

WEBVTT

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00:00:13.430 --> 00:00:16.560

Shanea N Turner-Smith: All right. Let's get started.

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00:00:16.930 --> 00:00:18.550

Shanea N Turner-Smith: We have a great

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00:00:19.890 --> 00:00:21.830

Shanea N Turner-Smith: program for you all today.

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00:00:22.130 --> 00:00:27.260

Shanea N Turner-Smith: So in the chat i'm going to be posting some resources for everyone.

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00:00:27.800 --> 00:00:30.340

Shanea N Turner-Smith: and then I will do some opening remarks.

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00:00:33.660 --> 00:00:45.400

Shanea N Turner-Smith: So good morning and welcome to another installment of the Dean Lecture series, I'm. Shanaya Turner, Smith, and one of the learning development managers for the Odei office.

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00:00:45.970 --> 00:00:57.180

Shanea N Turner-Smith: We are also gonna begin the live transfer. So you can enable that if that is something that you would like to have during our time this morning.

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00:00:58.330 --> 00:01:04.319

Shanea N Turner-Smith: and just note that live transcription. It's not going to be a perfect

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00:01:04.400 --> 00:01:19.720

Shanea N Turner-Smith: audio transcript, and so we invite you to take care of yourself as necessary during today's session, as we would not be taking a break in any feedback or issues that you may have with accessibility. You can please email us at D. Ls.

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00:01:19.860 --> 00:01:25.060

Shanea N Turner-Smith: Dash Odi at Edu, which can also be found in the chat.

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00:01:25.200 --> 00:01:43.290

Shanea N Turner-Smith: We ask that participants please use the Q. A. Function instead of the chat. It will do our best to answer your questions, but please understand we are working with a

set window of time. Should we not get to your question, we will work with the presenters to get unanswered questions posted on the Dean Lecture Series web page

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00:01:43.440 --> 00:01:51.370

Shanea N Turner-Smith: paste it in the chat you will find the resources, and I will now turn it over to vice Denuni as to introduce our guest lectures.

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00:01:52.350 --> 00:01:53.770

Ana Nunez MD: Good morning, everybody.

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00:01:53.770 --> 00:02:19.160

Ana Nunez MD: Holy moly is the weather something right? I mean we're sort of just sort of sitting at, you know. 38 and now we're going to go 83. I I don't know this. This dyslexia thing is kind of interesting in terms of our temperature piece, but we're kind of catapulting into spring, maybe summer. But I'm: okay, in terms of seeing those ice barges get little or mother. So so i'm, i'm. Okay, in terms of our change here a little bit on the warm side. I think that means I'm becoming a Minnesota.

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00:02:19.160 --> 00:02:47.970

Ana Nunez MD: We have a fabulous presentation today, you know. I will share with you that that vision and all things. Eyes holds a special place in my heart. Being a child who got classes in the first grade because of your sight of this. And so vision sort of a a super important thing, and hearing about some progress that we can improve, especially in. I. Banking is going to be really sort of compelling for the presentation. Our 2 presenters today, Julie Schmidt.

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00:02:48.160 --> 00:03:00.780

Ana Nunez MD: she her C. Ebt, is a Donor eligibility manager with lions gift of site. She is also one of the co-chairs and founders of the lions gift of site, equity, diversity, and inclusion committee

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00:03:01.150 --> 00:03:16.180

Ana Nunez MD: her colleague co-presenting is suddenly a research scientist that lines get to site with a focus on processing and distributing research tissues to academic and biotech institutions, striving to cure eye diseases and developing new therapies.

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00:03:16.180 --> 00:03:30.580

Ana Nunez MD: In addition he's conducted studies AIM to improve quality and delivery of corneal transplant tissues. He is also a current member of line. Gets the site. Dei Committee. Welcome Tole and Son. We're delighted to hear what you have to tell us.

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00:03:31.280 --> 00:03:34.090

Jolie Schmidt: and thank you so much for the introduction.

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00:03:35.140 --> 00:03:38.300

Jolie Schmidt: Would you mind giving me permission to share my screen? Please

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00:03:44.340 --> 00:03:55.400

Jolie Schmidt: sung, and I are very excited to be here today for this opportunity. We've done a lot of work recently to discover some of the opportunities that we have for improvement here at lines kept of site.

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So I am hoping this talk will be an eye-opening experience for everybody who's joined us today.

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00:04:01.470 --> 00:04:08.080

Jolie Schmidt: and and I still don't have

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00:04:18.610 --> 00:04:23.900

Ana Nunez MD: so like. How did you and Son get involved in vision? Related work?

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00:04:24.240 --> 00:04:44.060

Jolie Schmidt: Most people, when you ask that question, the answer is usually by accident, a lot of people don't realize exactly what I donation is, and what lines gift of site is. I was actually involved in donation before I transitioned over to my donation. Specifically I got my start in blood and plasma.

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Jolie Schmidt: so I kind of had an in already, but

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00:04:47.050 --> 00:04:48.930

Jolie Schmidt: sorry i'm actually not sure if I know you are

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00:04:49.080 --> 00:05:03.890

Sung J Lee: so. My mother was an lcu nurse here at the University hospital, and she ran into one of the recovery technicians at of Lgs.

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00:05:03.890 --> 00:05:23.130

Sung J Lee: and she mentioned that this position was out there, so I looked into the I bank, and at first there wasn't any positions available, so I started off as a volunteer, then moved up to a recovery technician, and then up to research scientists which I have been in this position for the past

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00:05:23.600 --> 00:05:42.600

Jolie Schmidt: 9, 10 years now. Very cool, very cool. All right. Well, let's get to it. Thanks. Alright. So, as I mentioned already, most people have an idea of what organ donation is, and what types of solid organs can be donated like a heart caving your lungs. But from my experience with talking to donor families.

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00:05:42.600 --> 00:05:52.760

Jolie Schmidt: more often than not the average person doesn't realize that it's even possible to donate your eyes. So I want to start off here by quickly defining for everybody what exactly, and I think is

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Jolie Schmidt: so, and I think is an organization that obtains, medically evaluates and distributes ocular tissue for transplant and research and medical education. In other words, we receive notification when a person is passed away, and we determine if they are medically suitable, to be an I donor for either transplant or research purposes.

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00:06:11.950 --> 00:06:27.420

Jolie Schmidt: We then obtain legal consent to move forward with the donation, recover the eye tissue, and do further evaluation on the tissue to ensure its stability. After that we'll process that tissue to prepare for surgery and distribute it to surgeons who then perform transplants on their patients.

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Jolie Schmidt: If the tissue is not suitable for transplant purposes. Our research team distributes it to researchers that they partner with or use it in our own ongoing studies. Here.

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Jolie Schmidt: So research tissue is used in a variety of ways to help advance the knowledge of many different eye diseases. But i'll let some tell you all about that later.

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Jolie Schmidt: Well, the lions get to site is a nonprofit. I Bank. We are accredited by the Iv. 18 Association of America. We are also in regularly inspected by the food and drug administration, and from here on what I'm. Going to refer to landscape of site as Lgs just for simplicity purposes.

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Jolie Schmidt: So Lgs is partnership with the University of Minnesota began over 60 years ago, when the Minnesota Alliance and the University combined their resources to create the Minnesota Alliance, ling.

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Jolie Schmidt: which we now call lines. Get to site. Dr. Harris, the chair of the Department of Ophthalmology at the time, developed a plan to ask the families of deceased patients at and affiliated hospitals to donate their left one size.

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Jolie Schmidt: He also worked closely with the school of mortuary science to establish an acceptable technique for removing donor eyes. George Dugan Alliance Club member gathered the support of the lions and arranged financial backing for an ibank.

