

[Music]

[Audience background noise]

[Chancellor Biddy Martin:] Good evening. Good evening. Welcome.

[Laughter]

You're so sweet. Welcome to everybody. I'm so glad that you've all come here instead of going to see Bob Dylan at the Overture Center.

[Laughter]

You made the right decision.

[Laughter]

You've come for an evening with Rebecca Skloot who is the author of the bestseller "The Immortal Life of Henrietta Lacks." So give me a big hearty Wisconsin welcome.

[Applause]

It's simply fantastic to see so many people come out to discuss a book, and this book in particular. This is the second year, as you know, of the Go Big Read Program and tonight's event is the highlight in our first semester series of events. The program is off to a great start; 5000 students received a copy of the book at Convocation. The book is being used in more than 80 courses, in everything from African American Studies and History to Plant Pathology and Sociology. It's being used widely in the Health Sciences. The Interprofessional Health Education Committee organized 47 one hour discussion sessions on the book. These have been led and are being led by staff and faculty and about 1000 Health Sciences students have taken part in these discussions in Science and Society, Race and Culture and Research Ethics. And I congratulate the administrations and also the faculty, the staff and the students in the Health Sciences for taking this on in the way that you have. Thank you very much.

[Applause]

As always, I want to thank the incredible Ken Frazier, the Director of the University Libraries who took on this project from the beginning.

[Applause]

We have a great steering committee for the project and that is led by Sarah McDaniel who has done a fabulous job again this year. Thank you Sarah.

[Applause]

Rebecca Skloot is a science writer whose work has appeared in the *New York Times Magazine*, the *Oprah Magazine*, *Discover*, *Science* and many other outlets. She's the guest editor of "The Best American Science Writing 2011." She's a contributing editor at *Popular Science* magazine. She has worked as a correspondent for WNYC's RadioLab and PBS's NOVA scienceNOW. *The Immortal Life of Henrietta Lacks* is her first book. It took her 10 years to do the work for this book and it instantly became a *New York Times* bestseller. That almost never happens. I think we should congratulate her on that incredible achievement.

[Applause]

The book was named a Barnes & Noble "Discover Great New Writers" pick for spring 2010. It's received widespread acclaim, as I'm sure most of you know, with reviews everywhere; *The New Yorker*, *The Washington Post*, *Science*. She's appeared on numerous TV shows and I watched her on the Colbert Report where I thought she did a great job with Stephen Colbert and that's not easy. (Laughter) The book is now being made into an HBO movie produced by Oprah Winfrey and Alan Ball. It's also been named for two book awards, finalist for two book awards; The Wellcome Trust Book Prize and The American Association for the Advancement of Science's Award for Excellence in Science Books. Rebecca Skloot, in addition to everything else she's done, has launched the Henrietta Lacks Foundation, a nonprofit organization that will, among other things, provide financial assistance in the form of scholarships to the descendants of Henrietta Lacks.

[Applause]

That's great.

[Applause]

The Foundation will also work to provide the Lacks family with help in covering the cost of health insurance, giving those who benefited from HeLa cells, including scientists, universities, corporations, and every single one of us a way to show thanks to Henrietta Lacks and her family. We congratulate her for doing that.

[Applause]

Let me just say one word about format, Rebecca will speak and then I have a list of questions that you all have contributed by way of the website, and I will ask as many of those questions as we have time to cover. But before that, it's my great pleasure and honor to welcome Rebecca Skloot.

[Applause]

[Rebecca Skloot:] Thank you. I'm really so excited to be here and I'm very deeply honored that you all chose to be here watching me speak instead of going and seeing Bob Dylan.

[Laughter]

And when I heard he was playing tonight, I was like; wow that's pretty stiff competition! When I walked in here initially, I was like; I'm going to have to resist the temptation to do a wave in here. This is a great room to be speaking in. I have to say, before I start talking about the book, how deeply honored I am that the book was chosen for the Big Read's program. There are a lot of writers who spend a decade or more in their offices by themselves working on a book that deserves incredibly wide readership. I know a lot of writers that have written great books that just never really made it out to the public for one reason or another. And not a day goes by that I don't feel incredibly lucky that mine is actually being read by large numbers of people, particularly students, you know the future scientists, the future lawyers, the future everythings the future patients, people who really, I think, need to hear this story. So, thank you very much for having me here and for reading the book.

