

Chagas Disease in the Americas Improving Access and Tools for Patient Diagnosis

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Los Angeles, California

Medecins Sans Frontieres/Doctors Without Borders
Drugs for Neglected Diseases Initiative (DNDi)
UCLA Program in Global Health

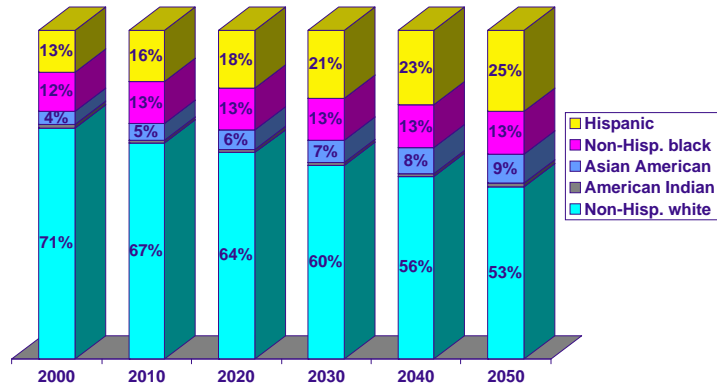
Presentation by:
The National Alliance for Hispanic Health

About the Alliance...

- **Mission:** To improve the health and well-being of Hispanics.
- Dedicated to community-based solutions.
- Largest network of Hispanic health and human service providers serving over 14 million people every year.
- Nation's foremost information source and advocate for the health of Hispanic communities.
- Broad range of Alliance members (e.g. national organizations, community groups, universities, for-profit corporations, individuals).



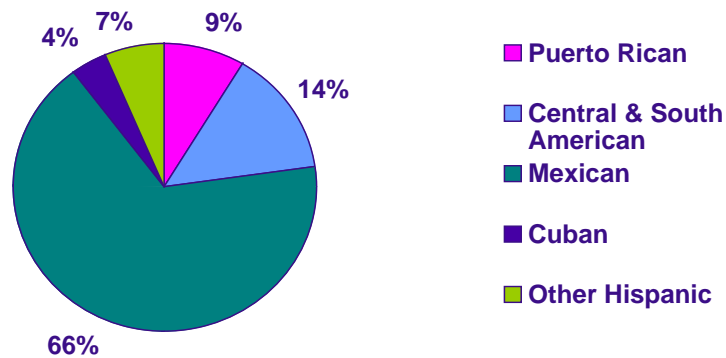
U.S. Population Composition



Source: U.S. Bureau of the Census. (2000 data for 50 states and D.C.) National Population Estimates – Characteristics, Jan. 21, 2003. (2010-2050 data for 50 states and D.C.) Projections of the Resident Population by Race, Hispanic Origin, and Nativity: Middle Series, Feb. 14, 2000 (revised). (2000-2050 data for Puerto Rico) Census International Data Base, Puerto Rico Total Mid-year Population 2000-2050; Dec. 31, 2001 (revised).

Note: Figures include the Commonwealth of Puerto Rico. American Indian proportion is less than 1 percent.

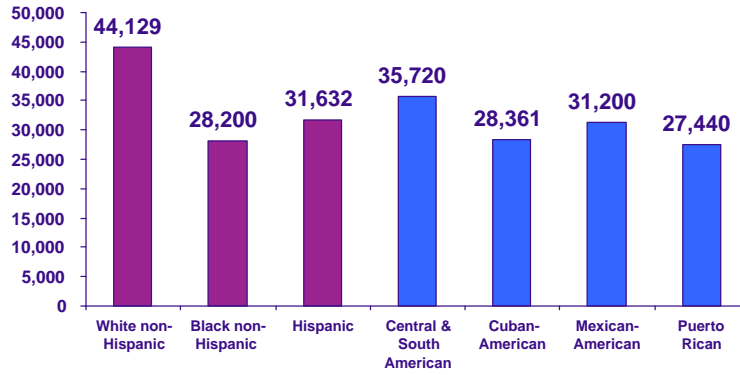
U.S. Hispanic Population by Origin



Source: U.S. Census Bureau. The Hispanic Population in the United States: March 2002. Current Population Reports, P20-545. Issued June 2003.