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Jolie Schmidt: So the end result is this ongoing, unique partnership between the Lions and the University of Minnesota. Well, we are owned and financially backed by the Minnesota Lion Fission foundation. We work alongside the and Department of ophthalmology.

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Jolie Schmidt: We're very fortunate to have the support of both the Minnesota Alliance and the University and our mission to restore site.

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Jolie Schmidt: So since the time that Lgs was founded in 1,960. We have served the needs of donors and recipients in Minnesota, Western Wisconsin, and eastern North Dakota.

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Jolie Schmidt: We distribute more than 1,000 corn. As for transplant and 1,000 eyes for research and medical education. and we distribute those tissues internationally.

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Jolie Schmidt: We also work very closely with donate. Like America.

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Jolie Schmidt: They are an organization that's dedicated to increasing the number of lives sealed and healed through organ saved and healed through organ tissue and I donation.

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so they strive to develop a culture where your donation is embraced as a fundamental human responsibility.

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Jolie Schmidt: It's very fitting that we were given this opportunity to speak here during the month of April, since it is donate life. America's signature, Donate life month

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Jolie Schmidt: back, in august 2,022. We were made aware that it was national minority donor awareness month.

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Jolie Schmidt: At that time Lgs challenged ourselves to dive into an area that was previously unexplored for us. Our partner relations team worked very closely with our business analyst to pull some data that was incredibly eye opening

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Jolie Schmidt: between January 2,019 and July, 2,022 lions gift of site received 54,924 referrals for potential donors

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Jolie Schmidt: in that time. About 12% of the referrals for people of color compared to 78, which were white. the remaining 10% are unknown, or the background. The data was not captured

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00:09:33.260 --> 00:09:44.160

Jolie Schmidt: out of the 6,768 transplant and research donors that came. Of those referrals only 4.7 were people of color compared to 90% white donors.

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00:09:44.310 --> 00:09:48.280

Jolie Schmidt: No one or not captured, made up about 5.3 of these donors.

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Jolie Schmidt: according to the Us. Census. Here is the state of Minnesota's racial breakdown for comparison.

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Jolie Schmidt: You can see we have about 78 per 78 of white individuals in the state of Minnesota while people of color make up their remaining percentage.

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Jolie Schmidt: There is clearly a big difference here

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00:10:08.700 --> 00:10:13.320

Jolie Schmidt: when you compare the 90% white donors and 4.7

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00:10:13.390 --> 00:10:14.820

Jolie Schmidt: people of color donors.

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Jolie Schmidt: So even with that, 10% of referrals where data was not captured overall. These percentages are showing that a referral population is not fully representative of the general population of Minnesota.

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Jolie Schmidt: The reasons for this are fast, and if you've been following this lecture series since it start, you already know that health care disparities are extensively documented for people of color compared to whites in the United States.

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Jolie Schmidt: Black and Latin. Next, people tend to receive fewer medical services and have less health care spending overall than white individuals.

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Recently the health and retirement study

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Jolie Schmidt: added a study to address end of life, care, and hospice planning.

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Jolie Schmidt: So what they found during that study was that people of color are also much less likely to engage in end of life planning and enroll in hospital services.

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00:11:06.790 --> 00:11:11.510

Jolie Schmidt: This can be for for a multitude of reasons, like including

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Jolie Schmidt: cultural approaches to end of life care, and the desire for more aggressive health treatments at the end of somebody's life.

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Jolie Schmidt: but also in equilibrium, access for communities of color to end of life, services like hospices, and everything nursing homes. So this evidence may explain some of our referral numbers, since a significant portion of lines. Get upside referrals, artists into a passed away on hospice.

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Jolie Schmidt: We also spend some time looking at our population of designated donors.

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Jolie Schmidt: When you check the box on your driver's license to be to register, to be a donor, or if you sign up on a donor registry

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Jolie Schmidt: or a state that you want to be a donor on your health Care directive, or will we refer to you in the industry as a designated donor? So those things are legal documents stating the individual's intent.

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Jolie Schmidt: So at the time of death, donation agencies have the legal authority to proceed with any organ tissue or I donation that those documents state are acceptable. Checking the box will also help provide your loved ones with a clear guide for how to proceed when they are approached by an agency to discuss donation

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00:12:19.860 --> 00:12:25.020

Jolie Schmidt: Designated donors make up over half of lines, get to size donor population.

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Jolie Schmidt: So during that January 2,019 to July, 2,022 timeframe. About 63% of our total donors were designated

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Jolie Schmidt: similar to our donor rates. White donor is made up about 90% of the individuals who are designated, while people of color, more designated, made up about 3.6%

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Jolie Schmidt: out of that 4.7 of total donors of color mentioned previously. nearly half of them at 47.9% were designated. However, this is still a lower rate compared to white donors who are designated about 63% of the time

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00:13:02.800 --> 00:13:10.810

Jolie Schmidt: additionally tissue for donated from a donor who is a person of color is much more likely to be used for transplant purposes rather than research.

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Jolie Schmidt: As you can see here, about 61% of white donors tissue was used for transplant. And 39% went to research. This is compared to 78 of donors of color you tissue using being used for transplant. Well, 22 of those went to research

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Jolie Schmidt: overall the loved ones of white donors appear to be more likely to give consent for research purposes compared to people of color.

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Jolie Schmidt: If a potential donor is medically suitable and also designated, we're able to honor the designation between about 80 to 90% of the time. We can assume that increasing the number of people of color who have registered to be donors would be a good way to increase donation in these communities overall.

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Jolie Schmidt: We can also assume that raising awareness for the benefits of research through I donation may increase donation as well.

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Jolie Schmidt: However, we know that neither of these things are that simple.

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00:14:07.130 --> 00:14:15.510

Jolie Schmidt: I'd like to pull from a piece that Mike Tramber, a fellow Ibanker, wrote for the Ibank Association of America during Black History month this year

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Jolie Schmidt: Mike discussed his experience growing up with a Northern white mother and a Southern black father in a predominantly black neighborhood. He recalled several memory memories of his parents arguing about whether or not to take him and his siblings to the doctor.

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Jolie Schmidt: He remembers being confused, and not really understanding that negativity and resentment that the black side of his family portrayed.

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Jolie Schmidt: He couldn't believe the accusations that they had, and couldn't understand how the cruelty they were saying were inflicted

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00:14:44.130 --> 00:14:46.150

Jolie Schmidt: could actually happen.

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00:14:46.340 --> 00:14:53.690

Jolie Schmidt: I mean the medical community community was supposed to be out there to help us. No. and none of this information was taught in schools.

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00:14:54.670 --> 00:14:59.250

Jolie Schmidt: So this yield his desire to investigate a little bit further, and he was shocked that

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Jolie Schmidt: these stories that his family was telling him were not only true. but they occurred in modern times, and had been completely deleted from mainstream curriculum.

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00:15:08.440 --> 00:15:24.530

Jolie Schmidt: So just a couple of examples of these are as follows: and i'm sure a lot of you here have already heard of these. But there's the test. The test P. Experiment, which was a 40 year study conducted by the Us. Public Health Service that left hundreds of black men with untreated syphilis without their knowledge or consent.

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00:15:25.220 --> 00:15:29.860

Jolie Schmidt: The care was with help, leaning money to go blind experience, mental breaks and die.

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Jolie Schmidt: The study ended as recently as 1,972.

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Jolie Schmidt: The Cincinnati radiation experiments performed at the Cincinnati General Hospital and funded by the department of defense tested the effects of radiation on the body. The participants were cancer patients in the hospital trying to receive life saving treatment, and instead they were forced to be test subjects without their consent.

