Talking Health Literacy

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Partnerships for Native Health
Partnerships for Native Health

- Funded and supported by National Institute of Health (NIH)
- P4NH’s mission to conduct community-centered research, training, education, and outreach to improve the health and quality of life of American Indian and Alaska Native populations
What is Health Literacy?

The degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions.
Health Literacy and Health Communication Study

• Surveyed 261 American Indians/Alaska Natives and conducted 4 focus groups in 2 rural and 2 urban tribal communities

• Our questions
  – Where people getting health information
  – What is their confidence in it
  – Where would they like to receive information from
  – What would give them greater confidence in that information?
Survey Results

When your information disagrees with your Doctor:

<table>
<thead>
<tr>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talk with Dr</td>
</tr>
<tr>
<td>Ignore it</td>
</tr>
<tr>
<td>Use what I trust</td>
</tr>
<tr>
<td>Something else</td>
</tr>
</tbody>
</table>

0 | 10 | 20 | 30 | 40 | 50 |

Talk with Dr: 50%
Ignore it: 10%
Use what I trust: 20%
Something else: 20%
Focus Group Results

- **Barriers to accessing health information**

Confidentially in rural communities

“There’s always an issue and always a problem [receiving care at the clinic], and then my family’s involved, from the receptionist on up to my co-workers. It’s like everybody knows what my business is and what has happened.”

**Readability**

“After I got information from the doctor, the language was what I [was] having [trouble with].”

**Lack of knowledge of how to use health insurance**

“I think we need to get used to having insurance. I don’t think we are utilizing it as well as we can as individuals. I think we’re still stuck in the IHS system.”
Where are they getting health information?

Online and social media

“Well, I don’t know that I trust the information, but I just—I go online and like this myself, personally, it’s what I had to—it’s what I did. It helped me with asking questions”

“Sometimes [the health care providers] said, there’s not good information [on the internet], but I don’t know how you would tell the good from the bad.”

Family members

“I think it’s very important that my children—they need to know the family health history on both sides and talk about what's going on with our health.”
• Where do they want to get health information from?

Digital Storytelling

“Most of them are like personal stories... they’ve actually had a disease and they tell about the process...but I would pay more attention if they were Native people Culturally attuned and health literate providers

“It was very frustrating because I didn’t know what they were tryin’ to explain to me, and it took a while to—I had to go see several doctors before I ever figured it out”

Community health workers and traditional healers

“My dad used pitch—he made pitch juice with....the willow buds that’s coming out now. He boiled it up and stuff and we used it for colds and everything...and we still use it.”
Case Study 1

A Targeted Approach to Increasing American Indian Organ Donation
Overview

• Project Background
• Focus Groups
• Results
• Campaign Materials & Events
• Zip code data
• Project Status
Chronic Disease and Kidney Failure

• American Indians suffer from disproportionately high rates of diabetes and kidney disease \(^1\)
  – Diabetes is the leading cause of kidney failure \(^2\)

• Among persons with advanced kidney disease, only transplantation increases long term survival \(^3\)

• Compared with Whites, AI/AN are less likely to receive kidney transplants, and wait twice as long for transplantation \(^4,5\)
Organ Donation

• Rates of consent for deceased donation in AI/AN are lower than in the general population \(^6\)

• 1% of candidates awaiting transplants are American Indian or Alaska Native, only 0.3% of all organ donors are American Indian or Alaska Native \(^7\)
  
  – Unique cultural and spiritual considerations
  – Mistrust of health care system
Project Specific Aims

Aim 1: Examine knowledge, attitudes, and behaviors regarding organ donation and transplantation among tribal college students.

Aim 2: Develop culturally tailored media materials to heighten awareness about the need for donation and benefits of transplantation.

Aim 3: Increase the number of American Indians and Alaska Natives who become organ donors.
“An ecologic or population health model emphasizes the importance of the **social** and **physical environments** that strongly shape patterns of disease and health as well as **our responses** to them over the entire life cycle.”

(Fielding, Teutsch, Breslow, 2010)
Timeline of Study

Phase 1

Y1
- Partner Selection
- Tribal Approval
- Resolutions
- MOU
- UW IRB

Y2
- Hire local coordinators
- Sites visits
- Begin focus groups

Y3
- Continue focus groups
- Develop all materials
- Host campaign events
- Administer field survey
- Diversity supplement to track diffusion of materials

Phase 2

Y4
- Continue Campaign Events
- Digital stories
- Continue survey of community

Y5
- Complete campaign events
- Data analysis
- Diversity supplement evaluation
- Key informant interviews
Partner Sites

- Partner sites were selected according to three criteria:
  - Level of interest in becoming a partner
  - Identification of faculty liaison to act as site coordinator
  - Established health program to host the project
Focus Groups
The organ donor willingness model (ODWM) guided the focus group discussion and questions.