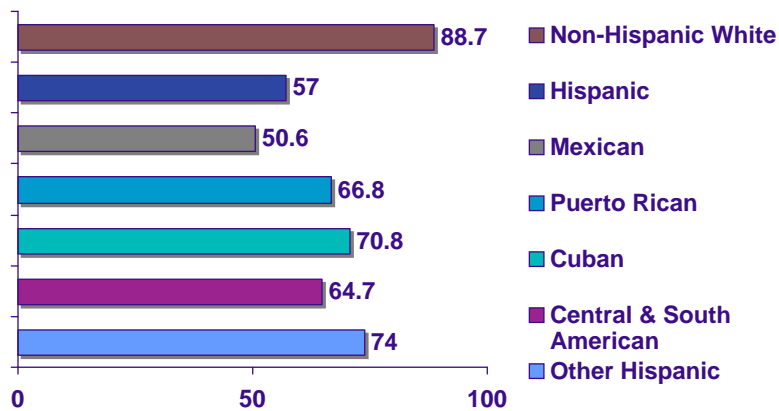
Note: Data does not include the Commonwealth of Puerto Rico.

Median household income by race/ethnicity and Hispanic origin



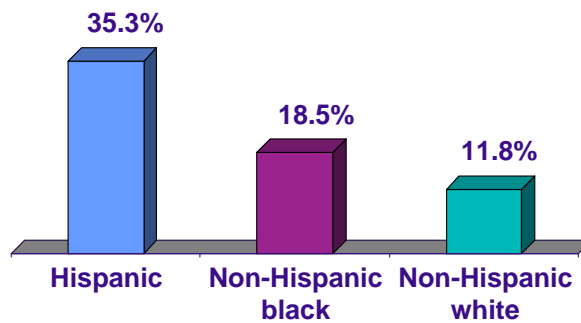
Source: National Alliance for Hispanic Health. "A Dream Deferred: Health Insurance and Hispanic Working Uninsured." in press. Analysis of March 2000-2002 combined Current Population Survey conducted by Dr. Sherry Glied, Columbia University School of Public Health, 2005.
 Note: Data set to 2001 dollars using Bureau of Labor Statistics Consumer Price Index.

Percentage of Population with at Least a High School Education, 2002



Source: U.S. Census Bureau. The Hispanic Population in the United States: March 2002. Current Population Reports, P20-545. Issued June 2003.
 Note: Data does not include the Commonwealth of Puerto Rico.

Percentage of working adults who are uninsured (18-64 years old)



Source: Centers for Disease Control and Prevention. 2003 Behavioral Risk Factor Surveillance System, Uninsured Surveillance, April 2005.
Note: Data does not include the Commonwealth of Puerto Rico.

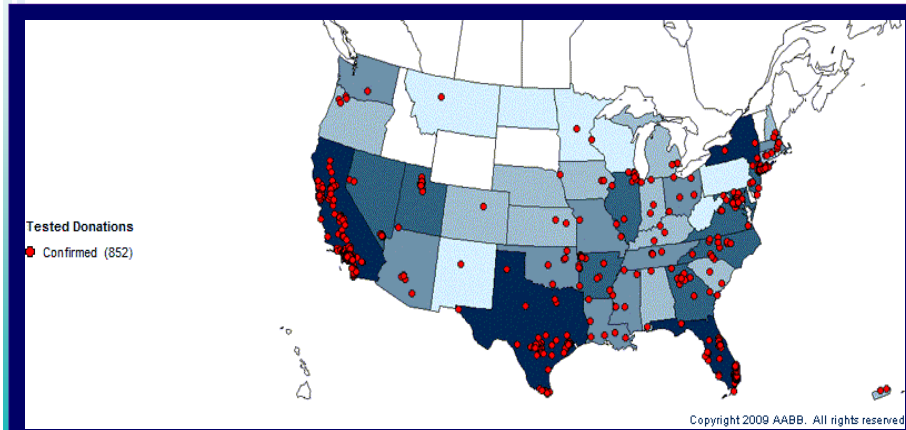
Chagas Disease Initiative (CDI)