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Jolie Schmidt: These patients were primarily black, and from lower socioeconomic backgrounds they were exposed to total or partially radiation, leading them to suffer unnecessary pain, damaged cognitive function and death.

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Jolie Schmidt: In addition to these atrocities, there are several studies that suggest higher morbidity and mortality rates in community of color relative to white communities. Black women are 3 to 4 times more likely to die from pregnancy. Related complications that are often preventable.

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Jolie Schmidt: Cancer mortality rates for native Americans are among the highest of all racial and ethnic groups in the United States.

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Jolie Schmidt: This stems, from both both mistrust of physicians or hospitals position related lack of cultural competency in caring for these racial or ethnic groups

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00:16:35.510 --> 00:16:48.590

Jolie Schmidt: and inadequate access to comprehensive health services. With all of these examples we've discussed in us history, it's no wonder the mistrust is. There there continues to be biased today in the treatment of people of color in medicine

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Jolie Schmidt: there are clearly many facets to this issue, but, as Mike Trammer stated in his article. The first step to moving in a positive direction is the recognition of the past.

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Jolie Schmidt: America cannot and should not run from or delete this history.

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Jolie Schmidt: It must be faced with head on with it must be faced, head on, with open discussion about moving the medical community forward in a constructive manner, with more understanding and representation.

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Jolie Schmidt: This applies to the donation community as well.

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Jolie Schmidt: So, as Mike stated it's easy to see why black individuals are hesitant to register as donors. They're fearful of how that might impact the medical care they do receive.

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Jolie Schmidt: I grew up in rural Northern Minnesota. I am a Cis straight white girl who is surrounded by other straight white people.

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Jolie Schmidt: It wasn't until I was in college that I even had to think about the possibility of other racial and ethnic groups, having a different experience with the medical community than I do.

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00:17:46.630 --> 00:17:54.760

Jolie Schmidt: I have my own trust issues due to experiences as a woman seeking care, but I still had very little exposure to other races.

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00:17:55.020 --> 00:18:05.960

Jolie Schmidt: and then I went to college in ran for North Dakota, so I still had very little exposure to other races. I was studying cultural and medical anthropology, and I was still blue with.

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00:18:06.040 --> 00:18:21.270

Jolie Schmidt: and then I had the opportunity to take a new course that was being offered, called the Anthropology of Death. This was taught by Dr. Pb. Stops double field. and she is a renowned forensic anthropologist, and one of the very few black and forensic anthropologists in the world.

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00:18:21.840 --> 00:18:31.650

Jolie Schmidt: One of her personal projects is for the over the last 20 years she's been leading efforts to recover and analyze human remains associated with the tel service massacre in 1,921

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Jolie Schmidt: So During this course with Dr. Stella Field, we spent a significant amount of time talking about organ tissue and eye donation, any increasingly blurred lines between life and death that occur as more medical advancements are made.

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Jolie Schmidt: I remember being absolutely horrified by doctors, double fields, personal opinions on organ donation.

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00:18:50.490 --> 00:19:02.420

Jolie Schmidt: She was adamant that nobody should register to be a donor, because, as soon as doctors found out that you were registered, they would stop treating you appropriately, and allow you to progress, to brain death or cardiac. Death to

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00:19:02.630 --> 00:19:16.280

Jolie Schmidt: harvest your organs. I was already working in donation at the time, though with living blood and plasma donors. and I couldn't believe that someone was a professional background like my professor could have what I believed to be

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00:19:16.640 --> 00:19:19.480

Jolie Schmidt: such an ignorant view about donation

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00:19:20.510 --> 00:19:35.490

Jolie Schmidt: Doctors double field, and I engaged in many debates during that semester, and i'm ashamed to say that even during that time, and even while I was studying medical anthropology and learning about some of the reasons why disparities in health care exist. I never made that connection.

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00:19:36.270 --> 00:19:48.790

Jolie Schmidt: It wasn't until I started working with lines gift of site, and having conversations with families of potential donors that I started to really understand where she was coming from, and why her opinions were so valid.

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00:19:49.400 --> 00:19:56.820

Jolie Schmidt: What the experiences that people of color have had with the medical community in the United States. How can I blame her for those concerns

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Jolie Schmidt: overcoming this trust in the medical community? Is our main challenge that we need to work towards to overcome as I as I, and the first step in doing so is understanding this history.

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Jolie Schmidt: Only then can we really begin to provide education and resources around donation and give people color. The opportunity to decide if register registering to be a donor is the right decision for them.

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Jolie Schmidt: So we spend some time touching on some of the reasons why the number of potential donor referrals that we receive may not be representative of the population of our service area, and we've also discussed designated donors, and some of the reasons why people of color may be less likely to register for donation or consent to donating for research.

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Jolie Schmidt: However, these aren't the only barriers that we unravel during our data collection.

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Jolie Schmidt: Well, Ellen, while Lgs overall referral rate for people of color is about 12. Only a small percentage of these into individuals go on to be donors.

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Jolie Schmidt: So once a potential donor referral is received their medical and social history, as well as the current circumstances surrounding their death, are screened against Lgs criteria, as well as regulations put in place by the Ibank Association of America and the food and direct administration.

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00:21:14.830 --> 00:21:30.440

Jolie Schmidt: When we're considering these regulations and criteria. people of color face several barriers to donation that do not affect potential white donors to the same degree. So

this slide here shows the top 20 reasons why people of color were referred for donation during 2,019 to 2,022.

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Jolie Schmidt: While many of these are common deferral reasons, regardless of race.

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Jolie Schmidt: social circumstances that are considered high risk such as jail time or homelessness disproportionately affect people of color.

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Jolie Schmidt: Well, homelessness itself is not, or to girl for donation. With every donor we are required to ask to interview someone who is very close to that person, and we ask a variety of questions about their medical and social history.

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Jolie Schmidt: So the likelihood of someone experiencing homelessness having a person in their life who can confidently answer those required questions is greatly decreased. and the likelihood of being exposed to other high risk concerns is increased.

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00:22:09.730 --> 00:22:16.970

Jolie Schmidt: The percentage of people of color differ due to jail, Time or prison was unfortunately not a surprise.

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Jolie Schmidt: and studies have found studies that have found that people of color are more likely to be stopped by police, detained pretrial, charged with more serious crimes, and sentenced more harshly than white people

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in Minnesota, in 2,017

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Jolie Schmidt: black people, were incarcerated at 9 point, one times higher, the rate of white, and then white people and native American people were incarcerated 14.3 times the rate of white people.

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00:22:43.190 --> 00:22:55.310

Jolie Schmidt: Nationally, Latinx people are also over over over, represented in prison and jails. But there's common data, misclassification and inconsistent reporting that make it a lot more difficult to measure those effects.

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Jolie Schmidt: So at this point in our data collection the lack of representation in our referrals and donors were clear to see. and with Lgs we were able to identify some of the ways in which we could do better when working with communities of color.

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00:23:10.380 --> 00:23:22.960

Jolie Schmidt: Unfortunately, people of color are not the only group impacted by social circumstances. Some members of the Lgbtq. I. A plus community, also face barriers that prevent their ability to be. I and tissue donors

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Jolie Schmidt: concern regarding HIV transmission via blood organ tissue, and I, Transplantation has existed since the early years of the Aids pandemic in the 1980 S. And 1990 S.

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00:23:35.860 --> 00:23:50.180

Jolie Schmidt: So, as a result in 1,994, the Cdc published published Guidelines for industries to prevent the transmission of HIV, and then later, Hepatitis, B. And Hepatitis, c. Were added to this through the transplantation of human tissue.

