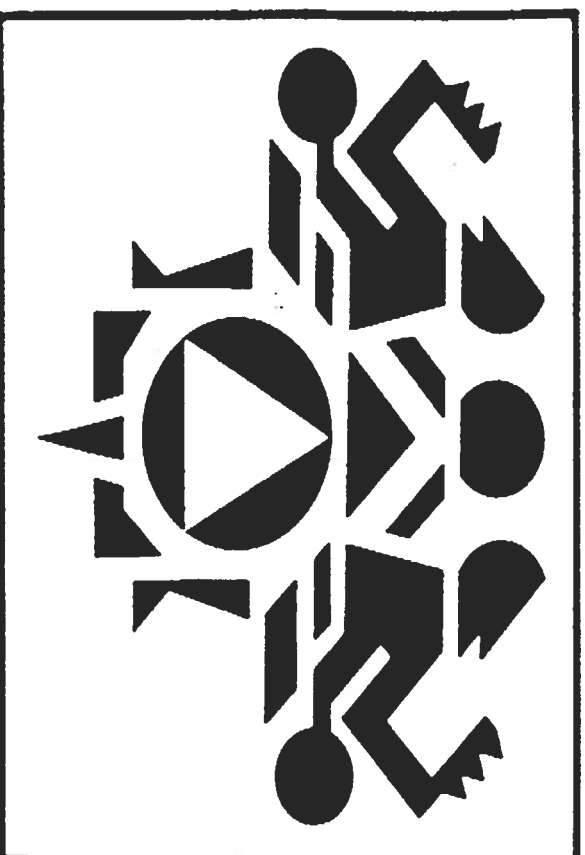


SUMMARY OF MINUTES



QUARTERLY BOARD MEETING

OCTOBER 16-18, 2012

UPPER SKAGIT CASINO RESORT

BOW WA

October 2012 Quarterly Board Meeting

Summary of Minutes

Issue	Summary	Action	Follow-Up
Area Director Report	Area Meetings: Direct Service Tribes have requested semi-annual meetings; we held one in September 2012 during ATNI annual meeting.	The beginning of the year we will hopefully have meetings set up with the direct service tribes.	
Area Director Report	Urban Directors meeting: Held one about 7 months ago; want to have them about every 6 months. Discussion will be about their contracts, their services and how the urban program at Headquarters can tie in with them and provide additional support.		
Area Director Report	2013 Injury Prevention Campaign has started. It is collaboration with the Health Board & the Northwest Washington Indian Health Board; both boards have received IHS funding for tribal injury prevention cooperative agreement projects. They need to do a pilot assessment in at least 2 tribal communities.	I want to develop an Elder Fall Prevention Program that integrates both the primary care that they are receiving plus work with the Public Health systems where they actually go out and identify potential trips and falls that our elders may face in their own home environment and in the community.	
Area Director Report	Staff Update: The Chief Medical Officer is still vacant. The Meaningful Use Coordinator is Dr. Woody Crow	It will be advertised.	
Area Director Report	CHEF fund; we had 115 CHEF cases that were received and processed for \$8.5 million.	Information requested on CHEF expenditures across all Areas; small user population always seem to get more CHEF money	Terry Dean will follow up on that request
Executive Director Report	Recognition of 10 years of service at the Health Board: Stephanie Craig-Rushing Nichole Smith Elaine Dado		
Federal Employee Health Benefits Program	It is the largest employer-sponsored group health insurance program in the world. Who can join; urban Indian organizations carrying out programs under title V of the IHCLA and tribes	Some of the features: no pre-existing condition limitations; no waiting periods; immediate coverage upon enrollment; enrollee out-of-pocket maximum; 96 available plans; plans contract with doctors & hospitals	

October 2012 Quarterly Board Meeting

Summary of Minutes

	and tribal organizations carrying out programs under the ISDEAA.	(provider network); no broker fees.	
Legislative Report	Medicaid/Medicare issues & implementation activities of the ACA	A lot work involved with states exchanges, preparing for the Federal Facilitated Exchange in Idaho	
Legislative Report	CSC Workgroup – the Director has charged the workgroup to evaluate changes that Dr. Grim adopted in the policy in 2003. In order to do that you need access to the data; the Director has been reluctant to provide the workgroup the data.	Approximately a year ago the Health Board filed a Freedom of Information Act request to the IHS. They still have not provided the data to the Board and to the workgroup. In follow-up to that, the Board has filed a law suit against IHS to release the CHS data. We are not the only plaintiff on the case; there are over 250 tribes and tribal organizations that are represented by Sonosky, Chambers law firm.	The Court will be letting the attorneys know what the timeline for that is to hear the case; if it gets that far.
Epi Data Repository	In 2011 a resolution; Northwest Tribal Data Repository Investigation was passed. The resolution directed us to look at partnering with Northwest Tribal College and develop a plan for a data repository. Today will be an update on what we have done to date and what direction to go in regarding the next steps. The project would probably cost upwards to \$1 million to do in-house. We have just gotten some extra money in the Epi Center core grant; \$80,000 for the coming year. Part of that is dedicated to another biostatistician/registry repository management person.	What we do now with research projects is return all data to the tribe when project is completed. Three options: 1. The first one is what we thought we were going to be able to do when we started & perhaps still will be the road we take. The Board staff develops, establishes and maintains its own Data Repository. This will take a tremendous amount of computer infrastructure & then architecture to get the data in; staff dedicated to this and cost of doing it in-house. There are no grants available at this time for this. 2. Second option is contracting with an existing experienced data repository;	A lot of information to digest. We will report more information at the next meeting.

