



SUMMER INTERNSHIP FOR INDIGENOUS PEOPLES IN GENOMICS

Summer 2018 · ISSUE 1 · The Inaugural Issue

SING has expanded internationally with the aim of discussing uses and limitations of genomics research in Indigenous communities.

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SING 2018 Seattle

This week has been an amazing culmination of the hard work of the organizing committee, including Drs. Katrina Claw, Nanibaa' Garrison, Ripan Malhi, Deborah Bolnick, Francine Gachupin, and Ms. Angela Neller. Given the strengths of the University of Washington, as well as the particular struggles that have gone on in the state of Washington, multiple special events were a part of the program for the week: a symposium on repatriating the Ancient One featuring tribal leaders, a pharmacogenomics workshop (including a tasty interactive demonstration), a Science and Policy forum featuring the Northwest-Alaska Pharmacogenomics Network, and a Sexy Science Confessions show! We also attended a tribal canoe landing in Tacoma that is part of the Power Paddle to Puyallup, welcomed faculty and alumni from SING Aotearoa, and sent some of our best on to Vancouver for the inaugural SING Canada!

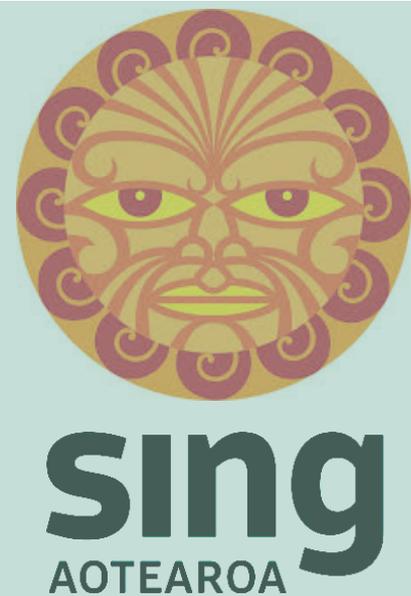
This year in Seattle showed the depth of leadership, capacity, skill, and talent that SING has amassed in the past 7 years, with one of the first participants who had become faculty leading planning with a veteran faculty member. Participants were engaged and engaging, bringing their experiences from Alaska to Mexico and much in between to discussions of ancient DNA, identities, and responsibilities.



Top: Staff, speakers, and participants of SING Seattle.
Bottom: Lab day spent purifying DNA for sequencing.

Their enthusiasm and indefatigability was admirable, as was their commitment to be present throughout the week despite commitments on pause back home. Participants also shared generously and are further deepening and developing connections, kinship, and possibilities throughout Indigenous communities. **§ Jessi Bardill**





Above: Staff, speakers, and participants of SING Aotearoa 2018.

In January, eighteen Maori interns from across the New Zealand gathered to increase their understanding of genomics, bioinformatics, ELSI, and cultural issues. SING Aotearoa 2018 was hosted at the Wellington School of Medicine with support from the Institute of Environmental Science and Research, and Plant and Food Research. The focus of this year's event was epigenetics and gene editing, to include a series of lectures, workshops, discussions, and a role playing exercise.

This is the third year that SING Aotearoa has been held, and we continue to get support

from SING USA with Joseph Yracheta attending as our international faculty member. This follows previous visits by Drs. Keolu Fox and Katrina Claw in 2017, and Drs. Nanibaa' Garrison and Jessica Bardill in 2016.

This is also the second year that SING Alumni Scholarships have been made available for past attendees to participate in SING USA and the Queenstown Research Week. Maori postgraduate students Jordan Housiaux and Anezka Hoskins were selected to represent SING Aotearoa at the Seattle-based event that occurred late July 2018. **§ Maui Hudson**

SING 2018 Canada

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From July 29 – August 4, 2018, we launched SING Canada at Simon Fraser University (SFU) near Vancouver, British Columbia. Hosted by SFU and co-organized with the Indigenous Science, Technology, and Society (STS) research group at the University of Alberta, we hosted 20 participants, 18 interns and 2 Indigenous community engagement and policy staff members from the Silent Genomes research project. Silent Genomes addresses the genomic divide by reducing access barriers to diagnosis of genetic disease in Indigenous children. Principal Investigator Laura Arbour also served as an ethics faculty member for our workshop this year.

