.14)	3.75-5.00	<0.001
I can explain treatments for ATLL	2.38 (1.28)	1.00-3.00	3.87 (1.04)	3.00-5.00	<0.001

Results

- “If mothers are told that breast milk is healthy, what can the mothers of Africa do to stop transferring the virus?”
- “If the disease had been discovered since 1979, why are we just hearing about it and wasn’t the world aware of it?”
- “It was enlightening because I did not know of this virus before this workshop”
- “This needs a great awareness in [my] country and even in America - is scaring I must say. More educational material is needed”

Would you be willing to Participate in Future Research efforts at HTLV-1?

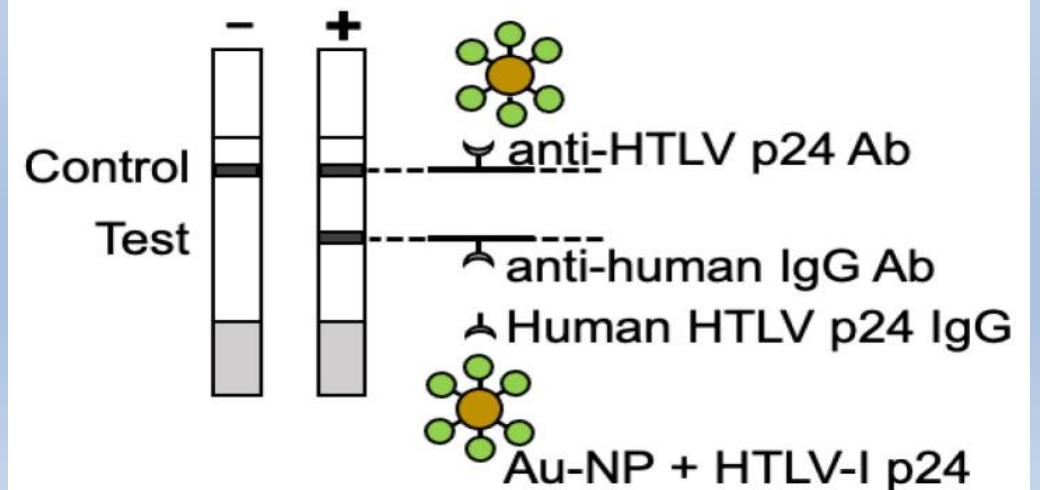


Discussion

- We identified an at-risk population within Philadelphia with poor understanding of HTLV-1, and a clear unmet need for accessible education on HTLV-1 and ATLL
- We demonstrated that reservations about research involvement can be mitigated by a thoughtful, culturally sensitive, and community-engaged approach
- While this is a small pilot, we demonstrated meaningful change in HTLV-1 knowledge and identified enthusiasm for participation in further educational and research efforts targeting HTLV-1

Next Steps

- Enact a mobile screening initiative for at-risk individuals of African and/or Caribbean descent
- Work with Dr. Pooja Jain's lab to validate a point-of-care fingerstick test for HTLV-1 in North America



Thank you!

- Special thanks to our team:

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- Pierluigi Porcu



Jefferson Office of Community Outreach and Engagement

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- Rebecca Melillo, MS
- Munjireen Sifat, PhD

ACANA

- Nettie Johnson, MD
- Abu Mansalay, MD

Drexel

- Pooja Jain, PhD



SIDNEY KIMMEL COMPREHENSIVE CANCER CENTER CONSORTIUM

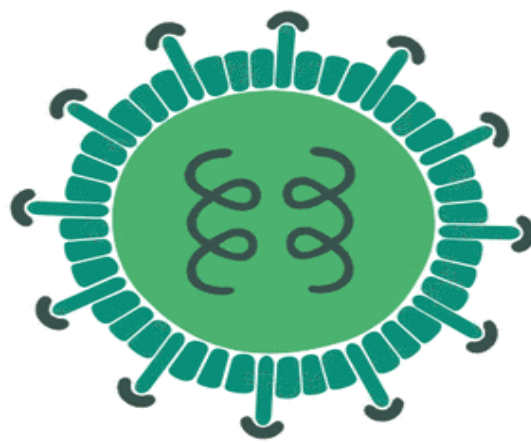


Thomas Jefferson
University



Drexel
UNIVERSITY

JeffersonHealth.org/Cancer



Global disparities in HTLV-1 research and response: A unique focus on Caribbean and Polynesian/Japanese populations

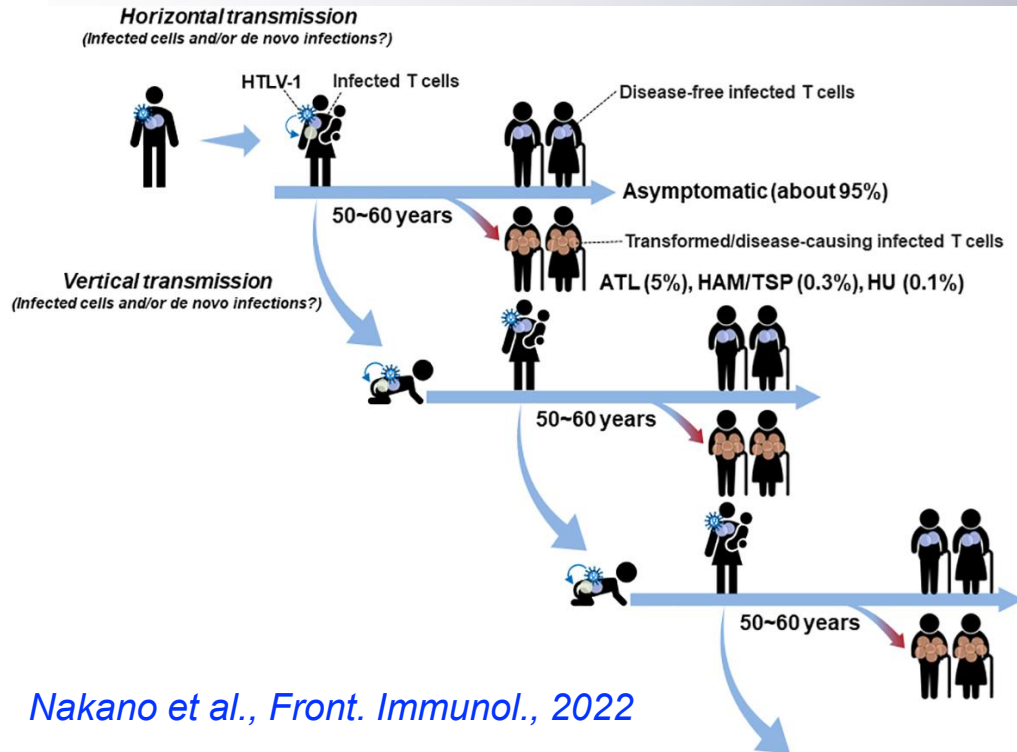
Ryan Hoffmann, Catherine A. MacNary, Shari Sawney, and Pooja Jain