138

00:23:50.790 --> 00:24:05.560

Jolie Schmidt: These guidelines were adopted by the FDA, and they remain in place to this day. based on the criteria based on the data and the technology as available. At that time certain donor exclusionary criteria was put in place.

139

00:24:06.180 --> 00:24:19.050

Jolie Schmidt: We used clinical, the clinical evidence available, and certain behavioral criteria to make these decisions. These criteria were associated at the time with HIV, Hepatitis b and hepatitis, c.

140

00:24:20.080 --> 00:24:33.590

Jolie Schmidt: When evaluating a potential donor. If there was evidence that these criteria occurred within the timeframe to find that individual would be considered high risk for having those communicable diseases and deferred for donation.

141

00:24:34.340 --> 00:24:51.520

Jolie Schmidt: There is a whole list of criteria that the FDA uses for this, and it includes things like using needles to inject drugs that were not prescribed by doctor, or having sex for money or drugs, or having sex with a person who has had a positive or reactive test for those viral infections

142

00:24:51.810 --> 00:24:58.340

Jolie Schmidt: for the purposes our purposes. Here. Today I am going to focus on these 3 criteria listed on this slide.

143

00:24:59.770 --> 00:25:10.760

Jolie Schmidt: Men who have had sex with men with another man in the preceding 5 years. Persons who have had sex in the proceeding in 12 months with a man who has had sex with another man in the preceding 5 years.

144

00:25:11.100 --> 00:25:16.120

Jolie Schmidt: and for a male donor physical evidence of anal intercourse, including

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00:25:18.230 --> 00:25:29.440

Jolie Schmidt: so at the time these are criteria were put into place. The blood banking industry had even stricter guidelines, making some of these behaviors in history lifetime deferrals rather than 5 years

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00:25:29.780 --> 00:25:34.920

Jolie Schmidt: revisions for organ and blood, came later in 2,013 and 2,015,

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00:25:35.090 --> 00:25:42.410

Jolie Schmidt: and reduced to the timeframe for deferral or male, to mail sex or Msm. To 12 months instead of 5 years.

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00:25:42.900 --> 00:25:48.900

Jolie Schmidt: Other criteria for organ later changed, and the deferral is now nothing As long as

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00:25:49.120 --> 00:25:51.560

Jolie Schmidt: high risk. Flavors are signed by the recipients.

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00:25:53.590 --> 00:26:09.320

Jolie Schmidt: When this original criteria was introduced, HIV. Screening tests were unreliable. For several months after exposure to the virus. it was argued that an exclusionary policy like this one, for male to male sex was necessary to protect transplant recipients.

151

00:26:09.630 --> 00:26:16.290

Jolie Schmidt: However, in the years since HIV, testing has become much more reliable within 4 to 8 days of viral exposure

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00:26:16.490 --> 00:26:27.990

Jolie Schmidt: and modern 0. Logical testing and a better understanding of HIV transmission through corneal transplants may mean that the FDA's 5 year deferral policy is no longer supported by evidence

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00:26:28.870 --> 00:26:35.390

Jolie Schmidt: In order to challenge the FDA's restrictions for individuals, with a history of male to male sex and other high-risk behaviors.

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00:26:35.510 --> 00:26:39.750

I banks across the country have been working together to gather evidence and data

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00:26:39.990 --> 00:26:48.070

Jolie Schmidt: We put together research studies, research and studies by infectious disease experts, including representatives directly from the FDA and the Cdc.

156

00:26:48.140 --> 00:27:03.940

Jolie Schmidt: Showing that the advancements and testing allow for accurate results much more quickly, and the 5 year deferral is obsolete. The I Bank Association of America submitted our first proposal on behalf of all 74 of its member I. Banks to the FDA, in 2,017.

157

00:27:04.240 --> 00:27:08.210

Jolie Schmidt: It's suggested changing the deferral criteria for a male to male sex.

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00:27:08.250 --> 00:27:15.910

Jolie Schmidt: changing that different criteria for male to male sex, and have it be updated to be more in line with the revisions for blood donation.

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00:27:16.410 --> 00:27:23.100

Jolie Schmidt: At this time in 2,017, that deferral was 12 months. The proposal we send received no response.

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00:27:25.520 --> 00:27:37.260

Jolie Schmidt: In June, the twentieth 20, the Public Health Service had once again revised the criteria for organ and blood donation. Individuals with a history of male to male sex were now deferred for 3 months instead of 12.

161

00:27:37.930 --> 00:27:45.210

Jolie Schmidt: This revision was made after taking into consideration the impact that COVID-19, had on the availability of blood and blood products.

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00:27:45.780 --> 00:27:54.800

Jolie Schmidt: However, despite the pandemic impacting, I and tissue donation in very similar ways, the criteria for these types of donation continued to remain unchanged.

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00:27:55.220 --> 00:28:03.570

Jolie Schmidt: In the meantime the data that just 13 of our 70 plus living the United States gathered showed that the current restrictions

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00:28:03.610 --> 00:28:07.140

Jolie Schmidt: resulted in the deferral of thousands of potential donors.

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00:28:08.180 --> 00:28:16.070

Jolie Schmidt: One study done by Dr. Michael Michael Pente, who is the founder of the organization legalized G. I looked at the Deferral and

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00:28:16.570 --> 00:28:20.740

Jolie Schmidt: the United States and Canada, Canada as a one year different.

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00:28:21.100 --> 00:28:37.830

Jolie Schmidt: He estimated that between 1,558 and 3,217 corneal donations were disqualified in the year, 2,018 alone, because of regulations for him, a prohibiting corneal donation by men who have had sex with another man in the preceding 5 years

168

00:28:37.950 --> 00:28:39.710

Jolie Schmidt: or one year in Canada.

169

00:28:41.340 --> 00:28:59.530

Jolie Schmidt: in 2,021, the Ivings once again pulled their resources together in an attempt to convince the FDA to make changes. Kristen Mathis with Vision Gift in Portland, Jennifer, dem Audio with the Ibank Association of America and Brian Philippe with Lions Medical I. Bank of Eastern Virginia, spearheaded. This second attempt

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00:29:00.080 --> 00:29:08.490

Jolie Schmidt: and their proposal to the FDA. They cited the FDA's own 20 August, 2020 guidance documents as an argument to shorten the deferral time.

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00:29:08.550 --> 00:29:09.710

Jolie Schmidt: and I quote

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00:29:10.020 --> 00:29:21.580

Jolie Schmidt: the totality of the surveillance information and the experience with a three-month deferral in other countries combined with the uniform use of nucleic acid testing for HIV, hepatitis, B. And hepatitis c.

173

00:29:21.640 --> 00:29:33.220

Jolie Schmidt: Which can detect each of these viruses well within a three-month period following initial infection leads the agency to conclude that at this time a change to the recommended 3 month deferral is scientifically supported

174

00:29:34.460 --> 00:29:40.500

Jolie Schmidt: of note. The United States is the only country in the world with a 5 year deferral, as showing here, you can see.

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00:29:40.620 --> 00:29:44.310

Jolie Schmidt: many countries do not have a deferral at all for male to male sex.

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00:29:44.450 --> 00:29:48.650

Jolie Schmidt: Others are just a couple of months, while some are 12 month to girls

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00:29:49.960 --> 00:29:55.220

Jolie Schmidt: put a quote a statement from the Ibank 2,021 proposal to the FDA

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00:29:55.680 --> 00:30:02.840

Jolie Schmidt: from a personal and community perspective. The lack of attention to this issue by the FDA is at this point, morally offensive.