In 2008, National Alliance for Hispanic Health received a grant from CDC to assess levels of knowledge about Chagas among:

- Hispanics/Latinos in the U.S.
- Health care providers serving Hispanics/Latinos



Chagas Disease in the United States



Source: <http://www.aabb.org/> (2009)

Methodology

- Conducted four (4) focus groups with Hispanic healthcare consumers
- Conducted four (4) focus groups with healthcare providers serving Hispanics/Latinos
- Total of 65 participants: 37 consumers and 28 providers
- Locations selected based on findings from blood donation screenings: Chicago, IL; Homestead, FL; Phoenix, AZ; Watsonville, CA
- Demographic information obtained through simple written survey

Demographic Information for Focus Group Participants

Consumers:

- Majority Mexican females aged 31-40 years
- Average time in the U.S. 6-15 years
- Reported best outreach method was educational materials in clinics

Providers:

- Mexican American females
- Reported never diagnosing or reporting Chagas
- Unaware of blood screenings and treatment options
- Would attend workshop or online training

Discussion Group Results:

Knowledge

Findings were similar for both healthcare consumers and healthcare providers:

- Majority had little, if any, knowledge about Chagas.
- Majority had never heard the various names used in Latin American countries for Chagas.
- Majority had never known someone with Chagas.
- No consumers and majority of healthcare providers unaware of health consequences.

Discussion Group Results: **Knowledge**

- No consumers and majority of healthcare providers did not know about blood screening guidelines
- Majority of consumers and majority of healthcare providers stated that Chagas was not as important as other health concerns (specifically, diabetes, HIV/AIDS)
- Majority of healthcare providers did not know about treatment options
- No healthcare provider had ever diagnosed a case of Chagas

Discussion Group Results: **Outreach and Education**

- Consumers and providers agreed that clinics, churches, and media provided good outlets for messages about Chagas disease.
- Also agreed that messages should be provided in both English and Spanish
- Preferred spokespersons for consumers included healthcare providers, an informed person who is also a member of the community as messengers
- In addition to above, providers also suggested health educators, family members, and celebrities as messengers

Discussion Group Results: Outreach and Education

- When asked about the best way to educate community members about Chagas disease, consumers indicated healthcare professionals or an informed and respected community member.
- Providers preferred a top-down approach, with providers learning about Chagas disease, then informing consumers

Recommendations

- Ensure that blood banks have bilingual staff available to address the needs of persons with Limited English Proficiency (LEP) (this can be achieved by working together with community)
- Work with blood collection agencies to develop effective educational materials to be given to persons with LEP who test positive for Chagas disease. Will this fuel anti-immigrant sentiment, creating even more fear?
- Develop an effective bilingual on-line training for health care professionals on Chagas disease, including information about infection, prevention, and treatment of the disease.

Recommendations Cont.

- Training on Chagas disease should be targeted to health care providers working in community clinics, Federally Qualified Health Centers, and migrant clinics serving clients of Central and/or South American origin.
- Consumers who test positive for Chagas disease should receive detailed information from their
- health care providers regarding the risks and benefits of Chagas disease treatment.

Fear Over Chagas Being Used to Fuel Anti-Immigrant Sentiment in US Expressed in all Four Communities

Myrta stated, **“This worries me because we are involved in the U.S. politics, and the government is trying to make us a target that we bring diseases that they do not have here. I am worried because we can be seen as another way to place blame on Latinos, that we are invading their country and they need to get rid of us all.”**

Rosa Julia, N.P. stated, **“extremely concerned that Chagas would be a factor to target Latinos but would also be a factor in exclusion from entering the U.S. or citizenship...just another reason why Latinos should not be allowed to come here.”**

Special Thanks to:

- Alivio Medical Center in Chicago, IL;
- *Concilio Latino de Salud* in Pheonix, AZ;
- Community Health of South Dade, Inc., Everglades Health Center, in Florida City, FL; and,
- *Salud Para La Gente* in Watsonville, CA.

Thank you!

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