Community Engagement

The Story of Heartland with the Latino Community
DISCLAIMER

Hispanic!
or
Latino!
or
LatinX!
How It Began: With the community!

- Clinical Geneticist
  - Hispanic children were coming to clinic later than most.
- A qualitative research project was implemented to identify the barriers to access to genetic services
- Our journey into the Latino communities began!
  - 26 families in Oklahoma, Kansas and Nebraska were interviewed
  - Found families with genetic conditions though Latino family support coordinators, genetic counselors, nurses, community agencies, day cares etc.
“In our culture we are very physical, we like to be greeted, ......[We need to] trust them and to tell them more about what is happening with the child. They should not be putting their hand on the doorknob ready to leave, or talking to the family while writing. ..... Look him in the eye, right? And show interest, and ask what the child is doing. Oh yes, greet the child too, do not ignore [her] even if it is special, looks different. Greet the child many times, and when they greet our children, we feel 100% better than we came in. ... Because we are seeing that the provider has an interest in curing him ....but also has a personal interest.”
Why Genetics? I don’t worry about genetics. I worry about my child. I worry about my other children. Our day-to-day life is hard taking care of our son. Our life is about medical appointments, physical therapy, speech therapy dealing with the school. Just taking care of him every day, like dressing him, changing his diaper and other things. I work long hours to cover his expenses as my wife takes care of everything else. We are exhausted. And genetics is a very small part our lives.
Barriers

- Delayed Referrals
- Relevance of Genetic Services
- Communication
- Expectations of Medical Care
- Information Delivery
- Community Programs
- Culture

7 factors that influence Spanish-speaking families’ access to genetics care
What is Working? (Bridge)

COMMUNITY

- Many Spanish speaking families live in the same communities
- Many visit the same clinics
- Family networks
- Home visiting programs
- Social networks
- Support groups
Early Intervention and Parent to Parent Networks

- Families learn about genetic services and other services through the Hispanic coordinators from the Parent-to-Parent Networks
- Families form strong and trusting relationships with the Hispanic coordinators.
- Families many times are referred to early intervention services before being referred to genetic services.
- Families form strong and trusting relationships with the home visiting staff and the bilingual interpreters.
- Many of the families asked the EI provider about their child's genetic condition
Hispanic Access Advisory Committee

Members:
Parents
Parent to Parent Coordinators
Early Intervention
Genetic Alliance
Genetic Service Providers
MSRGN
Family Voices National

Hispanic Access Advisory Committee
Little Rock, AR
October 12, 2016
Presentations and other Activities

- Early intervention (home visits)
- Interpreters
- Family Support Groups
- Genetic service providers
- Community health workers
- Others
Early Intervention Survey

• 517 providers were surveyed
• Of those who provide services to children with genetic conditions:
  • Only 5% of the providers had written information describing genetic services
  • Only 8% felt they had enough information to answer their parent’s questions.
  • A high percentage (92%) indicated that they would like more information on genetic conditions.
Why Videos?

• Visual aids express culture and customs better than written material.
• Literacy levels of first generation are lower than average.
• Latinos are big users of social media (WhatsApp and Facebook)
Our Goal

To produce animated videos that are culturally and family friendly that were written at the 6th level,
What it takes for a video production

Producer, director

Video Production

Latino Focus Groups, Families

Latina Team
Reality!!!

- Video Production
- Producer, director
- Latino Team
- Certified Translator
- Graduate Students
- Latino Focus Groups, Families
- English-Speaking GC
- Heartland Work Groups
- Spanish-Speaking GC
- Genetics Networks
- Interpreters
- GC Certified Translator
Production Company (Exclaim)

- Developing and finalizing the script
- Developing and editing the animation
- Voice actors
- Credits
- etc.
Muchas Gracias

Heartland’s Core Latino Team:
- Maria Isabel Frangenberg (Colombia)
- Graciela Sharif (Peru)
- Erica Herrera (Mexico)
- Mary Ann Coffman (Peru)
- Jessica Gutierrez (Mexico)
- Maria Castillo (Mexico)
- Coral Jimenez (PR)
- Lori Williamson 😊

Community:
- Families with children with Genetic conditions.
- Genetic Service providers
- Family networks (Latina coordinators)
- Heartland committees
- Genetic Networks
- Graduate Students
En agradecimiento a los intérpretes:

Hilda Sanchez-Herrera
Sanford Health

Jessica Gutierrez
Munroe-Meyer Institute for Genetics and Rehabilitation
University of Nebraska Medical Center (UNMC)
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The contents are those of the author(s) and do not necessarily represent the official
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Gracias por su colaboración:

Heartland Genetics Regional Network
Community Engagement Work Group

En agradecimiento a todas las familias que compartieron sus historias, su experiencia y su tiempo:

<table>
<thead>
<tr>
<th>Graciela Sharif (NE)</th>
<th>Leticia Basave (OK)</th>
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<tbody>
<tr>
<td>Norma Ramirez (NE)</td>
<td>Esly Peralta (OK)</td>
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<td>Leticia Franco (NE)</td>
<td>Angelica Casas (OK)</td>
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<td>Maura Granillo (NE)</td>
<td>Ivonne Lira (OK)</td>
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<td>Erica Herrera (OK)</td>
<td>Maria Castillo (CO)</td>
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<td>Maria Baca (OK)</td>
<td>Coral Jiménez (Puerto Rico)</td>
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Newborn Laboratory Screening for Genetic Conditions

In this country, all newborns receive a newborn screening test.
What Can I Expect from an Appointment at a Genetics Clinic?
How to Work With an Interpreter for a Medical Visit

Cambiaremos el medicamento de Jason
We’ll change the medication for Jason
What are Chromosomes and Genes?
What is Genetic Testing?
## Video Views

<table>
<thead>
<tr>
<th>Title</th>
<th>Views</th>
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<tbody>
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<td>What are Chromosomes and Genes? (Spanish with Spanish Subtitles)</td>
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<tr>
<td>What is Genetic Testing? (Spanish with Spanish Subtitles)</td>
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<td>What Can I Expect from an Appointment at a Genetics Clinic?</td>
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<tr>
<td>What Can I Expect from an Appointment at a Genetics Clinic? (Spanish with English Subtitles)</td>
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## How Viewers Find Our Videos

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<td>com.google.androidapps.classroom</td>
<td>7.0%</td>
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<td>FaceBook</td>
<td>3.3%</td>
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**Viewers’ Top Countries of Residence**

<table>
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<th>Country</th>
<th>Percentage</th>
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<td>Mexico</td>
<td>23.2%</td>
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<tr>
<td>Columbia</td>
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<tr>
<td>Peru</td>
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<tr>
<td>United States</td>
<td>4.6%</td>
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<tr>
<td>Argentina</td>
<td>3.3%</td>
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<tr>
<td>Ecuador</td>
<td>2.8%</td>
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<tr>
<td>Spain</td>
<td>2.5%</td>
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Utility of Educating the Hispanic and LatinX Population about Genetic Services Using Culturally Targeted Videos 2020

Carson A. Smith MS
Quantitative Study of the Latino Community Cont.

- The pre and post survey addressed information discussed in the videos to assess changes in the following categories:
  - Health Literacy
  - Health Communication
  - Knowledge in Genetics

- Sociodemographic factors were also assessed.
Quantitative Study of the Latino Community

- Trained and hired five bilingual study coordinators
- Recruited and interviewed 131 participants (mostly through personal relationships and community outreach)
- Implemented a pre and post survey (before and after watching two videos).
  - What is Genetic Services?
  - What are chromosomes and Genes?
Recruitment

UNIVERSIDAD DE ARKANSAS PARA LAS CIENCIAS MÉDICAS

BUSCAMOS PARTICIPANTES ADULTOS
Para un estudio destinado a aumentar el conocimiento sobre los servicios genéticos en la población en los Estados Unidos y territorios. Recibirá una tarjeta de regalo de $40.00 por una hora de participación.

BENEFICIOS:
• Aprender sobre los servicios genéticos por ver dos vídeos animados en Español
• Conectarse con especialistas y apoyo familiar

CONTACTENOS:
Carson Smith, B.S
(Para inglés) - (501)-912-5131
Mary Ann Coffman, MS, CGC
(Para inglés/español) - (405)-930-6888

UNIVERSITY OF ARKANSAS FOR MEDICAL SCIENCES

ADULT PARTICIPANTS NEEDED
This is a study aimed at increasing awareness and knowledge of genetic services among the Hispanic and Latinx population.
Participants must be fluent in Spanish, identify as Hispanic/Latinx in ethnicity, and live in the United States and territories. Participants will receive a $40.00 gift card for one hour of participation.

