**“The Last Disabled Oracle”

Presenter/Keeper of Time: Alex Kelly

First Speaker: Alice Wong**

**Respondents: Dr. Anja Kanngieser, Kera Sherwood O’Regan**

 **Transcription by Karina Aedo-Aguilera**

*[ambient intro music playing]*

ALEX: Hello everyone, I am your Keeper of Time, Alex K. I am in this moment with you. And I want to acknowledge the conditions of both the pandemic and the subject matter today's discussions. Both can generate big feelings for many of us, and in the interests of open and creative futuring, let us be mindful of what's going on for all of us in our lives beyond this assembly, and be caring with one another throughout the proceedings.

This is a moment when we urgently need to imagine new futures, to revisit our histories and to adjust to our present tenses. Our times are tumultuous, upsetting, and disconcerting. It's why we are all here. Amidst it all the steady work of making meanings, challenging meanings, contesting meanings, needs to continue. This is the work of all of us, especially artists who are so often pushed aside. Today we resist that push and we stake a claim for art.

My earrings tell us that this assembly takes place across time. My right earring says 2020 and my left hearing, says 2029. That puts us amidst contested versions of past, present and future stories. This is how it's always been, and today we will amplify this truth. We don't seek to create a single story we seek instead to write multiple stories with multiple voices. We need to be messy, respectfully messy. It's a difficult task, but it's possible with a leap of imagination that we’ll take together. So today wherever we are across this continent, and perhaps beyond its mythical borders, we assemble.

In the futures, we aspire to a time when an acknowledgement of country is not necessary. When awareness of country and its people is so embedded in our languages, knowledges, and ways of being and seeing, that it does not need saying.

We are, however, not there yet. And so we recognise that we are all on unceded land. We pay our deep respects to the wisdom, leadership, and storytelling of First Nations people.

I acknowledge the Jaara people of the Dja Dja Wurrung lands where I join you from, and in the spirit of 2029, we're paying rent to local organisation Nalderun.

*Wukan dhelkek Dja Dja Wurrung djayi ba marti guli ba duroyi.*

I give my respect to Dja Dja Wurrung country and their ancestors.

Today, collectively, we are sharing over 240 hours of time. That's a lot of time and a lot of precious energy and focus. So we thank you deeply for being here, and we invite you to bring your whole self to open up to new thinking and new possibilities. Before we welcome our first speaker, Alice Wong from the year 2029, I invite you to gather yourself to settle your presence and to ground yourself.

We'll take a moment collectively, but do whatever feels right for you. You can close your eyes, take a breath, press your fingers to your temples, let your shoulders relax, and let your hearts and minds open. Let go of old stories and get ready to practice new ones.

Let's take three deep breaths together.

*[inhaling and exhaling deeply three times]*

Welcome.

We are in 2029 and I'd like to welcome our first speaker Alice Wong.

Alice Wong is the president of the North American chapter of the Disabled Oracle Society. Originally founded in 2020, there are chapters of the Disabled Oracle Society in 50 countries with over 5,000 members. Alice lives in San Francisco on Turtle Island with six cats - Mittens, Patches, Blueberry, Mochi, Chester, and Oreo. Alice, you have 20 minutes and I'll keep time as is my responsibility. When you have 30 seconds of 2029 time left I'll make this sound

ALICE : Welcome everyone! It’s 4:15 pm Pacific time in California and I’d like to call to order the December meeting of the Disabled Oracle Society, North American chapter.

Screen share off please. To describe myself, I am an Asian-American woman wearing a black jacket with white stripes. I have a mask over my nose attached to a tube for my ventilator. While people are joining both online and in person, please help yourselves to some drinks and snacks and drinks in the back. Louise brought some Tim Tams back from her visit to Melbourne attending the Australian chapter’s annual meeting last month. Please remember we have people participating online, on the phone, and through an all new platform, beep boop beep. Be sure to follow the various streams from your device throughout our meeting today.