We thank our participants who came from across Canada and three came from the US. They included Métis, Mi'kmaq, Nishnawbek, Anishinaabe, Cree, Gitksan, Dakelh, Inuit, Mohawk, Choctaw, and Jñatrjo (Mazahua)/Ñuu Savi (Mixtec) Indigenous people, and others.



Above: SING Canada 2018 near Vancouver,

We also thank our sponsors: the SFU Faculty of Health Sciences, Faculty of Science, the VP Academic, the Department of Molecular Biology and Biochemistry and the Department of Biological Sciences, as well as

– continued from previous –

the SFU Indigenous Student Centre. Thanks to our additional sponsors, Genome British Columbia, Life Labs and Genome Canada (via Silent Genomes), Merck, the University of Alberta Faculty of Native Studies, and the Alberta Prion Research Institute that will be more central in next year's SING Canada program that will focus in part on chronic wasting disease (CWD).

Next year's SING Canada will be held at the University of Alberta in Edmonton. **§ Kim TallBear**

Press:

- Li, W. "[Genomics internship aims to rebuild trust with indigenous communities.](#)" The Star Vancouver. 2018, July 31 [online].
- Robinson, M. "[Indigenous students take on genomics in new research program](#)" Vancouver Sun. 2018, July 31 [online].



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SING Faculty

DR. FRANCINE GACHUPIN,

PhD, MPH

Since SING 2013
Host of SING 2017 Arizona
Steering Committee, SING 2018 Seattle

Assistant Director, Cancer Disparities Institute
Associate Professor, Family and Community Medicine
Assistant Professor, American Indian Studies GDP



THE UNIVERSITY OF ARIZONA
Cancer Center

Francine C. Romero Gachupin is an Associate Professor, Department of Family and Community Medicine, College of Medicine, University of Arizona. She is a Tribal member of the Pueblo of Jemez, New Mexico. She received her Doctor of Philosophy from the University of New Mexico (Albuquerque, New Mexico) and her Master of Public Health degree in Epidemiology from the University of Washington (Seattle, Washington).

She studies primarily chronic diseases and related behavioral risk factors (diabetes, cancer and cognitive impairment) among American Indians. Dr. Gachupin trained at the National Institutes of Health (1988-1998) and studied genetic variation in Athabaskan-speaking populations of the Southwest and Alaska. Through this work, she was introduced to SING by her doctoral chair, Dr. Jeffrey Long who was colleague to Dr. Ripan Malhi. Dr. Gachupin attended SING during years 2013, 2017, including hosting SING 2017 at the University of Arizona (UA). She was also on the planning committee and attended SING 2018 Seattle.

Aside from research, Dr. Gachupin teaches human subjects protection with a focus on biospecimens and serves on IRBs at UA and the Rocky Mountain Tribal Leaders Council IRB. Most of Dr. Gachupin's career has been working directly for tribes through tribal based epidemiology centers – Portland Area, Aberdeen Area, Albuquerque Area and Navajo Area. Dr. Gachupin envisions SING as the international professional association for indigenous geneticists. **§**

[@fcgachupin](#)

SING Alum
JOSEPH YRACHETA, MS
Since SING 2013

“In the beginning, a flash happened in the nothingness. The Sun was born along with the stars, moon and Earth. The Sun kissed the Earth and started a fire, from that Fire walked the first Purépecha person, colored black from the soot. Today, the Purépecha are the children of the Sun and that first fire.” Joseph (Joe) Yracheta considers himself Smoke from Many Fires, including the one in this Purépecha creation story. Indeed, the history of Amerindigenous people after European contact has been the mingling of many camps' fires in the service of Gerald Vizenor's concept of “survivance”.

Joseph Yracheta received his Master of Pharmaceutics from the University of Washington in 2014, for his work on metabolizing gene variants for drugs of narrow therapeutic index in Alaska and Montana Natives. He was classmates with Drs. Keolu Fox and Katrina Claw, who were then UW Chapter-SACNAS members and are now proud SING faculty.