October 2012 Quarterly Board Meeting

Summary of Minutes

		<p>looking at or in a university.</p> <p>3. Third option is to contract with an existing experienced data repository of an umbrella organization that permits organizations within it to control their data in their repository.</p> <p>4. The final option, the umbrella organization, would be a cologement of groups that would have one data repository but multiple organizations feed into it. We have talked with a group called Genetic Alliance; an organization of 1200 disease advocacy groups.</p>	
MOTION Minutes	Motion by Pearl Capoeman-Baller, Quinault Nation; 2 nd by Shawna Gavin, Umatilla Tribe to approve the June 2012 minutes.	MOTION CARRIED	
RESOLUTION #13-01-01	SR40 Maternal & Child Health Research Program Secondary Data Analysis	Motion by Stella Washines, Yakama Nation; 2 nd by Brenda Nielson, Quileute Tribe to ratify this resolution. MOTION CARRIED	
RESOLUTION #13-01-02	NIMHD Community-Based Participatory Research (CBPR) Initiative in Reducing & Eliminating Health Disparities: Dissemination Phase (R24)	Motion by Stella Washines, Yakama Nation; 2 nd by Cheryle Kennedy, Grand Ronde Tribe to ratify this resolution. MOTION CARRIED	
RESOLUTION #13-01-03	Exempt IHS & BIA Appropriations from Sequestration Required Under the Budget Control Act of 2011	Motion by Andy Joseph, Colville Tribe; 2nd by Cheryle Kennedy, Grand Ronde Tribe to approve. MOTION CARRIED	
RESOLUTION #13-01-04	Support Dental health Aide Therapist & Advanced Dental Therapists Educational & Scope of Practice Requirements	Motion by Stella Washines, Yakama Nation; 2 nd by Joanne Liantonio, Samish Nation to approve. MOTION CARRIED	
RESOLUTION #13-01-05	Centers for Disease Control & Prevention (CDC) Epidemic Intelligence Officer	Motion by Stella Washines, Yakama Nation; 2 nd by Joanne Liantonio, Samish Nation to approve. MOTION CARRIED	
RESOLUTION	Support NPAIHB CSC Litigation	Motion by Stella Washines, Yakama Nation;	

October 2012 Quarterly Board Meeting
Summary of Minutes

#13-01-06		send by Joanne Liantonio, Samish Nation to approve. MOTION CARRIED	
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Elders Committee

Tuesday October 16, 2012
Skagit Valley Casino Resort, Bow, WA

	Name and Title	Organization	Phone/FAX/E-mail
1	DAN GLEASON	CHEHALIS	360-273-5911
2	Bernadine Shriver	Grand Ronde	503-663-7624
3	Frances Kelle/ Angela	Snoqualmie Falls	425-888 6551
4	Thomas Lehman	Jameson	360 457-5772
5	Andy Joseph Jr.	Colville	509 631 4406
6	Janice Clements	Waban Springs	541-553-1196 ^{et} cassie
7	Branda Nelson	Skullie	360 814-4318 branda.nelson@ihsgov
8	Gladya Hobbs	SR	971-241-8484
9	Willie Chasing	NPA IIB sleep	
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Chehalis: Elders were treated to their Alaskan cruise in September and 47 elders toured South Dakota during the week of October 7-13, 2012. Touring the Crazy Horse and Black Hills Monument were highlights of the trip.

Grand Ronde: Elders now are receiving meals Tuesday-Friday and receive a meal at the casino on Monday. New elders housing is now available, they are solar powered and several are available that allow children to live with their family members. Elders and youth participated in a horseshoe tournament, September 17, 2012 and afterwards shared a meal. Bingo is offered twice a month and elders will have their Halloween Party, October 27th. Grand Ronde Clinic has added a Nurse Practitioner to their staff and now offer a physical therapy program.

Colville: Elders have gone on several trips and volunteer in a foster grandparent program. Andy is working with the Tribal Council on repealing the income guidelines that are within the foster grandparent program and deny those that would like to participate.

Warm Springs: Janice spoke to the committee on how elder and housing programs and volunteer programs were created on their reservation.

Snoqualmie Tribe has finalized the purchase of the building which will be their hospital. They have received a grant that allowed them to hire an elder coordinator. Elders have their lunches delivered by the coordinator, who has organized a retreat for their group, and assists them with home repairs. They recently returned from a overnight trip to Swinomish Casino and Resort.

With a future lobbying trip to DC, Andy will push for elder issues to be on the agenda.

Native Caring Conference will be held March 2013, Chinook Winds Casino and Resort and will be hosted by the Siletz Tribe. Bernadine and Gladys will forward information to committee members when they receive it.

Veterans Committee

Tuesday October 16, 2012
Skagit Valley Casino Resort, Bow, WA

	Name and Title	Organization	Phone/FAX/E-mail
1	Cathy Dawson, Minority Rep. Coordinator, VA Rep. Service		Cathy.dawson2@va.gov
2	Phil Dan	Swinomish	Normyd@frontier.com 360-466-1618
3	Sharon Wolf	Lummi Health & Family Services Coun.	SIWOLF09@comcast.net
4	Stephen Kutz	Cowlitz	360-731-2885 skutz.health@cowlitz.org
5	Jesse Paul	NKE PEACE	WAPTIS33@GMAIL.COM
6	BEVERLY LEMEN	UPPER Skagit	206-248-3900
7	John LEMEN	" "	" "
8	LUCIE JOE BOYD ^{TR}	SUGUAMISH	360 535 3514
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Personnel Committee

Tuesday October 16, 2012
Skagit Valley Casino Resort, Bow, WA

	Name and Title	Organization	Phone/FAX/E-mail
1	Bobby Puffin	HR Coordinator NPAIHB	503-416-3297
2	Jacqueline Bull ^{Left Hand}	NPAIHB	
3	Cassandra Red	Cowlitz indian tribe	360-666-2417/3605131243 csellardsreck@hotmail.com
4	Rose E Purser ^{Board Delegate}	Port Gamble Skiaion	360-297-6246
5	Shawna M. Gavin	CTUWR	541-429-7378 shawngavin@ctwr.org
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Behavioral Health Committee

Tuesday October 16, 2012
Skagit Valley Casino Resort, Bow, WA

	Name and Title	Organization	Phone/FAX/E-mail
1	Renee Cooke ^{14. Dir}	Neelink Jack	(360) 406-2106
2	Allen Broy	St Mary's Hospital	810 452 9641
3	Nancy Kirksey ^{Exec Hst}	CHUR-ITAC	NANCYKIRKSEY@pioneerlink.org 541-215-1945
4	SARAH ^{JICE} Saham, Chair	Wn Spjs. Con. Tribes HIT & WEL Com	SVL-553-1161
5	Suzanne Lane ^{MEMBER}	OPATHB	503-416-3293
6	Laverne Lane	Sauk-Sauittie	(360) 436-0131 ext. 223
7	Michelle Sobal	IHS	503 414 5596 michelle.sobal@ihs.gov
8	Colleen F Cawth	WA State DSHS - DIP	360-902-7816
9	Yancy Johnson	Confederated Tribes Colville	509-634-1803
10	Marilyn Scott		509 634-2216 yancy.johnson@colvilletribe.co
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Marilyn Scott.

