

# SUMMER INTERNSHIP FOR IN INTERNSHIP FOR INTERNSHIP

### Year 2019 · ISSUE 2 · The Expansive Issue

SING has expanded internationally with the aim of discussing uses and limitations of genomics research in Indigenous communities. Including: SING USA, Canada, Aotearoa, and Australia

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### **SING CANADA 2019**

The Summer Internship for Indigenous Peoples in Genomics (SING) Canada took place July 14-20, 2019 at the University of Alberta in Edmonton. In our second year, we focused on chronic wasting disease (CWD): the prion science, epidemiology, the ethics of CWD management; and wildlife co-management policies including the incorporation of Indigenous Knowledge (IK), and wildlife conservation and management in Alberta. SING Canada provided basic science training and highlighted how Indigenous knowledge values and analytical frameworks can be integrated with prion science to inform robust research, monitoring, and management of CWD in Alberta and beyond.

Fourteen participants took part this year, including undergraduate and graduate students and community members from Indigenous communities in British Columbia, Alberta, Ontario, Alaska, Arizona, and Australia.





Above: Faculty and participants of SING Canada.

Professors Kim TallBear and Jessica Kolopenuk collaborated with the University of Alberta Prion Research group and Faculty of Native Studies Ph.D. student Arlana Bennett who studies CWD and the implications for Indigenous peoples to organize the SING CWD program. Bennett's Master's thesis research findings demonstrated that Indigenous communities are not sufficiently participating in monitoring and management of cervids, specifically mule deer, white-tailed deer, elk, and moose as part of the Alberta mandatory Chronic Wasting Disease (CWD) management strategy.

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SING Canada will continue to partner with different universities across Canada on themes that are tailored to each geographic location. Future SING Canada locations include Quebec (with Concordia and McGill Universities in 2020), British Columbia (with SFU and Bamfield Marine Sciences Centre in 2021), and Nova Scotia (with Dalhousie University in 2022).

SING Canada 2019 was made possible by sponsorship from the University of Alberta Faculty of Native Studies and Faculty of Science, Genome Canada, Genome BC, Genome Alberta, Silent Genomes and LifeLabs, and the Alberta Prion Research Institute.



From January 21-25, we welcomed the fourth SING Aotearoa internship programme. In recent years, there have been significant advances in the fields of genetics and genomics, with an increasing focus on Indigenous species. All research conducted in Aotearoa New Zealand should involve consultation with Iwi Māori, so it is important that we understand enough about the technical, ethical and cultural issues to engage researchers in robust discussions.

We are grateful that researchers like Drs. Phil Ross, Patrick Biggs, Liggy Liggins and Prof. Barry Scott spent time with us to share their knowledge and experience. We were fortunate to



**Above:** SING women in the lab. [Photo credit: Deborah Bolnick]

#### Media Coverage:

• "Other Ways of Knowing." Genome Alberta. Genomics Blog Podcast. 2019 July 24 [online].

have a faculty mentor from the USA programme, Dr. Matt Anderson add an international dimension to the programme and bring his experience working with American Indian and Alaska Native interns.

While genetics has been a lightning rod for debate in past years we hope that this workshop provides a space to share ideas and thoughts in an informative way. Mā te mōhio ka mārama, Mā te mārama ka mātau, Mā te mātau ka ora. Through awareness comes understanding, through understanding comes knowledge, through knowledge comes wellbeing. Kia ora koutou katoa. § Maui Hudson





### **SING USA 2019**

It was an exciting week at the University of Illinois in Urbana-Champaign. SING 2019 started on the evening of July 28th with a SING staff panel discussing their first impressions of SING and how they became interested in genetics and research. The next morning bioethics was covered along with informed consent. The following morning was spent gearing up in white lab coats and slipping on gloves in the laboratory to extract mitochondrial DNA.

Next on the agenda was to talk more about historical trauma. We heard a well-presented presentation from Amy Bombay on Historical Trauma and Epigenetics: Studying Intergenerational Trauma, Resilience, and Strength among First Nations Peoples in Canada.

Many of the discussions of how genetics may be influenced by trauma were continued at the white lab coat makeover and dinner held at the Native American House on campus that evening. Everyone was able to show off their talent for drawing by creating designs, logos, slogans, or symbols that reflected themselves as an Indigenous scientist.

The next day was spent at the computer learning bioinformatics which was led by Dr. Hernandez. Epigenetic age was a presented the next day along with a presentation on the dangers of reductionism in health using genetic



data. Finally, community-based participatory research, previously conducted or ongoing, was presented by several speakers including Maria Avila, Jenny Davis, Joe Yracheta, Rene Begay, Jennifer Raff and Julie Beans. These presentations were important for students and faculty to see the work that is being conducted in several Indigenous communities across North America.

