National Meeting on Precision Medicine and Cancer in American Indian & Alaska Native Communities

A Dialogue on Cancer Research

Remarks by Congressman Tom Cole (OK-04) and Dr. Douglas Lowy, Acting Director of the National Cancer Institute

November 10 2016

Stephenson Cancer Center
The University of Oklahoma

Samis Education Center
National Meeting on Precision Medicine and Cancer in AMERICAN INDIAN & ALASKA NATIVE COMMUNITIES

AGENDA AT A GLANCE

THURSDAY, NOVEMBER 10, 2016

7:30 am
REGISTRATION AND CHECK-IN
Lobby, Samis Education Center Auditorium

8:00 am
Welcome & Opening Remarks
Samis Education Center Auditorium
Robert Mannel MD, Director of the Stephenson Cancer Center
Congresman Tom Cole (OK-04)

8:30 am
Session 1
Priorities: Cancer Disparities in AI/AN Communities
Samis Education Center Auditorium

10:00 am
BREAK
Lobby, Samis Education Center Auditorium

10:30 am
Remarks
Dr. Douglas Lowy, Director of the National Cancer Institute
Samis Education Center Auditorium

11:00 am
Session II
Principles: Partnerships for AI/AN Cancer Research
Samis Education Center Auditorium

12:30 pm
LUNCH
Lobby, Samis Education Center Auditorium

1:30 pm
Session III
New Initiatives: What are the Challenges and Opportunities in Cancer Precision Medicine, and How It Can Inform the Needs of Our Communities to Reduce Cancer Risk and Overcome Cancer Disparities?
Samis Education Center Auditorium

3:00 pm
WRAP-UP AND CONCLUDING REMARKS
Samis Education Center Auditorium
SESSION I

PRIORITIES: CANCER DISPARITIES IN AI/AN COMMUNITIES

DOROTHY RHOADES, MD / LINDA BURHANSSTIPANOV, MSPH, DrPH

The goal of Session I is to identify priorities in cancer research among AI/AN communities. Dr. Dorothy Rhoades will begin with a 15-minute overview:

1. Review national and regional differences in leading cancers among AI/AN
2. Brief introduction to new direction in cancer research: Precision Medicine
3. Brief introduction to tribal sovereignty, cultural considerations, and research design

Dr. Linda Burhansstipanov will then lead a facilitated discussion setting the priorities of cancer research among AI/AN communities. The following list includes questions to consider as possible priorities to participants. This list may also stimulate discussion identifying other research issues relevant to AI/ANs.

**Disparities:** What are cancer research priorities that have the potential to reduce disparities within AI/ANs? (E.g., how are excessive obesity, diabetes, tobacco use practices truly impacted by ongoing research interventions?)

**Environment:** How can research about environmental exposures in AI/AN communities explain or contribute to the increases in cancer and other chronic diseases?

**Access to Quality Care:** How can research interventions improve AI/AN communities’ access to timely cancer screening, diagnosis, treatment, and quality of life after a cancer diagnosis?

**Clinical Trials:** How might cancer clinical trials recruitment protocols be modified to include more AI/ANs? (E.g., high blood pressure excludes many AI/ANs from clinical trials.)
The goal of this session is to discuss elements of successful partnerships for cancer research in AI/AN communities. Dr. Dillard will provide a 15-minute overview of a successful research partnership followed by a facilitated discussion among attendees.

The overview will:

1. Provide a description of how a research department within a tribally owned/operated health care organization is partnering with AI/AN communities as an example of CBPR
2. Highlight three themes of tribal governance of research projects and data, rebuilding trust, and capacity building.

Facilitated discussion will include:

- **Transition from service programs to innovative research**: How can AI/AN service, evaluation or pilot efforts successfully evolve into innovative, competitive and culturally appropriate research studies
- **CBPR**: Which community-based participatory research (CBPR) principles are touted but not fully applied to AI/AN research studies and how can these issues be avoided in the future? What resources or capacity would need to be added or built?
SESSION III
NEW INITIATIVES: WHAT ARE THE CHALLENGES AND OPPORTUNITIES IN CANCER PRECISION MEDICINE, AND HOW IT CAN INFORM THE NEEDS OF OUR COMMUNITIES TO REDUCE CANCER RISK AND OVERCOME CANCER DISPARITIES?

CHERYL WILLMAN, MD / JUDITH KAUR, MD

The goals of the overview (Willman) are to provide:

1. A brief update of the capabilities of cancer precision medicine to detect cancer-promoting mutations, which may vary among populations and communities across the world.
2. A brief update of the capability of cancer precision medicine to detect evidence of specific environmental exposures related to cancer causation.
3. Examples where new precision medicine diagnostics, including cancer genome sequencing as well as other technologies, can be used to improve cancer outcomes by developing new and more effective treatments for cancer patients in all communities.

Facilitated discussion (Kaur) will be an opportunity for extensive discussion of the challenges and needs for implementing cancer precision medicine in AI/AN communities. This list of proposed discussion questions is provided for you to consider your perspective regarding new precision medicine capabilities, to determine if these capabilities are an important priority for your community, and to develop a framework for appropriate collaborative partnerships.

Cancer Precision Medicine and Genome Sequencing: What are your concerns regarding these new technologies and their use in your community? How can they be used, in a non-discriminatory way, to empower our communities to overcome cancer health disparities?

Frameworks for Collaborative Research: What considerations and requirements would you propose for such studies, given tribal sovereignty but also the rights of individual community members? Such considerations may include:
- The development of appropriate informed consents, legal agreements regarding the conduct of precision medicine and research, and conditions of data sharing plans between Tribal Nations and institutions/groups conducting precision medicine for health care delivery and future research. Are their best practices and examples?
- Appropriate informed consent for use of biospecimens used for diagnostics/research.
- Ownership of data generated from such collaborative studies.
- Joint reporting of data generated from such studies.

Education and Training: How can we facilitate education, training, and engagement in these new areas of science and medicine for:
- AI/AN tribal leaders and community members?
- AI/AN youth and students to become experts in these areas of science and medicine and the capability to lead the clinical and research efforts in their communities?

Integrative Medicine: How can we integrate the practices of traditional Indian Medicine with cancer precision medicine in respectful ways to assure a holistic approach to quality cancer care?

Sustainable Funding: How do we identify the funding to implement new precision medicine, programs, and infrastructure in our communities?