



HEARTLAND  
GENETICS SERVICES  
COLLABORATIVE

# Hispanic Access Project

Presenters: Mary Ann Coffman and Gene Hallford

# Story of Delayed Referral

- ▶ Child was diagnosed at 10 years of age with a progressive lysosomal storage disease.
- ▶ He started manifesting speech delays that was brought up by the head start teacher.
- ▶ Child was receiving services from pediatricians, specialists, psychologists and school staff since the age of 4 (most likely younger).
- ▶ Mom knew something was “wrong” and kept on changing pediatricians. She also felt isolated and helpless. She could only speak Spanish.
- ▶ The family network coordinator encouraged her to ask the pediatrician for a referral to genetic services.

## Story of Delayed Referral (cont.)

“the geneticist told me to live one day at a time, my child is calm, I am calm...before this (visit with geneticist) I wanted to do it my way because it isn't easy, to understand that one has a special child. Now, I don't do it my way. I do it his way, and it's like we live a softer life, calmer...”

# Hispanic Population Growth

- ▶ The combined US population rose by nearly 10% but Hispanic population grew by more 15 million (43%).
- ▶ The majority of this growth occurred in two regions, the Midwestern (which include KS, MO, NE, SD, ND and IA) with a 49% increase and the southern (which include OK and AR) with a 57% increase.
- ▶ The rate of population increase among Hispanics in the Heartland states averages more than 83% ranging from 114% in Arkansas to 59% in Kansas. The rate of changes are higher than the national average of 43%.

*From 2000-2010 (US Census Bureau 2011b)*

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Table 1

**Growth in Hispanic Population among  
10 Fastest Growing Hispanic States,  
2000-2011**

<b>State</b>	<b>Population in 2000</b>	<b>Population in 2011</b>	<b>% Change, 2000-2011</b>
Alabama	72,152	186,209	158
South Carolina	94,652	240,884	154
Tennessee	116,692	296,266	154
Kentucky	56,922	132,267	132
South Dakota	10,101	23,158	129
Arkansas	85,303	190,192	123
North Carolina	377,084	828,210	120
Mississippi	37,301	81,088	117
Maryland	230,992	488,943	112
Georgia	434,375	879,858	103

Notes: The states shown are the 10 largest by percent change in Hispanic population from 2000 to 2011. The overall U.S. Hispanic population grew 47.5% from 2000 to 2011.

Source: Pew Research Center tabulations of the 2000 Census (5% IPUMS) and 2011 ACS (1% IPUMS)

