

Breaking the Silence: A Special Screening for *Below the Belt*

Discussion Transcript

17:31:39 I'd also like to welcome those who those of you who are joining online. So we are live streaming as well and have virtual participants. So welcome. We're going to go into a little bit of a Q&A. I'll kick off with a few questions and then we will spend hopefully a good amount of time hearing from all of you.

17:31:57 And Shannon, I really just wanted to, you know, a lot of themes resonated for me with this film.

17:32:02 Chronic underfunding of research, out-of-pocket costs that women and their families go through, that girls go through, these deeply entrenched gender norms around our bodies and who controls them and who has voice over them. And it makes me think about a lot of the work that some of my colleagues in this room and at the Gates Foundation do where we're trying to grind down those barriers, whether it's through increasing access to services, whether it's family planning, maternal, newborn child health, or trying to inject more resources into the ecosystem so we can actually have, you know, take that 7 million and get it up to one

17:32:38 Billion like for diabetes around innovation for women's health. And I think, you know, just to kick off the conversation, what made you start this process? Why women's health? Why endometriosis?

17:32:50 Why this film and why storytelling? Thank you. Thank you, Sonia. And thank you everyone for being here and being part of this discussion.

17:32:57 And watching the film. I think like so many things, when we find something we're passionate about in life.

17:33:04 By the way, is this volume good? I feel like I'm like, it comes from a very personal place. I have endometriosis.

17:33:12 I first had symptoms at 16, yet didn't hear the word until 13 years later when I was 29.

17:33:19 And was told many things that may feel familiar to you right now. Things like, it's normal, it's part of being a woman. I was exaggerating of my personal favorite, not favorite, that I was trying to get attention.

17:33:39 And I remember thinking, I'm 16 years old. I know how to get attention. And this is definitely not how I would choose to get attention. And just really feeling confused about

the adults in my life, especially healthcare providers, telling me something about my own body that I knew not to be true.

17:33:58 And when you're young and an adolescent and being told those things, it's really troubling.

17:34:06 So basically, after my second daughter was born, I was reading a journal article about the seven times increased genetic risk, actually, among sisters and between mothers and daughters of endometriosis.

17:34:22 And that terrified me. Like, you know, nothing before the thought that, you know, my child, someone I love, you know, would go through the same thing that I had gone through because I learned that in the 20 years since I first had symptoms, nothing had changed. You know, there was still a diagnostic delay of 10 years. Doctors still didn't know how to really recognize symptoms of endometriosis.

17:34:43 It was still 50% of infertility in women is still due to endometriosis. This is still true today, by the way. And I thought, you know, I'm a filmmaker. I have this lived experience.

17:34:56 Maybe it's time that we point the lens on women's health and especially this condition, but use it as a way to look at all of women's health.

17:35:08 When people ask me what is below the belt about. I don't say necessarily it's a film about endometriosis. I mean, we know that it is. But I say, you know, it's a film about all of the things that we see wrong within women's healthcare today. It's menstrual taboo and stigma. It's gender bias. It's racial bias. It's misinformed doctors and historical lack of research funding. And barriers to care, whether

17:35:35 Be institutional, cultural, financial. It's not just one thing, but endometriosis is this perfect, awful storm that kind of encapsulates all of them. And if we can hopefully tell those stories of these people who you've met today who are brave enough To let a cam recruit into these most intimate and vulnerable parts of their lives, then our collective goal was to try to move the needle forward and change.

17:36:05 Thank you for that. If we could dig into, you know, thinking about storytelling.

17:36:11 On such an issue that there's a lot of silence around, but that there's also sort of an active pushback against, as we saw with the film, why storytelling? How does that add to the conversation why not looking at policy papers, scientific briefs? How does storytelling add to this conversation? Yeah, thank you for that. I think that all of those things have a role to play. Data has a role to play. Policy papers absolutely have a role to play. But story gives meaning and emotion to all of those things.

17:36:45 You know, we can make an even more meaningful impact if you have story, if you touch hearts and minds.

17:36:54 I always say if you can change hearts and minds, you can change policy.

17:36:59 Senator Warren and Senator Romney actually co-hosted a screening of this film on Capitol Hill for members of Congress.

17:37:06 And it was really wonderful to see. I mean, of course, they were making jokes about, oh, this is the only thing on Capitol Hill this week about women's health. You're going to have a Republican and Democrat up here standing together jokingly, but it probably is true, you know?

17:37:23 So it provides a space for people to come around in story and a safe space to go into it and learn about a human experience and this lived experience that is true. And then find that common ground that we all share, our shared humanity. And then from that, hopefully build a common platform for practical change. I mean, I say hopefully, but that is the goal. And that's the transformative power of storytelling, which, by the way, I mean, you guys all probably know you all wield that power. You all have your lived experience and your stories to tell.