I know a lot of you have actually read the book but that a lot of you haven't. And so, one of the things I'm going to do tonight is a combination of reading and talking to hopefully give an overview of the story for the people who haven't read it and a bit of a refresher, I guess, for those who have, and then also work in some answers to frequently asked questions that people who have read the book often have. So, I'm going to talk and do a bit of an overview and then we'll get to your questions, which I'm very excited about.

So, one of the things I want to do before I actually start reading from the beginning of the book is to just start with a definition of the term creative nonfiction, which is the kind of writing that I do. It's sort of an unfortunate name because it confuses a lot of people. Often when I talk about creative nonfiction, people think that it means the kind of nonfiction where you're creative with the facts, like maybe you make things up; and that's not the case. So creative nonfiction, there are a lot of different names for the genre, but creative nonfiction is nonfiction writing that is all true and journalistically accurate, reported just like journalism that you read in the newspaper or magazines but that is presented in a way that reads creatively, so it utilizes the tools of fiction like scenes and dialogue and character development and narrative; things that you don't usually see in the newspaper, so creative nonfiction is a very specific genre of nonfiction. Sometimes it confuses people because I do things like recounting dialogue that people said in 1951, when I obviously wasn't in the room. So often people think, well you sort of fudge those things a little bit, but in fact you don't. Part of the work of writing creative nonfiction is going back to, you know, written records, medical records, archives, diaries, using a lot of photo records and interviews. I was very lucky in writing this book that a lot of people who were involved in the story were still alive when I started. Ten years ago they were in their 80's and as I was researching the book a lot of them were dying and a lot of this history was sort of vanishing as I was doing my work. But, I was very fortunate to be able to interview a lot of people who were actually alive during this time.

So, I'm going to start off just by reading from the opening of the book when Henrietta Lacks goes to the hospital for the first time, which is in many ways where this story starts. Before I do, just for those who aren't familiar with the term HeLa cells, it's spelled H-E-L-A and it's an abbreviation for Henrietta's name. It's H-E for Henrietta and L-A for Lacks. And if, as I'm reading, it seems like I'm jumping around at all, it's because I am. These are condensed scenes that I'm going to read.

On January 29<sup>th</sup>, 1951 David Lacks sat behind the wheel of his old Buick watching the rainfall. He was parked under a towering oak tree outside Johns Hopkins Hospital with three of his children, two still in diapers, waiting for their mother Henrietta. A few minutes earlier she jumped out of the car, pulled her jacket over her head and scurried into the hospital past the colored bathroom, the only one she was

allowed to use. In the next building under an elegant domed copper roof, a 10½ foot marble statue of Jesus stood; arms spread wide holding court over what was once the main entrance of Hopkins. No one in Henrietta's family ever saw a Hopkins doctor without visiting the Jesus statue, laying flowers at his feet, saying a prayer, and rubbing his big toe for good luck. But that day, Henrietta didn't stop. She went straight to the waiting room of the gynecology clinic, a wide open space empty but for rows of long straight back benches that looked like church pews. "I got a knot on my womb," she told the receptionist. "The doctor needs to have a look."

The day before Henrietta went to the bathroom and found blood spotting her underwear. She filled her bathtub, lowered herself into the warm water and spread her legs. With the door closed to her children, husband, and cousins, Henrietta slid a finger inside herself and rubbed it across her cervix until she found what she somehow knew she'd find, a hard lump deep inside as though someone had lodged a marble just to the left of the opening to her womb. Henrietta climbed out of the bathtub, dried herself off and dressed. Then she told her husband, "You better take me to the doctor. I'm bleedin' and it ain't my time."

Hopkins was one of the top hospitals in the country. It was built in 1889 as a charity hospital for the sick and poor, and it covered more than a dozen acres where a cemetery and insane asylum once sat in East Baltimore. The public wards at Hopkins were filled with patients, most of them black and unable to pay their medical bills. David drove Henrietta nearly 20 miles to get there, not because they preferred it but because it was the only major hospital for miles that treated black patients. This was era of Jim Crow. When black people showed up at white only hospitals, the staff was likely to send them away, even if it meant they might die in the parking lot. Even Hopkins, which did treat black patients, segregated them in colored wards and had colored only fountains.

So when the nurse called Henrietta from the waiting room, she led her through a single door to a colored only exam room, one in a long row of rooms divided by clear glass walls that let nurses see from one to the next. Henrietta undressed, wrapped herself in a starched white hospital gown and laid down on a wooden exam table waiting for Howard Jones, the gynecologist on duty. Jones was thin and graying. His deep voice softened by a faint southern accent.