The ODWM considers individual knowledge, attitudes, beliefs and behaviors as determinants of willingness to become an organ donor.
Discussion Themes

• Knowledge of organ donation and transplantation
• Perceptions of community need
• General beliefs about doctors and medical system
• Spiritual and religious beliefs
• Plans on willingness to donate
• Attitudes regarding the family’s role
• View of existing organ donation materials
Recruitment

• Recruitment carried out by local site coordinators

• 99 participants recruited at tribal colleges by flyers, campus announcements, classroom presentations

• Eligibility criteria
  – American Indian or Alaska Native
  – 18 years or older
  – Affiliated with the tribal college (student, staff, faculty)
Analysis

- Descriptive content analysis
- Independent review of transcripts by 5 members of project staff
- Identified themes within and across focus groups coded into 4 categories
  - knowledge
  - attitudes
  - beliefs
  - behaviors
Results
## Focus Groups and Participants

<table>
<thead>
<tr>
<th>Tribal College</th>
<th>Date</th>
<th>Attendance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northwest Indian College</td>
<td>12/12/2008</td>
<td>8</td>
</tr>
<tr>
<td>Northwest Indian College</td>
<td>5/20/2009</td>
<td>16</td>
</tr>
<tr>
<td>United Tribes Technical College</td>
<td>10/22/2008</td>
<td>10</td>
</tr>
<tr>
<td>United Tribes Technical College</td>
<td>1/24/2009</td>
<td>9</td>
</tr>
<tr>
<td>Turtle Mountain Community College</td>
<td>1/23/2009</td>
<td>6</td>
</tr>
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<td>Turtle Mountain Community College</td>
<td>4/28/2010</td>
<td>16</td>
</tr>
<tr>
<td>Fort Peck Community College</td>
<td>7/14/2009</td>
<td>9</td>
</tr>
<tr>
<td>Fort Peck Community College</td>
<td>2/26/2010</td>
<td>13</td>
</tr>
<tr>
<td>Blackfeet Community College</td>
<td>2/18/2010</td>
<td>7</td>
</tr>
<tr>
<td>Blackfeet Community College</td>
<td>3/11/2010</td>
<td>5</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>99</td>
</tr>
</tbody>
</table>
Knowledge

- Community knowledge drawn from direct family experience with chronic illness
- Participants with family members on dialysis or with advanced kidney disease were knowledgeable about medical benefits of organ donation and medical process (e.g., referral, donor waitlist)

“...there’s a lot of people on the reservation that do have diabetes and that probably later on in life – with their diabetes – will be on dialysis. So I think it’s going to be a big part of our health plan, that we have to figure on that becoming a bigger problem.”
Knowledge (cont’d)

• Knowledge of the process required to become an organ donor (registration) varied across participants.

“People just have a vague idea of organ donation. You know, it’s not really advertised.”

“Just because it says on your license doesn’t mean that you are going to donate. You fill out a thing, some kind of application to donate.”

“There’s not a lot of information in this community about organ donors just for the fact that the religion most people carry here is, you just don’t do it.”
Knowledge (cont’d)

• Pathways to learning about organ donation were discussed. Television and movies were the two primary sources of information.

“I’ve seen it on TV. They advertise with it. To promote bone marrow….I’ve never actually tried to investigate on the reservation what kind of organs they want.”

“Yeah, I’ve seen on TV. Are you familiar with House? That show.”

“That movie, My Sister’s Keeper…..whatever this little girl needed, they could get it from her sister and she was pretty much born to donate to her sister – to keep her alive”
Attitudes

- Attitudes discussed in context of family’s role in decision making process
  - willing to honor written or clearly communicated requests of family members
  - unwilling to donate family member’s organs in absence of clear instructions of deceased person’s wishes

“…when my brother passed away – you know he was perfectly healthy and everything – and when the doctors asked if we wanted to donate his organs, we said no. I think that if you want to be an organ donor you should fill out the application and make it aware to your parents.”
Beliefs

• Non-biomedical, culturally based beliefs about organ donation were often attributed to elders or people described as “traditional”

• Participants described traditional beliefs as commonly held, but they were not necessary pervasive among participants themselves.