17:38:05 And small or large ways. This is just a large way to do it.

17:38:11 As you've gone on the road and shared this film and talked to many different audiences, can you share some of your reactions on how this has maybe changed hearts and minds or how it's maybe prompted different conversations.

17:38:24 Yes, it's certainly, we've screened this film on six continents so far. I'm holding out for Antarctica. I mean, what's going on? I'm going to have to just go down there and say, let's just do this.

17:38:37 Outdoor screening. Well, actually, I'm going to start with a question that I always ask.

17:38:47 How many of you have been in a doctor's office and for whatever reason or condition have felt minimized or disbelief for something you were sharing?

17:38:57 Right. So, you know, a large percentage, over half, I would say. And that has been the case in every room I've been in. And that is from Dubai to Mexico City to Dublin to London to New York City.

17:39:16 A majority of women's hands go up. And it doesn't matter what I've seen at age, race, socioeconomic background. That's a common denominator What is that? What does that tell us?

17:39:31 And it's not necessarily about endometriosis. It's about our experience and our sharing about who we are, you know, and being believed and having that autonomy and agency.

17:39:42 Of our own body. So it shows that we have a long way to go. I have no doubt that all of you are very capable, educated.

17:39:51 People in the room. So what does that say about all of us here?

17:39:57 So that's something I've learned that that's a common denominator. But of course, I've also learned in different conversations in different rooms, we have to approach women's health with a certain degree of nuance. We know that, you know, in sub-Saharan Africa, there are a lot of hurdles that we are not facing here.

17:40:19 In the Middle East, we were talking before, just girls not wanting to share menstrual pain symptoms with same-sex family members.

17:41:37 piece.

17:41:39 Could you talk about what came up in the development of the film and what reflections it would mean in expanding treatment and care.

17:41:48 >> That's not a simple question.

17:41:50 Thank you for that.

17:41:51 Wow.

17:41:52 You know, that's a lot to dig into.

17:41:56 I mean, I think that we can all recognize no matter who we are healthcare systems in place are not working for us necessarily.

17:42:04 And the challenges are different in different countries.

17:42:07 Here it's a profit driven model and we are all navigating that.

17:42:11 Like, what does it mean to find the best healthcare.

17:42:15 What does it mean when you're relegated to subpar care because of financial considerations because insurance won't cover your care.

17:42:22 What does it mean if you're in the UK and you have you're part of the NHS and you have extended wait times of years to see a specialist.

17:42:36 Symptoms in place are not working for the people they were built theoretically to serve.

17:42:42 So that's where we all come in, actually, to fill those gaps.

17:42:48 And if the institutions that are so ingrained and that are stagnant aren't working, then we either, first of all, have to try to find ways, innovative ways to fill the gaps.

17:42:58 Storytelling is one of them.

17:43:00 You know?

17:43:01 All of the things, I've just looked around in here, all these things are additional ways to do this, the work you do are ways to do this.

17:43:08 And then we fill in the gaps and that's kind of the interesting thing.

17:43:12 And I'm seeing it with this film.

17:43:15 Then the conversations at these institutions begin to change.

17:43:21 And the policies at these institutions begin to change because you've created such momentum and such chatter around it that then they feel, to feel compelled.

17:43:36 Some of the things that I found really enlightening are like the HIV/AIDS movements in '80s act up where they did policy and they did direct action.

17:43:47 They all around -- if you haven't studied the work they've done, it's really incredible.

17:43:52 When I was making this film, I talked to Greg Gonsalves at Yale.

17:44:02 So many commonalities, he was part of the act up and 80s and endometriosis stigma, it's about access to care, he said you've just got to make sure that people -- you can't be scared to make them uncomfortable.

17:44:14 That's it.

17:44:15 And that's one aspect.

17:44:16 But then you also have to be able to speak their language.

17:44:19 And he also told me, he's like, you don't need a thousand people to make change.

17:44:24 You maybe need 10 to 20 of the right people.

17:44:28 Someone who understands research, understands marketing, understands social media these days, you know.

17:44:36 And understands how Washington works.

17:44:40 And understands that the patient voice is critical.

17:44:45 But, yeah, I tend to -- anyway, I kind of meandered there but the idea is that let's learn from people who have come before us and let's build on that.

17:44:55 I always tell people, like, look at what we're trying to do, build on that.

17:44:59 Do better, learn what we're trying to do here with this film.

17:45:03 Use it.

17:45:04 And then build something.

17:45:06 >> Thank you so much.

17:45:07 I love how you brought up the HIV movement and I feel we have so much to learn from what that movement has done.