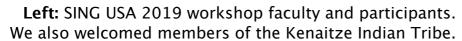
The final day was spent reflecting on the week and presenting ways to further the conversation on how genetic research can benefit or not benefit Indigenous communities. All participants ended the week meeting new friends, allies, mentors, and colleagues to reach out to about genetics.

Thank you for all your participation in discussions and engaging in the daily science scavenger hunt. Thank you to the planning committee for all your hard word in orchestrating the workshop to bring speakers to the workshops, setting up laboratory, and computer sessions, and bringing all participants together to learn from one another. § Rene Begay

#### Media Coverage:

 Herman, Christine. "How Scientists Are Partnering With Indigenous Communities For Genomics Research" WILL. Illinois Public Radio. Article and Podcast. 2019 Aug 1 [online].







**Right:** Analyzing their mtDNA. [Photo credit: Rene Begay]

### **SING AUSTRALIA 2019**

From Nov 10th to 16th, 24 Indigenous participants and 20 faculty (10 Indigenous) came together at Deakin University's Waurn Ponds Campus on the lands of the Wathaurong people, the traditional owners, for the inaugural SING Australia workshop. At present, there is a limited Indigenous workforce in genomics in Australia, making this workshop a necessary first step in establishing a network of current and future leaders of Indigenous genomics in Australia.

This network will help ensure that any benefits of genomics will be culturally safe and ethically used to help support the health, wellbeing and lives of Aboriginal and Torres Strait Islanders in Australia.

The week-long collaborative program covered technical and laboratory skills in genomics as well as theory, ethical and social implications of research, and the benefits and risks of genomics for Indigenous peoples. During the week, participants completed an extraction protocol to isolate DNA from a red river gum eucalyptus leaf sample, conducted a DNA library preparation reaction and did some initial bioinformatic analysis of the data. Deakin Genomics supported the program by running the sequencing reactions with products and reagents provided by Qiagen and Illumina.

#### Media Coverage:

• Knowles, Rachel. <u>Deakin University holds</u> workshop to connect Indigenous genomics researchers. National Indigenous Times (NIT). 2019 Dec 12 [online].



**Top:** SING Australia participants and faculty. **Bottom:** Participants pour remaining DNA extractions and samples back to the country.

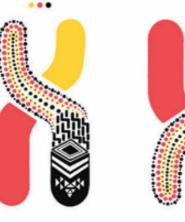
Overall, 24 scholars from around Australia participated in the week-long workshop. There were 20 academics from 13 different organizations across Australia. Support for this workshop was provided by the Australian Research Council Centre of Excellence for Australian Biodiversity and Heritage (CABAH) with laboratory materials support provided by Illumina and Qiagen.

§ Jacqueline Savard

@Jacquie\_Savard

### SING2020 INDIGENOUS GENOMICS CONFERENCE







#### UNIVERSITY OF WAIKATO, HAMILTON NZ INDIGENOUS PARTNERSHIPS IN GENOMICS SCIENCE

& Our Ancesters

## Summer Internship for Indigenous Genomics

The SING Consortium (SING Aotearoa, SING USA, SING Australia, SING Canada) is pleased to announced the inaugural SING Indigenous Genomics Conference to be held at the University of Waikato in Hamilton, New Zealand on January 23-24, 2020. The purpose of this event is to promote Indigenous partnerships in genomic science with a focus on research with human relations, research with relations in nature, and research with our ancestors. Speakers will talk about genomic science, ELSI issues, culture, and the interface with Indigenous knowledge.

Register here: <a href="https://www.ivvy.com.au/event/SING2020/">https://www.ivvy.com.au/event/SING2020/</a>





### SING Faculty Spotlight DR. PHILLIP WILCOX, PhD

Co-Lead of SING Aotearoa Since 2016 with Maui Hudson and Dr. Katarina Ruckstahl

**Kia ora!** Dr. Phillip (Phil) Wilcox is Ngāti Rakaipaaka, Rongamaiwahine, and Ngāti Kahungnunu. After studying forestry sciences as undergrad, he received his doctorate in Genetics and Biotechnology, with a diploma in Ara Reo Māori (Māori language).

Currently, he co-leads the Aotearoa Variome Project to develop a variome resource for use in delivering health benefits for Māori. Another project is a partnership with a tribal health provider to develop personalised medicine approaches. Always a champion of building Indigenous research capacity, he currently supervises four Māori graduate students in genetics and quantitative genetics.