Behavioral Health / Public Health Committee Meeting
Quarterly Board Meeting
October 16, 2012

Attendees:

Public Health:

Lona Johnson, Nooksack Tribe
Doug Wangen, Chehalis Tribe
Tam Lutz, NPAIHB
Luella Azule, NPAIHB
Suzanne Zane, NPAIHB
Rachel Ford, NPAIHB
Maria Gardipee, State of WA
Victoria Warren-Mears, NPAIHB

Behavioral Health Committee:

Rebecca Crocker, Nooksack Tribe
Colleen Bowles, Stillaguamish
Nancy Kiersey, CTUIR
LaVerne Lane, Sauk-Suiattle
Sal Sahmin, Warm Springs
Michelle Sobel, IHS
Colleen Cawston, WA DSHS
Yancy Johnson, Colville

Agenda

Public Health Survey (Rachel Ford)

Public health improvement training and technical assistance needs assessment survey. Please take time to fill it out and return it to Rachel. Rachel is still providing technical assistance to tribes interested in the accreditation process.

Q – Have any of the sites involved their tribal leadership to focus on health codes? A – Umatilla has been working on this. It might be helpful to have Umatilla representatives present at the QBM, to present on their process and how it has worked for them.

NPAIHB Grants (Tam Lutz)

We had a 30 day grant opportunity through NIHMHD that would continue the Native CARS study (which aims to improve child safety seats use) into a three year dissemination phase. Through this funding source, if you demonstrate that you've had success with your research, you are eligible for funds to translate and disseminate the findings, products and methodologies to other tribes (dissemination phase of the project). The six tribes involved with the original grant would be involved in the development of dissemination modules and helping to train other tribes. We should have a score by January, and would be funded by March at the earliest. The NPAIHB also submitted a three-year NIMHD planning grant June 27th with aims of determining what the available MV-related injury and mortality data is available, how the quality and usability of that data could be improved and pilot test in 1-2 communities applying that MV data to community interventions. Hopefully this planning grant, if successful, would lead to the opportunity to applying for a five year intervention phase.

Marilyn – The NWWIHB's Injury Prevention Coalition has been doing surveillance on child car seat use and child helmet use among NWWIHB tribes. We are starting to emphasize the importance of helmet use (especially with bikes, skateboards, motorized cars). We developed materials to share with our health start and after school programs, to provide information to our parents. We conducted a night study to look at night time visibility with and without reflective visibility gear.

3. The NPAIHB could contract with an umbrella organization that would allow us access to our data: Genetic Alliance. (This is what the workgroup is currently recommending, due to costs and benefits.)
 - a. Pro – Used to working with smaller groups; giving control over the data that belongs to those bodies. Our Tribal IRB would control access to that data. Cost would be under \$1,000 per dataset entered. This option would give us the greatest level of control over our data.
 - b. Con – Haven't worked with AI/AN Organization before.
4. We don't have to do anything, but that would limit our ability to apply for grant funding.

Q – If Tribes have their own IRB, how would that process work to access the data? A – We still need to work out the process that would be used. But only tribes who have participated in a study would have access to their own data. It's still tribal ownership of the data, it just offers a safe place to keep the data, and make sure that it's secured. All of the data is de-identified. IRB protocols will still have the opportunity to determine where it would be housed, and who would have access to it.

Q – Where are we in this process? Will there be opportunities for legal review? A – We are still early in the process. We are still exploring each of these three options. We can try the system with one dataset to see if it works for us, and then decide from there.

Q – How stable is the organization? A – They have been around for more than 10 years. Dr. Freeman will be covering some of this in more detail in his presentation tomorrow.

Discussion – I think this resolution will start the conversation with tribes and Genetic Alliance, to get more information about how this relationship would work.

Discussion – I would like to defer this resolution to the full Board or the Executive committee, to fully vet the questions and concerns that member tribes might have.

The group will forward the resolution to the Board for consideration, after the presentation tomorrow.

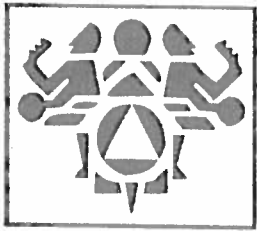
Legislative/Resolution Committee

Tuesday October 16, 2012
Skagit Valley Casino Resort, Bow, WA

	Name and Title	Organization	Phone/FAX/E-mail
1	John Stephens	Swinomish	jstephen@swinomish.nsn.us 360-466-7116
2	Tim Gilbert	Unatila / Yellowhawk	tim.gilbert@yellowhawk.org
3	Pearl Caposeman Baller	Quinault	pballer@quinault.org
4	CHERYL RASAR	SWINOMISH	crasar@swinomish.nsn.us
5	Leslie Wosny Health Administrator	Squamish	lwosny@sqwamish.nsn.us 360-394-8466
6	Kim Zillyett-Harris Health Director	Shoalwater Bay	kzillyett@shoalwater-bay.nsn.gov
7	ROBERTA RASAR NEZ PERCE council	NEZ PERCE TRIBE	roberta@nezperce.org
8	F. Scott Burrell DC. Health Admin.	Tulalip Tribes	sburrell@tulaliptribes.nsn.gov
9	Jin Ruskus		
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3. Exempt IHS and BIA Appropriations from Sequestration Required under the Budget Control Act of 2011. (Motion to pass by Roberta Bisbee; second by Scott Powell; unanimously approved).
4. Two resolutions to pursue funding opportunities were approved through the Executive Committee were ratified by the full Legislative Committee:
 - a. NIMHD Community-Based Participatory Research Initiative in Reducing and Eliminating Health disparities: dissemination Phase (R24).
 - b. R40 Maternal and Child Health Research Program Secondary Analysis.
5. Northwest Tribal Data Registry Repository: This resolution was shared with the Legislative Committee for informational purposes. The Public Health Committee will be reviewing this resolution.