17:45:16 One more question before we open up to the audience.

17:45:19 Thinking about -- thinking about private philanthropy, thinking about grassroots advocacy, public/private partnerships, how can those sort of bodies and those funding flows play a role, play more of a role, help to influence this conversation?

17:45:36 >> I mean, I think the first is just stating this is our goal.

17:45:40 This is what we're here for.

17:45:43 This is going to be our focus and then putting it to the forefront.

17:45:47 That seems simple or, like, obvious, but sometimes it's not, when you have that clear mandate.

17:45:53 And then finding the formula to do it.

17:45:56 And then understanding that we all have something to gain from it, the private sector, public sector employees, patients, providers, society.

17:46:12 We can all win together.

17:46:14 But within that, I've spoken with the World Economic Forum, and I understand we have to meet people where they are and talk about if you're at the World Economic Forum, you need to talk about the economic impact and how this is the way that we can, if we can fill these health gaps and put more women in the workforce and have more healthy workdays, then imagine the impact in the world economy.

17:46:39 So it's really about learning how to meet institutions where they are because we can literally show this conversation about how it can improve every aspect of society, it's just understanding, like, okay, this is the way we need to phrase this conversation for this group of people.

17:46:58 Because it's all true.

17:46:59 It's all true.

17:47:01 It's just -- yeah, giving it the care and the attention it deserves and having the data to back it up and then having a story to actually make people care about it instead of another spreadsheet, another white paper.

17:47:13 They're all important, but we've all got a lot of this.

17:47:17 So how do we stop it and get people to pay attention.

17:47:23 >> Thank you so much.

17:47:24 We'd love to open up the floor to all of you.

17:47:26 For those in the room, we have mic runners, feel free to raise your hand if you have questions, comments, anything you'd like to share.

17:47:33 For those online we'll be reading out your questions in real time.

17:47:36 So the floor is open.

17:47:49 >> My name is Antonia, and thank you so much for this film.

17:47:55 I've been looking forward to it all week.

17:47:58 I had my first laparoscopy a little over two weeks ago.

17:48:05 And going through that process just made me think about how is it that for a diagnosis you have to be under anesthesia, go through a major surgery and not even know if you have it or not.

17:48:27 I was wondering if during your filmmaking process, if any conversations about different avenues for diagnosis came up that didn't involve a major surgery like that.

17:48:44 >> Yes, thank you.

17:48:47 That's a critical question and it applies to all of women's health.

17:48:54 Yes, there are studies in process right now for biomarkers, blood tests, imaging tests, but nothing is definitive yet.

17:49:04 And it all goes back to historical lack of research funding for women's health in this country and around the world, because if we had --

17:49:14 basically a commensurate amount of research funding that basically meets the disease burden of end and related questions we'd have an answer to that we'd have a noninvasive diagnostic test we'd have a world where you go into your pediatrician or PCP or nurse practitioner with symptoms and they immediately recognize, oh, you know what, you may have endometriosis, I'm going to refer you to someone.

17:49:46 That's the difference.

17:49:48 And it's not just endometriosis, it's menopause.

17:49:52 It's PCOS.

17:49:54 It's fibroids.

17:49:56 It's so many different --

17:49:58 cardiovascular risk in young women.

17:50:00 There are so many things that we should know but we do not know.

17:50:06 Or doctors or healthcare providers do not feel equipped to recognize those symptoms.

17:50:13 And it all goes back to valuing women.

17:50:19 And I have great hope that things are changing and hopefully, I remain optimistic that they will change with a transformative amount of research funding, hopefully, in the public sector.

17:50:33 If not, I do see that funding coming in the private sector to fill those gaps.

17:50:40 A large answer to your specific question, but that's why and until we have that transformative amount of research funding we won't have that noninvasive diagnostic test.

17:50:56 Thank you.

17:51:05 >> I didn't quite understand the [inaudible] what exactly they were doing, were they blasting blood vessels away or cutting off something.

17:51:14 I didn't fully understand what the procedure and the solution is.

17:51:17 >> Okay, thank you.

17:51:18 So her question is in the surgery she was, in the surgery scene she wasn't quite sure what was happening.

17:51:25 And thank you for that.

17:51:27 Basically they were doing excision surgery, which is where the endometriosis is cut out and the difference, the distinction of that is important because the vast majority of OB/GYNs that may take a patient to the OR, they probably are not trained in advanced endometriosis surgery.

17:51:46 They have learned how to do ablation which is like taking a laser burning the surface of the lesion.

17:51:51 The issue with that -- and we were trying to impress upon the film and here -- you can't see how deep the lesion is.

17:51:57 You don't know that you've gotten all of it.