Several things prompted Dr. Wilcox on his current path: (1) a need for more Indigenous participation in modern genetic sciences, which includes Indigenous peoples doing the research, controlling it, and applying it to the benefit our people as an ultimate expression of tribal sovereignty, and (2) exploring and delivering the emancipatory potential of this form of 'western science' to reverse negative impacts of colonisation. Finally, (3) positive support and encouragement from various tribal leaders regarding pathways for genetic tools to benefit communities provides drive and motivation for his important work.

For Dr. Wilcox, SING has been an incredibly useful initiative for bringing Native peoples into genetics conversations and beyond as researchers, partners, and Indigenous people take control of the tools for delivering benefits to the wider tribal entities. SING also provides a 'safe' place for Indigenous researchers, especially younger researchers, to express and share concerns in an environment that is Indigenous-dominated. SING provides a platform for support networks that extend into the future.

The Māori term 'whānaungatanga' refers to the experience of being among a supportive, like-minded family. It is the feeling of being emotionally uplifted by surrounding oneself with other Indigenous geneticists and those interested in using these techniques appropriately and for our peoples' benefit.

"In every SING I have experienced," he says, "we have formed 'whānau' (a family) that has led to both new and enduring relationships." SING workshops serve as a reclamation of spaces once displaced by colonisation. Plus, the workshops enable one to meet some awesome Indigenous researchers! §

### SING Alum & Faculty JESSICA KOLOPENUK, MS

Participant SING USA 2013; Co-Lead of SING CANADA with Drs. Kim TallBear and Jessi Bardill

### @JessKolopenuk

Boozhoo! I am Cree from Peguis First Nation. Our nation, is nestled among the ancestral lands and shared territories of the Cree, Anishinabeg, Assiniboine, and Métis peoples. Our homelands sprawl out from the forks of the Red and Assiniboine Rivers in what is now Winnipeg, Manitoba, Canada.

Currently, I am an Assistant Professor in the Faculty of Native Studies at the University of Alberta. I am still completing my PhD in Political Science from the University of Victoria.

My research aims to understand what genomic knowledge means for Indigenous peoples and, additionally, what Indigenous knowledge can mean for genome sciences.

I examine 21st century techno-scientific contexts where advances in biotechnology are drawing academic, industry, and policy attention toward bio-based research, resources, technologies, and economies while driving new directions in the training of a biotechnologically skilled workforce. For Indigenous peoples, biotechnological innovations are permeating society with promises of improved human health and environmental sustainability, just as the fields of science, politics, law, and economy are (still) defined by colonial power imbalances.

I've always been interested in understanding how old ideas about racial difference inform new ones about biological variation and identity. The ways that Indigenous peoples have been racialized (perceived and constructed in terms of racial difference) have been integral to colonial projects of land theft and state craft. Key to our resistance must be our analysis of how others see us and come to know us.

There is and can be no research about Indigenous peoples and genomics that exists outside of the backdrop of colonialism, including logics of race that so insidiously live among scientific, political, and legal fields. Indigenous



### Specifically, my research engages:

- 1. <u>Forensic science</u> where DNA profiling is increasingly used to identify missing and murdered Indigenous women, girls, and Two-Spirit persons (MMIWG2S) (on this front, my policy idea, *An Indigenous Approach to Canada's National Missing Persons Program* won the 2018 Canadian Science Policy Centre's award of Excellence);
- 2. <u>Biomedical research</u> where the search for innate racial causes of disease has been replaced by the analysis of genetic immunological susceptibilities;
- 3. <u>Paleogenomics</u> where the scientific appetite for mapping Native American genomes still sees Indigenous bodies as experimental material in life as well as in death; and
- 4. <u>Bioethics</u>, which operates as the primary field that research institutions use to regulate the wideranging colonial power dynamics involved with doing genomic research with, about, and affecting Indigenous peoples.

knowledge of race, whiteness, and colonialism has much to teach scientific communities and cultures.

I envision a decentralized, non-hierarchical, and institutional network of SING faculty and alumni whose local and community-driven approaches to knowledge production act as leading examples globally for genomic research that centers Indigenous stakes. My hope is that our anti-colonial work in scientific fields will support our broader goals among Indigenous sovereignty movements.