He listened as Henrietta told him about the pain, the blood. She lay back on the table, feet pressed in stirrups as she stared at the ceiling, and sure enough Jones found a lump exactly where she said he would. He described it as an eroded hard mass about the size of a nickel. He'd seen easily a thousand cervical cancer lesions, but never anything like this, shiny and "purple, like grape Jello" he wrote later, and so delicate that it bled at the slightest touch. Jones cut a small sample and sent it to the pathology lab down the hall for diagnosis and then told Henrietta to go home.

Soon after he dictated notes about Henrietta. "Her history is interesting in that she had a term delivery of her fifth child here at this hospital September 19<sup>th</sup>, 1930" (sorry 1950), he said. No note is made in the history at that time or at the six weeks return visit that there is any abnormality of the cervix, yet here she was just three months later with a full fledged tumor. Either her doctors had missed it during her last exams, which seemed impossible, or it had grown at a terrifying rate.

So, Henrietta went home from the hospital and a few days later she got a phone call from Howard Jones telling her that the biopsy had come back as cervical cancer. She was 30 years old. So he called her

back into the clinic for treatment, which the standard treatment of the day was radium therapy. They would take tubes of radioactive material and sew those to the surface of the cervix and essentially leave them there for a few days to burn off the cancer. They did this under anesthesia.

So, Henrietta went back to the hospital and went under anesthetic and without telling her before applying the treatment to her tumor, her doctor just cut a little piece of her tumor and put it in a dish. He sent that down the hall to George Gey, who was the head of Tissue Culture Research at Hopkins. George Gey and many other scientists had been trying to grow human cells for decades and it had never worked. They would sometimes survive for a day or two but they would all eventually die. And no one knows exactly why but Henrietta's cells just never died.

So a few points I want to make, that people often ask about related to that; the first is was it standard for doctors to take samples from people without their consent? The answer is yes, absolutely. So in 1951 we didn't have the concept of informed consent that we have today. The term didn't exist. So, they would have never felt like they needed to get informed consent for really any research on a human subject, let alone research on a little bit of her, you know a little piece of her tissue that they would use in research. At the time we didn't even know what DNA was. So scientists had no idea that some day they would be able to look inside these cells and learn about Henrietta or her kids. They had no idea that these cells might some day be worth money. For them they were trying to grow really any cells they could get their hands on. They were taking samples basically from anyone who went into most research hospitals. In some ways that's still happening today, which we'll talk about later. And what they were hoping is that they could use cells, you know, for lots of different research projects.

The other question I want to address in there is why her cells grew. This is one of the most common questions I get. So, ok it was a mystery in 1951 why her cells grew. We must know now, right? We actually really don't. It's sort of a fascinating part of the story in that her cells grew and then scientists just ran with them and started doing research. They never really looked back, so no one ever stopped to wonder why her cells grew when all these other cells died. So we still really don't have the answer to that question. We know a few things about her cells. One of them being is that she had HPV, the virus that causes cervical cancer, so that is what caused her cancer in the first place. She had multiple copies of it so some scientists think; well maybe there was something about her DNA that interacted with the viral DNA in a special way. She also had syphilis which can weaken your immune system and cause cancer cells to grow aggressively, but so did a lot of other people in the 50's, so that doesn't really explain it either. At this point it's still a mystery.

I talk in front of groups of scientists often and this question comes up. There is often this moment where they look at each other and they're like, "we don't know that? Why don't we know that? We know everything else about HeLa cells and we can't actually answer that question?" There are a group of scientists in California who are trying to get me a better answer to that question. We'll see what happens.

But one of the things we know about Henrietta's cells is that one of the things that made them so valuable for science is that they grew with this incredible intensity. So within 24 hours of her leaving the hospital, her cells were doubling their numbers every 24 hours. There was one dish, then two, then four and then eight. It really quickly took over the lab.