Since it’s December and we’re about to embark upon another decade in the 21st century, let’s take some time to review the major issues and challenges we faced as disabled oracles. Established in December 2020, these nine years have been difficult with the coronavirus, the phage in 2024, and the increasing changes in weather patterns and global migration in the last five years. All of these crises have disproportionately impacted marginalized people, especially communities of color and indigenous, poor, older, and disabled people.

The planet is literally more hostile to people like us and yet the greatest existential threat we face is from other humans who believe congenital disabilities are something to be fixed and eliminated through gene therapy and human gene editing, also known as HGE.

Share screen please. Eugenics has always been with us but in the next 10-15 years we know HGE will be widely available to the public, since the press conference this past August by McEdit, a multinational corporation planning to provide high-end boutique services for people who want to give their future generations the best chance at life. They didn’t announce the date of their launch, but reports say it’s likely to take place in 2030 or 2031 at the very latest. The fact that there was such fanfare and little opposition to McEdit means we have a lot of work ahead of us as disabled oracles.

Screen share off. What does the advent of McEdit mean for us? How do we, imperfectly perfect creatures, argue against these seductive narratives about being better, stronger, healthier? How do we address the very real ethical implications behind this technology?

Before we have a discussion on what to do next, let’s go back and review some basics. This may be useful for some of the newer members.

Share screen please. Many years ago the Center for Genetics and Society described human genetic modification as “...the direct manipulation of a genome using molecular engineering techniques.” This is often referred to as human gene editing, or HGE.

Next slide. There are two types of modification: somatic and germline. We are focused on germline modification because it would change the genes in eggs, sperm, or early embryos. This means subsequent generations would also carry those changes.

Screen share off. CRISPR-Cas9 is one gene editing tool that became popular because it’s fast, cheap, and accurate. CRISPR was used in 2018 by He Jiankui, a researcher who announced at an international conference that he produced genetically edited babies in an attempt to make them resistant to HIV. He was sentenced to 3 years in prison for illegal medical practices in 2019.

At that time germline modification was a red flag for ethical reasons but it wasn’t banned or regulated in every country. Over the years tools such as CRISPR became more sophisticated and slowly opposition to the unknown consequences died down. Excitement around the science and possibilities of eliminating disease outweighed any questions about the underlying assumptions about health, disability, and difference. The idea of giving babies an advantage whether it’s less likelihood of developing a disease or enhancing other traits was irresistible to people with the means to give their kids quote unquote the best. The best, meaning a life without a disability. And this is why McEdit and its subsequent competitors are on the horizon for commercial and undoubtedly militaristic purposes.

The Disabled Oracle Society began in 2020 in the midst of the coronavirus pandemic when sick and disabled people sounded the alarm about the importance of wearing masks, the value of accessibility, and the interdependence of all communities. It became very clear who was considered disposable and who was not as institutions and governments developed medical triage guidelines. The casual ableism, racism, and ageism went unchecked in debates around restarting the economy with the terms such as ‘acceptable losses’ and ‘high risk’ as if those lives weren’t worth living or saving.

Share screen please.Now, I know Twitter doesn’t exist anymore, but here’s an antique Tweet from March 18, 2020 where I said disabled people are modern day oracles in response to a Tweet by Emily Johnson who wrote, “We need to talk about how US states have legalized murdering disabled and chronically ill people by taking them off critical equipment they already had or denying care should they be moved outside their home or facility care situations. And how providers justify this.”

Next slide. The actual catalyst to the formation of the Disabled Oracle Society came from an article in July of that year from the New York Times as part of a series of stories marking the 30th anniversary of the Americans with Disabilities Act, a civil rights law for disabled people. An article by Katie Hafner titled, “Once Science Fiction, Gene Editing Is Now a Looming Reality” featured several parents of disabled children, scientists, and bioethicists. And only ONE person with a disability.

Next slide. My friend and fellow oracle Rebecca Cokely Tweeted: “Hey ⁦[@nytimes](https://twitter.com/nytimes)⁩ how DARE you have a writer who doesn’t identify as DISABLED write about what CRISPR means for OUR community as part of your [#ADA30](https://twitter.com/hashtag/ADA30?src=hashtag_click) spread?!?! Your ableism really knows NO bounds.”