BENEFITS:
• Learn about genetic services by watching two animated videos
• Connect to specialists and family support networks if desired

CONTACT US:
Carson Smith, B.S
(For English) - (501)-912-5131
Mary Ann Coffman, MS, CGC
(For English/Spanish) - 405-930-6888
In our study 88 (67.2%) of participants had baseline knowledge of the utility of genetic testing and the implication for family members, but 90.1% of the participants reported some lack of knowledge around accessing genetic services and/or the services available in a genetic clinic.”
Utility of educating the Hispanic and Latinx population about genetic services using culturally targeted videos – Phase 2: Exploring the participants’ perspectives, attitudes, and actions taken post-video

Bethany R. Johnson MS
Quantitative and Qualitative study of the Phase I Participants

- Mixed Method Design
- Hired and trained 3 study coordinators
- Recruited 13 participants from Phase 1
IMPLICATIONS/RESULTS:

- Videos should be available to patients prior to the genetics clinic visit.
- Videos have value for peer-to-peer support.
- The videos served as a tool to let others know about genetic services.
Testimonial Video
“Es una desesperación que uno como papa no saber la causa. Mi niña tiene tanto atraso en su desarrollo. Como a las tres yo noté que la niña no volteaba, no quería levantar la cabeza, la sentí muy flojita de los músculos. Yo pedí que lo manden al neurólogo. Entonces la doctora me dijo pienso yo que es mejor mandarles a genéticas.”
It is a desperation that one as a parent does not know the cause. My daughter is so behind in her development. About three months, I noticed that she did not turn around, she did not want to lift her head, I felt her muscles were very weak. I asked that they send her to a neurologist. Then the doctor told me, I think it is better to send them to genetics
No hay barrera. Cuando uno quiere, lo logra. ...debe de haber disposición y aquí vamos rompiendo cada reto. Mi hijo es un gran guerrero. Tiene doce años y es un niño muy caroñoso.

There is no barrier. When you want, you achieve it. ...there must be willingness and as we go, we are breaking each goal. My son is a great warrior. He is twelve years old and is a very affectionate child.
Preliminary Themes

- Empowerment by the Latina coordinators and Early intervention staff.
- Importance of a diagnosis.
- Importance of early intervention services.
- Hesitation to have other family members tested
Conversation with a School Principal

- New immigrants (diverse)
  - Countries
  - Socioeconomic
- Blending of cultures
- Bilingual schools
- Rules for newcomers
- Where to refer?
¿Ahora que?
Full Circle!

- Many Spanish speaking families live in the same communities
- Many visit the same clinics
- Parent to Parent Networks
- Home visiting Programs (Early Intervention)
- Social Networks
- Support groups
- *Many Children attend the same schools.*
“In our study, 88 (67.2%) of participants had baseline knowledge of the utility of genetic testing and the implication for family members, but 90.1% of the participants reported some lack of knowledge around accessing genetic services and/or the services available in a genetic clinic.”
IMPLICATIONS/RESULTS:

- Videos should be available to patients prior to the genetics clinic visit.
- Videos have value for peer-to-peer support.
- The videos served as a tool to let others know about genetic services.
Words of Wisdom???

What is access for the genetic service provider?

What is access for the Family?
We have the tools!

Videos.
Postcards
Ready to learn more about Genetic Testing?

Watch our informative videos designed to walk you through the process step-by-step. We're here to help you feel confident and informed so you can make the best decisions for your family's health.

HEARTLAND REGIONAL GENETICS NETWORK
You can view the videos on our website at: www.heartlandcollaborative.org

Scan Me
To Watch Our Videos with English Subtitles

¿Listo para aprender más sobre las pruebas genéticas?

Vea nuestros videos informativos diseñados para guiarlo paso a paso a través del proceso. Estamos aquí para ayudarlo a sentirse seguro e informado para que pueda tomar las mejores decisiones para la salud de su familia.

HEARTLAND REGIONAL GENETICS NETWORK
Usted puede ver los videos en nuestro sitio web: www.heartlandcollaborative.org
How can these videos be used?

Genetic Service providers
Medical specialists
Community
  Home Visiting Programs
  Family to Family Networks
  Peer to Peer
Other
Muchas Gracias

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- Maria Castillo (Mexico)
- Coral Jimenez (PR)
- Anayeli Herrera Morales (Mexico)
- Alex Obregon
- Lori Williamson 😊

Community:

- Families with children with Genetic conditions.
- Genetic Service providers
- Family networks
- Heartland committees
- Genetic Networks
- Other health service providers
- Graduate Students
- Study coordinators
- Academic Faculty
- Many Others!!!
Muchas Gracias

Lori Williamson
Ann Chou
Gene Hallford
Barb Jackson
Cara Vaught
HRSA
Lorraine Seeberg (Exclaim)
Brittany Burnside
¡El Fin!