The same thing happened in her body. So the cells, that nickel sized tumor, spread to almost every organ in her body. She died within about 8 months of being diagnosed leaving her 5 kids behind. They didn't ever know these cells had been grown; she never knew. Her kids just sort of went on with their lives, which were pretty difficult lives. They were in poverty in East Baltimore. The cells went on to really revolutionize medicine. So initially George Gey was just sending them out to anyone who would use them in research. He would take a vial to the airport and find a flight attendant or a pilot who was going to wherever he wanted the cells to go and he would say, "will you put this in your pocket and take this to," you know Minneapolis, or India or wherever, which is amazing for anyone who has gone through airport security lately. It's sort of an incredible thought. Then scientists would meet the cells on the other end and then grow them in their lab and then give them to their friends who would give them to their friends. Then pretty soon a factory was set up at the Tuskegee Institute where they began mass producing her cells to the tune of about 6 trillion cells a week and sending those out to laboratories around the world. So the volume of cells that grew from that one little sample is sort of inconceivable. There is one scientist who calculated if you could have saved them all and put them on a scale that by today they would weigh more than 50 million metric tons, which is more than 150 Empire State Buildings. Cells weigh almost nothing, so it's an amazing number of cells.

They were used to do a lot of very important science. They were used to help develop the polio vaccine. They went up in the first space missions to see what would happen to human cells in zero gravity. Her cells were the first ever cloned. Her genes were some of the first ever mapped. We can trace a lot of our most important cancer medications, the HPV vaccine, all sorts of important advances that we rely on today back to research on her cells.

And her family didn't know any of this was happening until the early 70's when 25 years after Henrietta's death some scientists decided to track down her children to do research on them, to get samples from them so they could study her children's DNA to learn more about HeLa cells. So Henrietta's husband had a third grade education. He didn't know what a cell was. He got this phone call one day. They way he understood it was, "we've got your wife, she's alive in a laboratory; we've been doing research on her for the last 25 years and now we have to test your kids to see if they have the cancer that killed her," which wasn't what the scientist said at all but they just didn't know that the family didn't understand. Henrietta's husband initially thought they had her in a cell like a prison cell. That was the only kind of cell he'd ever heard of.

So her family got sucked into this world of research that they really didn't understand. This was particularly traumatizing for her daughter Deborah, who at the time was nearing her 30<sup>th</sup> birthday, and all she knew was that her mother had died around 30 and that she, Deborah, had always lived in fear of her own 30<sup>th</sup> birthday thinking she would probably die as well. So the doctor coming to test the family seemed to make sense in that realm but also pretty soon her family figured out that she wasn't alive; couldn't go visit her like you could before she died, but what it meant to have part of her alive was very unclear for Deborah. She very much believed that her mother's soul was alive in these cells. Scientists would come to the house and she would say things like, "can my mother rest in peace if you're shooting these bits of her up to the moon and injecting them with chemicals; does this somehow hurt her in the afterlife?" The scientists had no idea how to respond to her. She would ask questions like, "can you look in these cells me and tell me what my mother's favorite color was and whether she liked to dance?" At some point one of the researchers gave her medical school genetics textbook and said, "Here read this; this will tell you what you need to know about your mother."

Henrietta's kids were deaf and hard of hearing and they'd gone through most of their education with no one realizing that. They never really learned to read or write very well. They also didn't really learn how to ask questions of people in authority. They just sort of went along with the research and kept giving samples. This went on for many many years. Eventually her sons found out that people were buying and selling these cells. So in addition to all the important research done on them, they were also the first cells ever commercialized. For her family this is a very sore point. To this day, they can't afford health insurance. They are very poor. They would often say, "If our mother's cells were so important to medicine, why can't we go to the doctor? People are buying and selling them, so essentially where's our cut," which is a question that a lot of people are asking.

It really raises issues that we're dealing with today. There are a lot of big questions about who should profit off of research on any biological materials, whether it's scientists or patients or anyone and how do you sort of settle that question? This is something people are still wrestling with today.

I came along in the late 90's. My plan was to write a book about Henrietta. I had no idea what her family had been through. By the time I came along, in addition to the research that was done on her kids, her medical records had been released to the press and published without the family's consent. Some of their medical information had been published. They had had con artists come along trying to steal their mother's medical records. The number of crazy things that had happened to this family was sort of hard to believe. Then I came along and had no idea. All I knew was that there were these amazing cells and that I wanted to know this woman they came from. For the family, I was just one in a long line of people who came to them wanting something from them having to do with these cells, particularly white people, and it had never worked out very well for them.