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00:30:03.210 --> 00:30:10.570

because the technology is such that a viral infection resulting from these hybrid high-risk behaviors can be detected within days of transmission.

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00:30:10.670 --> 00:30:15.510

Jolie Schmidt: The current policy is at best interpreted as discriminatory rather than scientific.

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00:30:17.160 --> 00:30:28.020

Jolie Schmidt: I also believe it's important to note that, according to current FDA policy. a heterosexual person who has been in a sexual relationship with someone known to be infected with HIV

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00:30:28.190 --> 00:30:33.820

Jolie Schmidt: would be deferred for one year after their last sexual contact with the infected individual.

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00:30:34.290 --> 00:30:47.510

Jolie Schmidt: A hypothetical, monogamous donor who has had mail to mail sex with never been exposed to. HIV, however, would remain ineligible to donate his corn, as for 5 years after his last actual contact.

184

00:30:49.050 --> 00:30:55.830

Jolie Schmidt: Something that is of considerable importance to me personally is the effect that these requirements can have on donor families.

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00:30:56.120 --> 00:31:03.130

Jolie Schmidt: My department's role at Lgs is to have those hard conversations with donor families about donating their left one's eyes.

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00:31:03.520 --> 00:31:09.130

Jolie Schmidt: In their time of grief they may find some kind of relief in something positive coming from their loss.

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00:31:09.530 --> 00:31:12.750

Jolie Schmidt: as was written in the Eda, a 2,021 proposal.

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00:31:12.830 --> 00:31:18.440

Jolie Schmidt: This is a fundamental part of cadaver tissue donation providing a bridge between loss and hope.

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00:31:19.530 --> 00:31:24.410

Jolie Schmidt: knowing that their loved one's gift went on to enhance or save the life of someone else's comfort.

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00:31:24.430 --> 00:31:38.030

Jolie Schmidt: and it is absolutely devastating to be on the phone with a family member, and hear the deployment that their disappointment and sadness, when they learn that donation isn't an option simply because of their loved ones sexual orientation or preferences.

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00:31:39.120 --> 00:31:49.610

Jolie Schmidt: Our second proposal to the FDA was submitted by that I think Association of America's President Kevin Corbyn in 2,021, and as of today we have still not had a response.

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00:31:50.100 --> 00:31:53.740

Jolie Schmidt: as I think we are required to follow the FDA's criteria.

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00:31:53.910 --> 00:32:04.880

Jolie Schmidt: We can now only wait and hope that if changes are made, they are made based on data and science, not on a lingering fear based on past conditions and long discredited biases.

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00:32:05.600 --> 00:32:14.770

Jolie Schmidt: An adjustment to these current restrictions could help add some semblance of fairness, and restore dignity to an unjustly stigmatized population

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00:32:15.120 --> 00:32:23.150

Jolie Schmidt: In the meantime, lgs has been making the the adjustments that we are able to internally to better serve the Lgbtq a plus community

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00:32:23.300 --> 00:32:24.520

Jolie Schmidt: and their families.

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00:32:25.120 --> 00:32:43.470

Jolie Schmidt: The FDA Guidelines focus specifically on transplant donation, and their restrictions do not apply to research and medical medical education. Well, we are currently still unable to recover the cornea of people with the previously mentioned Social and medical, is room for transplantation for transplantation purposes.

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00:32:43.750 --> 00:32:56.400

Jolie Schmidt: Lgs has updated our own internal criteria to allow them the opportunity to donate for the purpose of research and medical education. research and medical education is an incredibly important part of what we do here in Lgs.

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00:32:56.420 --> 00:33:05.940

Jolie Schmidt: I'm. Going to turn things over to suddenly one of our research scientists to discuss from the research perspective why it's important to focus on Dei efforts in IP:

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00:33:07.960 --> 00:33:33.010

Sung J Lee: Thank you, Jolie. Hello, everyone. So my part here is, I will discuss the importance of donor, eye tissues, and ophthalmic research mit ctl, and and also the importance of incorporating diversity equity and inclusion from a research angle. So first off, i'd like to explain how research tissues are utilized, and the primary use, as Julie mentioned earlier, is studying eye diseases 250.

201

00:33:33.270 --> 00:34:01.490

Sung J Lee: But throughout the world there are thousands of ophthalmic researchers that are conducting studies, learning about eye diseases, and they are developing potentially new therapies and cures for these eye diseases. Now, in order for them to study the eye disease

and to be able to conduct their experiments, they need to have access to these human eye tissues instead of animal models, because, in order to get a strong understanding of how a disease progresses.

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00:34:01.490 --> 00:34:12.010

Sung J Lee: they need to be able to study an actual human eye. Also another use for these tissues is the innovation of new surgical instruments and equipment.

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00:34:12.080 --> 00:34:41.219

Sung J Lee: As you know, technology is advancing at a rapid rate these these days and that advancement also pertains to medical devices. So, like a lot of new equipment that is being made out there, and especially for those that are used in processing transplant tissues, or in this, in in surgeries it is very important to test the safety and the efficacy of these instruments. So, in order for them to test out these instruments, human research tissues are necessary

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00:34:41.219 --> 00:34:50.520

Sung J Lee: for this to be done. Another area that I Tissues are important, for research is pioneering new evaluation techniques of transplant corneus

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00:34:50.520 --> 00:35:13.040

Sung J Lee: for those of you unfamiliar with I banking. The majority of the processing of transplant tissues is completed at the ibank. The I bank has a space. We have the necessary equipment, and most of all we have the expert laboratory scientists who are able to complete the manipulations of the transplant tissues according to a surgeon's criteria.

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00:35:13.040 --> 00:35:13.960

Sung J Lee: So.

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00:35:13.980 --> 00:35:43.380

Sung J Lee: just like the instruments, there are new techniques and procedures that are being done to to transplant cornea, and before we are providing these to an actual patient, we need to test that the cornea is still viable, and it's still healthy after all the manipulations that we've conducted on it. So in order to test that we also made research tissues and that aspect, and Finally, every year there are new ophthalmic medical students that are learning

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00:35:43.800 --> 00:36:01.180

Sung J Lee: eye surgery, such as cataracts and retinal detachment surgeries, and in order for them to learn and to become proficient as they become a full time surgeons. They need to be able to practice these procedures, and they contact us at Lgs or other Iban

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00:36:01.180 --> 00:36:04.980

Sung J Lee: for these research tissues, so they are able to practice.

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00:36:05.270 --> 00:36:10.820

Sung J Lee: So next I would like to bring up some common misconceptions regarding eye tissues.

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00:36:10.820 --> 00:36:33.620

Sung J Lee: So over my years working here at Lgs. We've had multiple tours of individuals, and in particular, in this case it's lions, international members. And I've had multiple discussions where a individual would say, You know I would really love to donate my eye tissues, but I just feel like the eyes that I have right now are just no longer good.

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00:36:33.620 --> 00:36:43.880

Sung J Lee: and they would mention i'm well into my nineties. I've had 2 previous cornea surgeries, and I also have a known eye disease. So

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00:36:43.950 --> 00:37:13.060

Sung J Lee: after I hear that I had to make sure that she realizes that, although some of that those conditions may be a rule up for transplant, but there are still many uses for those tissues and a research front, as there are multiple researchers out there, and if the eye happens to have an eye disease, it's even more valuable to a individual scientist who is studying that eye disease to help them develop a new therapy or cure

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00:37:13.620 --> 00:37:38.380

Sung J Lee: to demonstrate the shortage of research eye tissues. There was a survey conducted by Arbo, which is a international Eye conference that takes place annually. Here in North America, and the survey indicated that 43% of the researchers in attendance find it difficult or very difficult, to get an adequate supply of human eye tissues to conduct their research.