**Department of Microbiology and Immunology
Drexel College of Medicine
Philadelphia, PA, USA
RH957@drexel.edu**

**22nd International Conference on Human Retrovirology:
HTLV and Related Retroviruses
HTLV2026**



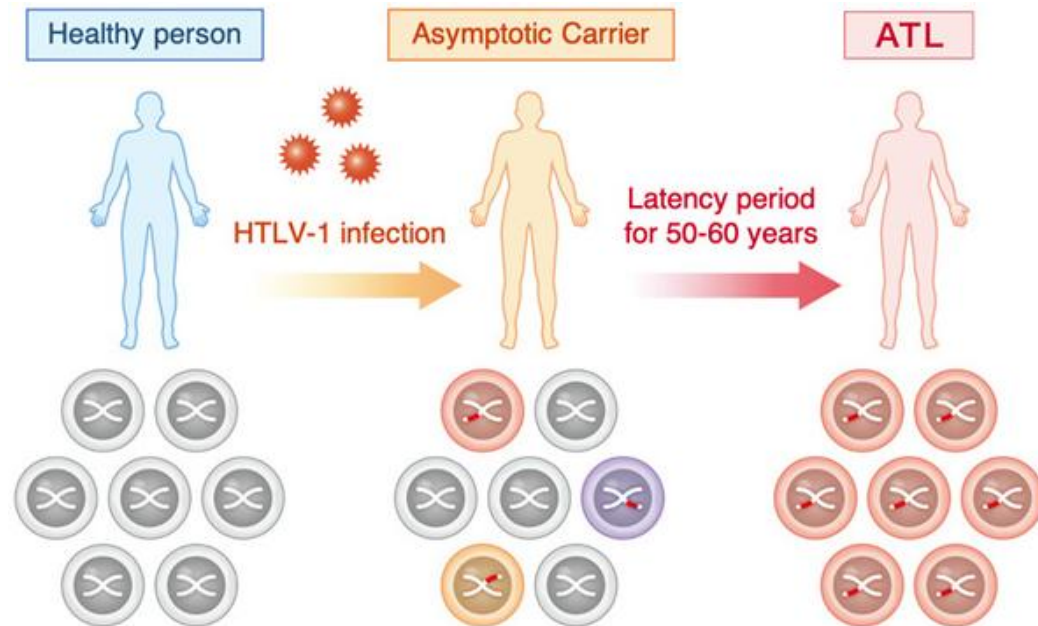
HTLV-1 Pathogenesis Obscures Public Health Surveillance



Nakano et al., Front. Immunol., 2022

- Prolonged latency obscures transmission monitoring and delays diagnosis
- Limited screening and lack of national surveillance in the United States further contributes to under recognition
- **Silent transmission + delayed diagnosis = unknown public health burden**

- HTLV-1 is transmitted through breastfeeding, sexual contact, and blood exposure
- Most infected individuals remain asymptomatic for decades while still capable of transmitting the virus
- Disease onset is highly delayed;
 - ATLL may develop 10-70 years after infection
 - HAM/TSP can develop months to decades post infection



Matsuo et al., Nature Communications, 2022



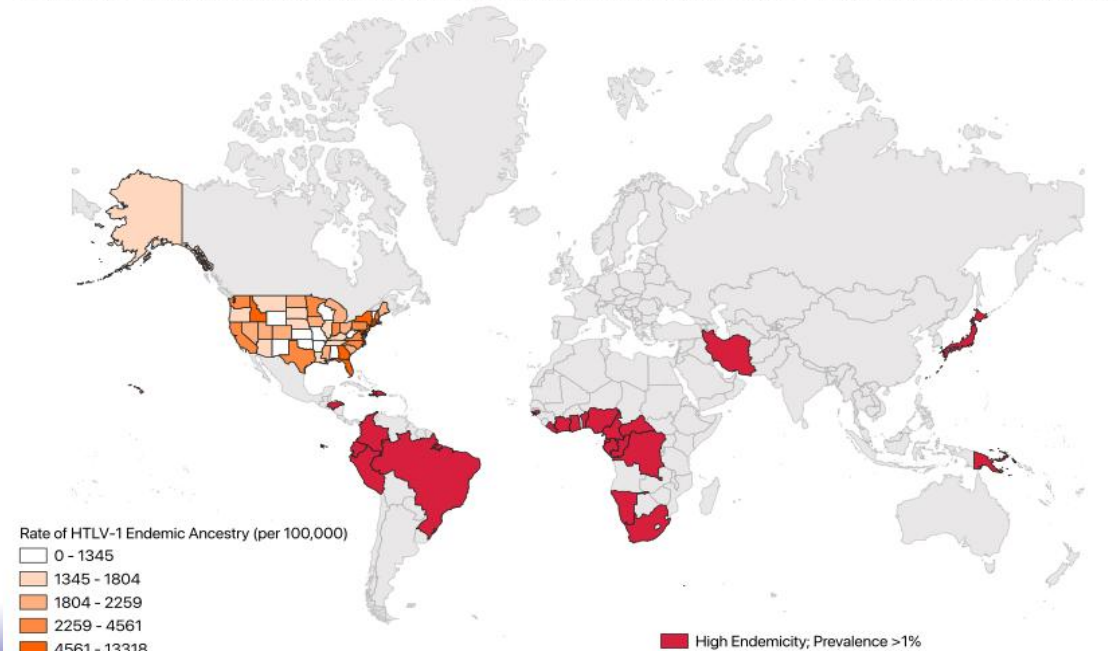
Epidemiology and Global Burden



- HTLV-1 is unevenly distributed worldwide and exists in endemic clusters.
- SW Japan has historically reported prevalence rates exceeding 10%.
- Afro-Caribbean populations show some of the highest reported rates worldwide (1-6%).
- Certain Polynesian/Melanesian populations have elevated HTLV-1 prevalence though surveillance remains limited.

Region/Country	Estimated HTLV-1 Prevalence (%)	Dominant Transmission Routes	Surveillance/Screening Practices	Key Notes
Jamaica	1-6	Vertical (breastfeeding), Sexual	Blood donor screening; limited antenatal	Higher prevalence in women/older adults
Haiti	2-5	Vertical, Sexual	Blood donor screening; minimal population surveillance	Sparse contemporary data
Trinidad & Tobago	1-2	Vertical, Sexual	Blood donor screening only	HAM/TSP clinically recognized
Martinique/Guadeloupe	1-5	Vertical, Sexual	Systemic surveillance (France)	Disproportionate literature coverage
Southwestern Japan (Kyushu/Okinawa)	4- 10	Vertical, Sexual	Nationwide antenatal screening	Declining incidence in younger cohorts
Pacific Islands (Papua New Guinea, Solomon Islands, etc.)	2-14	Vertical	Limited/no routine screening	HTLV-1 subtype C

Global HTLV-1 endemic regions and U.S. distribution of populations with ancestral or nativity links to endemic areas



- Globalization and migration has introduced HTLV-1 into non-endemic countries including the United States.
- Large diaspora populations from endemic regions now reside in major U.S. metropolitan areas.
- These populations are historically underrepresented in U.S. epidemiologic studies and highlight broader gaps in U.S. surveillance.