“well most Indians around here believe that Indians should go back to the ground with what they were born with.”

“I think it’s morally right to donate your organs. It’s really good...whether they be agreeing with traditional values or not. It’s the right thing to do. That’s the bottom line.”
Beliefs

• Beliefs about the health care system were similar across sites.
• Higher levels of distrust associated with decreased willingness to become an organ donor.
• Perceived inadequacies in health care quality and access.

“Well, we were just saying how it’s more or less IHS doctors up here but maybe if it was in [large city named] or any other place I would definitely trust the doctors.”

“A lot of the health care we get up here isn’t up to standards, I believe, because of the tight budget.”
Behaviors

- Most participants reported a living donation to a family member or friend was an acceptable form of organ donation.

“I think that I wouldn’t want to be a donor. But I guarantee you, if my brother needed it – and my family knows that. No matter what my beliefs are on me, I’m always willing to put my family before me.”

“To me, if I ever donated an organ, I think it would have to be a really close person like my kids, or something.”
Behaviors

- Among participants unwilling to become organ donors, concerns about being healthy enough and adhering to a healthy lifestyle emerged

“I don’t think I would because…I know you have to have a certain lifestyle for that – to keep your immune system up and healthy. But not everybody can. I sure can’t keep healthy.”
Discussion

• Clear patterns of family-level decision making emerged across focus group sites

• Direct family experience with chronic illness associated with increased knowledge of medical benefits of donation

• Findings confirmed that attitudes about organ donation and transplantation are influenced by cultural beliefs.

• Mistrust of the health care system must be considered in future health campaigns, along with future research of the message interference that may take place as a result
Campaign Events
## Campaign Events by Site

<table>
<thead>
<tr>
<th>Tribal College</th>
<th>On campus</th>
<th>Off campus</th>
<th>Total Events</th>
</tr>
</thead>
<tbody>
<tr>
<td>Turtle Mountain Community College</td>
<td>5</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>United Tribes Technical College</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Blackfeet Community College</td>
<td>3</td>
<td>19</td>
<td>22</td>
</tr>
<tr>
<td>Fort Peck Community College</td>
<td>3</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Northwest Indian College</td>
<td>8</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Total</td>
<td><strong>57</strong></td>
<td><strong>-</strong></td>
<td><strong>57</strong></td>
</tr>
</tbody>
</table>
Campaign Materials
Campaign Materials
Campaign Materials
Survey Overview

- 1,231 surveys collected
- 16-items
- Demographics: age, education, marital status
- Family history
- Attitudes about chronic illness
- Donor registration intention
- Type of materials seen and ranking of influence
### Demographics

<table>
<thead>
<tr>
<th>Variable</th>
<th>N = 1,231</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19 years or less</td>
<td>265</td>
<td>22</td>
</tr>
<tr>
<td>20 - 29 years</td>
<td>265</td>
<td>22</td>
</tr>
<tr>
<td>30 - 39 years</td>
<td>235</td>
<td>20</td>
</tr>
<tr>
<td>40 years or more</td>
<td>440</td>
<td>36</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>743</td>
<td>62</td>
</tr>
<tr>
<td>Male</td>
<td>456</td>
<td>38</td>
</tr>
<tr>
<td><strong>Children</strong>*</td>
<td>758</td>
<td>66</td>
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</table>

*A total of 758 respondents reported having children*
## Demographics

<table>
<thead>
<tr>
<th>Variable</th>
<th>N = 1,231</th>
<th>%</th>
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<tbody>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some high school</td>
<td>91</td>
<td>8</td>
</tr>
<tr>
<td>High school</td>
<td>346</td>
<td>29</td>
</tr>
<tr>
<td>Current college student</td>
<td>240</td>
<td>20</td>
</tr>
<tr>
<td>Completed college degree</td>
<td>321</td>
<td>27</td>
</tr>
<tr>
<td>Technical or vocational school</td>
<td>62</td>
<td>5</td>
</tr>
<tr>
<td>Graduate school</td>
<td>140</td>
<td>12</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>581</td>
<td>46</td>
</tr>
<tr>
<td>Married/partnered</td>
<td>510</td>
<td>42</td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>110</td>
<td>9</td>
</tr>
<tr>
<td>Widowed</td>
<td>34</td>
<td>3</td>
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</table>
## Family History and Attitudes