I want to talk for a second about how I first learned about the cells. This is a question I often get. I learned about the cells when I was 16 in a basic biology class. That story is in the book. My teacher, for reasons that I still don't entirely know, knew her name. So often students hear about these cells in class; "there are these incredible cells that have been alive since the 50's" and that's really usually all you get. For some reason my teacher knew her name and he wrote it in big letters on the board and then said, "She was a black woman." And then that was it. Class was over and he erased the board. I went up to him after and I was like, "What else do we know about her? Who was she? Did she have any kids and what do they think about all this?" He just said, "Sorry, no one knows. If you're curious, do a little research and see if you can find anything. I'll give you a little extra credit if you write up something."

This was in 1988. And at the time, I was planning to be a veterinarian. I had no interest in being a writer, but something about that moment just grabbed me. One question that people often ask me is why? So then you were obsessed with these cells for decades; you spent all of your life working on this book. I think one thing I realized after the book came out and I started talking about this was that I think the reason why that moment grabbed me the way it did is because when I was 16 my father was very sick. He had gotten a viral infection and no one really knew what was wrong with him. But he had gone from being this marathon running super dad kind of guy to just being completely incapacitated. He couldn't really walk. He lost his memory. We just didn't know if he was going to live. It was a very scary time. One of the things he did was enroll in a drug study at the local medical school. My job as a teenager was to drive Dad to the hospital four times a week to get these mysterious infusions. I would do my homework in the middle of this big room where lots of different patients who were that were

involved in research studies. I was just surrounded by the world of research on human subjects and my dad was one of them. You know, there is a lot of fear that comes with that. Are they hurting him? But there is hope; are they going to make him better? In the end we were sort of disappointed because nothing happened. And I was grappling with all those emotions when I ended up in this classroom where I heard about the cells. I really think that's why I latched onto it. I thought I was a kid going through something and my first question was what did her kids think about that? I think I had a connection to her family from pretty early on.

But at the same time I also had this deep connection to the science side of the story because I was already working in veterinarian hospitals and really determined to be a vet and very much a science geek. I was totally into the science of the cells. I would do research on the actual cells in school. I had spent all these years just sort of obsessed with these cells and then I called her family, not knowing any of the rest of the story, and they just said, "Ah, Yeah...no, we're not going to talk to you." I didn't realize why but they had a lot of good reasons to not trust me.

It took about 1½ years to really win their trust and get them to start talking to me for the book. Part of how I did that was essentially by sharing information with them. At that point they still didn't know what a cell was. I said to Deborah in particular at one point, "You know, you can come with me when I'm trying to do my research. I'm not trying to hide anything from you." And so, she does that and the book really traces the story of the HeLa cells and the science and then very much becomes a story of Deborah and it's a story about what happens to a family when you lose a mother and the world gains these incredible cells as a result, and her trying to wrestle with all of that.

I'm going to read one more quick scene and then we're going to open it up for questions. This is from a later section of the book. One of the first things Deborah and I did together was to go into a laboratory at Hopkins so she could see her mother's cells for the first time. And the scientist whose lab we're in is named Christoph. The other person there is Zakariyya, who is Deborah's youngest brother. The only other thing you need to know is there is a mention of a contamination problem in here. This is a part of the story that is sort of amazing and almost sounds like science fiction. At some point in the 60's scientists realized that Henrietta's cells had contaminated hundreds of other cell cultures, so after her cells initially grew scientists started growing lots of other samples and eventually realized they were actually just growing and regrowing HeLa over and over again not really realizing it. A large controversy erupted because of this and this is actually what led scientists to eventually track down her kids. There is a reference to that in here, so that's what that is about.

Christoph the scientist, the way we ended up in his laboratory was that he had read a short article that I had written in a magazine and he had the reaction that I hear from scientists almost every day, which was essentially, "Oh my God! I had no idea. I have been working with these cells my entire career. I use them every day in my lab. I feel like I owe a lot of my professional life to these cells and I never once stopped to wonder where they came from or whether she had given permission or whether she has a family who cared." This is something that often people, when I do the Q&A's, they often think well scientists aren't very happy with the story being out there, right? This is not something that they're particularly proud of. In fact, scientists are very very happy to learn this story. A lot of it is because most scientists learned from very early in their careers that HeLa cells came from a woman named Helen Lane which was a pseudonym that was put out basically to throw journalists off the track of

finding Henrietta's family. Most scientists have been told misinformation about the cells from the beginning. So, they're very happy usually to learn the actual story.

