



WINTER ISSUE 08' UI Quarterly

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The Urban Indian Quarterly

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Living in interesting times Ralph Forquera Executive Director



There is a saying: "may you live in interesting times." We are certainly living in interesting times, perhaps unprecedented times. Like you, I cannot escape the nightly deluge of bad news about the economy, the rising cost of gas and food, the financial system collapse, the rise in unemployment, and the lack of access to even basic health care for a growing number of Americans.

"The UIHI continues to strengthen our standing as a premier information source for Urban Indian health."

Our new president will enter this role under the burden of an economic weight that will influence the nature of our work both directly and indirectly. Government at all levels will be faced with making difficult choices about how best to use declining tax revenues. Private philanthropy will have fewer dollars to give to worthwhile charities as portfolio values disappear.

On the health care front, we do not see a health care plan that will make things better, in my opinion. Native people, like other Americans, will face even greater access and financial challenges in acquiring needed health care assistance for the near future. It is in this context that we must begin to assert our leadership and demonstrate our worth if we are to endure.

While conditions have changed, the factors that will influence decisions for the future have not. Data will continue to be the engine that will drive decision making in health care. Those who have solid, well organized and defensible data will be in a stronger position to influence decision making than those with less scientifically sound presentations. The UIHI continues to strengthen our standing as a premier information source for urban Indian health. We have created mechanisms to track health conditions, have created substantial data bases to assure quick and accurate analysis on issues, and have built the technical relationships essential for demonstrating effectiveness, and are positioned to get sound data into the hands of decision makers in a timely fashion.

Leadership is about anticipating the future and using all of the tools available to you to influence this future for the benefit of your mission and goals. We believe that the work of the UIHI is at the very forefront of where decision makers will turn for the information they will use for directing the future. With your continued cooperation and support, we will use this tool to survive this crisis and even position ourselves for opportunity when the crisis is quelled. ●

Want to know what's happening at UIHI?

The UIHI has created a Communications Broadcast to share data, project, and report information with our partners. Subscribers will receive monthly data snapshots and report publication announcements.

Subscribe today! Go to: <http://www.uihi.net/Public/NewsletterSubscriptions.aspx>

Did you know that...

Colon cancer is the second most common cancer for AI/AN women and the third for AI/AN men. American Indians & Alaska Natives are more likely to be diagnosed at later stages, when cancer is most difficult to cure. To learn more about "Urban Indian C.A.R.E.S. (Colon and Rectal Education and Screening) project" contact Alice Park at 206-812-3034 or alicep@uihi.org



Data – can't live with it, can't live without it

Maile Tauai'i, Scientific Director

We live in a time where data drives policy, funding, and more. Everything we do requires documentation of need, impact, or cost effectiveness. For this purpose, data is an essential component for decision making, advocacy, and education.

But what happens when the data doesn't exist or doesn't represent what we know to be true in our communities? Too often, the results are predictable; communities continue to be silenced, leaving people's needs invisible, while health disparities grow.

There are a number of national efforts to monitor the health of the population. While data gathered by these efforts may be used to inform programs and services for larger populations such as Whites, African Americans, Hispanics, and Asians, very little information can be gleaned to support services for smaller populations such as ours, the American Indians/Alaska Natives.

Strategies need to be implemented to resolve limited access to critical health information. Three possible strategies to consider are; 1) combining multiple years of population data, 2) aggregating racial populations with similar health characteristics, and 3) over-sampling of under representative populations.

First, combining multiple years of data is a statistically valid technique implemented when one years worth of data does not provide enough information to achieve statistical significance. The only drawback of this method involves identifying trends over that aggregate period of time and thus findings for trends are, at best, limited in meaning and utility.

Second, combining similar population groups is another strategy that should be considered. An example of this is the Native Hawaiians/Pacific Islanders (NH/PI) and American Indians/Alaska Natives (AI/AN) population data. Because of the statistically small size of the population in their data sources, most federal agencies do not publicly release data on American Indians and Alaska Natives. Interestingly, American Indians/Alaska Natives and Native Hawaiians/Pacific Islanders share many similar health concerns, as well as a common experience with the United States as Indigenous people. Thus, publicly reporting American Indian/Alaska Native and Native Hawaiian/Pacific Islander as a combined group would lead to statistically more accurate health status reporting resulting in more effective health improvement policy efforts.