17:52:00 Imagine if you have a tumor, if you have cancer in your body, do you want a surgeon to go in and burn the top of what he or she can see or do you want them to know, definitively, they have cut the tumor out?

17:52:12 That's the same situation.

17:52:15 And the issue is that for decades we've relegated women with endometriosis to OB/GYNs who don't necessarily have that requisite skill or that confidence to cut it out.

17:52:28 So they are doing the ablation surgery with a laser.

17:52:32 And it's one aspect of a multidisciplinary treatment plan for endometriosis that's really important, but I think it makes common sense.

17:52:44 Until the disease is out of your body, how can your body heal?

17:52:47 And that's what we were trying to make the point.

17:52:49 Does that answer your question?

17:52:53 >> I guess I just want to know is it the little blood --

17:53:03 >> It's a disease process.

17:53:05 It's not blood.

17:53:06 It's like a material, lesion of endometriosis.

17:53:10 It's uterine-like tissue that grows in other parts of the body outside of the uterus.

17:53:18 >> My question is sort of related.

17:53:21 I don't think from the movie I've got a definition of what endometriosis means.

17:53:26 It's outside of the uterus, is that what you're saying?

17:53:29 >> It is.

17:53:30 Endometriosis is basically tissue that's similar to the lining of the uterus but not exactly the same.

17:53:35 And it grows in other parts of the body.

17:53:39 A lot of times in the pelvis but not necessarily.

17:53:41 It's actually been found in every organ, from the spleen to the brain, and basically it causes scarring.

17:53:52 Organ dysfunction.

17:53:53 A lot of bowel dysfunction, for example, urinary dysfunction, diaphragmic dysfunction and pain.

17:54:03 It's important to note that not every person's symptoms are the same.

17:54:08 It really depends on where the disease is.

17:54:10 And again we need more research because a lot of the latest research is showing that actually endometriosis may be different types of disease, like different phenotypes.

17:54:19 That's why some people present with, like, minimal disease that may show up in surgery but they have debilitating pain.

17:54:27 Whereas, others may not even know they have the disease until they can't get pregnant and they have surgery and they have Stage 4 endometriosis.

17:54:44 It's everywhere.

17:54:44 We need research to understand and until we know that we are putting together the best-case scenario to try to treat it.

17:54:51 Trying to treat it with surgery, trying to do multidisciplinary modalities to minimize symptoms.

17:54:58 That's what we are left with.

17:55:02 >> [Inaudible].

17:55:05 >> The question is what kind of doctor do you go to to treat endometriosis?

17:55:11 You go to someone who is a specialist, who sees patients with endometriosis every day.

17:55:17 There are not very many of them, but there are some around the world.

17:55:22 In the U.S. and a lot of developing countries are --

17:55:26 there's a specialist emerging, which is exciting.

17:55:31 And, for example, maybe there are surgeons who operate on many different endometriosis cases a day.

17:55:36 I would say that they also are open to pelvic floor physical therapy and understand nutrition and mindfulness and a lot of other approaches to overall health because lack of disease maybe does not equate health but if you can take it out of the body, then you can start on a process toward health.

17:55:56 The issue is it's a full-body systemic disease.

17:55:59 We know that the endocrine system is involved.

17:56:01 We know the immune system is involved.

17:56:05 But we just don't know how all of the pieces work together yet.

17:56:09 So we need the research.

17:56:14 >> There's one hand in the back over here.

17:56:17 And then we'll come up to the front.

17:56:20 >> Hi, I really appreciate what you said about the power of storytelling and given other information you shared about intersectional types of experiences when you think about women spanning the gamut of economic class, race, et cetera, I guess I'm curious about the choices you made of which stories to highlight and how, can you just talk about how you selected those women and if there were difficult parts of, oh man we wanted to showcase this type of story but for whatever reason -- I was also

17:57:02 Wow, all the resources she had and for a grandfather who voted for a lot of things that were detrimental to women's health why was curious where does that all fit together and what other stories had to get cut and if you made more, which types of stories you would feature.

17:57:18 >> Thank you.

17:57:18 Thank you for that question.

17:57:20 I think that's every filmmaker tries to -- you do the best you can when you have a documentary.

17:57:26 It's not a -- I didn't write this story, necessarily.

17:57:29 I didn't create the stories out of thin air.

17:57:33 These are humans going through these real experiences.

17:57:39 So how do we invite an audience in to be there and witness those experiences in a way that not only validates those experiences but invites you to also see the honesty and truth in what they're going through in their own life.

17:57:58 That's what I was trying to do.

17:58:00 I thought it was important when I met Jenna, who was the nurse.

17:58:04 She's clearly a very intelligent woman.

17:58:06 She's a nurse.