Screen share off. When I saw that, something inside me snapped. Here we are, disabled oracles since the beginning of time, warning society and telling our truths, and being completely sidelined once again. This is nothing new or unique. Throughout history marginalized, troublesome, or undesirable people are not believed or taken seriously. We elicit discomfort and disrupt people’s binary ideas of normalcy. Our warnings have been silenced in order to uphold the status quo. Even when we make persuasive arguments, we are not at the center, despite our extensive scholarship and wisdom. For instance, I interviewed Dr. Jaipreet Virdi in August 2020 about her book,*Hearing Happiness: Deafness Cures in History*, and she said this about the future of cures such as human gene editing.

Share screen please. “There is no guarantee that genetic engineering will eradicate hereditary deafness nor any certainty that it will not cause any further complications. Moreover, this is essentially at the core, a form of cultural genocide…”

Next slide. “...to argue that this needs to be ‘avoided’ at the level of genetics is an affront to generations of Deaf people who do not perceive themselves to be genetic defects.”

Screen share off. That was a brief overview of our origins and I share this because the mission remains constant: We tell our stories and truths in our own words. We define who we are and our place in the world. We fight to be seen and heard. We live in defiance with joy and radical acceptance.

You voted me as the President of the Disabled Oracle Society this year and I take this responsibility seriously. Friends, I too am tired of defending my worth everyday to people obsessed with having everything faster, shinier, newer. We try to reach people where they are, engaging in a number of creative ways. We assert the danger and uncertainty to future generations with altered genomes and how it will impact the entire human race. We repeat our main talking points all the time—that all people have worth, that no person should be left behind,and that technology is never neutral. We also try to point out how technology reinforces white supremacy, ableism, and all forms of structural inequality. This is not new with too many tragic examples to list.

What can we do? How do we love and hold each other up so we can keep on going as a community? How can we harness our imagination to create a world we want to live in right now and in the future?

At this time, I’d like to open it up for discussion and questions. Let me see, *[Alice plays an audio]* “Hi, I’m Emily from New York City. What is the role of a disabled oracle?”

Thanks, Emily. It’s totally up to you. What are you comfortable talking about? Just living your best life is a form of resistance. As I mentioned earlier, I don’t have the answers or even a strategy yet on how to engage with McEdit and the millions who will become their customers. But I’m good at asking questions. I’m good at telling my personal story within a larger political context. In asking questions, I want people to consider other perspectives and why germline human gene editing is incredibly troubling and problematic for so many communities, not just disabled people.

Since we’re almost out of time, here’s one final question: *[Alice plays an audio]* “Hi, I’m Grace from Tempe, Arizona, longtime disabled oracle. I’m scared. What is the point of doing all of this if we’re going to become extinct?”

Thanks, Grace. I’m really scared too. Things feel overwhelming and impossible everyday. Just know that you have a choice on how much you want to do. I believe everyone has the capacity to change the world while we are still alive in big and small ways.

Screen share, please.I’m reminded of this Tweet from 2017 by Dr. Ruha Benjamin, a sociologist and author of *Race After Technology: Abolitionist Tools for the New Jim Code,* “remember to imagine and craft the worlds you cannot live without, just as you dismantle the ones you cannot live within.”

Stop share screen. As disabled oracles, we continue to build and create on the knowledge and dreams of our ancestors. They left their mark on the planet as will we. After we’re long gone, we will show up in other ways. Someone will see and discover us and we’ll be speaking with them from the past.

I don’t know if this helps, but think about the ancestors that mean something to you. Connect with the people close to you right now and the stories passed down by your elders. Know that we are in this together collectively and that our brilliance as oracles will not be denied. I call upon the power and wisdom of my disabled ancestors such as Stella Young, Carrie Ann Lucas, Ki‘tay Davidson, Ing Wong-Ward, Harriet McBryde Johnson and Stacey Park Milbern. I have my memories and their words to guide me. And I hope this bit of advice brings you comfort because we should embrace every single moment while we can.