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00:37:38.380 --> 00:37:50.850

Sung J Lee: But if there were enough quantity, for of these research tissues up to 88% of these scientists state that they would be more than happy to use the human eye tissues.

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00:37:50.860 --> 00:38:01.350

Sung J Lee: So now that I've explained how these research tissues are used now, i'll explain the importance of diversity among research eye tissues, Julie, please.

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00:38:03.000 --> 00:38:22.830

Sung J Lee: So, although all human beings are susceptible to eye diseases. There are certain eye diseases that are more prone to certain ethnic groups. For example, one of the studies published by American Academy of Ophthalmology, or Ao for short states that, compared to white Americans.

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00:38:22.950 --> 00:38:44.910

Sung J Lee: black, Latin, X. And ind indigenous Americans have a much higher risk of developing diabetic retinopathy, primary, open angle, vlaucoma, and cataracts, while Asian Americans are significantly greater risk for developing acute or narrow angle angle of glacoma, which is also glaucoma. But it is a different form of that.

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00:38:45.010 --> 00:38:55.080

Sung J Lee: Another study conducted by nature. Journal states that while age-related macular degeneration, or amd for so short predominantly affects white individuals.

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00:38:55.080 --> 00:39:18.440

Sung J Lee: Diabetic retinopathy, and glacoma are more prevalent among black individuals, and furthermore, responses to therapeutic interventions from medications to surgery also very considerably by ethnicity and a third example is a study, a published by all about vision, which indicates that ethnic backgrounds may have a role in the development of myopia which is near citedness.

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00:39:18.440 --> 00:39:23.770

Sung J Lee: and the study found that children of Asian descent were more likely to become myopic.

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00:39:23.770 --> 00:39:44.370

Sung J Lee: So, although all forms of research tissue is very important, this These studies indicate the importance of having a diverse population of research tissue being available as different ethnic groups are affected by different eye diseases more than certain other groups.

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00:39:44.370 --> 00:39:54.830

Sung J Lee: So, to help visualize this situation, I will show you another study that was conducted by Ao Jolie, please.

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00:39:56.090 --> 00:40:15.940

Sung J Lee: So here are 2 maps of the United States, and Ao did a study conducting the prevalence of primary open angle of coma amongst people in the United States, with the darker colors indicating there is a higher prevalence, and the lighter color indicating there is a lower prevalence.

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00:40:15.940 --> 00:40:25.950

Sung J Lee: So the map on the left indicates the numbers of individuals that have primary open angle of a coma in the year of 2,011, and using the current trends.

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00:40:25.950 --> 00:40:38.990

Sung J Lee: the map on the right is the year 2,050, and this is what they predict. The prevalence of primary open angle of coma in the United States will be, and, as you can see in both maps. On the left and right.

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00:40:39.020 --> 00:40:51.450

Sung J Lee: The darker colors are more fixated towards the southern parts of the United States, and in the Southern States there is a higher population of Black and his

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00:40:51.690 --> 00:41:04.010

Sung J Lee: Latinx individuals. So while this prevalence in the South is indicative, how are

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00:41:04.050 --> 00:41:09.710

Sung J Lee: I banks and researchers trying to help cure this. So, Julie, please.

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00:41:10.800 --> 00:41:24.660

Sung J Lee: in order to do the research researchers do need to have research eye tissues from not just one ethnic group, but from all ethnic groups. But in order to do this there are certain challenges that are being experienced

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00:41:24.660 --> 00:41:35.280

Sung J Lee: to repeat some of the stats that Jolie mentioned earlier, there is a higher prevalence of white donors that are willing to donate the eye tissues for research

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00:41:35.280 --> 00:41:47.980

Sung J Lee: over people of color, which is 22% instead of 39%. Another challenge that appears just due to the lack of donors of people of color.

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00:41:47.980 --> 00:42:00.540

Sung J Lee: Donate for research is the studies of the eye diseases that are pertaining to these individuals, such as a diabetic retinopathy or a close angle of a coma, are experiencing limited progress just because

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00:42:00.540 --> 00:42:09.470

Sung J Lee: scientists don't have the adequate number of samples for them to keep studying the disease and developing new therapies and and cures.

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00:42:09.740 --> 00:42:10.930

Sung J Lee: Also.

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00:42:10.930 --> 00:42:40.790

Sung J Lee: one issue is that not all I banks in America are capable, or have the ability to recover whole. I donor tissues for research here at Lgs. We are, I believe, top 3. I bank in the United States at distributing tissues for research and training purposes, both domestically and internationally. But as you saw on the map a lot of those Southern States where the color was a lot.

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00:42:40.790 --> 00:42:53.760

Sung J Lee: Unfortunately, a lot of those I banks do not recover a whole lot tissues for research. So there is a lot of potential donors that who may be open to

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00:42:54.090 --> 00:43:07.710

Sung J Lee: donating their eyes for research, but do not have the opportunity to. And lastly, another challenge is not all. I banks have a a common criteria for recovering tissues. So.

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00:43:07.710 --> 00:43:22.150

Sung J Lee: But here, at the lines gift of the site, we, since we are one of the biggest ivanks in the United States, with. In regards to research tissues, we are open to recovering research tissues from.

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00:43:22.270 --> 00:43:33.060

Sung J Lee: and all of some groups of people, including the Lgbtq. I. A plus community which, unfortunately, not all ivings are open to recovering for research.

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00:43:33.060 --> 00:43:43.560

Sung J Lee: So now I will go back to Jolie, and she will explain a further outreach that Lgs is doing to promote a Dei amongst the community.

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00:43:44.090 --> 00:43:52.220

Jolie Schmidt: Thanks, song. So we are still in the very early stages of beginning to address some of the challenges and opportunities that we've discussed here today.

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00:43:52.410 --> 00:44:09.710

Jolie Schmidt: Our partner Relations team has been absolutely instrumental. As we've started working on outreach and education. Mandy Long and Lynn Bell for have been reaching out to student groups within the University of Minnesota. They attended the student activities there which led to meetings with other student groups.

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00:44:09.760 --> 00:44:10.640

and

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00:44:10.990 --> 00:44:20.550

Jolie Schmidt: they were able out of the result of that, they were able to have a really important conversation with a board member from one of the student groups supporting Latinx students.

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00:44:20.820 --> 00:44:28.410

Jolie Schmidt: This Board member shared his group's hesitation to meet with Lgs due to deep rooted trust in the medical community and their perceptions of donation.

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00:44:29.150 --> 00:44:43.190

Jolie Schmidt: So having this conversation, gave our partner Relations team and our newly founded Lgs Edi Committee. Another push to show that we needed to find a new way to do outreach in order to approach communities of color.

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00:44:43.920 --> 00:44:57.350

Jolie Schmidt: Our partner, relations manager, Patti Stockdale, has also been working to raise awareness of the opportunities we have to do better to serve communities of color by presenting the data that we collected at several different, You know, director meetings and hospices

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00:44:57.450 --> 00:45:10.830

Jolie Schmidt: making fun of directors and hospice employees, aware of their ability to refer potential donors. might give more individuals and their families the opportunity to learn about I donation and decide if it is the right choice for them.

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00:45:11.830 --> 00:45:27.530

Jolie Schmidt: Lgs is going to continue to partner with our organ tissue, and I donation on agencies across the country to address the challenges that we're facing as well. While the number is vary per area. The opportunities for improvement we've discussed here today are not unique To Lgs

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00:45:27.760 --> 00:45:40.060

Jolie Schmidt: it is the responsibility of the donation community as a whole, to work together to find ways to do better. Over the last several years there's been a large influx of I. Banks beginning to focus on their own internal Ddi efforts.