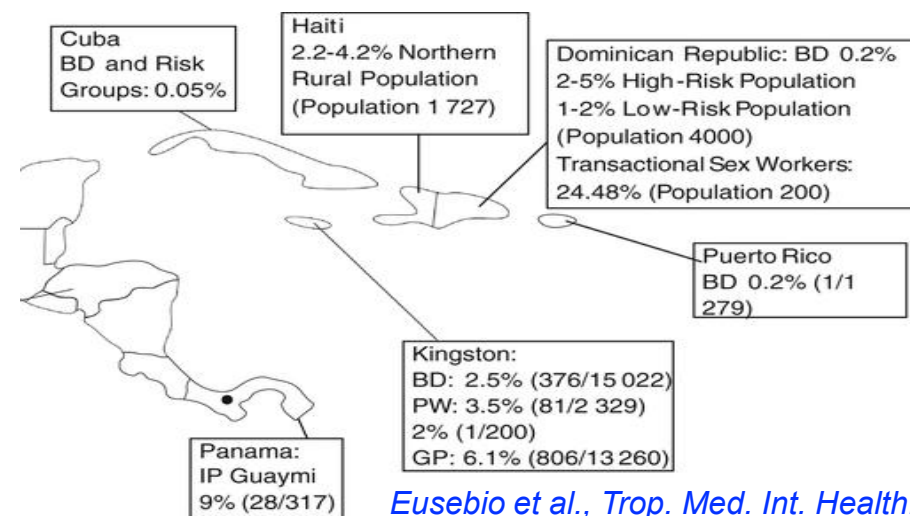


HTLV-1 in Afro-Caribbean Regions



- HTLV-1 is endemic throughout the Caribbean, with seroprevalence ranging from approximately 1-6% in countries including Jamaica, Haiti, the Dominican Republic ([Prioetti et al., Oncogene, 2005](#)).
- Molecular epidemiologic studies indicate that Caribbean HTLV-1 strains cluster with West/ Central African lineages, reflecting introduction during the transatlantic slave trade and sustained vertical transmission within Afro-descendant communities.
- Data across the Caribbean is uneven, with robust longitudinal surveillance in some territories (e.g., French Caribbean regions) but few population studies in independent nations.

Ancestry Group	Major U.S. Population Clusters	Endemic Region of Origin	HTLV-1 Screening in U.S.	Public Health Implication
Jamaican	NY/NJ, FL, MA	Caribbean	Blood donor only	Likely underdiagnosis
Haitian	NY, FL, MA	Caribbean	No antenatal screening	Ongoing vertical transmission risk
Dominican	NY/NJ, FL	Caribbean	No routine screening	Risk obscured by aggregation



Eusebio et al., Trop. Med. Int. Health, 2019

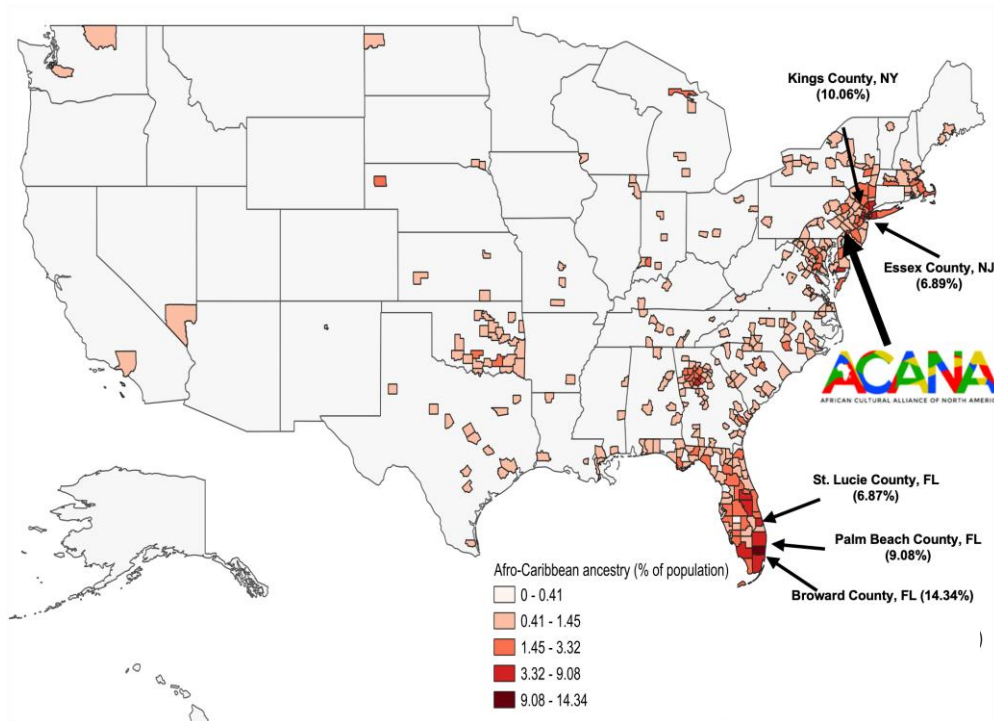
- U.S. Afro-Caribbean populations are concentrated in metropolitan regions such as New York/New Jersey, Florida, and Massachusetts, where HTLV-1 screening is not routinely performed.
- Absence of U.S. surveillance systems, antenatal screening, and ancestry-linked data collection likely results in substantial underdiagnosis of HTLV-1 among Afro-Caribbean immigrants and their descendants.
- Transmission in Caribbean populations is driven by mother-to-child transmission through prolonged breastfeeding and by sexual contact, rather than injection drug use. ([Gessain et al., Frontiers in Microbiology, 2012](#)).



HTLV-1 in U.S. Afro-Caribbean Populations



- Previous studies in cooperation with the African American Cultural Alliance of North America (ACANA) in Philadelphia showed low levels of initial knowledge about HTLV-1, but a sharp increase in knowledge following educational sessions (*Altieri et al., Viruses, 2025*).
- Future community-informed studies must take place to determine risk in communities and educate on potential malignancies.