Joe joined SING in 2013 as a student on the recommendation of Dr. Katrina Claw and has been a part of SING since (except for 2017 SING-Arizona). After graduating, he moved back to the Cheyenne River Sioux Nation and now works for a small Native-owned research company called Missouri Breaks Industries Research, Inc.

He is currently involved with 4 main projects: 1) the Center for Ethical Indigenous Genomic Research (CEIGR), with Dr. Paul Spicer as Primary Investigator (PI), is an Ethical Legal Social Issues (ELSI) grant on Native attitudes on genomics, research and biobanking; 2) the Stanford Precision Health for Ethnic and Racial Equity (SPHERE), with Drs. Bonnie Maldonado and Mark Cullen as PIs, is an ELSI grant for education, implementation, and return of benefits from genomic research; 3) the Factors in Pediatric Asthma for American Indian children (FIPA), Dr. Lyle Best as PI, is a genetic epidemiological study on the triggers and treatment of asthma; and 4) the Strong Heart Water Study (multiple PIs), where he is looking at arsenic exposure and biomarkers for early kidney injury in American Indians with and without rapid arsenic metabolism gene variants.

However, it is the SPHERE project that has made the biggest impact for Indigenous researchers who know Joe. This project, in part, involves strategizing and positioning capacity and policies around biobanking.

He is working with other SING alumni such as Krystal Tsosie, who contributes bioinformatics advice, ethical best practices for Indigenous communities and research education curricula. Dr. Fox is also involved in planning, with the possibility of teaching CRISPR and other cell culture techniques for the Native biotech students in South Dakota. Last, but not least, Dr. Matt Anderson is contributing time and expertise for a microbiome analysis and training component to the Cheyenne River and Missouri Breaks toolbox.

Joe, at 52 years old with 5 children, will receive his DrPH from the Bloomberg School of Public Health at Johns Hopkins University in 2019. He was inspired to pursue this path late in life by the injustices that Amerindigenous people suffer and subsequent compounding by poor healthcare and outcomes. He feels that SING is one of the fundamental home bases that puts Native students in the Omics research captain's chair. This ship is big and new, and the waters it will sail are unknown. It is better to have Indigenous people at the helm for a change, rather than waiting out the voyage in the cargo hold. §



[@ZaKapu](#)

Above: Joseph Yracheta, SING Seattle 2018. Intellectual House, University of Washington.



SING Alum ALEC CALAC, BS Since SING 2017

Miiyuyam, notúng Alec Calac yaqáa! Hello, my name is Alec Calac! I am from the Pauma Band of Luiseño Indians, a small federally-recognized Indian tribe in San Diego County. I attended SING 2017 at my alma mater, the University of Arizona. I graduated from UA in 2016 with a BS in Neuroscience and Biology. I became aware of SING through Drs. Teshia Solomon and Francine Gachupin at the UA Native American Research and Training Center. At the time, I was working in a neuroimaging laboratory at the NIH and also applying to MD/PhD programs. Aside from the torrential monsoon rain, I had a wonderful time at SING. I value Indigenous mentorship, and that is exactly what I found at SING. Towards the end of our meeting, Dr. Gachupin shared this quote, **"While informative, the knowledge of population history garnered from the study of genes is not the ultimate authoritative tenet on tribal identity, self-identity, or social consciousness."** – I had to step back and realize how powerful her statement was.

[@ajcalac](#)

Above: Alec Calac (Luiseño) at the Newseum in Washington, DC. While attending SING, he was also a Health Policy Fellow for the National Indian Health Board and had prior involvement as the Chapter President for SACNAS at the University of Arizona.

Today, I am a first-year MD/PhD student at UC San Diego School of Medicine. With a background in neuroscience and strong interests in tribal public health and policy, I want to make meaningful contributions to academia and Indian Country as a Luiseño physician-scientist.