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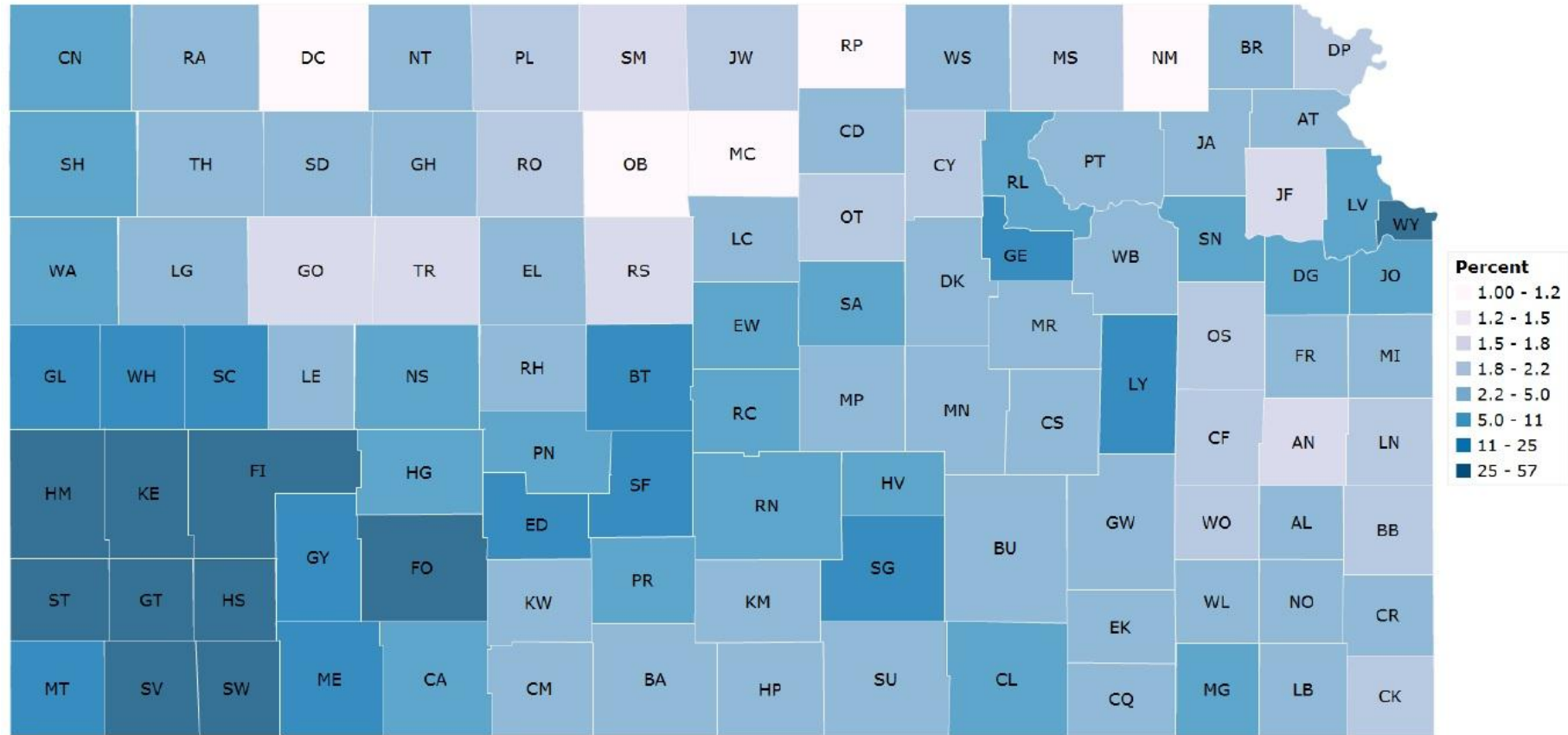
# Latinos as Percent of Population per State 2011

State	Hispanic Population	Hispanic as % of state population	Hispanic births as % of all state births	% of Hispanics that speaks a language other than English at home
Oklahoma	347,000	9%	12%	65%
Kansas	307,000	11 %	15%	66 %
Nebraska	174,000	9%	15%	71%
Arkansas	190,000	6%	11%	76%
Iowa	154,000	5%	8%	66%
Missouri	214,000	4%	6%	56%
South Dakota	23,000	3%	n/a	n/a
North Dakota	15,000	2%	n/a	n/a

# Hispanic Natality

States	2000			2010			2013		
	All Births	# of Hispanic Births	% of Hispanic of all Births	All Births	# of Hispanic Births	% of Hispanic of all Births	All Births	# of Hispanic Births	% of Hispanic of all Births
Oklahoma	53,238	4,357	8.7	53,238	6,931	13	53,369	7,208	13.5
Kansas	40,649	4,761	12.0	38,719	6,428	15.8	38,839	6,143	15.8
Missouri	76,759	2,661	3.4	76,759	4,334	5.6	75,296	3,931	5.2
Arkansas	38,540	2,335	6.1	38,540	4,047	10.5	37,832	3,834	10.1
Nebraska	25,918	2,589	9.5	25,918	3,943	15.2	26,095	3,895	14.9
Iowa	38,719	2,135	5.6	38,719	3,092	7.9	39,094	3,175	8.1
South Dakota	11,811	223	2.1	11,801	506	4.2	12,248	521	4.2
North Dakota	9,104	125	1.6	9,104	303	3.3	10,599	436	4.1