17:58:07 She was at UCLA when all this was going on, and she still felt that she would take her partner, she learned that if she would let him speak for her she got what she wanted faster.

17:58:20 And it just shows you, she was, like, at the end of the day I knew what I needed, if it got me what I needed, then I just did it.

17:58:27 Because in that moment that's what I needed.

17:58:29 But I just thought it was very telling about what we as women go through when we're just, like, let's just be practical here, this is what we need so let's just do this.

17:58:39 Sometimes we can go stand on the mountain and talk about it, but sometimes we just need, like, a solution, and that's what she was alluding to.

17:58:48 Kyun, I saw her art online and I just thought it was incredibly beautiful and moving and spoke to the experience of being a woman, the femininity and fertility and all the things that go into that, and she just is such a love will I -- lovely person that with her infertility journey it was important to highlight because of having endometriosis.

17:59:15 Yes, Emily, when I first met her she was 17 years old.

17:59:20 And clearly -- not a secret about the fact that she comes from a affluent background and her grandfather is Orrin Hatch, long serving senator.

17:59:36 But at the end it shows that he loves his granddaughter sees her suffering and all of a sudden it becomes quite relevant and important, and I think we can all identify with that.

17:59:48 We see that all the time, by the way.

17:59:50 It doesn't matter who you are.

17:59:52 It doesn't matter how famous or powerful you are, you're human.

17:59:55 If someone you love is affected, you are going to care about that issue.

18:00:00 If you're personally affected by that issue you will care about it.

18:00:04 He was an incredible advocate and willing to work, hey, willing to work across the line, joking with Elizabeth Warren.

18:00:13 I mean, that's kind of great, actually.

18:00:19 Bipartisanship, there you go, to accomplish something.

18:00:22 And with Laura, who is in Canada, her fight to try to get basically to get specialized care, that was something that I thought was really important to highlight.

18:00:35 So basically to answer your question, each of their journeys I thought highlighted a different aspect of trying to get care and then just the lived experience of different people.

18:00:47 And it doesn't cover everything.

18:00:49 Nothing could be exhaustive.

18:00:50 I talk about with endometriosis, if we covered every aspect of endometriosis in every person, it would be like the series Netflix has ever seen and nobody would want to watch it, you know what I mean?

18:01:05 So we have to try to tell the story as well as we can in the time that we have available and then have this discussion like we're doing right now about everything beyond it.

18:01:17 >> We have an online question we want to address.

18:01:19 What are you hopeful about for the future of research, treatments and policies?

18:01:25 >> I am hopeful -- I'm hopeful that you guys are all here fighting, trying to change some things substantively.

18:01:35 I'm hopeful that conversations about women's health are happening, for example, in Washington.

18:01:40 I'm a new member of an NIH/NICD committee and as a patient and a lawyer to help talk about grants coming into the NIH and how do we actually fund research that will actually change lives.

18:02:00 That's exciting.

18:02:01 I'm hopeful that through the spirit of collaboration we can keep moving the conversations forward and that -- I don't know, I mean, we've got to hope, right?

18:02:14 Who is hopeful?

18:02:15 Let's be hopeful, right?

18:02:18 Let's be optimistic.

18:02:19 It's a trying time, but there are a lot of really good people, really smart people working on this.

18:02:25 So I have a lot of faith.

18:02:29 Being in here with you and being in other rooms where these conversations are taking place, I'm, like, all right, we've got each other's back.

18:02:36 We're going to keep going, and that gives me hope.

18:02:44 >> I'm Brooke, I'm an endometriosis excision surgeon here in Seattle I opened a multidisciplinary clinic called full spectrum fibrin endometriosis.

18:02:57 >> Let's clap for that.

18:03:00 [APPLAUSE]

18:03:01 We have two gynecologist, endometriosis focused dietician and acupuncturist and pelvic floor therapist we're trying to embody that multidisciplinary approach not only with the expert level pelvic surgery but with everything afterwards which I think was a big piece missing my question in my mind is one of the biggest problems is the women are going to OB/GYNs for the surgeries and the OB/GYNs are being told and trained for doing these surgeries mostly doing ablation.

18:03:31 I know it wouldn't be a solution to every problem, but I really feel like splitting obstetrics and gynecology into two sub separate specialties would do a lot because every gynecologist would have four years of surgical training as opposed to basically the one year they get in a combined program.

18:03:47 And then it might have to be an endometriosis fellowship after that.

18:03:50 But I think that one thing could solve so many problems, and I was just curious what you thought about that.

18:03:55 >> I think it's a great idea.

18:03:58 You convince ACOG.

18:04:02 I mean, yes! Absolutely! That would be incredible.