In closing, let’s read the motto of the Disabled Oracle Society: We are the past. We are the present. We are the future. We are forever.

See you all in 2030, meeting adjourned.

ALEX: Thank you so much, Alice. It's been an incredible nine years. And I really appreciate you allowing us to join the gallery of this meeting of the Disabled Oracle Society. I know that there's many here today who will go on to become founding members of other chapters. So thank you for your inspiration from 2029.

And now we're going to turn to our two respondents. Like us, they've only now heard Alice's address from 2029 for the first time. Our first respondent is Dr. AM Kanngieser.

Dr. Kanngieser is a writer, geographer and sound artist, author of several books and seminal artworks—sound works. Anja, we're delighted to have you here. I've learned so much from you about the politics of listening. And I'm very grateful that today we have the chance to listen to your reflections. You have seven minutes, I'll keep the time as is my responsibility, and when you have 30 seconds left, you'll hear this sound. *[ringing a bell]*

But before we begin, could you let us know which time you're responding from. Are you in 2020, or 2029?

ANJA: I am responding from 2029.

ALEX: Brilliant. Thank you, Anja.

ANJA: Thank you so much Alex, and thank you so much to Alice Wong, a brilliant president of the Disabled Oracle Society, and someone with such wise words that truly resonate.

I wanted to pick up a little bit, Alice, on something that you were saying when you were talking about the human gene editing, and what gets left behind when things get cut out. And the thing that I wanted to talk about, and the thing that I was thinking about, was what gets cut out is the ability to wait.

As disabled people, what we know is how to wait. We know how to sit, we know how to watch, we know how to listen, we know how to take our time. We know the value of time. And one of the things that we really learned during the last 10 years—mean, we've always known it anyway, so the last 10 years wasn't all that much different in that sense—was that white supremacist societies, colonial ways of thinking, were about the speeding up of time, and it didn't like the time that we lived in. It didn't like the fact that we took longer, that we saw time differently.

When you were talking, one of the things that I was thinking about was my great aunt, who couldn't use her hands. She had such gnarled arthritic hands that she could barely hold anything, but what she used to do a lot is she used to work with plants. And my great aunt had the most beautiful home full of orchids, plants that are notoriously difficult to tend to, plants that have all sorts of different ways of living and dying. And my great aunt, every day, spent all day with her hands in that soil, tending to those orchids, speaking to those orchids, taking the time that the orchids required her to take.

And there was an understanding I think that she had, that all disabled people have—particularly disabled people that are further minoritized: Black disabled people, Indigenous disabled people, poor disabled people—that you have to wait until the time is there for you to be allowed to be open about who you are, live the life that you live.

And my great aunt, she spent her time talking to her plants, she spent her time understanding what it means to be interdependent with the world. She spent her time listening to the clouds, she spent her time watching the grass, she spent her time with the people that she loved.

And when you were talking about the human genome editing, that's what I was really thinking about. What they took away from us, what they tried to take away from us. The knowledges that we have about how to live with others and how to live within the world and to take care of each other and to take care of the world. Because that's what we have. Those are the kinds of skills and knowledges and sensitivities that we have. Because we know that things travel differently.

We can't afford to place our bodies into the timelines that capitalism enforces on us. We can't afford to try to force ourselves into that, and those timelines never care about us in the first place. Am I trying to edit out our sensitivities towards different ways of being towards slownesses, towards being careful around things? It was one of the things that they really, really tried to stop.

I was thinking also that, in taking our time, in living along these different times, what we really cultivated was attunement, paying attention in ways that other people didn't place much value in, or maybe didn't even notice. Paying attention in ways that a lot of people wouldn't even think about, or care about. Paying attention to small things and gestures and moments of love and joy, like you spoke about as well. Kindnesses that came through messages that came through touch, that came through a phone call, that came through us holding each other in mind, and holding each other with love, and thinking of each other across countries and oceans and continents.