# Resident Population: Hispanic or Latino Origin 2010





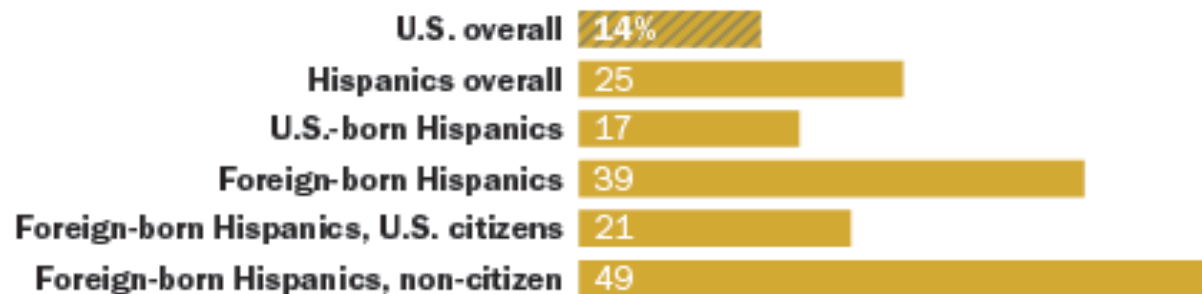
# Hispanic Children with Special Health Care Needs

Percentage of Children with Special Health Care Needs (CSHCN) in 2009/2010	USA	Heartland Region
CSHCN Total	15.1%	15.7%
Hispanic CSHCN	11.0%	11.7%
Hispanic CSHCN in an English Language Household	14.4%	16.2%
Hispanic CSHCN in a Spanish Language Household	8.2%	7.3%

*The National Survey of Children with Special Health Care Needs Chartbook 2009-2010 (June 2013)*

## Hispanic Immigrants More Likely than U.S.-born To Lack Health Insurance

*Percent without health insurance in 2014*



### U.S.-born Hispanics by age:



### Foreign-born Hispanics by age:



Note: Respondents were asked if they currently had health insurance.

Source: Pew Research Center analysis of March 2014 Current Population Survey

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# Heartland's Observations

- ▶ The number of Hispanic children served at the genetics clinics did not accurately reflect the Hispanic demographics of the community.
- ▶ Genetic service providers expressed concerns that the Hispanic children's first visit was later than the average child and were many times lost to follow-up.
- ▶ Genetic service providers expressed the concerns about the lack of bilingual providers, appropriate translation services and literature written in Spanish at the genetics clinics.

# Heartland's Questions

- ▶ What are the barriers to accessing genetic services?
- ▶ What can genetic service providers do to provide culturally competent quality care for Hispanic patients?

# How do we begin to answer these two questions?

- ▶ By designing a qualitative research project involving a collection of in depth interviews in Spanish of families from the Hispanic community who are caregivers or adults with a genetic condition.
  - ▶ Key informants
  - ▶ Advisory committee

# Key Informants

State	Organizations
Oklahoma	<ul style="list-style-type: none"><li>▪ Latino Community Development Center</li><li>▪ Oklahoma University Latino Clinic</li><li>▪ Oklahoma Family Network</li><li>▪ Oklahoma State Department of Health (Epidemiology)</li><li>▪ Oklahoma University Health Sciences Center (Genetic Services)</li><li>▪ Hispanic Down Syndrome Association of Central Oklahoma</li><li>▪ Oklahoma State Genetics Coordinator</li></ul>
Kansas	<ul style="list-style-type: none"><li>▪ Kansas Department of Health and Environment (Epidemiology)</li><li>▪ Families Together Inc.</li><li>▪ Farm Worker Health Program</li><li>▪ Wesley Medical Center Wichita (Genetic Services)</li><li>▪ University of Kansas Medical Center (Genetic Services)</li><li>▪ Children's Mercy Hospital (Genetic Services)</li><li>▪ Kansas State Genetics Coordinator</li></ul>
Arkansas	<ul style="list-style-type: none"><li>▪ University of Arkansas for Medical Sciences (Genetic Services and other faculty)</li><li>• Arkansas Disability Coalition (Minority Outreach)</li><li>▪ Arkansas Reproductive Health Monitoring System</li><li>▪ UAMS Medical Home Latino Clinic</li><li>▪ Arkansas State Genetic Coordinator</li></ul>
Nebraska	<ul style="list-style-type: none"><li>▪ Parent Training Information</li><li>▪ Munroe-Meyer Institute, University of Nebraska Medical Center (Genetic Services)</li><li>▪ Nebraska State Genetic Coordinator</li></ul>