Finally, over sampling of under-representative racial groups is the most effective way to ensure data is representative of the population and that findings are generalizable. Funding limitations are often used as justification for not making these important efforts to be inclusive of under-represented minority groups. The sampling efforts of national surveys are designed to mirror the racial demographics of the population. While this is very effective for larger groups, it is ineffective for the smaller minority populations such as AI/AN (1% of US) or NH/PI (0.1% of US) whose numbers are small. This systemic failing in data gathering, in effect, mutes the voices of our community. Funding needs to be allocated to collect enough data on every racial group to understand their individual needs and monitor the health of their specific populations.

Efforts must be made to provide all communities with access to important health information. Regardless of the size, all populations deserve the right to understand their patterns of disease, knowledge of their health disparities, and other important information necessary for monitoring their own health aspects of life. It is abhorrent that the full extent of the health of racial minority groups is hidden and misrepresented because of limited resources. The accurate health of all population groups need to be understood if truly meaningful changes in the existing structures of inequality are ever to be overcome. ●

UIHI Scientific Conference Updates

Meghan Jernigan, Project Coordinator

The UIHI presented at the 20th Annual Native Health Research Conference (co-sponsored this year by the Indian Health Service, the Northwest Portland Area Indian Health Board, and the Native Research Network, Inc.). The conference attracted public health professionals from across the spectrum including; researchers, physicians, policy makers, community members, and students. UIHI staff distributed Family Health History toolkits and Lead Project Coordinator Alice Park MPH presented information from our family history project. Participants strengthened their knowledge of trends in Native research, participated in debate style discussions around ethics in Indian research, and nominated UIHI's Scientific Director Maile Tauai'i PhDc Chair of the Native Research Network for 2009-2010. For questions contact mailet@uihi.org.



The UIHI presented results from multiple research projects at the 136th annual American Public Health Association meeting held in San Diego, California October 25-29th. Presentation topics included the role of oral tradition in the collection of family health history, health and health-influencing behaviors among urban American Indians and Alaska Natives, and an analysis of American Indian and Alaska Native infant deaths in the Pacific Northwest. This conference provides a unique opportunity for AI/AN and Native Hawaiian health professionals to present their research findings, elevating the often overlooked health concerns confronting urban Indians. In addition, APHA provides exposure to best practices in health research, public health policy, and countless opportunities to grow as health professionals. For questions about the presentations and scientific posters, please contact us at info@uihi.org. ●

Regional partnerships to reduce American Indian/Alaska Native AI/AN disparities in infant mortality

Shira Rutman, Project Coordinator

Metropolitan areas within the Pacific Northwest region report some of the highest infant mortality rates for American Indians/Alaska Natives (AI/AN) in the country. The UIHI has engaged in regional collaboration to better understand the forces leading to infant mortality disparities and to identify effective strategies in preventing fetal and infant death in this population. Partners include: Native American Women's Dialogue on Infant Mortality, Northwest Portland Area Indian Health Board, Oregon Health Sciences, Seattle-King County Public Health, and the Urban Indian Health Institute. This unique multi-agency partnership conducted a collaborative Perinatal Periods of Risk (PPOR) analysis to examine excess mortality rates and strategies to address preventable deaths, among AI/AN in the Pacific Northwest region (Washington, Oregon, and Idaho).

Findings from the Perinatal Periods of Risk assessment indicate a need for interventions to address the areas of maternal and infant health and prematurity among AI/AN in this region. The partnership has focused, and is continuing to focus, on bringing the results to regional and national groups including: Tribal, State and local government policymakers, community, public health and advocacy organizations, educational institutions and healthcare staff and providers. Response from the presentation of study findings have included: focused advocacy of increased funding for maternal and child health staff, plans for cultural adaptations of health promotion materials, further analysis of specific areas of concern among regional AI/AN communities, program priority setting and additional collaborations with interested stakeholders.

There are a number of benefits and challenges in a regional partnership focused on eliminating disparities in AI/AN fetal-infant mortality. Despite challenges such as lack of adequate funding and coordination between agencies in a large geographic area, this regional partnership has provided information that is being used throughout the region to address disparities that exist in infant mortality, maternal and infant health, and prematurity in AI/AN communities.

This unique Pacific Northwest partnership of organizations, that came together for the purpose of eliminating disparities in infant mortality among AI/AN, may be a model for other regional partnerships. Below, one of the partners shares about the benefit of the project to her work.

"As a program manager, I appreciate this partnership. I work for a local public health jurisdiction and am not a data person. Yet, the work of this group in conducting the PPOR analysis and in spreading it widely has allowed me to use the analysis of the data to inform our decisions about the 2009 infant mortality prevention program. I was able to invite the epidemiologist to present the analysis to a group of community stakeholders who then went through a process of identifying and prioritizing program elements for our 2009 program. It was helpful to have the analysis to inform the decision making, and it was helpful to have the participation of some members of this partnership in our group. It's good work. I do think it could be done elsewhere." For more information please contact Shira Rutman: shirar@uihi.org or 206-812-3030. ●

"...the Pacific Northwest region report some of the highest infant mortality rates for AI/AN in the country."