Adjourn at 1:00 p.m.



NORTHWEST PORTLAND AREA INDIAN HEALTH BOARD

Burns-Paiute Tribe
Chehalis Tribe
Coeur d'Alene Tribe
Colville Tribe
Coos, Suislaw &
Lower Umpqua Tribe
Coquille Tribe
Cow Creek Tribe
Cowlitz Tribe
Grand Ronde Tribe
Hoh Tribe
Jamestown S'Klallam Tribe
Kalispel Tribe
Klamath Tribe
Kootenai Tribe
Lower Elwha Tribe
Lummi Tribe
Makah Tribe
Muckleshoot Tribe
Nez Perce Tribe
Nisqually Tribe
Nooksack Tribe
NW Band of Shoshone Tribe
Port Gamble S'Klallam Tribe
Puyallup Tribe
Quileute Tribe
Quinault Tribe
Samish Indian Nation
Sauk-Suiattle Tribe
Shoalwater Bay Tribe
Shoshone-Bannock Tribe
Siletz Tribe
Skokomish Tribe
Snoqualmie Tribe
Spokane Tribe
Squaxin Island Tribe
Stillaguamish Tribe
Suquamish Tribe
Swinomish Tribe
Tulalip Tribe
Umatilla Tribe
Upper Skagit Tribe
Warm Springs Tribe
Yakama Nation

Resolution No.:13-01-03

"EXEMPT IHS & BIA APPROPRIATIONS FROM SEQUESTRATION REQUIRED UNDER THE BUDGET CONTROL ACT OF 2011"

WHEREAS, the Northwest Portland Area Indian Health Board (hereinafter "NPAIHB" or the "Board") was established in 1972 to assist Tribal governments to improve the health status and quality of life of Indian people; and

WHEREAS, the NPAIHB is a "tribal organization" as defined by the Indian Self-Determination and Education Assistance Act (P.L. 93-638 seq. et al) that represents forty-three federally recognized tribes in the states of Idaho, Oregon, and Washington; and

WHEREAS, in accordance with the definitions of the Indian Self-Determination and Education Assistance Act at 25 USCS § 450b, a tribal organization is recognized as a governing body of any Indian tribe and includes any legally established organization of Indians which is controlled, sanctioned, or chartered by such governing body or which is democratically elected by the adult members of the Indian community to be served by such organization and which includes the maximum participation of Indians in all phases of its activities; and

WHEREAS, the NPAIHB is dedicated to assisting and promoting the health needs and concerns of Indian people; and

WHEREAS, the primary goal of the NPAIHB is to improve the health and quality of life of its member Tribes; and

WHEREAS, the Balanced Budget Control Act of 2011 (P.L. 112-25) provides for sequestration of federal discretionary funds to in order to reduce the federal deficit by \$1.2 trillion over ten years unless Congress passes and the President signs legislation to appeal the Budget Control Act; and

WHEREAS, the Office of Management and Budget (OMB) has issued, "OMB Sequestration Update Report to the President and Congress for Fiscal Year 2013," in which it reports that the impact of sequestration and the Indian Health Service (IHS) funds would be subject to full sequestration which OMB estimates to be 8.2%; and that the Special Diabetes Program for Indians funds would be subject to 2%, which would result in an overall reduction of \$355 million in FY 2013; and

WHEREAS, the IHS is only funded at approximately 60% of its level of need¹ and a budget reduction of \$355 million would have a serious effect on the ability of the IHS to provide health care services to American Indian and Alaska Native and the IHS Budget Formulation

¹ The IHS Federal Disparity Index (FDI) is used to cite the level of funding for the Indian health system relative to its total need. The FDI compares actual health care costs for an IHS beneficiary to those costs of a beneficiary served in mainstream America. The FDI uses actuarial methods that control for age, sex, and health status to price health benefits for Indian people using the Federal Employee Health Benefits plan, which is then used to make per capita health expenditure comparisons. It is estimated by the FDI, that the IHS system is funded at less than 60 percent of its total need. See: Level of Need Workgroup Report, Indian Health Service, available: www.ihs.gov.

CERTIFICATION

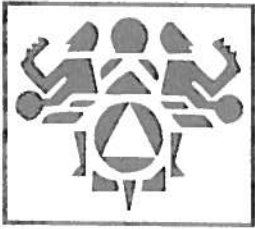
NO. 13-01-03

The foregoing resolution was duly adopted at the regular session of the Northwest Portland Area Indian Health Board. A quorum being established; 30 for, 0 against, 0 abstain on Oct 18, 2012.