Those kinds of attunements is what they wanted to get rid of as well. They wanted to break our bonds to each other, they wanted to break our care for each other, and they wanted to break the ways that we love each other. The ways that we see each other and the ways that we turn towards each other.

Because we spend so much time turning away and being turned away, that those moments where we refuse to do that, where we build our own worlds where we build our own loves where we build our own desires… They couldn't have that.

And they didn't want us to have that. And so they tried to get rid of everything that kept us alive and joyful and connected to one another. They tried to get rid of our oracle sensibilities, they tried to get rid of the ways that we felt other worlds and other things and other beings and other spirits and each other.

I don't know how well it's gonna work, though, them trying to get rid of that. I don't know how much they think that they can splice and cut and weed out and break apart. Because I think it still remains, I think that we always remain across all those timelines that you mentioned, and I think that nothing can really be done to eradicate that or to erase that, because Alice, as you said, we have always been, and we always will be. And there are so many of us that we can never all be found.

There are so many of us living in so many different kinds of ways, and talking to each other and sharing our stories, and remembering each other's hands, in flowers and all of your cats, and all of the other things that keep us here and keep us together. The candles that we burn, the altars that we make, the books that we send each other and read to each other, the poetry that we write, the songs and sounds that we create.

I think that will always live on across those timelines, Alice, so I thank you so much. I thank you so much for being here and for being you and everything that you bring.

Thanks.

ALEX: Thanks, Anja, I'm going to carry that notion of atunement with me.

And now I'd like to round out our triangulation of ideas by inviting Kera Sherwood O’Regan to join us on stage. Kera is an Indigenous multidisciplinary storyteller and activist based in Aotearoa, New Zealand. Kera, we're humbled to have you with us today to share your insights.

You also have seven minutes, and I'll take time as is my responsibility, and when you have 30 seconds left, I will use this⁠—although I probably won't because it's too hard to ever stop anyone⁠—but *[ringing bell]* this will be the sound. Thank you Kera.

KERA: [37:26] Tēnā koutou katoa… Ko Kera Sherwood O’Regan ahau. E kōrero ana ahau anō Awarua Te Waipounamu. Ke te whenua o toku iwi o oku tupuna te iwi Ngai Tahu

So… *Kia ora* everybody. I’m Kera.

I am calling from the present or, since I’m in Awarua, in Bluff, on the whenua, on the land of my ancestors, at the very very bottom of the South Island of Aotearoa. I guess I'm technically calling from a little bit in the future to those of you who are based in te whenua moemoeā, in Australia.

Wow, is all I can start with. I think hearing Alice's kōrero, and, Anja’s response has given me a lot of emotions, thinking about a lot of things. And I think the main thing that it calls to mind for me is the importance of whakapapa. So in our Māori culture, we talk a lot about whakapapa, which is around our genealogy. So it's the connection that I have to my parents, my grandparents, my ancestors. And I think it's probably quite fitting that I'm calling here from Bluff, a place that I don't get to spend a lot of time. But I'm looking out over here to the ocean and to some of the islands and things that my ancestors would have, you know, known very well like the back of their hands. And I think Alice’s kōrero or Alice's discussion has brought up, similar for me, thinking about whakapapa. So our genealogy both ancestrally, but literally embodied and those genes.

And then also been excited and thinking about, “Wow, what a future if we have Alice Wong, you know, the president of this Disabled Oracle Society. That sounds like a club that I want to join.”

But I guess I wanted to touch on one thing in particular, that hearing about gene editing as an Indigenous disabled woman makes me think a lot about discussions that I've also had with my whānau, my family, and my sisters, my beautiful, wāhine toa friends, who I am so influenced by in such a positive way and learn so much from.

And one of my friends is actually doing her PhD looking at the connections around what does it mean to be looking at DNA, and the sovereignty of that data as Indigenous people. Because we know that within our communities, genetic information is very very sacred.

