

Contextual Basis for a New Educational Intervention on Living Kidney Donation and Transplant for American Indians

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- The investigator would like to disclose no conflicts of interest related to this presentation.

Research Program Partners

□ Tribal Communities

- Leaders, Advisors, Facilitators, Tribal Colleges and Universities, Tribal Health Directors and Staff, and Community Members

□ Health & Allied Health Organizations:

- SD Lions Eye Bank, Dialysis Centers, Health Centers, Sanford Research, Sanford Transplant, Hennepin County Medical Center, Minneapolis Medical Research Foundation, LifeSource

□ Project Teams

- Students, Co-investigators, Staff
- Advertising firms, Photographers



Funding Sources

US DHHS, HRSA, Division of Transplantation:

- CFDA 93.134 *Social and Behavioral Interventions to Increase Solid Organ Donation*
 - ▣ #R39OT01211, 2003-2007 “Sharing the Gift of Life”
 - ▣ #R39OT07542, 2006-2010 “Tribes Sharing Life”
 - ▣ #R39OT24207, 2012-2015 “A Circle of Learning”

US DHHS, NIH, Nat’l Center for Minority Health Disparities

- #U54MD008164, 2012-2017, “LKDT Education for Dialysis Patients”
 - ▣ Amy Elliott, Sanford Research, Center PI - “Collaborative Research Center for American Indian Health,” Fahrenwald, Research Project PI

A portrait of a young woman with long brown hair, wearing a grey jacket and a small earring, looking directly at the camera. The background is a blurred landscape with snow and grass under a blue sky.

April, 2013:

- ~117,000 registrants on the organ
- transplant waiting list
- 101,000+ kidney

In 2014:

- ~ 29,500 transplants
- ~ 17,100+ kidneys

**“Through it all, I kept my
faith in Lakota.”**

**Woepe Claymore
Cheyenne River Sioux Tribe
Kidney Transplant Recipient**

Organ Donation Need and Challenges for American Indians

6

□ Type 2 Diabetes

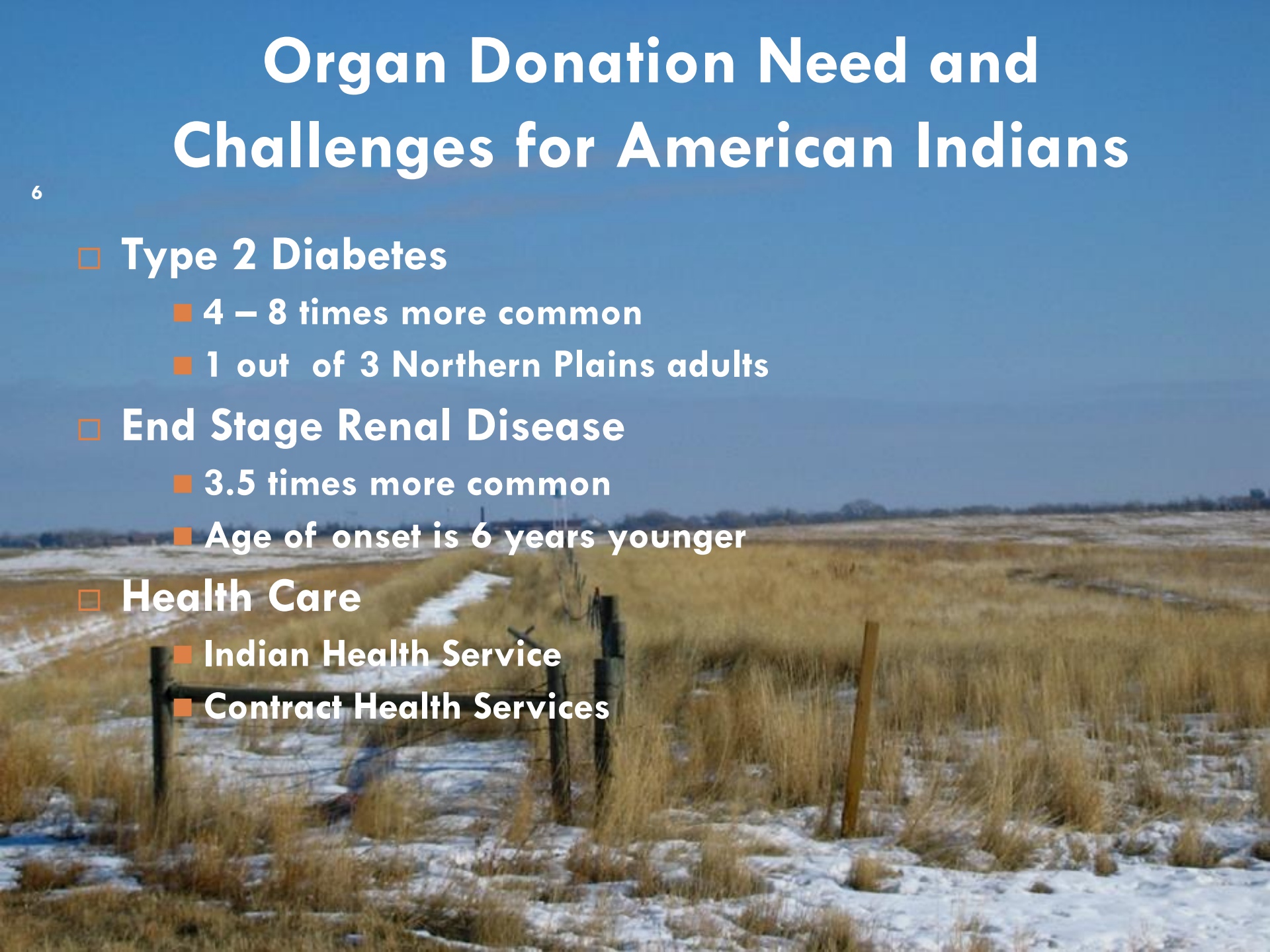
- 4 – 8 times more common
- 1 out of 3 Northern Plains adults