Andrew C. Joseph Jr.
Chairman

10.18.12
Date

Brenda N. [Signature]
Secretary



NORTHWEST PORTLAND AREA INDIAN HEALTH BOARD

Burns-Paiute Tribe
Chchalais Tribe
Coeur d'Alene Tribe
Colville Tribe
Coos, Siuslaw &
Lower Umpqua Tribe
Coquille Tribe
Cow Creek Tribe
Cowlitz Tribe
Grand Ronde Tribe
Hoh Tribe
Jamestown S'Klallam Tribe
Kalispel Tribe
Klamath Tribe
Kootenai Tribe
Lower Elwha Tribe
Lummi Tribe
Makah Tribe
Muckleshoot Tribe
Nez Perce Tribe
Nisqually Tribe
Nooksack Tribe
NW Band of Shoshone Tribe
Port Gamble S'Klallam Tribe
Puyallup Tribe
Quileute Tribe
Quinault Tribe
Samish Indian Nation
Sauk-Suiattle Tribe
Shoalwater Bay Tribe
Shoshone-Bannock Tribe
Siletz Tribe
Skokomish Tribe
Snoqualmie Tribe
Spokane Tribe
Squaxin Island Tribe
Stillaguamish Tribe
Suquamish Tribe
Swinomish Tribe
Tulalip Tribe
Umatilla Tribe
Upper Skagit Tribe
Warm Springs Tribe
Yakama Nation

Resolution No.:13-01-04

Support Dental Health Aide Therapist and Advanced Dental Therapists' Educational and Scope of Practice Requirements

WHEREAS, the Northwest Portland Area Indian Health Board (hereinafter "NPAIHB" or the "Board") was established in 1972 to assist Tribal governments to improve the health status and quality of life of Indian people; and

WHEREAS, the NPAIHB is a "tribal organization" as defined by the Indian Self-Determination and Education Assistance Act (P.L. 93-638 seq. et al) that represents forty-three federally recognized tribes in the states of Idaho, Oregon, and Washington; and

WHEREAS, in accordance with the definitions of the Indian Self-Determination and Education Assistance Act at 25 USCS § 450b, a tribal organization is recognized as a governing body of any Indian tribe and includes any legally established organization of Indians which is controlled, sanctioned, or chartered by such governing body or which is democratically elected by the adult members of the Indian community to be served by such organization and which includes the maximum participation of Indians in all phases of its activities; and

WHEREAS, the NPAIHB is dedicated to assisting and promoting the health needs and concerns of Indian people; and

WHEREAS, the primary goal of the NPAIHB is to improve the health and quality of life of its member Tribes; and

WHEREAS, on January 31-February 1, 2011, the IHS Director convened the IHS Contract Support Cost Workgroup to make recommendations to improve the fairness and equity of the Agency's CSC Policy; and

WHEREAS, the Alaska Native Tribal Health Consortium and the Indian Health Service (IHS) Community Health Aide Program Certification Board developed the Dental Health Aide Therapist Program as an expansion of the well-established Community Health Aide Program (CHAP) to address the unmet dental care needs for Alaska Natives; and

WHEREAS, dental therapists work under the supervision¹ of a dentist, performing cleanings, fillings, and simple extractions and present a tremendous opportunity for addressing the unmet dental care needs in Indian Country; and

WHEREAS, the Indian Health Care Improvement Act requires that Dental Health Aide Therapists may operate outside of Alaska only where similar midlevel dental providers are authorized by state law and in most instances will need to be supported by state legislation; and

WHEREAS, NPAIHB adopted Resolution No. 11-## to support and approve such legislation creating a licensing program for Dental Health Aide Therapists and Advanced Dental Therapists

¹ The term "supervision" is not intended to stipulate a defined term or requirements for any state statute governing dentistry and that in most states general supervision does not require the dentist to be physically present or to personally examine or diagnose the patient. In Washington this type of supervision is defined as "off-site supervision".

CERTIFICATION

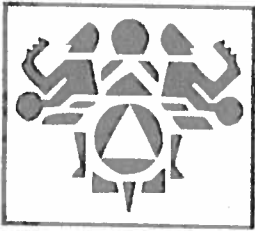
NO. 13-01-04

The foregoing resolution was duly adopted at the regular session of the Northwest Portland Area Indian Health Board. A quorum being established; 30 for, _____ against, _____ abstain on Oct 18, 2012.

Andrew C. Joseph Jr.
Chairman

10-18-12
Date

Brenda N. [Signature]
Secretary



Resolution #13-01-05
Centers for Disease Control and Prevention (CDC)
Epidemic Intelligence Officer

**NORTHWEST
PORTLAND
AREA
INDIAN
HEALTH
BOARD**

Burns Paiute Tribe
Chehalis Tribe
Coeur d'Alene Tribe
Colville Tribe
Coos, Suislaw &
Lower Umpqua Tribe
Coquille Tribe
Cow Creek Tribe
Cowlitz Tribe
Grand Ronde Tribe
Hoh Tribe
Jameson S'Klallam Tribe
Kalispel Tribe
Klamath Tribe
Kootenai Tribe
Lower Elwha Tribe
Lummi Tribe
Makah Tribe
Muckleshoot Tribe
Nez Perce Tribe
Nisqually Tribe
Nooksack Tribe
NW Band of Shoshone Tribe
Port Gamble S'Klallam Tribe
Puyallup Tribe
Quileute Tribe
Quinault Tribe
Sumish Indian Nation
Sauk-Suiattle Tribe
Shoalwater Bay Tribe
Shoshone-Bannock Tribe
Siletz Tribe
Skokomish Tribe
Snoqualmie Tribe
Spokane Tribe
Squaxin Island Tribe
Stillaguamish Tribe
Suquamish Tribe
Swinomish Tribe
Tulalip Tribe
Umatilla Tribe
Upper Skagit Tribe
Warm Springs Tribe
Yakama Nation

WHEREAS, the Northwest Portland Area Indian Health Board (hereinafter "NPAIHB" or the "Board") was established in 1972 to assist Tribal governments to improve the health status and quality of life of Indian people; and

WHEREAS, the Northwest Portland Area Indian Health Board is a "tribal organization" as defined by the Indian Self-Determination and Education Assistance Act (P.L. 93-638 seq. et al) that represents forty-three federally recognized tribes in the states of Idaho, Oregon, and Washington; and

WHEREAS, in accordance with the definitions of the Indian Self-Determination and Education Assistance Act at 25 USCS § 450b, a tribal organization is recognized as a governing body of any Indian tribe and includes any legally established organization of Indians which is controlled, sanctioned, or chartered by such governing body or which is democratically elected by the adult members of the Indian community to be served by such organization and which includes the maximum participation of Indians in all phases of its activities; and