### SING Alum & Faculty KATRINA CLAW, PhD

Since SING USA 2011; Participant SING Aotearoa 2017 Host of SING 2018 Seattle

Yá'át'ééh shik'éí dóó shidine'é (Hello my friends and my people)
Shí éí Katrina yinishyé (My name is Katrina)
Tó'áhani nishłį́ (My clan is Near the Water Clan)
Deeshchii'nii bashishchiin (I am born for the Start of the Red Streak People Clan)
Tódích'íí'nii dashicheii (My maternal grandfathers are of the Bitter Water Clan)
Bit'ahnii dashinalí (My paternal grandfathers are of the Under His Cover Clan)
Dá'ák'e halani déé' naashá (I am from Many Farms)
Ahéhee (Thank you)

# My biggest update is that I started my position as Assistant Professor at the University of Colorado Anschutz Medical Campus.

I will be starting what, I think, will be the first Diné (Navajo)-led lab! My research focuses on personalizing medicine, pharmacogenomics, and using genetic data for tailored treatments. I also examine the ethical, social, and legal (ELSI) implications of genomic research in American Indian, Alaska Native, and other Indigenous communities around the world.

During my first SING in 2011, I met some really great people, and I especially remember that the world of ELSI research opened up to me. Before SING, I had taken only a few ethics-related training experiences, and none of the training was specific to Native Americans. It was a powerful experience to hear the perspectives of others trained in these fields and then attempting to use and share these teachings in my own department and research. Also, it was

important to meet other Indigenous peoples who were interested in genomics and hear their stories about why they chose this path.

Since then, SING has been a welcomed annual event for me. I am always excited to reconnect with SING faculty members and new participants. I not only get to learn about awesome new science (epigenetics, plant based genetics, cancer genetics, etc.), but I also have learned to teach, mentor, listen and share. SING 2018 also taught me a lot about how to organize a budget and schedule and effective strategies to get buy-in from university officials!

I am very excited that SING is becoming more international, and next month will be the first time that all the SING workshops from the USA, Canada, New Zealand, and Australia will gather in New Zealand at the SING Indigenous Genomics Conference. It will be powerful, and I hope will move us forward in a good way. Our work as Indigenous scientists and members of our respective communities has only begun, and this is an exciting time to be in this space. §

Below: A picture of Dr. Claw butchering a sheep on the Navajo Nation.



### **SING Faculty** SHAYNE BELLINGHAM, PhD

SING Australia

I am a Wotjobaluk man from the Wimmera region of Victoria and have always have had an interest in genetics due to a personal family connection with cystic fibrosis. This disease inspired me to pursue a PhD in Genetics at the University of Melbourne, becoming the first Aboriginal and Torres Strait Islander person to complete this doctoral degree of study. Now I am Senior Research Officer at the Lowitja Institute, Australia's National Aboriginal and Torres Strait Islander Research Institute. I am also a member of the majority-led Indigenous Governance Board for the National Centre for Indigenous Genomics.

My favourite part of the SING Australia program was seeing participants learn, in a matter of days, to extract and sequence DNA from a gum leaf to determine its origins. It was amazing to see participants link genomics knowledge with Aboriginal and Torres Strait Islander Ways of Being, Knowing and Doing through connection to culture, country and spirit.

I hope that the SING program continues to empower emerging Indigenous researchers and scholars to bring leadership and voice to the rapidly advancing fields of genomics.



Note: My views are my own and nonreflective of my institutional affiliations.

### **SING Alum** MELISSA EIDMAN, BA

Participant SING 2012 and 2014

Aee-ye-kwee! Hello! I am glad to see you! I am a member of the Yurok Tribe of California.

For as long as I can remember, I have always wanted to be a physician because our communities are in dire need of dedicated and passionate providers. Earlier in my undergraduate career. I understood that physicians of the future must have a firm understanding of genetics and genomics. I thought SING would be a neat opportunity to merge my interests in genomics with my Yurok identity.

The thing I remember and value most about SING is the time we took to discuss the ethical, spiritual, and cultural implications of genomic research—really all types of research involving Indigenous peoples. Too often we scientists get caught up in the excitement of research and discovery and forget the broader impacts of the work we do. The many discussions we had on this topic have stuck with me, which is something I think about regularly when hearing about or considering research.

### Currently, it is an exciting time for me. I am starting medical school at Stanford University!

I began as a community college transfer student to Stanford in 2014, graduated with a BA in Human Biology in 2017, and then worked in Urban Indian Health for 2 years.



@yurok.med



I am just really excited to see all the things SING alumni do. Such incredible friendships and professional relationships are made within and across cohorts. The collaborative and interdisciplinary work made possible by this opportunity are incredible! §

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
- Rene Begay
- Kim TallBear
- Maui Hudson
- Jacqueline Savard
- Shayne Bellingham
- Phil Wilcox
- Jessica Kolopenuk
- Katrina Claw
- Melissa Eidman

### For information on next year's SING, please contact:

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# Summer internship for INdigenous Peoples in Genomics (SING Consortium)

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