# Heartland's Hispanic Access Advisory Committee

Name	State	Title
Graciela Sharif	NE	Outreach Coordinator, PTI Nebraska
Bridget Cannon- Hale	NE	Executive Director, PTI Nebraska
Carmen Paniagua	AR	Nurse Practitioner, Advanced Practice Nurse Geneticist, Department of Emergency Medicine University of Arkansas for Medical Sciences
Eduardo Ochoa	AR	Pediatrician, Medical Home Latino Clinic and University of Arkansas for Medical Sciences
Klaas Wierenga	OK	Medical Geneticist, Heartland Co-Director, Oklahoma University Health Sciences Center
Erica Herrera	OK	Family Support Coordinator, Oklahoma Family Network
Joni Bruce	OK	Executive Director, Oklahoma Family Network
Maria Santillan	KS	Minority Outreach Coordinator, Families Together, Wichita Kansas
Lola Laredo	KS	Outreach Coordinator, Families Together
Shobana Kubendran	KS	Genetic Counselor, Wesley Medical Center Wichita
Jennifer Roberts	KS	Genetic Counselor, University of Kansas Medical Center Kansas City
Janda Jenkins	MO	Genetic Counselor, Children's Mercy Hospital Kansas City

# Barriers identified through key informants

- ▶ Genetic services
- ▶ Language
- ▶ Translation services in genetics clinics
- ▶ Poverty and educational barriers
- ▶ Transportation
- ▶ Fear
- ▶ Cultural



# Qualitative Research Project

- ▶ Based on this preliminary information which was provided by the key informants, the qualitative research study was designed.
- ▶ The study was approved by the IRB from UAMS on April 2014.

# Design & Methods

- ▶ Initial Discussions with Mary Ann About Project:
  - ▶ Project Based on Informal Interviews with Community Leaders
  - ▶ Need for Systematic Data Collection
  - ▶ Need Clearly Defined Goals
  - ▶ Identification of Best Research Method to Achieve Goals
  - ▶ Identification of Study Population
- ▶ Qualitative Approach, Open-Ended Interviews
- ▶ Spanish Only Interviews, with Thematic Analysis of Spanish Transcripts
- ▶ Number of Interviews Increased to Allow Within/Between State Comparison.

# Data Quality and Integrity

- ▶ Initial Concern that Informal Interview Results Might Bias Data :
  - ▶ Careful Construction of Study Questions and Question Review
  - ▶ Creation & Training of Interview Team
  - ▶ Review of Initial Interviews to Detect and Correct Bias
- ▶ Concerns Over Word Meaning, Language Use, and Translation
  - ▶ Potential Interpretation & Translation Differences Discussed at Analysis Sessions
  - ▶ Use of Dr. Obregon-Tito as Transcriptionist and Outside Interpreter
- ▶ Each Transcript Analyzed by Research Team, Then Analyzed by State
- ▶ Themes Identified, Grounded Theoretical Methodology Applied, Working Hypotheses are being Formulated, to be used for Future Analyses

# Recruitment of families and coordination

- ▶ Recruitment was done in partnership with the family networks, Hispanic outreach coordinators and health professionals that serve the Hispanic community.
  - ▶ Oklahoma: Oklahoma Family Network
  - ▶ Nebraska: PTI of Nebraska
    - One World and PTI
  - ▶ Kansas: Families Together
    - EL Centro
    - The Center of Advanced Fetal Medicine KUMC
    - Bilingual Genetic Counselor
    - Project Eagle KUMC
- ▶ Coordination of family interviews took a lot of telephone calls and time for both our collaborating partners and the Heartland staff

# Interviews

- ▶ Interviews were conducted in:
  - ▶ Oklahoma City, OK: 8 interviews
  - ▶ Omaha, NE: 10 interviews
  - ▶ Kansas City and Wichita, KS: 8 interviews
- ▶ These were conducted in-person and in Spanish by the study coordinators.
- ▶ Interviews were recorded and lasted from 2 to 3 hours.
- ▶ The locations included homes, family network facilities, and public libraries.