WHEREAS, the NPAIHB is dedicated to assisting and promoting the health needs and concerns of Indian people; and

WHEREAS, the primary goal of the NPAIHB is to improve the health and quality of life of its member Tribes; and

WHEREAS, in furtherance of this goal in 1997, NPAIHB established the Northwest Tribal Epidemiology Center (*EpiCenter*) in an effort to improve the quality of American Indian and Alaska Native (AI/AN) epidemiology data; and

WHEREAS, the *EpiCenter* has gained national recognition for developing and implementing many useful and innovative projects to improve the health and quality of life of Northwest tribes and has served as a national model for other Indian Health Service (IHS) areas to emulate in establishing their *EpiCenter* programs; and

WHEREAS, the Centers for Disease Control and Prevention's (CDC) Epidemic Intelligence Service (EIS) has invited the Northwest Tribal *EpiCenter* to become a host site for an EIS officer, to provide professional development opportunities for an incoming EIS officer for the 2013-2015 class; and

WHEREAS, the Portland Area Indian Health Service (PAOIHs) and the NPAIHB will work collaboratively, through the supervision of Tom Weiser, MD, MPH and Tom Becker, MD, PhD, to provide multiple learning opportunities that will support the mission of the EIS program; and

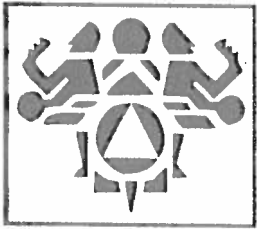
WHEREAS, this opportunity will provide additional support to current projects that address health disparities in AI/AN populations with regard to chronic diseases, injuries and infectious diseases; and

WHEREAS, a successful proposal for this CDC training program would provide an opportunity for the CDC to work closely with the PAOIHs, and the NPAIHB to mentor a public health professional; and

WHEREAS, the goals of this initiative are consistent with the goals and objectives of the PAOIHs, NPAIHB, and the *EpiCenter*; and

THEREFORE BE IT RESOLVED that the NPAIHB endorses and supports an effort by staff of the *EpiCenter*, under the guidance of the Executive Director, to submit a proposal to CDC to host an EIS officer for the 2013-2015.

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Resolution No.:13-01-06
"Support NPAIHB Contract Support Cost Litigation"

**NORTHWEST
PORTLAND
AREA
INDIAN
HEALTH
BOARD**

Burns Paiute Tribe
Chehalis Tribe
Coeur d'Alene Tribe
Colville Tribe
Coos, Siuslaw &
Lower Umpqua Tribe
Coquille Tribe
Cow Creek Tribe
Cowlitz Tribe
Grand Ronde Tribe
Hoh Tribe
Jamestown S'Klallam Tribe
Kalispel Tribe
Klamath Tribe
Kootenai Tribe
Lower Elwha Tribe
Lummi Tribe
Makah Tribe
Muckleshoot Tribe
Nez Perce Tribe
Nisqually Tribe
Nooksack Tribe
NW Band of Shoshone Tribe
Port Gamble S'Klallam Tribe
Puyallup Tribe
Quileute Tribe
Quinault Tribe
Samish Indian Nation
Sauk-Suiattle Tribe
Shoalwater Bay Tribe
Shoshone-Bannock Tribe
Siletz Tribe
Skokomish Tribe
Snoqualmie Tribe
Spokane Tribe
Squaxin Island Tribe
Stillaguamish Tribe
Suquamish Tribe
Swinomish Tribe
Tulalip Tribe
Umatilla Tribe
Upper Skagit Tribe
Warm Springs Tribe
Yakama Nation

WHEREAS, the Northwest Portland Area Indian Health Board (hereinafter "NPAIHB" or the "Board") was established in 1972 to assist Tribal governments to improve the health status and quality of life of Indian people; and

WHEREAS, the NPAIHB is a "tribal organization" as defined by the Indian Self-Determination and Education Assistance Act (P.L. 93-638 seq. et al) that represents forty-three federally recognized tribes in the states of Idaho, Oregon, and Washington; and

WHEREAS, in accordance with the definitions of the Indian Self-Determination and Education Assistance Act at 25 USCS § 450b, a tribal organization is recognized as a governing body of any Indian tribe and includes any legally established organization of Indians which is controlled, sanctioned, or chartered by such governing body or which is democratically elected by the adult members of the Indian community to be served by such organization and which includes the maximum participation of Indians in all phases of its activities; and

WHEREAS, the NPAIHB is dedicated to assisting and promoting the health needs and concerns of Indian people; and

WHEREAS, the primary goal of the NPAIHB is to improve the health and quality of life of its member Tribes; and

WHEREAS, on January 31-February 1, 2011, the IHS Director convened the IHS Contract Support Cost Workgroup to make recommendations to improve the fairness and equity of the Agency's CSC Policy; and

WHEREAS, NPAIHB sent the IHS Director a letter to support Andy Joseph's chairmanship of the CSC Workgroup and to follow-up on the CSC Workgroup's first meeting to explain that the Workgroup could not conduct an evaluation of the IHS CSC Policy and that in order to proceed with an assessment of the Policy that the Workgroup would require access to CSC expenditure data; and

WHEREAS, the IHS Director refused to provide the CSC Workgroup access to data and consequently NPAIHB filed a Freedom of Information Request (FOIA) suit to remedy the refusal of the IHS Director to provide the CSC Workgroup with Agency records that are subject to disclosure under the FOIA for (FY 2010, FY 2011 and FY 2012); and

WHEREAS, because NPAIHB is the lead entity that filed the FOIA request it is appropriate that the Board be the lead plaintiff in the lawsuit that represents over 250 Tribes and tribal organizations in eleven States who are all assisting to financially support this effort.

NOW THEREFORE BE IT RESOLVED, that the Northwest Portland Area Indian Health Board support the filing of the CSC suit to force the IHS to provide Contract Support Costs public expenditure data to support the work of the CSC Workgroup and to ensure that the recovery of costs incurred for operating IHS programs and the allocation of adequate contract support cost funds are fair and adequate.