As the literal embodiment of our whapapapa, of our tupuna, of our ancestors, we have a lot of cultural practices in te ao Māori, in our Māori culture that teach us to look after that information, and learning about our ancestry is a sacred practice. It’s a sacred practice to go and look at our whakapapa written down, and to hear the stories of our ancestors, and also when we think about the things that contain our DNA, including our blood, our hair, our fingernails, we have many cultural practices around preserving those and taking care of those parts of our body, that are now, you know, coming off our body.

And so for our people, we think a lot about whakapapa when we think about gene editing. And I think a lot around our sovereignty over that data, because we know that as Indigenous peoples as well as disabled people, very often that sort of information is used to uphold a system that doesn’t care about us, and that will use that information to further widen the inequities that our people face.

And in particular, something that really concerns me, is seeing how this information then drives the sort of actions that happen, right? Like it’s political. You know—even having the science—doesn’t exist in a vacuum, but it is political because it drives what happens to our people, and very often what it seems to drive is focusing on this end result. “Oh well we can come up with cures for this,” or “we found out that all these Māori have these genes for… maybe they were just predisposed to diabetes, maybe they were just predisposed to X, Y and Z,” and so it really harms us on both sides.

It harms us on the side of those of us who are tāngata whaikaha, disabled Indigenous people, it harms us, and it also harms our wider whānau as well because rather than thinking about what are the underlying structures that give cause to the inequities that our people face, and the massive health inequities that have, in this country, and around the world for our other indigenous relatives, rather than going back and thinking about how colonisation has impacted our health and our wellbeing, our society wants to focus on these interventions, which, as we know are causing so much harm.

It also makes me think about eugenics, which is also sadly something that’s very front-of-mind in Aotearoa at the moment. With the End of Life Care bill and referendum at the end of 2020, which we are absolutely not as a society ready for, in my view, to have that discussion. And it just makes me think how consistently these “solutions” are put forward. And the solutions that they are actually looking for are not solutions to problems that our communities are really worried about, but the solution as a solution to our existence, because our existence is always seen as a problem of some kind.

But onto the hopeful side of things, hearing Alice in this future makes me so excited. It makes me excited because I think “Gosh I must have been friends with Alice Wong for a good old decade by then!” and that’s something that brings a huge amount of joy to me. It makes me excited because having people like Alice working in these spaces and redefining our identities as oracles, I think will make such massive... *[inaudible]*

… and it also makes us think about the importance of recognising the link that we are—and our whakapapa, and these genealogies, whether that’s ancestral in a biological sense, or ancestral in a cultural sense— we are all going to be ancestors and we are all living ancestors today. And it makes me think about the importance of those who are coming up, growing up underneath, emerging from the soil and from these communities.

And it makes me think about all of the disabled young people who are growing up and who are going to be looking at people like Alice and Anja, and any of the many fantastic disabled oracles, that are now so front-of-mind with social media. It makes me profoundly excited to think about the role we can have in supporting them and their identities and their understanding of disability. And I just know that in a couple of months’ time, that in the next session of the Disabled Oracle Society meeting, or the next annual meeting, I just know that there are going to be a bunch of feisty young ones ready to tackle McEdit, and to stage whatever kind of protest might be needed, and that gives me so much joy.

Nō reira, kia ora koutou, nga mihi nui kia koutou, kia ora

ALEX: Thanks so much Kera. Now I would like to invite President Wong back, just to close out this section of the assembly. Alice, I wanted to see if you have any last perspectives on these thoughts from the past and the future.

ALICE: Well, I just want to thank the two respondents. That’s not an easy thing to do, to listen to a talk and to then have to extemporaneously respond to it, you both did such thoughtful and very personal responses, and I’m very touched by it.

You know, I feel like this is where us as disabled people together, either in virtual or in-person spaces, there’s this alchemy that happens when we connect and when we share these spaces. And I feel like, to me, that’s the most hopeful thing about the future, that people kind of exist forever in whatever form. Whether it’s non-corporeal or just through the mushrooms and grass that comes out of the earth. And also there are stories and words and art. I’m just very grateful to have this opportunity here with this organisation, to be invited, and just to be in a community with you all.

ALEX: Thank you Alice

*[ambient music plays]*