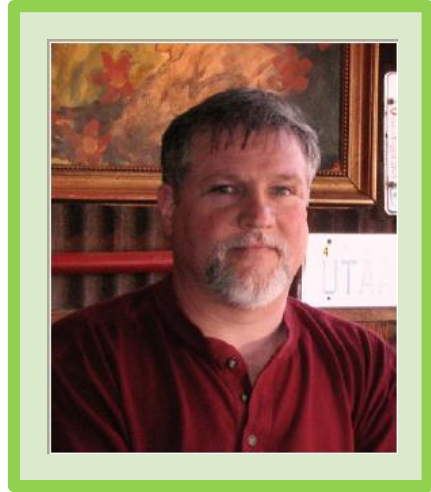
# DATA ANALYSIS

- ▶ All interviews have been transcribed in Spanish.
- ▶ Interviews are being analyzed in Spanish.
- ▶ Oklahoma and Nebraska interviews have gone through the first analysis.
- ▶ Analysis is done through a team approach (telephone calls).

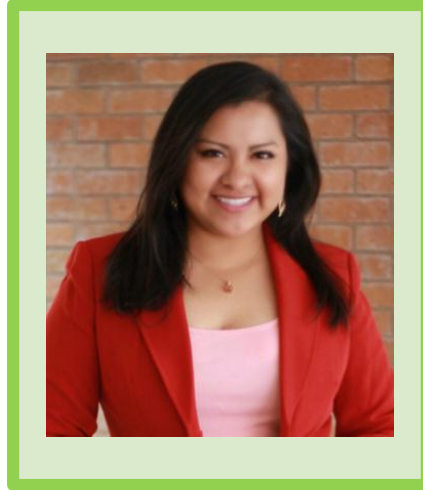
# Meet the Team



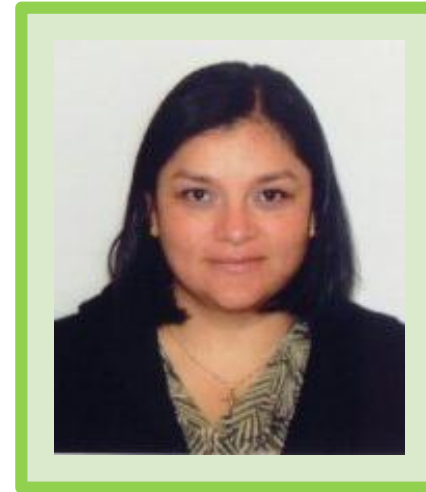
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Medical Sciences

# Hispanic Access Project: Team Approach





# Themes...thus far

- ▶ Variability of translation services, including modality and the integrity of the translation.
- ▶ Lack of genetic knowledge and understanding of the need for genetic services.
- ▶ Families expressing dissatisfaction with services with regard to how the provider treated them and not the quality of services.
- ▶ The critical role of the Hispanic family network coordinators and the bilingual early intervention staff plays in empowering the families to being proactive in seeking medical and financial services.

# Recommendations for 2015-2016

- ▶ Complete the data analysis.
- ▶ Reconvene the advisory committee.
- ▶ Address the availability of education/information resources to explain services and inheritance in a meaningful way.
- ▶ Assess the impression of many interviewees asserting that interpretation services are not always accurately translating the conversation.
- ▶ Assess the role of the health services and family support systems that has the most contact with the Hispanic families.

# VEIL OF GRATITUDE

*¡Muchas*



*Gracias!*

Questions