HTLV-1 and ATLL: Epidemiology, Oncogenesis, and Opportunities for Community-Informed Research in the United States

Adrian Altieri ^{1 2}, Sean Patrick Reilly ^{2 3}, Abu Mansalay ⁴, Alan Soo-Beng Khoo ^{1 2},
Nettie Johnson ⁴, Zafar K Khan ⁵, Amy Leader ², Pooja Jain ^{2 5}, Pierluigi Porcu ^{2 3}

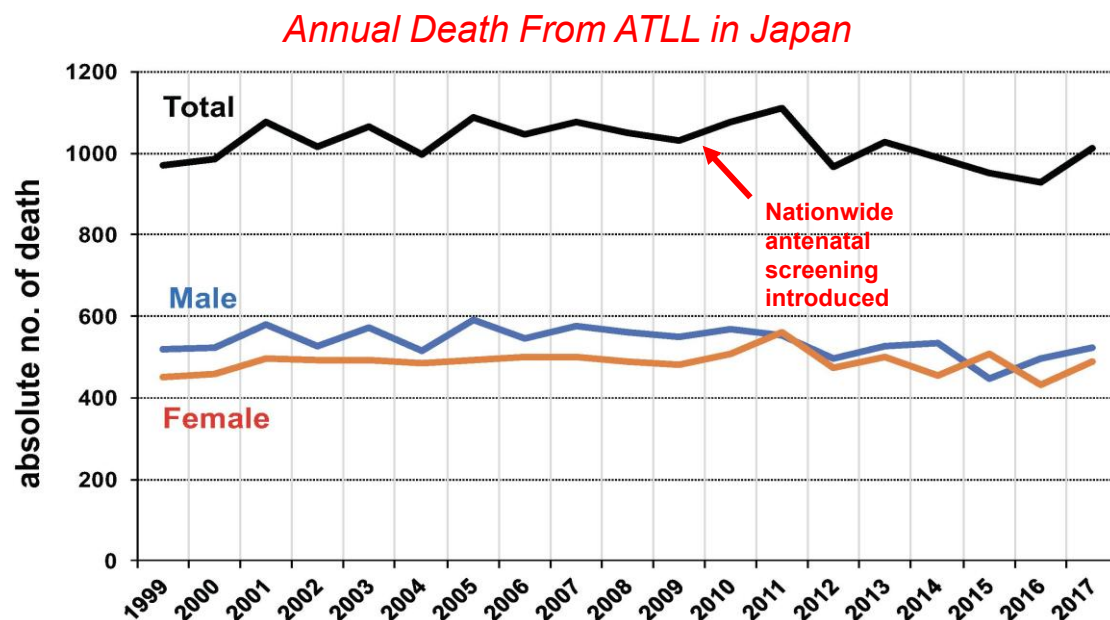
Question	Pre-Test Mean (SD)	Pre-Test IQR	Post-Test Mean (SD)	Post-Test IQR	Percentage of Participants Responding Yes
I have heard of HTLV-1	3.25 (1.59)	1.75-5.00	3.89 (1.37)	3.25-5.00	
I know how HTLV-1 spreads	2.61 (1.27)	1.50-3.00	3.90 (1.26)	3.00-5.00	
I know of ways to prevent HTLV-1 transmission	2.72 (1.45)	1.25-3.75	3.81 (1.24)	3.00-5.00	
I know where HTLV-1 is most common	2.46 (1.32)	1.00-3.00	3.97 (1.30)	3.00-5.00	
I know of screening tests for HTLV-1	2.54 (1.25)	1.00-3.00	4.03 (1.07)	3.00-5.00	
I have heard of ATLL	3.04 (1.27)	2.00-4.00	4.10 (1.02)	4.00-5.00	
I know of ATLL risk factors	2.48 (1.16)	1.00-3.00	4.10 (1.14)	3.75-5.00	
I can explain treatments for ATLL	2.38 (1.28)	1.00-3.00	3.87 (1.04)	3.00-5.00	
I am willing to participate in future research about HTLV-1?					80.77%



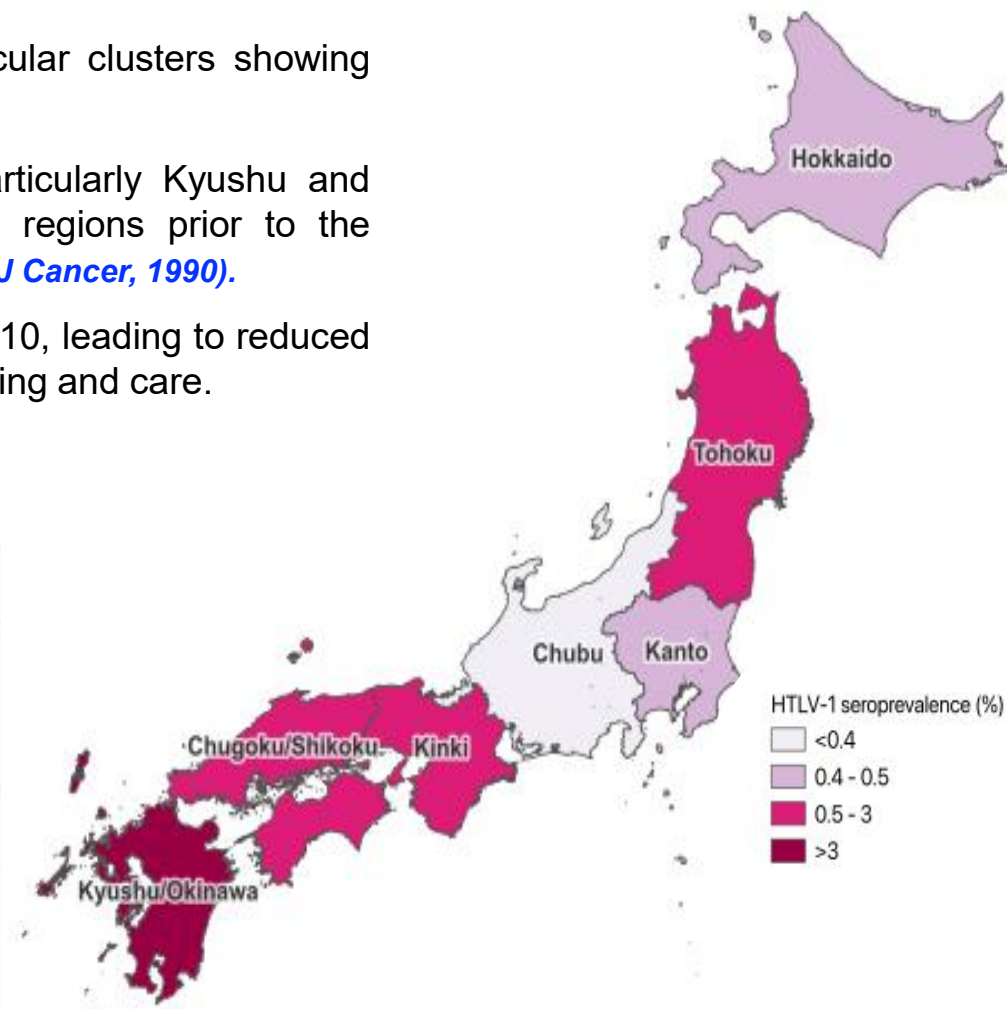
HTLV-1 in Japan



- HTLV-1 epidemiology in Japan is heterogenous, with particular clusters showing some of the highest seroprevalence globally.
- HTLV-1 is historically endemic to southwestern Japan, particularly Kyushu and Okinawa, where prevalence has exceeded 10% in some regions prior to the implementation of nationwide screening programs ([Tajima, Int J Cancer, 1990](#)).
- Japan introduced universal antenatal HTLV-1 screening in 2010, leading to reduced mother-to-child transmission and improved linkage to counseling and care.



