



## MEETING AGENDA

# An “Indigenous Reference Genome”: Ethical, Cultural, Policy, and Governance Considerations

October 27-30, 2024

The Banbury Center, Lloyd Harbor, New York

This meeting was organized by  
**Krystal Tsosie**, Arizona State University,  
in consultation with  
Keolu Fox, University of California, San Diego

This meeting was supported by the  
Cold Spring Harbor Laboratory Corporate Sponsor Program

## SUNDAY, OCTOBER 27, 2024

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**Afternoon** Arrivals and check-in at Robertson House

**6:00 pm** Reception and dinner

## MONDAY, OCTOBER 28, 2024

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**7:15 am** Breakfast

**8:30 am** **Welcome**

Rebecca Leshan, Banbury Center

Krystal Tsosie, Arizona State University

**9:05 am** **SESSION 1: Histories – Cell Lines and Eugenics**

Chairperson: Krystal Tsosie, Arizona State University

Tina Lasisi, University of Michigan

Joanna Radin, History of Medicine, Yale School of Medicine

Jenny Reardon, University of California, Santa Cruz

Plenary Discussion



**10:50 am SESSION 2: International/National Sequencing Efforts**

Chairperson: John Burnett, University of Miami

Karen Miga, University of California, Santa Cruz

Erich Jarvis, HHMI, The Rockefeller University

Ira Hall, Yale University

Plenary Discussion

**12:15 pm Luncheon**

**2:05 pm SESSION 3: Genomics, Culture, and Relations**

Chairperson: Mildred Cho, Stanford University

Māui Hudson, Whakatohea, University of Waikato

Phillip Wilcox, University of Otago

Plenary Discussion

**3:40 pm SESSION 4: Indigenous Biobanking**

Chairperson: Trevor Reed, Arizona State University

Kelle Dhein, Arizona State University

Joseph Yracheta, Native BioData Consortium

Plenary Discussion

**4:45 pm DAY ONE WRAP-UP**

Moderator: Krystal Tsosie, Arizona State University

Outstanding Discussions; Summary

**6:00 pm Reception and dinner**

## **TUESDAY, OCTOBER 29, 2024**

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**7:15 am Breakfast**

**8:30 am Overnight Thoughts, Preview of Day Two**

**8:40 am SESSION 5: Healthcare Delivery for Rural Indigenous Communities**

Chairperson: Jenny Reardon, University of California, Santa Cruz

Gayle Dine'Chacon, medical director and tribal advisor

Alex Brown, Australian National University

Plenary Discussion



**9:55 am SESSION 6: Gene-based Therapeutics**

Chairperson: Ira Hall, Yale University

John Burnett, University of Miami

Alan Shuldiner, Regeneron Genetics Center

David Duggan, City of Hope & Translational Genomics Research Institute

Plenary Discussion

**11:30 am SESSION 7: Intellectual Property**

Chairperson: Sandra Soo-Jin Lee, Columbia University

Trevor Reed, Arizona State University

Robert Cook-Deegan, Arizona State University

**12:50 pm** Luncheon

**2:35 pm SESSION 8: Government Policy**

Chairperson: Joseph Yracheta, Native BioData Consortium

Vence Bonham, National Human Genome Research Institute, NIH

Sara Hull, National Human Genome Research Institute, NIH

Karina Walters, Tribal Health Research Office, NIH

Plenary Discussion

**4:20 pm SESSION 9: Media**

Chairperson: Tina Lasisi, University of Michigan

Joseph Lee, freelance journalist

Usha Lee McFarling, STAT

Plenary Discussion

**4:45 pm DAY TWO WRAP-UP**

Moderator: Krystal Tsosie, Arizona State University

Outstanding Discussions; Summary

**6:00 pm** Reception and dinner



## WEDNESDAY, OCTOBER 30, 2024

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- 7:15 am Breakfast
- 8:30 am Overnight Thoughts; Preview of Day Three
- 8:45 am **SESSION 10: Health & Technology Equity – Moving Forward**  
Chairperson: Phillip Wilcox, University of Otago  
Mildred Cho, Stanford University  
Sandra Soo-Jin Lee, Columbia University
- 10:30 am **SESSION 11: Meeting Wrap-up, Next Steps**  
Chairperson: Krystal Tsosie, Arizona State University  
  
Summarizing key meeting discussions, outstanding issues, planning output(s)  
Next steps, responsibilities, timelines
- 12:10 pm Luncheon; Participant Departures

## PARTICIPANTS

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- Vence Bonham**, National Human Genome Research Institute, NIH
- Alex Brown**, Australian National University
- John Burnett**, University of Miami
- Mildred Cho**, Stanford University
- Robert Cook-Deegan**, Arizona State University
- Kelle Dhein**, Arizona State University
- Gayle Dine'Chacon**, medical director and tribal advisor
- David Duggan**, City of Hope & Translational Genomics Research Institute
- Ira Hall**, Yale University
- Māui Hudson**, Whakatohea, University of Waikato
- Sara Hull**, National Human Genome Research Institute, NIH
- Erich Jarvis**, HHMI, The Rockefeller University
- Tina Lasisi**, University of Michigan
- Joseph Lee**, freelance journalist
- Sandra Lee**, Columbia University
- Usha McFarling**, STAT
- Karen Miga**, University of California, Santa Cruz
- Joanna Radin**, History of Medicine, Yale School of Medicine
- Jenny Reardon**, University of California, Santa Cruz
- Trevor Reed**, Arizona State University
- Alan Shuldiner**, Regeneron Genetics Center
- Krystal Tsosie**, Arizona State University
- Karina Walters**, Tribal Health Research Office, NIH
- Phillip Wilcox**, University of Otago
- Joseph Yracheta**, Native BioData Consortium