A bitter sweet Aloha

Maile Tauai'i, Scientific Director

Eight years ago, I arrived on the shores of your great land. Naïve, young, inexperienced and full of excitement, I was accepted with open arms and put to work by a visionary man and community. While not much has changed related to my excitement and dedication, I'm only a little less naïve, slightly older, and a little more experienced. You allowed me to spread my wings, taught me valuable lessons, and believed in me as I charged in directions unknown. To all of you I owe so much; your love, support and encouragement will never be forgotten.

As I return to my island home, I will remember these valuable lessons that you have taught me:

- **Never forget what is important; the people, the land, and the culture**
- **Never give up**
- **Never accept a zeroed budget**
- **Impossible is possible**
- **Look for partners in the most unlikely places**
- **Beauty, creativity and partnership are born from challenges**
- **With a little data you can change minds**
- **Trust and honor the people you work with, they are irreplaceable**
- **Demonstrate success**
- **Welcome the people home to the Native community, we all need to be welcomed**
- **I am not an Urban Native, but a Native that happens to live in an Urban area. I'm no less Native because of where I live.**



There are so many more lessons that you have taught me; too many to list, but will be remembered and cherished forever. It has my pleasure and honor to serve the American Indian and Alaska Native community. While I look forward to my return home to Hawaii to serve my community, it brings me great sorrow to say aloha to all my new family and friends in Indian Country. I know that our paths will continue to cross, as we all work towards healing our Native communities. Mahalo for all you have taught me. Mahalo for allowing me to serve. Mahalo for helping me find myself.

Until we meet again.

Aloha – Maile

Maile Tauai'i will defend her PhD dissertation in Health Services, Public Health Informatics, in February 2009 and returning to Hawaii to establish the Native Hawaiian Epidemiology Center housed at the Native Hawaiian Health Board, Papa Ola Lokahi. Her husband and two children, Lemao and Malia will be relocating to Hau'ula, Hawaii on December 16th. Maile will stay on contract with the UIHI to assist in transition. ●

New UIHI Staff

Jim LaRoche, Project Associate

Meghan Jernigan, Project Coordinator, received her Masters in Public Health from Columbia University in May of 2007, and has over five years experience in the field of public health. Prior to working for UIHI, Meghan was a Udall Intern for the U.S. Senate Committee on Indian Affairs, a Field Director for Project REACH at Columbia University, and grants developer for Hospital Audiences, Inc. in New York City. Her previous research experience has focused on social and economic determinants of health, the impact of racism on health behaviors, and chronic disease management in Native communities. In her free time, Meghan enjoys theatre, politics, and food! She was born and raised in Tulsa and is a member of the Choctaw Nation of Oklahoma.

Annie Phare, Project Associate, received her Masters in Public Health from the University of Washington through the Community- Oriented Public Health Practice program. She gained interest in public health as a career while attending Occidental College in Los Angeles, California, where she received her BA in Sociology. Annie is currently working on projects involving injury prevention, viral hepatitis, and health literacy. You may see Annie sometime this next year as she will be working with many of you on viral hepatitis work. Outside of work, Annie enjoys cooking, travel, and activities outdoors. She is a member of the Lummi Nation and grew up on the reservation, located near the Canadian border in Western Washington.



Mary Kummer, Administrative Assistant, may be your first point of contact for UIHI. Her commute to work includes a thirty minute ferry ride across Puget Sound. She is a member of the Makah Indian Nation where she was raised at Neah Bay which is located at the northwestmost point of the continental United States.

Jenny Lee, Project Assistant, (photo left) received her Bachelor of Arts from Haverford College with a major in Anthropology. She relocated to Seattle from New Jersey and is learning to say pop instead of soda. Jenny is one of the most well traveled of our staff and just returned from Indonesia.

Jenny Serpa, Project Assistant, is the newest addition to UIHI. Jenny received a Bachelor of Arts from the University of Washington with Honors in Anthropology focusing on Educational Research in 2006. Besides indigenous movements, she is interested in photography, art, writing, and travel. Jenny is Quechua, with her father's family hailing from Lima, Peru. ●

Maile Tauli'i - returning home

Ralph Forquera, Executive Director

This December, Maile Taulii will return with her family to Hawaii. From the first day Maile came to work at the Seattle Indian Health Board, even before the creation of the Urban Indian Health Institute, her goal was to return home. In the past eight years, Maile has become the cornerstone of the UIHI. Her energy, intellect, understanding, and dedication to the community-based control of important decisions through research and scientific inquiry are at the heart of the UIHI experience. When she returns home, Hawaii will gain a true leader. For us here at the SIHB/UIHI, we have reaped enormous benefit with the bar set extremely high.