18:04:09 The issues at play are there are a lot of politics and bias and we have to navigate those channels.

18:04:22 >> [Inaudible].

18:04:23 >> Absolutely.

18:04:27 I mean, if I, for example, your question or someone asked about which surgeon, I would for sure ask if I needed surgery I would ask, okay, do you also deliver babies?

18:04:40 Because if they do, I know I wouldn't want a surgeon who is up until 4:00 a.m. delivering babies scrub in for my surgery that could be many, many hours at 6:00 a.m. it just doesn't make sense.

18:04:55 But it happens, like she said, every single day.

18:04:59 Yes, I think it would make sense to have that division.

18:05:03 It's something that conversations have happened.

18:05:06 And it's just finding the political will of people in power to agree to that.

18:05:18 >> Hi, my name is Victoria.

18:05:21 I have a question and an anecdote.

18:05:24 And I think the question kind of follows on from the last question, and it was: Are medical schools now teaching --

18:05:33 is endometriosis part of the curriculum?

18:05:35 And my anecdote is, a friend's kid is now a transgendered medical student in the Bay Area who now presents as a white male, and it's been amazing to them how they are getting preferential treatment as a male versus what the females in school are getting.

18:05:58 Just fascinating for somebody to be able to see it from both sides.

18:06:02 >> That's interesting.

18:06:03 >> But wondering if curriculums are including endometriosis so at least there's an awareness where there wasn't before.

18:06:09 >> It's my understanding that still it's -- endometriosis is covered like in an hour in medical school and like a laundry list of benign gynecologic conditions.

18:06:23 I mean, that's my understanding.

18:06:24 Again it's trying to create an end run around it because getting curricula changes is a mountain that takes a very long time.

18:06:32 We've screened this film in 23 medical schools so far around the country and that is in partnership with the medical schools, with faculty, with the administration.

18:06:41 We have a panel discussion like this and talk about endometriosis and I taught a bio medicals class at Harvard Medical School last year we showed first year medical students the film and talked about the issues, talking about the menstrual stigma and gender bias and everything through this lens, and I was very heartened by the response of the first year medical students because they were, I would say category outraged this was going on.

18:07:14 They had no idea.

18:07:15 And what the post survey screening survey is, they remember endometriosis in a different way now because we've touched their hearts and minds.

18:07:24 We've told them stories about endometriosis.

18:07:29 And now we feel confident and we're still following up how to see how to replicate that class, but the idea that, again, story, coming in with medical education in a way that sticks, for example, for lack of a better word.

18:07:45 And that's the hope.

18:07:46 I mean, until medical curricula catches up, then we'll continue to do the end runs and filling the gaps, that's the hope.

18:07:54 >> Hi there.

18:07:55 My name is Alex.

18:07:58 I have just a comment.

18:08:01 Dr. Winner was my surgeon last year.

18:08:03 I just wanted to give a shout out to her and say thanks and it's nice to see you here.

18:08:10 >> Thank you.

18:08:15 >> >> This was such a great video, and an amazing tool to get awareness around endometriosis.

18:08:23 I'm curious, do you have plans on bringing awareness on other women's health issues like recurrent urinary tract infections and ovarian cysts chronic conditions that women live with on a daily basis and they impact women globally.

18:08:39 Just curious if this is one step towards other, bringing awareness to other women's health issues?

18:08:46 >> Yes, thank you.

18:08:48 Yes.

18:08:48 We're in the early stages of the next project which will also be in women's health and looking at a lot of basically some of the studies that have come out of the World Economic Forum with the economic impact across nine different conditions, including endometriosis, but also menopause, maternal mortality, cardiovascular risk.

18:09:08 Basically looking at, well, what is the common denominator here and why don't we fix it?

18:09:13 And finding a way to use storytelling to go with that, go with the numbers, to go with the data, to say, okay, we're going to push this forward, and it also includes yes those taking a deep dive into some of the other healthcare conditions but also saying, like, it just makes good sense to fund it and to put more attention to all of them.

18:09:36 So it's early going yet, but, I mean, my heart and my passion is always going to be within endometriosis as a patient but I also know that it's so relevant to the larger conversation and that as we solve or work toward solutions for endometriosis, then we work towards solutions in all of women's healthcare.

18:09:58 It's a model upon which a roadmap upon which to solve a lot of different healthcare conditions.

18:10:08 >> I see one hand in the back.

18:10:16 >> I'd just like to add a little joke.

18:10:20 I love to -- comedy is always welcome.

18:10:24 >> I'll take it and hopefully give it to you as a pelvic floor physical therapist I like to tell my graduates I graduated in 2000.

18:10:37 And what I learned S 1234 is it keeps poop and pee off the floor bdabmp.

