

Genomics 101 – October 10, 2020

Guest Speakers: Dr. Leah Wang Dowsett and Dr. Keolu Fox

28 Unique Respondents

Evaluation Questions

1. Your reason(s) for attending this webinar (check all that apply)

- Curious **(13)**
- Related to the work I do **(13)**
- To learn more about what this means for Native Hawaiians **(25)**
- To learn more about what this means for other indigenous peoples **(17)**
- To be aware about the benefits of genomic science **(17)**
- To be aware of concerns about this type of research. **(15)**
- Other: _____

2. How relevant was this information to you?

Very Relevant OK Not Relevant

5	4	3	2	1
(17)	(8)	(3)	(0)	(0)

3. Did the webinar meet your expectations?

Exceeded expectations Not what I expected

5	4	3	2	1
(18)	(5)	(4)	(1)	(0)

4. How would you rate the materials/slides presented?

Excellent OK Difficult to understand

5	4	3	2	1
(17)	(4)	(3)	(2)	(0)

5. Do you plan to attend the upcoming sessions in this series?

- Ancient Genomics **(23)**
- Current Genomic Studies **(21)**

6. What would you like to hear more about regarding Genomics?

- I've learn a great deal as they say evolution of genome or gene studies. Bone harvesting is a reality. Our ancestors bone is sacred yet benifical from cell formation to mitochondria and so on and how big company RX benefits it because of this. Pros and con. So awesome. My cousin did a gene blood test to see the possible illness. She was ok. How accurate is a blood test.

- hopefully after all the next 3 sessions, some of the specifics that we now know about the gene issues related to specific diseases and/or ethnic groups
- What does advocating for Native rights and sovereignty as they pertain to genetic information look like in clinical practice? (for geneticists, genetic counselors, and other genetic professionals)
- I would like to hear more about the informed consent process in genomics research, which may include the long-term storage and use of data.
- Are there ways for us to volunteer in any capacity? To help with research? To be volunteers as participants in research? To help spread the news, etc. Keolu, I loved how you posed several questions at the end to think about and share in discussion with our 'ohana. Perhaps you could even add action steps (i.e. petitions we can sign, indigenous research we can support, etc.)
- Next steps for us as kanaka maoli. I realize we are on an education campaign and then surveying our community but there is probably some discussion already occurring on future ways forward.
- Protection
- Relationship with COVID-19
- Can you outline a dream scenario for k̄anaka run biobank? What other expertise do we need? Computer scientists, lawyers, people to build a facility?
- How we are all connected through Genomics.

7. Comments for our presenters.

- Thank you Leah and Keola for the excellent background, accessible to non-scientists, and a riveting account of the Native history and perspective of health studies. Help us develop a virtual repository of NH genomic data and associated environmental and phenotypic data, that cannot be plundered.
- Even though im not in the md field, i hear about the ancestry.com. how does that swab tie in on worldwide connection. This always puzzle me.
- Many thanks! That was very eye-opening for me regarding problems I didn't know existed. It provided valuable context for me to better understand systemic racism and the disputes over TMT, Kahuku windmills, and Waimanalo. It also helped me understand

how big pharma squeezes more profits out of research and development by not compensating test subjects, which in hindsight is so unfair. You show great courage to share your mana'o and it is deeply appreciated.

- Excellent presentations and discussion!
- Amazing job!!! both so wonderful.

- The presenters were excellent. Although I am not a scientist, I found the information provided by the presenters very clear and easy to follow. Thank you!

- I cannot tell you how grateful I am for this amazing opportunity to learn. I had chicken skin throughout the entire presentation and am still sitting here in awe at the wonderful work you both are doing. Leah and Keolu, mahalo for your dedication and passion in this extremely important field and for sharing your mana'o with us. Mahalo to Emmett, JoAnn, and Kim for being such awesome moderators and hosts. I'm so excited for the upcoming sessions. Mahalo nui!

- I can not praise the presenters more. Both were articulate, knowledgeable, passionate and relayed the information with eloquence. I feel a bit of an imposter because I am a lay person with zero experience in this field. But both Fox and Dowsett spoke without medical jargon enough that I could follow along and included clear slides into the presentations that it was easy for me to understand. These two presenters exceeded my expectations. I am so grateful I had the opportunity to listen tonight.

- Appreciated having the diversity of presenters (clinician and PhD researcher, etc. Really added to the richness of the discussion. Appreciated the basics shared with Dr. Dowsett's presentation. Dr. Fox's presentation was fascinating and I wish he had more time to go into some of the historical info in more depth! Looking forward to the next presentations!

- Well done!
- Mahalo
- Excellent!
- Mahalo nui for your amazing work and sharing with us!
- Great presenters and knowledgeable.

- What do you see as logical next steps toward educating the lāhui on this topic?

- Could you do a possible risk/possible benefits brainstorm with community -- I think it's important to hear the hopes and fears, both of which can be tempered with good reliable information. Might be a good way to gauge people's mis/understandings.
- Can you talk a little bit about what unit should be making decisions about kānaka maoli participation in genetic sequencing/biobanking (e kala mai if I use the wrong terms here)? Individuals? Families? Agencies? Governments? Because we are related (aka

share genetic material), I'm wondering at what 'level' decision-making matters. I assume all. But for example, if I have strong feelings about my genetic information not being in a database, but someone else in my family does participate, there's nothing I can do about that.

- I would like to hear from those who participated in the creation of the Paokalani Declaration on these new developments and whether or not they think what was written suffices or if it needs to be expanded/updated?
- I wish we got a little bit more of an introduction from both of the presenters. And maybe some clarity on how Leah's and Keolu's work relate to each other.
- Thank you both for taking time to lay the groundwork on this important topic. It's something that feels overwhelming, but we can't afford to ignore it. I found the examples from other indigenous groups (good/bad) really useful.
- Keolu, you mentioned the potential and power of being able to identify genealogical connection to land, but we already have that. I feel anxious about the introduction of "quantifiable evidence" as a standard, where there is not currently one. I see so much danger in this, particularly if there are multiple people found in an area -- how would that play out with the claims of all the living descendants? How would this contend with Leah's final point (that we are not just 'ōiwi by our genetic material, but also by our mo'olelo, our mo'okū'auhau, our kuleana)? I don't want to sound hypercritical, I really enjoyed and appreciated your presentation, but would love to dive deeper on these kinds of questions.