SING is a great forum for discourse and will increase the capacity of tribes to conduct research and train the next generation of Indigenous scholars. Empowering them is paramount to the future of our nations. §

It was -50 degrees Fahrenheit in rural North Dakota when Arizonan Krystal Tsosie drove into town to begin her new role as co-investigator of the Genetics and Pre-Eclampsia Study (GPS). This study is one of few long-standing examples of community-based research involving Indigenous women from the Turtle Mountain Band of Chippewa Nation. For now over 15 years, original PI Dr. Lyle Best, MD, has studied genetic determinants of pre-eclampsia and found three variants associated with the phenotype on the *CRP* gene. In the past year, work on this project has been mentioned in *Science News*, *ASBMB Today*, and *Tribal Colleges Journal*.

Krystal's previous project was utilizing large-scale epidemiologic databases to find novel variants relating to health disparities in African American women's health, so the switch to Indigenous women's health disparities was something that she always envisioned as a long-term goal.

In addition, Krystal is working with Joseph Yracheta on various projects, including starting a biorepository called the Native BioData Consortium. In her professional career, she was a programmer-statistician for the nation's largest health-care management organization, so she continues her love of programming by serving as PI for a couple of grants on genomics education curricula, to add onto her role as Instructor at Turtle Mountain Community College.

Since she attended the inaugural SING 2011, Krystal

SING Alum KRYSTAL TSOSIE, MPH, MA Since SING 2011

has graduated with her Master of Bioethics and Master of Public Health in Genetic Epidemiology. In 2019, she will soon graduate with her PhD in Genomics and Health Disparities at Vanderbilt University. §



[@kstsosie](#)
tmccgenetics.org

Above: Krystal Tsosie, Nashville, TN.



SING Consortium Publications

As a result of several years of discussions regarding the ethical engagement of Indigenous peoples in genomics, the SING Consortium proudly presents the following resources to guide future research:



Human Biol. 2017 July; **89(3)**.
Chaco Canyon Hungo Pavi ruins.
Photo: National Park Service,

Chaco Canyon Dig Unearths Ethical Concerns

Katrina Claw, Dorothy Lippert, Jessi Bardill, Anna Cordova, Keolu Fox, Joseph Yracheta, Alyssa Bader, Deborah Bolnick, Ripan Malhi, Kim TallBear, Nanibaa' Garrison

Pointing to ethical issues involving genomic analyses of ancient DNA from the Chaco Canyon site, we explore limitations of the Native American Graves Protection and Repatriation Act regarding "culturally unaffiliated" ancestors and suggest future best practices for researchers, museums, federal agencies, journals and granting agencies to ethically engage Native American communities.



Supplementary Materials Figure 1.
Photo Credit: Rick W.A. Smith
Science 27 Apr 2018; **360(6387)**.

Advancing the Ethics of Paleogenomics

Jessi Bardill, Alyssa Bader, Nanibaa' Garrison, Deborah Bolnick, Jennifer Raff, Alexa Walker, Ripan Malhi

Given recent scientific attention to DNA testing of ancestral remains of Indigenous peoples, we offer much needed Indigenous perspectives on ethical best practices in paleogenomics. In addition, we also highlight examples of community-based practices in which engagement of recent relatives is conducted to minimize cultural and ethical harms, produce stronger scientific interpretations, and improve relationships between scientists and Indigenous peoples.



Figure 1 of **Nature Comm**
Issue 9: 2957 (2018).

A Framework for Enhancing Ethical Genomic Research with Indigenous Communities

Katrina Claw, Matt Anderson, Rene Begay, Krystal Tsosie, Keolu Fox, Nanibaa' Garrison

Despite advances due to integration of genomics technologies into healthcare, Indigenous peoples remain underrepresented in genetic and clinical health studies. To encourage and foster collaboration with Indigenous communities, we propose six principles for ethical engagement in genomic research.

We thank all of those who contribution to this issue of the SING newsletter, and we hope that this will serve to further unite the SING alumni community.

- Krystal Tsosie
- Joseph Yracheta
- Jessi Bardill
- Maui Hudson
- Kim TallBear
- Francine Gachupin
- Alec Calac

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Summer Internship for Indigenous Peoples in Genomics (SING Consortium)

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