18:10:46 Actually the truth but I was the one student as an adult student in PT school in our cadaver course, I wanted to know why we couldn't see the female parts.

18:10:58 And I was told by the male doctor, like, that's not important.

18:11:03 Don't worry about it everything is fine.

18:11:06 So it was really frustrating.

18:11:10 So in a sense of the word we've come a long way and being able to talk about this because I was shut down in that coursework, and I was pretty angry but didn't have the sense or knowledge that -- I didn't know what I wasn't learning.

18:11:31 So I uses feel so grateful that we're learning so much more and we're here discussing this and you're showing it out into the big world.

18:11:39 So thank you.

18:11:39 >> Thank you.

18:11:45 We have a question in the front.

18:11:46 I don't know if there's any other questions from online.

18:11:50 We'll do one online and then come back into the room.

18:11:57 >> [Inaudible].

18:12:05 >> When I was 17 a doctor told me I have endometriosis and without all the consequence what that means.

18:12:12 I had to take a lot of medicine it was at the time the medicines weren't taking anymore.

18:12:16 I started to receive some shots.

18:12:18 Then the shots were not working either and I started to take another medicine, but then I did something that I didn't do for that reason but it was just something that happened.

18:12:28 I started to do a meditation that it was ten days in silence, and that to me helped me to understand the pain it was something that it was going to be there but I was going to

be able to separate from that and then I started psychology, like that helped me, too, there's a lot of things that it comes from our mind, too, and watching your documentary, I saw that kind of like I am relating that every month I was having this anxiety that I'm going to be in pain.

18:13:00 So I was like thinking that all the month.

18:13:03 That was causing me more pain.

18:13:05 So going back the meditation that I do that I learned a little bit that kind of controlling with some breathing, some healing ourselves like kind of with our hands and all these thoughts it was kind of calm minds.

18:13:20 I think that now is like something that I'm still having that but it's kind of different.

18:13:26 It's like I feel that now I'm kind of learning how to control that.

18:13:33 I think Ginger was something that helped me a lot, and I think there's some cases that sometimes I took that pill that helped me but when I got married it was like I don't want to be in waiting with that pain in that special day but like besides that it was something that I have to learn how to control that.

18:13:53 And I think that helped me a lot.

18:13:56 >> Thank you.

18:13:58 Thanks for that.

18:14:00 >> We have one question online -- okay.

18:14:02 >> Hi, I'm Cheyenne.

18:14:04 I also have endometriosis.

18:14:06 Your film really resonated with me.

18:14:09 I was wondering what advice do you have for us in this audience as to how we can raise awareness?

18:14:15 I'm an artist and tech professional.

18:14:18 I use my platform to raise awareness.

18:14:20 I actually promoted your film to my community of followers when it came out when it was on PBS.

18:14:27 But I don't know if you had any recommendations there.

18:14:30 >> Thank you.

18:14:32 Thanks for that.

18:14:33 And, I mean, that's exactly what I tell people is like we all have a role to play and you know your skill set, your experience, your expertise, and utilize it.

18:14:45 You're an artist.

18:14:47 Utilize -- ask yourself, like, that's something that whatever feels true to you to help spread awareness.

18:14:56 There are -- I would say follow that first of all and whatever that means to you and beyond that if you want specific things like we have a school nurse program, for example, and you can go on and we send free nurse toolkits to anybody in the community.

18:15:15 If you go to endowhat.com or any of the social media you can link to and you can put the school name, the school nurse, the name if you have it, and we'll send resources, links to the film and they can get continuing education with a partnership we have through northeastern, and we're launching a program it's in partnership with Mayo Clinic and targeting frontline workers what you need to know about endometriosis, nurse practitioners, physicians, primary care providers and the idea they'll be de

18:16:09 .

18:16:10 It's where they can get toolkits.

18:16:12 It's free.

18:16:13 You've just got to share the information.

18:16:15 >> Similar to that, building on that idea, are there any emerging leaders or leaders in research on the future of endo?

18:16:24 >> I'm not quite qualified to say any one researcher over another researcher necessarily.

18:16:31 I will say we screened this film in partnership with the NIH a few months ago.

18:16:36 And we screened for all 20,000 employees across 27 institutes, and the goal with that is we had a live panel discussion with Dr. Janine Clayton, one of the directors of the office of research of women's health and Gianna beach, the NIH/NICH director and the goal was to invite researchers of all backgrounds to consider women's health to consider endometriosis when they're thinking about what they're going to focus on next and what they can bring in their respective fields into women's health.

18:17:12 So I'm excited about that conversation.

18:17:16 And hopefully ask me in another year I may have some names for you.

18:17:24 >> Wonderful film.