<table>
<thead>
<tr>
<th>Family History</th>
<th>N = 1,231</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family member with serious kidney disease</td>
<td>121</td>
<td>11</td>
</tr>
<tr>
<td>Someone close to you on dialysis</td>
<td>327</td>
<td>29</td>
</tr>
<tr>
<td>Family member with diabetes</td>
<td>521</td>
<td>46</td>
</tr>
</tbody>
</table>

### Personal History

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Has serious kidney disease</td>
<td>45</td>
<td>4</td>
</tr>
<tr>
<td>Has diabetes</td>
<td>150</td>
<td>13</td>
</tr>
</tbody>
</table>

### Attitudes

<table>
<thead>
<tr>
<th>Statement</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Will probably get diabetes sometime in my life*</td>
<td>347</td>
<td>37</td>
</tr>
<tr>
<td>I can prevent diabetes*</td>
<td>961</td>
<td>90</td>
</tr>
</tbody>
</table>

*respondents strongly agree or somewhat agree
## Ranking of Materials

<table>
<thead>
<tr>
<th>How much do these influence a person’s decision to register as an organ donor?</th>
<th>A lot</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Written materials (posters, brochures)</td>
<td>47</td>
<td>44</td>
<td>9</td>
</tr>
<tr>
<td>Digital videos</td>
<td>57</td>
<td>33</td>
<td>11</td>
</tr>
<tr>
<td>Talking with family</td>
<td>63</td>
<td>27</td>
<td>9</td>
</tr>
<tr>
<td>Talking with project staff</td>
<td>54</td>
<td>34</td>
<td>12</td>
</tr>
<tr>
<td>Other</td>
<td>44</td>
<td>27</td>
<td>29</td>
</tr>
</tbody>
</table>
## Donor Registration Intention

<table>
<thead>
<tr>
<th>Response</th>
<th>N = 1,231</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Already registered an organ donor</td>
<td>288</td>
<td>23</td>
</tr>
<tr>
<td>Registered as donor today</td>
<td>185</td>
<td>15</td>
</tr>
<tr>
<td>Considering registering</td>
<td>238</td>
<td>19</td>
</tr>
<tr>
<td>Not considering</td>
<td>517</td>
<td>42</td>
</tr>
<tr>
<td>Intend to discuss organ donation with family</td>
<td>490</td>
<td>41</td>
</tr>
<tr>
<td>Have already discussed organ donation with family</td>
<td>219</td>
<td>18</td>
</tr>
</tbody>
</table>
## Donation Groups

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>Not Considering</th>
<th>Considering</th>
<th>Registered at Event</th>
<th>Already Registered</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will or have discussed organ donation with family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>&lt;.0001</td>
</tr>
<tr>
<td></td>
<td>142 (28%)</td>
<td>179 (76%)</td>
<td>143 (81%)</td>
<td>243 (87%)</td>
<td></td>
</tr>
<tr>
<td>Ranking of Influence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Written materials*</td>
<td>174 (38%)</td>
<td>112 (52%)</td>
<td>96 (60%)</td>
<td>136 (51%)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Digital stories*</td>
<td>178 (42%)</td>
<td>133 (64%)</td>
<td>91 (62%)</td>
<td>185 (70%)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Talking with family member*</td>
<td>208 (50%)</td>
<td>141 (67%)</td>
<td>111 (72%)</td>
<td>207 (76%)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Talking with project staff*</td>
<td>205 (50%)</td>
<td>141 (67%)</td>
<td>111 (73%)</td>
<td>207 (76%)</td>
<td>&lt;.0001</td>
</tr>
</tbody>
</table>

* Response = A lot
## Predictors of Organ Donation

<table>
<thead>
<tr>
<th>Survey Item</th>
<th>Not Considering N = 517</th>
<th>Considering N = 238</th>
<th>Registered at Event N = 185</th>
<th>Already Registered N = 288</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>College or higher education</td>
<td>184 (37%)</td>
<td>81 (35%)</td>
<td>108 (59%)</td>
<td>148 (52%)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Has children</td>
<td>291 (61%)</td>
<td>133 (59%)</td>
<td>126 (77%)</td>
<td>206 (76%)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>30 years old or more</td>
<td>268 (53%)</td>
<td>97 (42%)</td>
<td>125 (69%)</td>
<td>183 (64%)</td>
<td>&lt;.0001</td>
</tr>
</tbody>
</table>
Zip Code Registry