□ End Stage Renal Disease

- 3.5 times more common
- Age of onset is 6 years younger

□ Health Care

- Indian Health Service
- Contract Health Services



Donation Need & Consent



- Demand for kidney donors
- Low deceased donor consent rates
- Willingness to donate a kidney is present
- HLA-match better within tribes
- Better outcomes with transplant

Working together

Tribal priorities: relate to the community

Trust: committed presence, integrity

Values & beliefs: respect, community benefit

Message: community based approach



Tribes Sharing The Gift Of Life

*Salish Kootenai:
Stories*



Purpose



- The purpose was to explore the contextual factors that impact LKDT attitudes and educational needs among American Indians.
- Individual interviews with dialysis patients ($n = 5$) were conducted to gather formative data on the topic.
- Qualitative description method.
- Findings were used to collaboratively create a new educational program designed to increase knowledge of the benefits and risks of living kidney donation and transplant (LKDT) among American Indians on kidney dialysis.
- Some skill building for talking with family about transplant is part of the program.

Goals and Outcomes



During Project

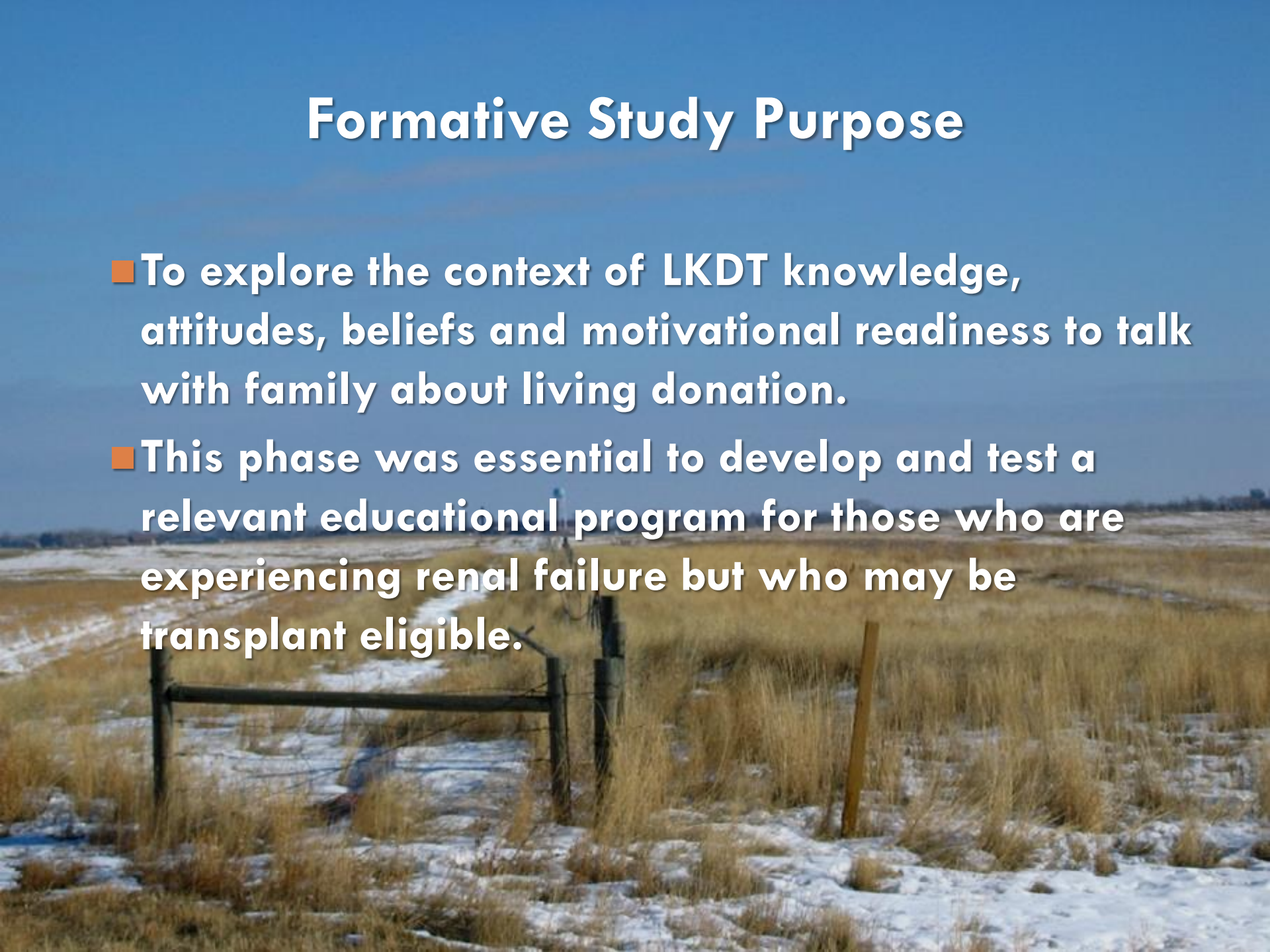
- To work with tribal advisors to develop an educational program on LKDT.

Upon Completion

- The education will be available to tribal health sites, dialysis settings & communities.

Formative Study Purpose

- To explore the context of LKDT knowledge, attitudes, beliefs and motivational readiness to talk with family about living donation.
- This phase was essential to develop and test a relevant educational program for those who are experiencing renal failure but who may be transplant eligible.



Design and Methods

- **Design: Qualitative Description (Sandelowski, 2000).**
- **Methods: Semi-structured interviews**
 - Approvals
 - Recruitment
 - Procedures
- **Data Management and Analysis**
 - Transcription
 - N-Vivo
 - Coding and verification with 3 members of the project team
- **Data Interpretation and Verification**
 - Community Advisory Board Members