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Draft: NORTHWEST PORTLAND INDIAN HEALTH BOARD (NPAIHB)

**Proposal to Establish a Data Repository
October 17, 2012**

I. Background

This document is being presented in response to Resolution #11-02-04:
Development of Plan for a Northwest Tribal Data Repository.

t directed staff at the NPAIHB EpiCenter to partner with the Northwest Indian College Centers for Health (NWICCH) to develop a plan for a Northwest Tribal Data Repository to be housed at the NPAIHB, which details: physical data security; compliance with all human subjects and data privacy regulations, including HIPAA; data archiving to protect from loss; compliance with strong, tribally focused IRB requirements; and protections from data misuse.

The Northwest Portland Area Indian Health Board (NPAIHB) supports responsible research involving tribes and American Indian people in general. By "responsible research" we mean that investigators conduct research that is sensitive to and respectful of the needs and culture of American Indian/Alaska Native (AI/AN) people and is conducted with full permission of involved tribes in accordance with current research standards as codified in federal and tribal law, and related policies.

Data Repositories are part of health research in the 21st century. Congress, the National Institutes of Health, and other funders require that research data are available to additional researchers beyond the primary ones, and promote data repositories as the means to make the data available. In addition, Tribes, Indian Health Boards, and Tribal-based researchers may want certain research data stored for their future use in a data repository with sensitivity toward, and responsibility for, the concerns and values of Indian Tribes, Indian communities and people, and Tribal-based organizations such as Indian Health Boards (IHBs) and Tribal Colleges and Universities (TCUs).

The NPAIHB has listed components of Researcher Sensitivity and Responsibility:

Researcher Sensitivity

- Ensure understanding and good communication
- Respect tribal culture and traditions
- Respect tribal sovereignty and self-determination
- Respect concerns and opinions of community
- Respect local research priorities and needs
- Respect individuals, families, and communities
- Respect human participants' rights and dignity
- Exclude over-studied populations from participation
- Demystify research

- Be accessible
- Provide feed-back and findings in a timely manner
- Respect a tribe's right to decline participation
- Respect the autonomy and decisions of the tribe

Researcher Responsibility

- Communicate and coordinate with tribal leaders
- Negotiate tribal and community consent to participate
- Maximize benefits and minimize risks
- Protect human participants and sensitive data
- Comply with informed consent process
- Obtain appropriate approvals to conduct research such as; service unit director, tribal, IHS research committee, and IRB approval
- Do not begin research until all approvals are obtained
- Share results of the research with the tribes
- Protect participant and tribal identity
- Build capacity within the community
- Comply with the agreed-upon protocol specifications
- Comply with tribal and IHS publication clearance

(http://www.npaihb.org/epicenter/conducting_research_in_indian_country/) Accessed 10/2012

II. NPAIHB Data Repository

The Northwest Portland Area Indian Health Board (NPAIHB) Data Repository will store data from research involving American Indian and Alaska Native (AI/AN) Tribes, communities, and people, and involving IHBs and TCUs. The NPAIHB is committed to ensuring that the NPAIHB Data Repository will benefit AI/AN individuals, Tribes, communities, IHBs, TCUs, and high quality research, and therefore ultimately the public. This commitment is important to funders and to this Data Repository. The NPAIHB developed this document to maximize the value of high quality research in Indian Country.

This document outlines the NPAIHB's expectations, policies, and practices for its Data Repository. They are based on best practices across a wide array of innovative, ethical, and conscientious organizations engaged in person-centered and community-centered research and scientific discovery involving AI/AN Individuals, Tribes, communities, and organizations. The NPAIHB intends this document to provide all interested parties with information about the NPAIHB Data Repository's sensitivities and responsibilities.

The **sensitivities** and **responsibilities** of the NPAIHB Data Repository are in part based on the NPAIHB's "Researcher Sensitivities and Responsibilities," above. The **structure** of the NPAIHB Data Repository has been proposed after investigation of alternatives by the Data Repository Planning Group.

A. Sensitivities of the NPAIHB Data Repository

The Data Repository must:

1. Ensure understanding and good communication among participating individuals, Tribes and communities, IHBs, TCUs, and researchers and their institutions;
2. Respect Tribal and AI/AN culture and traditions;
3. Respect Tribal sovereignty and AI/AN self-determination;
4. Respect concerns and opinions of the community;
5. Respect local research priorities and needs;
6. Respect individuals, families, and communities;
7. Respect human participants' rights and dignity;
8. Respect research, researchers, and research institutions;
9. Include data from only research projects that were sensitive about and responsible for AI/AN Tribes, communities, and people, and IHBs and TCUs;
10. Assist communication between researchers and AI/AN participants and partners to explain and demystify research and AI/AN concerns;
11. Be accessible, through adopted policies and procedures, to Tribes involved in the stored research;
12. Provide data, using approved policies and procedures to be developed and approved by the NPAIHB staff, in a timely manner back to original Tribes and authorized users;
13. Respect the right of a participating AI/AN Tribe, community, IHB, or TCU to exclude its research data from the repository; and
14. Respect Tribal sovereignty and decisions of the AI/AN Tribes, communities, and people, and IHBs and TCUs involved in the research.