Iwanaga, Frontiers in Microbiology, 2020



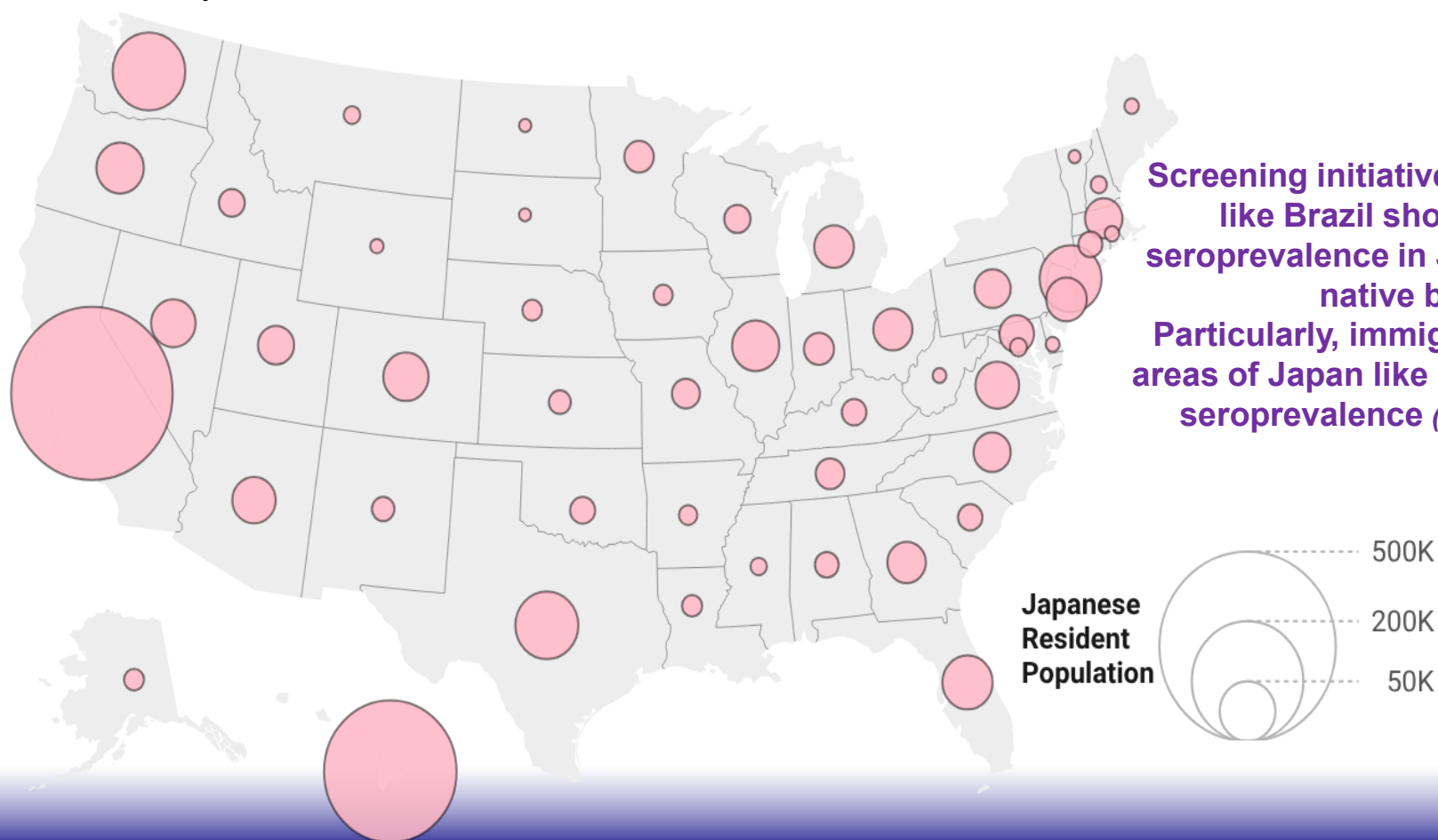
**Based upon the data from Satake et. al 2007*



HTLV-1 in U.S. Japanese Populations



- HTLV-1 infection among Japanese American communities is likely underrecognized until late-stage disease, including ATLL or neurologic complications.
- Japanese migration to Hawai'i and the U.S. West Coast has introduced HTLV-1 risk into U.S. settings that lack comparable screening or surveillance frameworks.
- Despite well-established endemicity in southwestern Japan, there is no targeted screening or surveillance in high-density U.S. communities like Hawaii and California.



Screening initiatives in non-U.S. countries like Brazil show significantly higher seroprevalence in Japanese Immigrants than native born individuals