 - Clinical Advisory Board Members

Results

- Overall broad themes that emerged from the analysis that were specific to the educational program and topical needs:
 - a cautious approach toward LKDT conversations,
 - a concern for others,
 - and expectations for culturally-sensitive education.

Cautious Approach to Talking with Family

- Difficult Discussion

“I talked with my] children, but personally I wouldn’t want to put them through that because they are more worried for me and that’s something that may happen to them.”

“It went okay. A couple of them said, “We will give you a heart dad...right away.[laughing] They didn’t have no concessions about not doing it.”

Cautious Approach to Talking with Family

- Experiential Context

“I guess I’ve never really asked anybody.”

“I don’t know, I probably wouldn’t [talk with family], I’m not the person to ask for something.”

“Yeah, I explained it all and what I learned.....I told them that they could be donors, but that doesn’t mean that we will match up.....I also explained that they weren’t necessarily the best candidates for kidney donors.”

Concern for Others

“Everything [about the education] is sensitive....so it would be kind of hard to choose a [specific] topic [to include].”

“I had things explained to me at the hospital, I agreed to everything.”

“I guess it would be taking caution and not trying to push. Just explaining the whole process and what can be expected and not to push. Like saying you got to do this or else (laughing).”

Concern for Others: Community Support

- Understanding

“I think they’d like to have support from anyone in the community could help them out..... (crying) so they won’t feel alone on dialysis.”

“You don’t know how close a person comes [making a harmful choice]. Just... ya know... constant conflict.”

Educational Knowledge to Convey

“What goes on?” “I don’t know.” “I hardly understand it myself.”

“What are the steps taken?”

“Everything from getting their meals, after care, and resources available.....somebody has to go with to help take care of them.”

“....time limits, financial responsibilities.”