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00:45:40.180 --> 00:45:55.880

Jolie Schmidt: and last year the I Bank Association of America, from form to their very first de I Committee, full of I bank employees from around the United States organ and tissue banks are also continuously introducing new efforts and working with the communities that they serve

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00:45:56.060 --> 00:46:07.560

Jolie Schmidt: in June of 2022, the Tribal Council of Turtle Mountain, adopted the Grayson initiative, which is a law that adds organ I and tissue don donor registration onto tribal identification documents.

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00:46:07.790 --> 00:46:19.260

Jolie Schmidt: Minnesota's organ procurement organization and a very close partner of Lgs life source was instrumental in this process. They helped provide resources and support to the advocates that made all of this happen.

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00:46:20.590 --> 00:46:31.870

Jolie Schmidt: So dea dei efforts are still very new to lions. Get the site, and, to be honest taking on as important of an initiative as this For our first time in our organization's history is a little terrifying

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00:46:31.930 --> 00:46:38.780

Jolie Schmidt: since we first collected our data and started identifying these opportunities. One of our biggest questions has been, how

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00:46:38.920 --> 00:46:53.470

Jolie Schmidt: how do we do this? And how do we make changes that we need in the most effective way possible. I'm the type of person who wants to make big changes right away, and I've had to take a step back and recognize that with something like this it's going to take time to do it the right way.

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00:46:53.830 --> 00:46:59.650

Jolie Schmidt: Large amounts of progress are not going to be to be made immediately, and I've had to tell myself that that's okay.

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00:46:59.770 --> 00:47:01.910

Jolie Schmidt: Any progress is good progress.

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00:47:01.930 --> 00:47:12.550

Jolie Schmidt: and Lgs is really fortunate to have the resources that the University of Minnesota provides to assist with this process, but even with those i'm sure that we are going to make some mistakes along the way.

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00:47:13.160 --> 00:47:19.030

Jolie Schmidt: Even so, i'm really excited to be a part of these efforts, and see the improvements that we will make in the future.

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00:47:19.270 --> 00:47:30.950

Jolie Schmidt: And of course it is. It is Donate life month, and I have to plug this just a little bit If you would like to register to be an organ tissue, and I, donor, please do so by visiting. Register me.org.

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00:47:31.660 --> 00:47:39.800

Jolie Schmidt: So thank you very much for the opportunity to be here today, and we're going to turn things back over to Vice-president news for any questions.

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00:47:40.470 --> 00:47:58.400

Ana Nunez MD: Great. Thank you so much, really. Lots to think about. I'm just wondering. And and again, maybe it's a timing thing, but I do know that the you is pretty unique, because it's a Med school that actually has mortuary science, and i'm wondering whether there's any cross

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00:47:58.400 --> 00:48:16.290

Ana Nunez MD: training or awareness raising in terms of our mortuary science students, you know, in terms of just having conversation about sort of. I transplanted and things like that. So just that's one thing that sort of comes to mind, and then the second piece is the folks that grace and initiatives

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00:48:16.290 --> 00:48:20.680

Ana Nunez MD: for those folks. I it was too fast. Were they Ojibwe, or they were different tribe.

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00:48:20.820 --> 00:48:25.550

Jolie Schmidt: a turtle mountain, and I am afraid

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00:48:25.880 --> 00:48:28.630

Jolie Schmidt: that I do not remember which

269

00:48:29.410 --> 00:48:31.650

Jolie Schmidt: they are part of.

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00:48:31.650 --> 00:48:53.480

Ana Nunez MD: Yeah. So so we certainly have, and we're very proud of having. So there's one of 3 in the nation as sort of native American associate Deans, and so I would sort of reach out to include our very, very busy Dr. Mary own, and and sort of just have a conversation, because I think that it might be wonderful to be able to expand some of the work

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00:48:53.480 --> 00:49:08.520

Ana Nunez MD: in terms of sort of those relationships. You know, the the most impactful thing that I heard told to me from sort of a patient in the community is, she says you know, all the time people talk about that, You know

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00:49:08.580 --> 00:49:33.990

Ana Nunez MD: patients. Don't trust doctors patients. Don't trust the medical, you know, sort of an arena, and my question is, what have you done to prove? Trust to us right? And and so it's it isn't just like, Trust me, i'm a doctor, you know it isn't. Trust me, i'm doing something nice. It's like. What have we done in terms of sort of garnering that trust, and and I guess part of it to me sort of wonders. You know. What are the stories

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00:49:33.990 --> 00:49:38.470

Ana Nunez MD: of underrepresented minorities who've had the gift of sight.

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00:49:38.470 --> 00:50:03.450

Ana Nunez MD: who had success in terms of sort of, you know, dealing with their cataracts, or benefited from this? And sort of do we do. We get to know those folks? Do? I mean, yes, for violating Hipaa, and they have to say it's okay. But like you know, I think that it becomes this sort of like. Do this and this altruistic thing when people are just doing the best they can just to get by. And so you know. How is this going to help their mom, their dad.

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00:50:03.450 --> 00:50:11.630

Ana Nunez MD: their niece, their nephew? What are those stories? So you can say? This is the difference it made in terms of someone's life.

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00:50:11.960 --> 00:50:22.220

Ana Nunez MD: You know. I think that there's some really humbling number out there that by the age of 75 half of Americans in the Us. Will have some kind of eye disease.

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00:50:22.220 --> 00:50:40.020

Ana Nunez MD: That's kind of mind blowing right? And so, if we can sort of do research to change those numbers or decrease the impact. That would be pretty profound. But i'm i'm wondering in terms of maybe some of the collaborations you have. There needs to be some communication and sort of tell some of the success stories.

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00:50:40.030 --> 00:50:57.610

Jolie Schmidt: Yeah, definitely. And one of the things that we always love to do is bring in volunteers, whether they are donor families or recipients, so that they can tell their story on Sunday. Actually Sunday, the sixteenth, we have our annual donor family recognition program.

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00:50:57.610 --> 00:51:07.460

Jolie Schmidt: We put this event on every single year, and bring in donor families from the last year to celebrate the lives of their loved ones.

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00:51:07.460 --> 00:51:20.370

Jolie Schmidt: And At these events we always have a variety of speakers. Usually we have a donor family. We have a recipient, a transplant surgeon, who talks about their experience actually restoring site to individuals.

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00:51:20.510 --> 00:51:22.880

Jolie Schmidt: and there is one particular volunteer.

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00:51:22.900 --> 00:51:41.710

Jolie Schmidt: and I unfortunately cannot remember her name right now. I wish Jody our family services liaison. I wish she was here right now, she can tell me, but she's an amazing woman. She is like the 3 Time Corny over the recipient, and the way that she tells her story is just fantastic.

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00:51:41.720 --> 00:51:52.090

Jolie Schmidt: and I would love to get her, and more involved, as we do, more outreach with communities of color and other ethnic groups, because her story is

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00:51:52.170 --> 00:51:53.020

Jolie Schmidt: so

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00:51:53.100 --> 00:51:59.090

Jolie Schmidt: important. Her name is Maria Joni. Just text me

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00:51:59.270 --> 00:52:28.790

Ana Nunez MD: all right. So Barbara Por would said. This is Chippewa, which belong in terms of the boat Chipway. Certainly we have tons of others in terms of Red Lake and fun, black and and sort of white earth, and we have lots of folks in terms of our tribal community. So maybe there's a way to sort of do a snowball thing of making new friends in that space. One of our attendees said: My husband, passed away a few months ago. We were approached and agree to his. I Donation both worked and research that you and we didn't know about this program. So probably communication is important.