So, this scene is just the first little bit of Deborah and I in this laboratory. Christoph walked toward us through the lobby of his building, smiling, hand outstretched. He was in his mid 30's with perfectly worn denim jeans, a blue plaid shirt and shaggy light brown hair. He shook my hand and Deborah's, then reached for Zakariyya's but Zakariyya didn't move. "Ok," Christoph said looking at Deborah, "It must be pretty hard for you to come into a lab at Hopkins after what you've been through. I'm really glad to see you here." Christoph threw open the door to his lab with a sweeping tah dah motion and waved us inside. "This is where we keep all of the cells" he yelled over a deafening mechanical hum that made Deborah's and Zakariyya's hearing aids squeal. Zakariyya's hand shot up and tore his from his ear. Deborah adjusted the volume on hers, then walked past Christoph into a room filled wall-to-wall with white freezers stacked one on top of the other rumbling like a sea of washing machines in an industrial laundry mat. She shot me a wide-eyed terrified look. Christoph pulled the handle of a white floor-to-ceiling freezer and it opened with a hiss releasing a cloud of steam into the room. Deborah screamed and jumped behind Zakariyya who stood expressionless hands in his pockets. "Don't worry" Christoph yelled. "It's not dangerous. It's just cold. They're minus20 like your freezers at home. They're minus80. That's why when I open them, smoke comes out."

He motioned for Deborah to come closer. "It's all full of her cells" he said. Deborah loosened her grip on Zakariyya and inched forward until the icy breeze hit her face and she stood staring at thousands of inch tall plastic vials filled with red liquid. "Oh God!" she gasped. "I can't believe all that's my mother." Christoph reached into the freezer, took out a vial and pointed to the letters HeLa written on its side. "There are millions and millions of her cells in there" he said, "maybe billions. You can keep them here forever; 50 years, 100 years, even more. Then you just thaw them out and they grow." He rocked the vial of HeLa cells back and forth in his hand as he started talking about how careful you have to be when you handle them. "We have an extra room just for the cells," he said. "That's important because you don't want HeLa cells to contaminate other cultures in a lab." He explained how the HeLa contamination problem happened, and then said, "Her cells caused millions of dollars in damage. Seems like a bit of poetic justice, doesn't it?" "Oh, my mother was just getting back at scientists for keeping all them secrets from the family," Deborah said. "You don't mess with Henrietta. She'll seek HeLa on your ass!"

[Laughter]

Christoph reached into the freezer behind him, grabbed another vial of HeLa cells and held it out to Deborah, his eyes soft. She stood stunned for a moment, staring into his outstretched hand, then grabbed the vial and began rubbing it fast between her palms like she was warming herself in winter. "She's cold," Deborah said cupping her hands and blowing onto the vial. Christoph motioned for us to follow him to the incubator where he warmed the cells, but Deborah didn't move. As Zakariyya and Christoph walked away, she raised the vial and touched it to her lips. "You're famous," she whispered, "Just nobody knows it."

Ok, I'm going to stop there, and take questions. Thank you.

[Applause]

[Chancellor Martin:] Thank you very much. So while I sort out these questions, Christoph has a strong sense that Hopkins has a responsibility to the Lacks family, at least as you report it. You don't really take a stand on that, do you?

[Rebecca Skloot:] No, I don't. Can everyone hear the questions? In the back, are you ok? No I don't take a stand. I felt it was very important in this book for me to convey the various sides of the story and put them out there to the world and essentially say: you know "discuss." There are a lot of issues that are raised in the book: everything from access to education, race and class in health care, and this big question of does someone owe something to the Lacks family? Does science? And actually, Christoph, he really felt like science owed something to the family. He didn't have a particular, and I think he was very happy to be at Hopkins and to be able to offer them something. I think he felt like Hopkins, in a sense, owed them information. He was just so astonished that when he found out that still, at that point this was decades after the family first learned about the cells. They'd been asking questions of people at Hopkins for years. It was just dumbfounding to him that no one had tried to answer those questions. So, I think he felt like they owed the family information. Christoph definitely was of the mind that, you know, if people are profiting off these things, why shouldn't the family profit?

One of the things that is interesting about this story is that so many; everybody has their own take on that issue. And I felt like my job was to put it out there to get people to sort of think about what is your take on that issue? Do you think that science owes the family money? Do you think that it's sort of everyone's duty to donate samples to science to move science forward because everyone, you know, essentially benefits. That's often been the thinking. Though, of course, it complicates things in the United States when not everyone does actually benefit because we don't all have access to health care.