• Were able to track local changes in the number of donors by zip code (obtained from Living Legacy and donor registries) for some partner states.
• The zip code tables show pre-intervention donor consent counts (2009), followed by donor consent counts during the intervention of the health messaging campaign (2010-2012).
• Note: Intervention peeked in late 2010-2011
Northwest Indian College Surrounding Zip Codes

<table>
<thead>
<tr>
<th></th>
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<tr>
<td>98513</td>
<td>400</td>
<td>1253</td>
<td>1344</td>
<td>338</td>
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<tr>
<td>98327</td>
<td>113</td>
<td>394</td>
<td>517</td>
<td>114</td>
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<tr>
<td>98433</td>
<td>226</td>
<td>791</td>
<td>861</td>
<td>223</td>
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<td>98501</td>
<td>441</td>
<td>1395</td>
<td>1585</td>
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<td>98503</td>
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<td>1362</td>
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<td>98509</td>
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<td>2</td>
</tr>
<tr>
<td>98516</td>
<td>252</td>
<td>777</td>
<td>874</td>
<td>213</td>
</tr>
<tr>
<td>98540</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>98558</td>
<td>2</td>
<td>15</td>
<td>13</td>
<td>5</td>
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## Fort Peck Community College Surrounding Zip Codes

<table>
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<tbody>
<tr>
<td>59255</td>
<td>18</td>
<td>40</td>
<td>60</td>
<td>16</td>
</tr>
<tr>
<td>59201</td>
<td>25</td>
<td>73</td>
<td>109</td>
<td>39</td>
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### Blackfeet Community College Surrounding Zip Codes

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<th></th>
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<tbody>
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<td>58385</td>
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Project Status

• Back to our Ecological Model – continuing our work with partner communities.
• Project expanded into the tribal dialysis centers in new round of funding (2012-2017)
• Targeted donation focus
Acknowledgments

National Institute of Diabetes and Digestive and Kidney Diseases RO1 DK079670
Participating Tribal Colleges
LifeCenter Northwest
Community members
Artists and project staff
References


Culturally Adapted Strategies to Enhance Kidney Donations in Native Communities
Core Intervention – House Calls Plus

- In home educational sessions
- Improve Access to Transplantation
- Medical options in a cultural context
- Promote family conversations
- Patient navigation
The “CAS” Project
House Calls Plus

- Welcome family and friends
- Read verbal consent form to guests
- Family and friends complete the pre-test
- Conduct the House Calls educational session on Living Donor Kidney Transplant
- Share Digital Stories
- Family and Friends Complete the post-test
- Give out incentives to Family and Friends
- Thank everyone for coming.
The “CAS” Project
After the House Calls....

- Dialysis Patient completes survey 1 week post House Calls
- Dialysis Patient completes survey 6 weeks post House Calls
- Community Health Educator contacts dialysis patients every 1-2 months to check on progress on transplant wait list
- Community Health Educator provides patient advocacy assistance
The Challenge

Pretty straightforward, right?

Not exactly.
Starting to Communicate

- Social Workers: Busy People, Can they ID AI/ANs, Who is telling what story?
- Dialysis Center waiting room: Does it work?
- Beginning the relationship
- Be attuned and respectful every step of the way
Continuing the Relationship:
Let’s Schedule a House Call!

- Large group or small group --- it is an event!
- Make guests comfortable.
- Roll with the flow.
- Explain about research fidelity.
- Every guest receives a curriculum and a digital story dvd.
In Part 2, we will talk about:

- Living Kidney Donation
- Risks for Donors
- Benefits for Donors
- Deciding to Donate
- Donor Evaluation Process
- The Transplant Procedure

Dialysis is a lifesaving treatment.

Dialysis is a lifesaving treatment, but it can only do a small part of the work of a healthy kidney.

Kidney transplantation is an operation that places a healthy kidney from another person into your body. This one new kidney takes over the work of the two failed kidneys.
Insights

❖ Persistence
❖ Respect their decisions
❖ Restraint
❖ Support them where they are at
❖ Advocate
❖ Need to have health literacy at all levels
❖ Community support
Discussion 😊

- What are some the barriers to health communication in your community? What’s worked and what didn’t work?
- What is the hardest information to get out to your community? How have you addressed this?
- Are your providers communicating well with their patients? Are they trained to do this?
- What are your experiences in accessing culturally appropriate health materials? Do you have access or have you made your own?
Digital Story Training Resources

http://ndigidreams.com

http://www.storycenter.org

http://www.npaihb.org
Thank you!

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