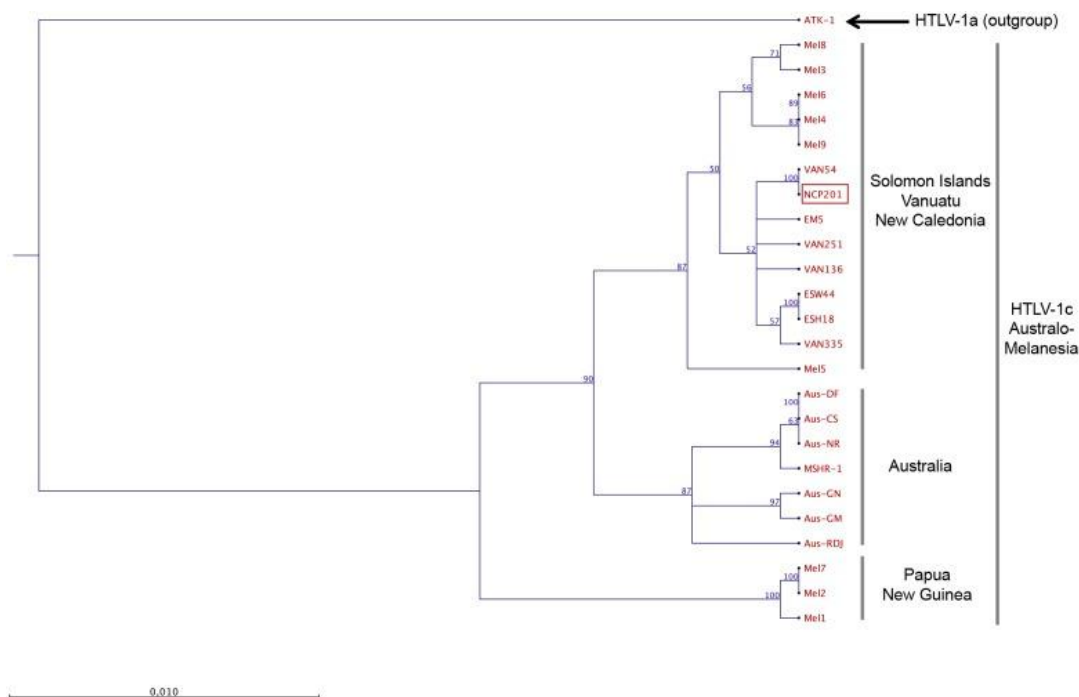
Particularly, immigration from southwestern areas of Japan like Okinawa maintained higher seroprevalence (Murphy, West J. Med., 1993)



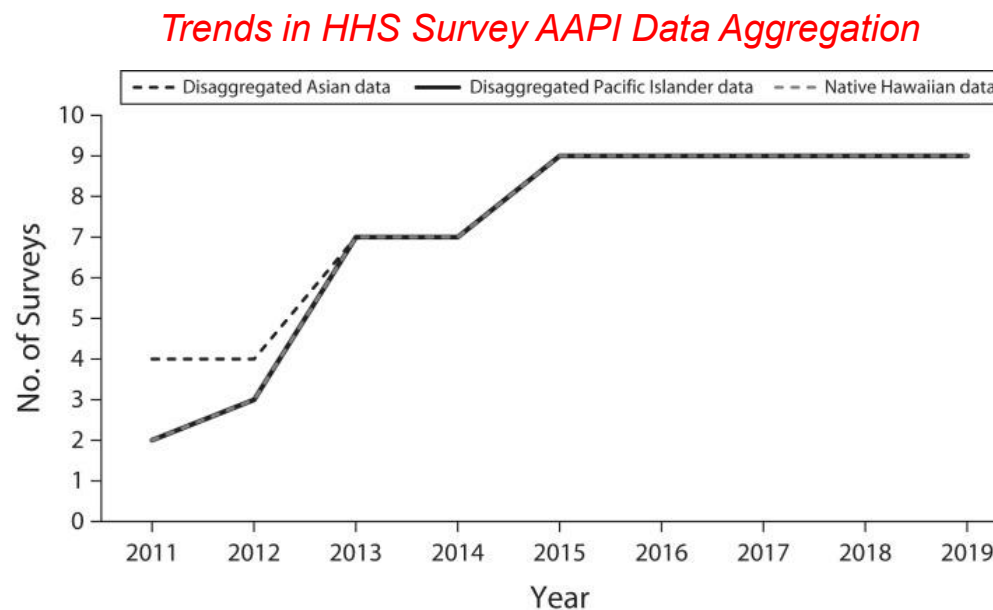
HTLV-1 in Southwest Pacific Regions and U.S. Pacific Islander Populations



- Pacific Islander populations face some of the highest global HTLV-1 prevalence rates, having its own subtypes, yet risk remains largely invisible in the U.S. due to absence of targeted screening and surveillance programs ([Einsiedel et al., PLoS Negl Trop Dis., 2021](#)).
- Aggregation of Pacific Islanders within broad “Asian American and Pacific Islander” data categories obscures HTLV-1 risk profiles and prevents development of culturally specific interventions.
- Limited antenatal screening access sustain vertical transmission and persistence of HTLV-1 in Pacific Islander communities.



Cassar et al., PLoS Negl Trop. Dis., 2017



Nguyen et al., APHA, 2022



Barriers to HTLV-1 Care in the U.S. – Provider & Surveillance Gaps



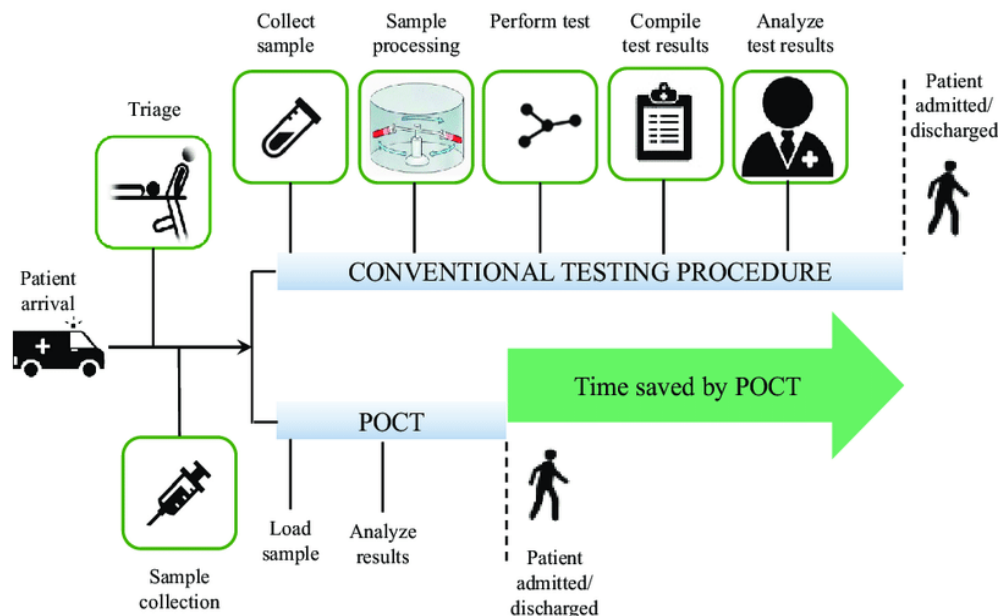
- HTLV-1 is rarely included in U.S. medical education, residency training, or clinical guidelines, resulting in low awareness among primary care providers, obstetricians, neurologists, and oncologists.
- Many clinicians are unfamiliar with HTLV-1 risk factors or confuse HTLV-1 with HTLV-2, leading to missed or dismissed opportunities for testing.
- HTLV-1 is not a nationally reportable disease in the United States, and no centralized surveillance or registry exists to track infections or outcomes.
- Current U.S. prevalence estimates rely heavily on blood donor screening, which was designed to protect the blood supply and does not capture community-level burden.
- In the absence of standardized screening guidelines or U.S. Preventive Services Task Force (USPSTF) recommendations, HTLV-1 testing is rarely performed in routine clinical care.