So I tried to put all these things out there to start a discussion. I think it was very important to me to not demonize the scientists. I often hear from readers that they flip-flop. The book is structured in this braided way where you jump back and forth in time and between the Lacks family story and the scientists, and I often hear from readers who say, "I was reading the science section and I was like yeah science! Science is awesome! This is all great!" Then I got to the family section and I was like, "Boo science! That was really bad what they did to the family." That tells me; that is what I wanted really. You cannot look at this story and say that this science is bad, we don't want this to happen and it shouldn't have happened. I wanted to challenge that without putting my opinions in there and saying, "This is what I think you should think" because that doesn't do much for anybody.

[Chancellor Martin:] That's very interesting. I just wonder how many people in the audience experienced the book as having a point-of-view, even though our author is saying she didn't intend to represent one side or one point of view. Did anybody experience it as if it had a point of view? Yeah.

[Rebecca Skloot:] Yeah, I think people often do. I often hear from people who tell me what my opinion was in the book. Often I hear very different opinions of what I said in the book. Sometimes people will stand up and say, "You were very clearly arguing that the family deserves money." Then other people who stood up would say, "I'm very glad that you weren't arguing that the family needs money or should get money from this." I think a lot of those people come to it with their own interpretation of what I'm saying. The fact that the family story is so present in the book for some people is like, "Well then obviously she was leaning in that direction." I think it depends on the reader really.

[Chancellor Martin:] Ok, I'm going to go to questions from our students. There are some great questions from our students. First from some U.S. historians, some grad students, in a seminar including 21 students who came up with the following questions: Your choice to include yourself in the narrative allows your readers to engage with the reality of relationships that exist between researchers and subjects. In our graduate history seminar we discussed some of the benefits of this technique, especially its transparency. We also discussed some of the issues that may emerge when a white researcher becomes central to a story that deals so heavily with issues of racial and class inequality in the medical field. Take us through your decision to include yourself in the telling of the story. What did you see as the potential risks and rewards of this course of action and what kinds of conversations did you have with the Lacks family and your editors about this narrative choice? That's a lot of questions, but I know you've read them in advance. But they are wonderful questions. Are any of the 21 students here who formulated those questions?

[Hands in audience raised]

Yes! Well you did a great job. So go ahead.

[Rebecca Skloot:] Yeah, it's a great question. Initially coming to this story, I had no interest in being in the book at all. I teach writing and I harp on my students all the time and tell them "stop inserting yourself into other people's stories," which is something that young writers do all the time, because in some ways it's easier to write in the first person than it is to take yourself out completely and to paint a picture without being able to say "oh, I saw this and I saw that." So I'm very anti-writers sticking themselves into people's stories as a rule. So I went into this thinking this was very much a journalistic endeavor and there was no place for me in the story. Then as Deborah and I started traveling together and going out and she would come with me occasionally when I did some of my research, we ended up in situations that neither one of us, I think, could have really anticipated the impact that it would have on her and how dangerous, in some cases, it was. So there were some cases, at one point there is a whole story line about Deborah's sister who died when she was 15, when the sister was 15. Deborah never knew her. Her sister had been institutionalized at this place that was called The Home for Crazy Negroes. She was there because she was epileptic and Henrietta wasn't able to take care of her at a certain point. Deborah had always thought something bad happened to her sister there; she didn't know what. She very much wanted to find it. It was on the same trip actually that started with seeing the cells. Just that moment of seeing the cells for the first time was so exciting for Deborah. It was sort of stressful to be in Hopkins but also exciting. There were so many emotions tied up in that.

We went straight from there to this mental institution where we found some of the most horrendous information about her sister, more than I could have possibly imagined we would find. It turns out that her sister was used in research without the family's consent having nothing to do with HeLa cells, that was really pretty brutal stuff. And this institution where her sister was, being a black person in the South during the Jim Crow era was a very difficult and painful thing. Being a young black girl in a mental institution in the South during that era was something that few people can even imagine how horrible that was. Deborah was sitting next to me when I learned this, when I found a lot of this information. She very much wanted to be. There were a few points where I said, "Are you sure you want to? I can look at this stuff and show it to you later. You sure you want to be here?" She was absolutely determined to learn this information. I couldn't have really stopped her at that point if I had

tried, but it was traumatizing. She really had very dangerous reactions to it, to the point where she almost had an actual stroke.