B. Responsibilities of the NPAIHB Data Repository

The NPAIHB Data Repository shall:

1. Comply with the Policies and Procedures approved by the NPAIHB for the Repository;
2. Comply with review and approval procedures by NPAIHB and other relevant organizations (Tribes, IHBs, TCUs, communities, and IHS);
3. Communicate and coordinate with AI/AN leaders and organizations;
4. Negotiate the terms of consent to store their data by Tribes, AI/AN communities, and AI/AN-based organizations;
5. Maximize benefits and minimize risks to Tribes, AI/AN communities, and AI/AN-based organizations;
6. Meet all relevant standards by the Tribes, AI/AN communities, and AI/AN-based organizations involved, and federal and state regulations regarding privacy, research ethics, and protection of individual, Tribal, and community participants;
7. Include in its practices the health concerns and health priorities of the Tribe[s], AI/AN community[ies], and AI/AN-based organizations originally involved;
8. Protect individual and communities participants and sensitive data;
9. Include data from only research that had obtained approvals by relevant and appropriate administrative personnel (for instance, the Service Unit Director for clinic-located research), the involved Tribes, AI/AN communities, AI/AN-based organizations, IRB[s], and NPAIHB Data Repository Committee;
10. Include in the Data Repository only research that complied with informed consent processes for individual, Tribal, community, IHB, and TCU participants;
11. Comply with the protocol specifications of each research project agreed-upon by the involved or relevant Tribes, AI/AN communities, AI/AN-based organizations, and IRBs;
12. Not store research data until all necessary approvals to store the data are obtained from the involved or appropriate Tribes, AI/AN communities, AI/AN-based organizations, and IRBs;
13. Share stored research data with future users under the following procedures, in all cases using Application for Data approved by the NPAIHB Data Repository Committee,
 - Share stored research data with the Tribe[s] originally involved, as requested,
 - Share stored research data with qualified future users listed in the

- research protocol approved by the involved or relevant Tribes, AI/AN communities, AI/AN-based organizations, and IRBs,
- Share stored research data with qualified future users other than those listed in the approved research protocol, applying through the funder or directly to the NPAIHB Data Repository;

14. Protect the identity of individual, Tribal, and community participants; and

15. Help build capacity within the Tribes and communities of the original research.

C. Structure of the NPAIHB Data Repository

1. The NPAIHB's Data Repository Planning Group examined three different possible options for the NPAIHB Data Repository's structure.

- **NPAIHB staff develops, establishes, and maintains its own Data Repository.**

Major advantage[s] of this option:

- The NPAIHB's control is maximal, because the NPAIHB Board controls the actions of the staff.

Major disadvantage[s] of this option:

- The costs to procure and maintain the hardware, software, and personnel with expertise in data repositories is maximal, because the NPAIHB currently does not have the hardware, software, or personnel; and
- The time needed to establish a Data Repository would be maximal, due to the time to acquire what is needed; and
- Because the required state-of-the-art hardware and software are continually changing, the costs to maintain and repeatedly update the hardware and software would be large

- **The NPAIHB contract with an existing, experienced, data repository located at or in a university.**

Major advantage[s]:

- The cost of the repository is low, because the NPAIHB would use another's existing hardware, software, personnel with expertise, and maintenance and updates; and
- The time needed to establish a Data Repository would be minimal, due to all resources being already in place.

Major disadvantage[s]:

- The university-based data repositories the Planning Group is familiar with appear to be relatively rigid in their policies of control of the data, and to be less able or unable or unwilling to let NPAIHB, Tribes, and Tribal-based organizations control their own data.

- **Contract with an existing, experienced, data repository of an umbrella organization that permits each organization within the umbrella to control its data in the repository.**

Major advantage[s]:

- The NPAIHB's control is close to maximal, because the umbrella organization's policy is that each organization controls its data; and
- The cost of the repository is low, because the NPAIHB would use another's existing hardware, software, personnel with expertise, and maintenance and update; and
- The time needed to establish a Data Repository would be minimal, due to all resources being already in place.

Major disadvantage[s]:

- The NPAIHB must first verify that the umbrella organization has the correct policies and values concerning the control by each member organization, and that the umbrella organization values and respects the concerns of the NPAIHB; and
- the NPAIHB must first verify that the umbrella organization has the required hardware, software, maintenance and update, and expertise for the NPAIHB's Data Repository.

2. The Planning Group believes that the **Genetic Alliance** is an umbrella with the required values and policies, and also with sufficient hardware, software, and expertise, for the NPAIHB to partner with for its Data Repository.

- The Genetic Alliance is an umbrella organization of 1,200 disease advocacy groups, the great majority of which were organized by consumer advocacy people. (Most consumer advocacy people are family of people with the rare genetic disease in question.)
- The leaders of the Genetic Alliance, and the leaders of many of its member organizations, have experienced struggles with academic researchers and academia similar to the struggles that Tribes and Tribal-based organizations (including the NPAIHB) have experienced. The reason for the similar experiences is that the some researchers or their institutions dislike being directed by other than academic researchers.
- Ms. Sharon Terry, President/CEO of Genetic Alliance and Mother of two children with a rare genetic disease, has consulted with Canadian First Nations about First Nations establishing repositories, and with the (then) Director of the IHS Research Program and Chair of the IHS National IRB -- Bill Freeman -- about the same issues. Her husband, Patrick, was co-founder of the Genetic Alliance Registry and BioBank, and also has consulted with Tribal-based organizations.
- The similarity of experiences in research projects of the Genetic Alliance by some of its members, and by Ms. Sharon Terry (CEO of the Genetic Alliance) herself, with the experiences of the NPAIHB and Tribes, suggest that the Genetic Alliance may be an ideal organization with which the

NPAIHB can partner. Ms. and Mr. Terry's contacts and consultations with First Nations and tribal-based organizations, and earlier contact with Bill Freeman, strengthen the trust that the planning group has in contracting with the Genetic Alliance.

D. Recommendations for the Board's consideration.

We recommend that the NPAIHB:

1. Accept the Sensitivities and Responsibilities of the NPAIHB Data Repository listed above; and
2. Authorize the NPAIHB staff to draft a detailed Governance Plan for the Data Repository, and bring it to the Board for its approval; and
3. Authorize the NPAIHB staff to investigate whether a contract with the Genetic Alliance is feasible and appropriate for this Data Repository; and
4. Authorize the NPAIHB staff to explore the feasibility of a NPAIHB run data repository.
5. Present a cost analysis of all of the options explored to the Executive Committee
6. Draft a Dear Tribal Leader letter to be sent to all Tribal Chairs in Idaho, Oregon and Washington to discuss the process occurring and solicit ideas and information from Tribal Council.
7. Authorize the NPAIHB staff to bring to Board for its approval a draft detailed plan of the structure for the NPAIHB Data Repository.