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00:52:28.910 --> 00:52:37.170

Ana Nunez MD: you know, and I think sometimes maybe when people you know bundle it up, they don't necessarily sort of highlight eyes into the vision, and so on, so forth.

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00:52:37.170 --> 00:52:53.240

Ana Nunez MD: And sometimes, when you say donation, it's sort of it doesn't doesn't direct to which body part right? So are there ways to to highlight it? Or are there things that are needed in terms of, you know, continuing education for health professionals to raise their awareness. What do you think?

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00:52:53.550 --> 00:53:16.630

Jolie Schmidt: There is always always a need for education, and that is, that's one of the responsibilities of our Partner Relations Department. They have been focusing a great deal on reaching out to Hospice agencies over the last several years to make them more aware of donation, because, as you said, when people say Oregon donation, they just kind of lump it all together. I didn't really thought about.

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00:53:16.630 --> 00:53:33.650

Jolie Schmidt: And the way the Minnesota Driver's license system is set up when you check the box to be donor, You all, it says is donor, whereas other or other states have a list of all of the possible Oregon size and tissues that you can donate, and you can select exactly what you want to move forward with.

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00:53:33.730 --> 00:53:42.720

Jolie Schmidt: So we're we're always looking for new ways we've done. We've we've been out. We get the state there previously through.

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00:53:42.750 --> 00:53:52.850

Jolie Schmidt: As I mentioned before, student activity errors reaching out to medical professionals, we very recently were fortunate enough to have our

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00:53:53.000 --> 00:53:58.220

Jolie Schmidt: a second living donor in the history of our organization.

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00:53:58.500 --> 00:54:11.080

Jolie Schmidt: Absolutely amazing story. We this is very unusual. It's also he's it. It was the first living donor to be used for transplant purposes at Lgs. Previously it was only research that was allowed.

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00:54:11.280 --> 00:54:18.810

Jolie Schmidt: and in that opportunity we were able to talk to several physicians who had absolutely no idea

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00:54:18.820 --> 00:54:31.540

Jolie Schmidt: that this was a possibility. and we they were able to ask if we had a patient in the future undergoing something similar. Would something like this be an option? So, being able to have those conversations

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00:54:31.600 --> 00:54:35.920

Jolie Schmidt: with providers, and with end of life, care

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00:54:36.200 --> 00:54:39.700

Jolie Schmidt: professional. So those are huge opportunities.

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00:54:40.380 --> 00:54:43.200

Ana Nunez MD: Great. Dr. Feel asked.

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00:54:43.420 --> 00:54:57.400

Ana Nunez MD: What about are there opportunities for you all to sort of join and bring sort of some screening options to community clinics that are focused in terms of native American and Latinx folks. And if so, how would you even go about to to arrange something like that.

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00:54:58.260 --> 00:55:06.940

Jolie Schmidt: That is an excellent question, and that is more of a partner. Relations question, not really my area, unfortunately.

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00:55:07.350 --> 00:55:09.120

Jolie Schmidt: Oh. we here?

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00:55:09.570 --> 00:55:12.460

Sung J Lee: Well, at least from a research standpoint.

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00:55:12.650 --> 00:55:27.680

Sung J Lee: One thing I've noticed that was really engaging for people is when we had those tours is just showing the examples of what kind of research is being done with these tissues, because everybody knows that donor tissues can be used for transplant. But

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00:55:27.710 --> 00:55:35.330

Sung J Lee: I don't think everybody is aware that research is also being conducted with these samples. So when they realize that oh.

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00:55:35.560 --> 00:56:05.330

Sung J Lee: my friend, here and I, we are both experiencing macular degeneration or some eye disease of that sort. They have that covid bond, and they're both very interested. Oh, this kind of research is that being done here, this kind of therapy is now being developed. So after they hear about all that information, then they get excited, go back to their local club, and then they disperse that information. So that was a at a small scale with our ibank one way that we are trying to outreach.

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00:56:05.400 --> 00:56:14.730

Sung J Lee: But in order to reach other States and a more widespread reach. There have to be another way of expanding that message and using a

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00:56:14.820 --> 00:56:31.120

Sung J Lee: per, say, a larger microphone to get that message out there, but I think even emphasizing research to individuals that does fascinate a number of people because they're not aware of it. And just new things being developed. It really intrigues a lot of people.

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00:56:31.440 --> 00:56:41.280

Ana Nunez MD: I think one of the things that comes to mind sign when you're saying this is that you know, originally addressing sort of a cataract was a really long procedure.

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00:56:41.280 --> 00:56:59.940

Ana Nunez MD: and now it's I won't say minutes, but it's a pretty short procedure, right? And that wouldn't have happened without research as well as some of the complications. And so I think again, it's a piece piece of this sort of tell the story. Dr. Field asks, do you have

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00:56:59.940 --> 00:57:13.340

Ana Nunez MD: community education efforts that that address both the reality of sort of the history of medicine? Some of the stuff, Jolie, that you covered to sort of say, Sure we we acknowledged this, is it? We acknowledged the trauma is

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00:57:13.340 --> 00:57:33.160

Ana Nunez MD: we're you know we're in this different place to sort of say, we want you to be the recipients of all the advantages in terms of advances in terms of I care. But this is what it takes. Does that does that exist? Can Can they sort of do? A. You know? 3, 1, one call you up, and you know, come to a community place and give them this talk and and tell about some of these things.

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00:57:33.550 --> 00:57:36.320

Jolie Schmidt: That is, that's exactly what we're working on right now

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00:57:36.530 --> 00:57:50.540

Jolie Schmidt: we are. I guess that we're still very new to this entire process, and we are still trying to figure out the best possible way to have those conversations and acknowledge the history and figure out

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00:57:51.010 --> 00:57:54.880

Jolie Schmidt: what we can do to earn that trust. So that's

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00:57:55.270 --> 00:58:05.750

Jolie Schmidt: those are our goals currently. While we're working with our Edi Committee and partnering with our partner relations team trying to figure out the best way to have those conversations and

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00:58:05.850 --> 00:58:07.060
Jolie Schmidt: to.

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00:58:07.740 --> 00:58:09.310
Jolie Schmidt: We have started

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00:58:09.790 --> 00:58:27.530
Jolie Schmidt: with a couple of things internally. But we're not quite ready to release them to the public quite yet, and we are also always looking for more resources for people who have done similar things before, even if it doesn't have anything to do with donation, I think.

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00:58:28.050 --> 00:58:36.020
Jolie Schmidt: as a part of the medical community, it's our responsibility to all work together to figure out the best ways to overcome

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00:58:36.070 --> 00:58:40.250
Jolie Schmidt: all of this mistrust and all of the challenges that

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00:58:41.680 --> 00:58:44.460
Jolie Schmidt: the medical community has instilled.

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00:58:44.480 --> 00:58:51.420
Ana Nunez MD: Yeah, Well, maybe getting some of your advocates to join you on a community advisory would be really a great way to kind of develop some partnership

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00:58:51.420 --> 00:59:18.910
Ana Nunez MD: we're at time. I want to be mindful of everybody's schedule and some Thank you so much for joining us. This was awesome. We'll just say if they have any questions they'll just reach out to you right in terms of some of these things. I know that there might be people that are interested in engaging with you, so we'll direct them to you as well, and you know maybe a year from now you come back and tell us some of your successes in terms of making a difference. So appreciate all your hard work and enjoy the sunshine.

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00:59:18.910 --> 00:59:20.750
Ana Nunez MD: Take care, take care of

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00:59:21.060 --> 00:59:22.560
Sung J Lee: Thank you.