Mosquera et al., IJC, 2024



Barriers to HTLV-1 Care in the U.S. – Diagnostic & Access Gaps



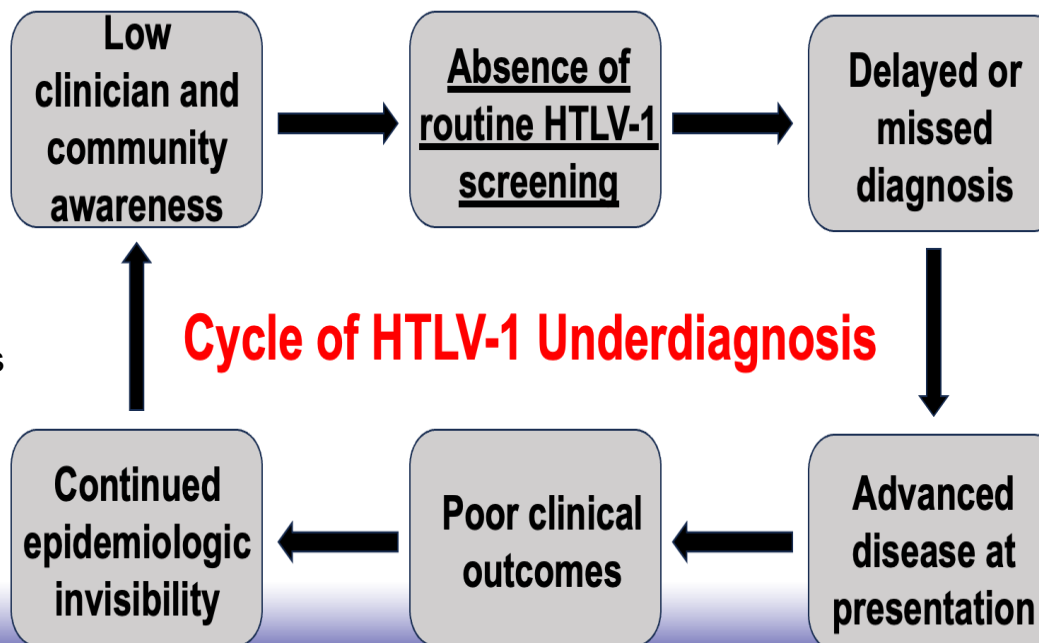
Srinivasan, Journal of Laboratory Automation, 2015

Access Barriers

- Inconsistent insurance coverage and reimbursement discourage clinicians from ordering HTLV-1 testing, particularly for underinsured patients.
- Access to specialty care for HTLV-1-associated conditions is concentrated in a small number of academic centers, creating geographic barriers to diagnosis and management.
- Geographic barriers force many patients, especially those in rural, island, or underserved urban communities, to travel long distances or forgo follow-up care.

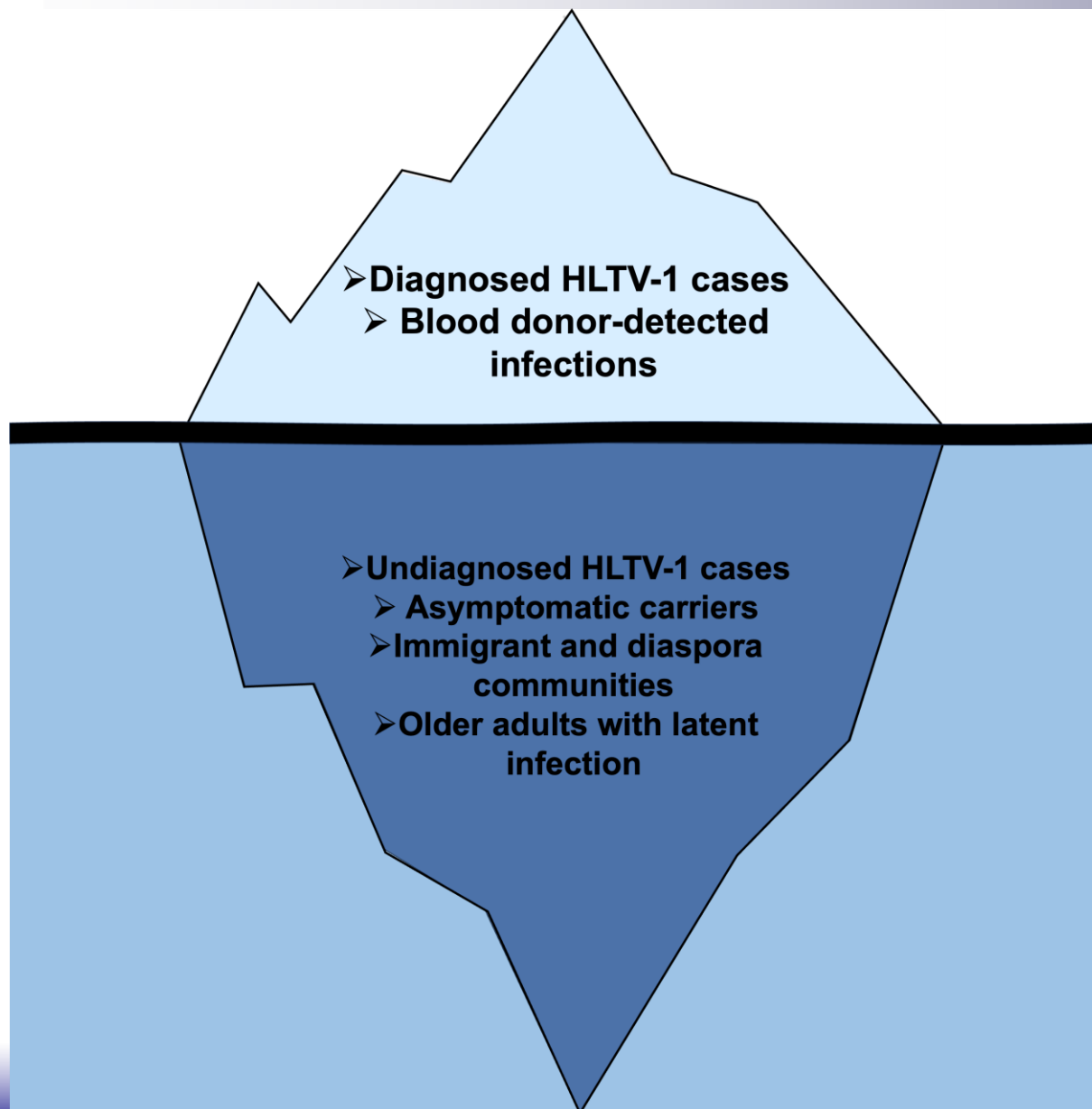
Diagnostic Barriers

- Standard HTLV-1 testing depends on laboratory-based serologic and confirmatory assays that are often unavailable in community clinics and safety-net healthcare settings.
- Confirmatory testing is frequently delayed or sent to reference laboratories, increasing loss to follow-up after initial screening.
- Limited availability of validated point-of-care or rapid HTLV-1 diagnostics restricts community-based screening and epidemiologic studies.