When Maile first came to work for me in late 1999, she told me directly that she was here to learn, get her education, and take this experience back to her people in Hawaii. During her eight years with the SIHB, Maile completed her formal education, she has earned an MPH and is currently a doctoral candidate in Health Services from the University of Washington, she plans on defending her dissertation this February. She has had two beautiful daughters who are destined to be leaders in their own right. Seeing her goal come to fruition was very satisfying to watch.

Maile's work will always be the heart and soul of the UIHI. It is impossible to even try and replace her. But while we are losing a key piece of the UIHI leadership as Maile moves back to Hawaii, we also know that she has crafted a solid foundation that will allow us to keep the UIHI at the forefront of information management for urban Indians in decades to come.

Change is always difficult and losing such a key cornerstone of the UIHI family places an even greater burden on those of us who remain. Fortunately, Maile has amassed an exceptional group of people who share her passion and desire to serve urban Indian people. While we will miss her, we are confident that she will continue to make positive change in the world as she has these past eight years. Join me in wishing Maile, Keni, Lemao, and Malia a wonderful life in Hawaii. ●



Urban Indian C.A.R.E.S.

(Colon and Rectal Education and Screening) Alice Park, Lead Project Coordinator

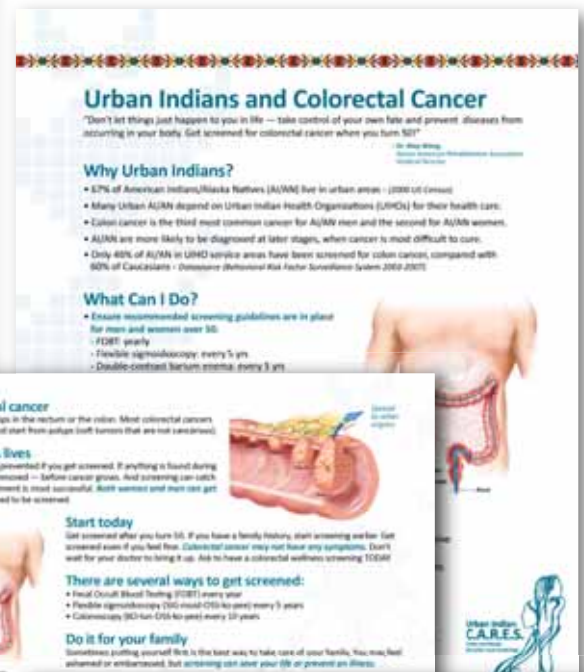
The UIHI is pleased to release materials developed from the Urban Indian C.A.R.E.S. (Colon and Rectal Education and Screening) project. The goal of Urban Indian C.A.R.E.S. is to promote education, testing, and treatment of colorectal cancer for urban American Indians and Alaska Natives (AI/AN) through the Urban Indian Health Organizations (UIHO) nationwide.

Cancer is the second leading cause of death among AI/AN. Colorectal cancer is one disease that can be prevented or successfully treated if detected early. But AI/AN are less likely to be diagnosed with colorectal cancer at the localized stage and more likely to be diagnosed at the distant stage, have a lower probability of survival and higher risk of death once diagnosed compared to whites.

The materials (see below) include a community poster and postcard featuring a Native American colorectal cancer survivor, and a factsheet that may be used as part of a health promotion campaign. Additionally, the templates for all materials are available for customization, such as to replace the photo and story with a local survivor to make the materials more community-specific. There will be more to come from the Urban Indian C.A.R.E.S. project in preparation for March colorectal cancer month, including a media toolkit with sample press releases, templates for education fact sheets and guidelines for media opportunities to promote colorectal health and wellness. ●



“Cancer is the second leading cause of death among American Indians/Alaska Natives (AI/AN).”



Ruby was diagnosed with colon cancer at age 27. Since then, she has been diagnosed many times. But Ruby will never give up - NO MATTER WHAT.

Her type of colon cancer runs in her family. Her grandchildren and daughter also have it. They all have regular colon screenings. But they go through it together...as a family.

“I think it is easy for many people to just give up and not work at staying healthy or going to get that test. It takes someone like me to sit and talk with them and hear my story - we need to talk to another we trust about cancer.”