Overall Context of Education

“Booklets would be good.”

“ We have a book already about kidney failure and I think that is really informational. I think videos would help too and can show them more about it.”

“Stories.”

“Family.”

“I don’t think that there is a whole lot that is related to the tribal part of it except more or less family.”

Next Steps



- Intervention developed collaboratively
 - Theme: Hope and Healing
 - 24 minute video
 - Companion booklet
 - Basic education to encourage family conversations
 - Stories from donors, recipients, elders, health care providers
 - Basic Concepts: Pros, Cons, building confidence, making decisions, family support
- Group randomized community trial of the intervention is underway at dialysis centers.

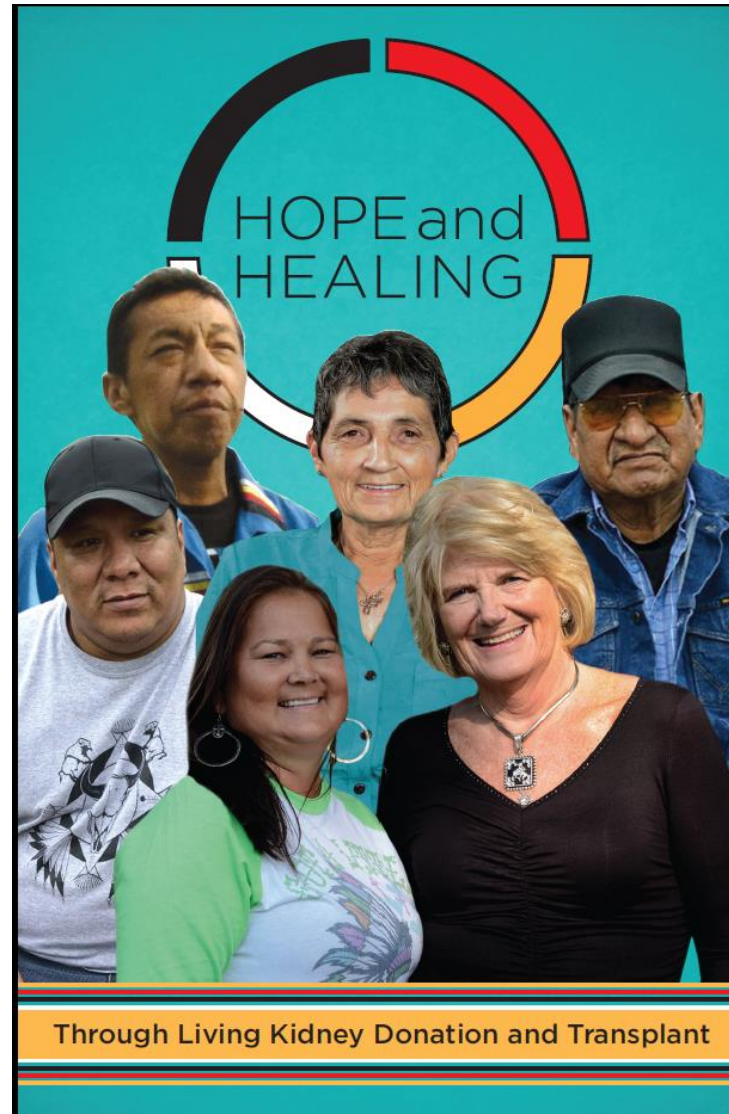
HOPE and HEALING

Through Living Kidney Donation and Transplant



24 minutes

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REASONS WHY PEOPLE CHOOSE KIDNEY TRANSPLANT

TO BE THERE FOR MY GRANDKIDS

"When I got my kidney I said the same thing, I said, 'Thank you God.' From now on I'm going to be right there for my kids and my grandchildren. One good thing I got out of my transplant is my sobriety and the love from my children and the respect that I have for my son Gary Jr."

- Gary Sr., Living Kidney Transplant Recipient



FREEDOM FROM DIALYSIS

"When I was on hemodialysis, I would go to dialysis, and if I wasn't at the dialysis center, I'd be sleeping. I wasn't able to go outside and play with my son because I was so tired."

- Gena, Living Kidney Transplant Recipient



TO DO WHAT YOU LOVE BEST

"For me it's about spending time with your family, living at home and doing what you love best, like playing the flute which helps me focus."

- Jerry, Dialysis Recipient



TO EAT AND DRINK FREELY

"After transplant I could eat watermelon, I could drink water when it was hot and not have to worry about being overloaded and I could enjoy it."

- Gena, Living Kidney Transplant Recipient