Barriers to HTLV-1 Care in the U.S. – Community & Structure Gaps



- Immigrant and minority communities at elevated risk for HTLV-1 may avoid healthcare engagement due to concerns related to immigration enforcement, documentation status, and data sharing.
- HTLV-1-associated stigma related to sexual and vertical transmission discourages testing, disclosure, and family-based screening.
- Language barriers and limited access to culturally concordant providers hinder effective communication about HTLV-1 risk and prevention.
- Pacific Islander populations are frequently aggregated within broader racial categories, obscuring HTLV-1 risk and preventing targeted public health interventions.
- Historical experiences of medical exploitation and exclusion contribute to mistrust of screening programs and research participation in affected communities.



Conclusions and Future Directions

- *HTLV-1 remains profoundly underrecognized in the United States due to reliance on passive detection strategies, including blood donor screening, rather than population-based surveillance.*
- *Ancestry-linked risk among Afro-Caribbean, Japanese, and Pacific Islander populations is obscured by absence of routine screening, aggregation of demographic data, and limited clinician awareness.*
- *Long asymptomatic latency, combined with lack of antenatal and primary-care testing, contributes to delayed diagnosis and frequent presentation with advanced HTLV-1-associated disease.*
- *International models demonstrate that targeted screening and community-based approaches reduce transmission and improve detection, showing missed opportunities within U.S. public health framework.*

Road ahead.....

- *Implement ancestry-informed, community-based HTLV-1 screening initiatives using low-cost, point-of-care diagnostics in high-risk U.S populations*
- *Integrate HTLV-1 testing into existing clinical touchpoints, including prenatal care, HIV/HBV clinics, and neurology/hematology pathways*
- *Leverage lessons from international HTLV-1 programs to inform U.S. policy development, clinician education, and equitable inclusion in clinical research*



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ACANA

Abu Mansalay, PhD

Netti Johnson, PhD



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Strengthening community engagement to advance HTLV public policies in Brazil: from invisibility to national representation

Jair Brandão de Moura Filho, Ministry of Health of Brazil

Conflicts of interest

I have no conflicts of interest

Background

- It is estimated 800,000 people are living with HTLV (PLWHTLV) in Brazil
- HTLV has historically remained neglected within public health agendas, with limited awareness among health managers, healthcare professionals, and civil society organizations (CSOs)

This descriptive case report summarizes national initiatives aimed at promoting HTLV visibility and community engagement.



Opening session of the workshop on HTLV, in Belém 2024.

Results

- Between 2023 and 2024, seven state-level workshops were conducted, bringing together health managers, healthcare providers, researchers, and Civil Society Organizations representing both PLWHTLV and key populations.



Presentation of the HTLVida social movement's experience and discussion with other social movements in São Luís 2023

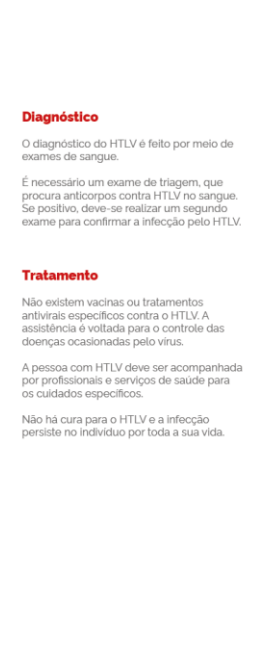
State HTLV Workshops “Coming Out of Invisibility”

- Purpose
 - Raise awareness among health workers and civil society about actions to promote, prevent and care for people with HTLV;
 - Promote the sharing of community experiences of people living with HIV/AIDS, Tuberculosis, Viral Hepatitis, and HTLV.
- Target audience
 - Managers and health workers from HIV/STI testing centers and specialized care services;
 - Civil Society Organizations focused on HIV/AIDS, Tuberculosis, Viral Hepatitis and other STIs, and other CSOs representing vulnerable populations (Black population, LGBTQIA+, sex workers, etc.).

No	Local		Date	Number of participants
	State	City		
1	Maranhão	São Luís	August 8th, 2023	49
2	Pará	Belém	June 14th, 2024	46
3	Paraíba	João Pessoa	July 10th, 2024	35
4	Rio Grande do Norte	Natal	August 07th, 2024	39
5	Piauí	Teresina	August 13th, 2024	44
6	Espírito Santo	Vitória	September 17th, 2024	68
7	Pernambuco	Recife	October 30th, 2024	59
			Total	340

We propose 50–80 participants per workshop to encourage more qualified and productive discussions among participants

The materials delivered at the workshops are:



Folder with HTLV information about:

- What is HTLV
- Signs and symptoms

- Forms of transmission
- Diagnosis
- Treatment
- Prevention

And the Pin of HTLV

Some Pictures of the Workshop:

Maranhão (São Luís)



Pará (Belém)



Piauí (Teresina)



Paraíba (João Pessoa)



Rio Grande do Norte (Natal)



Espírito Santo (Vitória)



Pernambuco (Recife)



Results

- In 2025, during the International HTLV Symposium, the Civil Society Organization HTLVida, in partnership with Ministry of Health of Brazil and the State Health Department organized a national meeting of PLWHTLV held one day prior to the symposium.
- This event marked the creation of the **National Network of People Living with HTLV (RNPHTLV)**



Results

One of the main priorities of the President of Brazil is community engagement. In the context of HTLV, people living with HTLV are at the center of policy development and decision-making processes, including participation in advisory and decision-making committees.



Conclusion

HTLV Workshops “Coming Out of Invisibility”

- In 2026, for all states were offered the opportunity to participate in a workshop, with the organization and execution of the events currently underway.
- Promoting social participation has proven essential to accelerating the implementation of HTLV public policies and elevating HTLV as a public health priority in Brazil, demonstrating the value of collaboration **between government, science, and civil society.**



22nd International Conference on Human Retrovirology:
HTLV and Related Retroviruses
HTLV2026

June 3-6, 2026 | Philadelphia, Pennsylvania, USA



Thank you. Obrigado!

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Jair Brtandão

On behalf of...



Mayra Aragon



Adijane Oliveira de J.



Márcia C. Brandão



Pâmela C Gaspar



Draurio Barreira



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XVIII Simpósio Internacional
sobre HTLV no Brasil

HTLV

26 a 28 de outubro de 2027
Belo Horizonte, MG, Brasil

Pre-events start in October 24th 2027