18:17:25 Thank you for creating it.

18:17:26 I work in molecular diagnostics.

18:17:29 I would love to hear a bit more about what is the definitive diagnostic technique.

18:17:35 And secondly, what's done for patients who have already undergone the excision therapy to ensure that either it's not coming back or it was all excised?

18:17:46 Is it just symptom-based if a woman feels better then it's assumed she's okay or does she have to repeat an invasive procedure at some regular interval?

18:17:58 >> The first is the only way to definitively diagnose an endometriosis you take a patient to surgery and the biopsy confirms it's endometriosis.

18:18:11 That's the only way.

18:18:13 I was saying earlier I hope there are more noninvasive diagnostics in the works there's encouraging things with imaging happening, but right now it still feels like -- you need a specialized radiologist.

18:18:27 A radiologist that specialized experience and expertise to see it on a scan.

18:18:35 So it's still emerging, but I feel optimistic.

18:18:41 I mean, as far as surgery, I would say let's ask a doctor that.

18:18:46 I don't feel qualified to say the course of action if that's something we want to talk about.

18:18:58 >> [Inaudible].

18:19:02 And in terms of afterwards, the data is a little bit mixed about whether or not going on hormonal suppression afterwards reduces the risk of it coming back after surgery for the cysts on the ovaries the data is good that going on the birth control pill reduces the type of cyst to coming back but for more diffused endometriosis the studies are mixed.

18:19:26 We don't have a great answer for how not to make it not come back and has it come back is an important question and unless there's something obvious showing up on imaging, you're really sort of left trying to figure out if there's something else causing pain like spasm of the pelvic floor muscles or is it another disease, and that's tricky and most

endometriosis excision surgeons only see patients for surgery there's a void where do they go afterwards they're not sure who to see if they need mor

18:19:57 That's why I put together this whole team is to try to answer that question, but we still don't know when patients have surgery they feel better for a couple of years then start having pain again.

18:20:10 There's no clear answer for what to do in that situation.

18:20:12 >> Thank you for that.

18:20:13 Thank you for being here and your question and I invite you to come into this field and help us answer these questions.

18:20:21 >> Thank you so much everyone.

18:20:22 We're going to close this part of the Q&A, but I do hope you are able to stay around for a little while and connect with Shannon and connect with others in this room.

18:20:31 I think maybe just one last question to you, Shannon, a key takeaway for me I won't dance moderately I'll dance vigorously I have to learn square-dancing, but what would you leave us all with in terms of just final thoughts and final words as we wrap?

18:20:48 >> Oh, wow, okay.

18:20:50 Thank you.

18:20:50 First of all, thank you everyone for being here.

18:20:52 The fact that you're here and part of and witnessing this and part of this conversation is part of the solution.

18:21:00 It's part of the answer about how we move forward and seeing all of your faces and your engagement gives me hope.

18:21:07 That's what gives me hope and optimism as we move forward.

18:21:13 So I would say if you have endometriosis and you're struggling, there are answers.

18:21:19 There are providers who can help you.

18:21:23 And that's one of the hardest things, I think, is when you feel like you are going through something and you don't have someone to help you and you do feel alone.

18:21:34 So that's what more than anything I want to keep it there and say that you're not alone; you can find someone who can help you.

18:21:43 You can get your life back.

18:21:45 And you can have a fulfilling life with endometriosis.

18:21:48 It's about community.

18:21:50 Plugging into that community and finding a healthcare provider or team of healthcare providers who can help you and that's where I'd like to leave it.

18:22:00 >> Thank you so, so much.

18:22:02 And with that I'll hand back to Deborah for some final remarks.

18:22:06 >> Yeah, thank you.

18:22:07 Thank you, both.

18:22:08 This was a testament to the power of storytelling and how it can shift our perspectives and inspire us all to take action.

18:22:15 I hope you all leave today thinking about how you can get involved.

18:22:19 Sounds like many of you already are.

18:22:21 We'd love to get your feedback on the program tonight.

18:22:23 So there's a QR Code on the screen.

18:22:27 It's a very quick survey, very helpful for us as we continue to think about how we can improve our programs.

18:22:34 There's also a hard copy that my staff and colleagues are handing out.

18:22:40 If you would rather do it with a hard copy feel free if you have any other questions we'll be here for another half hour there might be food and drinks in the back.

18:22:50 I'm not sure, but feel free to stay and hang out a little bit.

18:22:56 I'm Deborah.

18:23:00 And if you have any questions about our programs I'm happy to address them.

18:23:05 We have a slide to thank our partners who helped get the word out about our event we partner with our alumni association and Kanona at the University of Washington which I think is here with us this evening.

18:23:19 So thank you all.