COLON SCREENING CAN SAVE YOUR LIFE.
Get screened after you turn 50. If you have a family history, start screening earlier. Don't wait for your doctor to bring it up. Ask to have a colorectal wellness screening TODAY.

For more information about CARES contact the Urban Indian Health Institute, Seattle Indian Health Board at (206) 812-3030 or info@uihi.org. Supported by Grant from Prevent Cancer Foundation.

ORGANIZATION CONTACT INFORMATION:



W.E.A.V.I.N.G. Resources for Urban Indian Women's Wellness

(Women's Education & Awareness: Vision for Increasing & Nurturing Good Health) Jessica Folkman, Project Coordinator

As many people know, October was National Breast Cancer Awareness month. What people may not know, however, is that this October was also the launch of the UIHI's project, Weaving Resources for Urban Indian Women's Wellness (The WEAVING Project). Through the WEAVING Project, UIHI's goal is to help increase breast and cervical cancer screening among urban Indian women by providing technical assistance to state breast and cervical programs and urban Indian health organizations.

To help accomplish the goal of increased breast and cervical cancer screening among urban Indian women, the WEAVING Project will be offering a range of services to all Urban Indian Health Organizations (UIHO) and state breast and cervical early detection programs (BCCEDP). These resources include: online resources (e.g. self assessment toolkits, data collection resources, culturally appropriate community outreach and educational materials); reports (e.g. best practices and models of success); regular conference call meetings and annual national trainings.

Additional services will also be provided to select sites. These services include: staff training activities; internal capacity building services; on-site meeting facilitation and other assistance as requested. (If you are interested in becoming a site that receives these additional services, please contact us at the email or phone number listed below – we would love to hear from you!).

In mid-October, WEAVING Project introductory packets were mailed to all 34 UIHO, as well as 19 state BCCEDP. In these packets, you will find project information, as well as breast and cervical cancer factsheets (see example of fact sheet below) for the urban American Indian/Alaska Native population. WEAVING Project staff are available to speak with each site by phone to answer questions and discuss the project in more detail.

The UIHI looks forward to working with you all on this very exciting and important project! ●

The collage features several key documents:

- FACT SHEET: Breast and Cervical Cancer Among Urban American Indian & Alaska Native Women**
 - Urban Indian Population: According to the 2000 US Census, more than half of the American Indian and Alaska Native (AI/AN) population in the United States lives in urban areas. Approximately one million AI/AN live in urban Indian health organization (UIHO) service areas. Of this group, 573,225 identify as AI/AN alone, of whom:
 - 195,890 (34%) are female ages 18 and older
 - 47,634 (8%) are female ages 50-64
 - 23% of females ages 18 and older are living in poverty.
 - Cancer: A Leading Cause of Death
 - Cancer is the second leading cause of death among urban AI/AN.
 - New cases of breast cancer in AI/AN nationwide = 63.7/100,000 (2002-2004)¹
 - New cases of cervical cancer in AI/AN nationwide = 6.3/100,000 (2002-2004)¹
 - Breast cancer in AI/AN = 10,87/100,000
 - Cervical cancer = 1,86/100,000
 - Breast and Cervical Cancer Screening (2002-2007)
 - 13.7% of AI/AN women never had pap smear test (Age 18+)
 - 4.9% of White women never had pap smear test (Age 18+)
 - 18.8% of AI/AN women never had physical breast exam by doctor (Age 40+)
 - 8.1% of White women never had physical breast exam by doctor (Age 40+)
- Breast and Cervical Cancer Diagnosis and Survival**
 - Stage III and IV Breast Cancer Diagnosis, American Indian and White, 1992-1998¹
 - AI/AN: 6.8% Stage IV, 18.9% Stage III
 - White: 4.5% Stage IV, 6.8% Stage III
 - Five Year Survival, Breast and Cervical Cancer², American Indian/Alaska Native and White Women, 1994-2004^{1,3,4}
 - AI/AN: 73.3% (Breast), 78.3% (Cervical)
 - White: 88.7% (Breast), 89.7% (Cervical)
- WEAVING RESOURCES FOR URBAN INDIAN WOMEN'S WELLNESS**
 - BACKGROUND: Cancer is the second leading cause of death for urban American Indian and Alaska Native women. Screening services are essential for cancer prevention and early detection. UIHOs have a higher rate of late stage breast cancer than White women.
 - PROGRAM SERVICES: Available to all UIHOs and state BCCEDPs. Includes technical assistance, program staff training, and a map of the United States.

For more information on the WEAVING Project, we encourage you to visit our website at: www.uihi.org/the-weaving-project. We can also be reached by phone at (206) 812-3030 or email at info@uihi.org.