And that sequence of events, which those of you who read the book know the various amazing and crazy things that follow. I would come home from these research trips with stories like this and there were faith healings and something like an exorcism where someone exorcises the cells from Deborah and tries to put them into me. I would come home with these stories and my editor or my friends would say, "You have to put that in the book. That is so clearly part of the story because what they're going through it shows really the effects that all these years' worth of issues having worked and researched on them and various things affected them." I would say, "No, no, no; it's not my story, it's their story." At a certain point, really when Deborah's health was in jeopardy I realized that it wasn't that I was inserting myself into their story; it was that I had become a character in their story because I was another person who had come along wanting something from them and had put Deborah in situations where she was having very real effects. And some of them were really good and some of them were really bad.

The word transparency came up in that question, and that is the thing that drove me to do it. I realized at a certain point that it would be dishonest to leave myself out. I talk about other journalists who had had effects on the family, and not putting my own effects in there would have been a pretty glaring omission. Interestingly, in terms of my conversations with the family about it and with my editors, basically everybody involved was pushing me to do this, including Deborah, and I was the one who was resisting the longest. There at the moment where the exorcism happened; that was the moment where I went, "Oh, geez. Alright, I have no choice obviously but to be in the book." Deborah always said that was the moment, that was Henrietta hitting me over the head with a frying pan to tell me that I had to be in the book. She was like, "Well you wouldn't listen before." For Deborah she felt like that was an important part of the story.

The race thing, there are a lot of questions all tied up in one, in terms of being a white writer and coming to this, obviously that's a very important, you know, issue in the book. And in the beginning, the fact that I was a white writer coming to them, it was like how was I different from any other people who had come along wanting something from them and maybe someday potentially benefiting from it, profiting from it? We wrestled with a lot of that, Deborah and I and the rest of the family. That was part of them coming to trust me, was learning about my intentions and very early on I told them this was something I had thought about and I didn't want to be someone who some day would profit off of the book without sharing some of that with them essentially because of what they had been through. So I told them very early on about these plans to set-up this foundation and that some of the proceeds of the book would go in there and various other things. The movie rights I worked very hard to make sure that the family was getting money out of that. Various and many different things, basically anything having to do with the book, some of that goes into this foundation. Some of the movie is going directly to them.

That was part of the discussion because with the family it can't not be. That really wasn't the core of what got them to trust me. That was sort of one of the many things. What's interesting is Deborah really believed that; she would get really frustrated when people would make the story into one about race. Obviously you can't take race out of the story. You know, there's a long history of African Americans being used in research, minorities of all kinds, without consent and this is part of that story. But for Deborah she was like this is a story about class, this is a story about everyone. She actually came to really believe that it was important that I was white. We would have these long conversations about

that. She often said that she really believed that I had better access to the story and that I would in some ways be able to tell a story that a black reporter wouldn't. Which I fought against that. I said, "No, no. We're beyond that. That's not true." But I think in some ways she was right. These scientists who I went to to talk to them about the research that was done on the kids they were a generation of scientists that grew up, they were doctors who grew up with segregation. They did not interact with black people, really, period. That was part of why they didn't talk to her family in the 70's. I was able to get them to talk to me for long periods of time. Deborah would say, "I know you don't want to think about this, but they would not do that if you were black." So we had a lot of interesting discussions about that, the significance of me being white. But for Deborah she always felt like it was an important part of the story.

[Chancellor Martin:] The same students ask about the ethics of ethnography, which I think is really part of the question you were discussing. Can you all hear me ok? Thank you. And how you made ethical calculations as you changed from writing about science to historical and biographical foci. Did you feel your ethics or the thoroughness of your research, either one, was ever compromised by those decisions; to put yourself in the narrative and/or to change methods as you went?

[Rebecca Skloot:] Yeah, I didn't really change methods as I went. From the beginning I was really open with the family. I felt it was incredibly important to, you know here I am writing a book about informed consent and getting people's consent for things, so obviously I had thought a lot about and thought it was very important to get their consent and that it be informed. So we talked a lot in the very early days and throughout the project about what it means to be written about. I laid out all the different scenarios. It could be that I spend; I mean I certainly didn't imagine it was be quite as many years as I spent but I said I could be working on this forever and I may never get a publisher. You could be spending all this time with me and it may go nowhere or I may get a publisher and maybe no one is going to read it or maybe like everyone is going to read it and then they're all going to want to call you at home and all sorts of new reporters are going to want to call you and suddenly you're going to be in the spotlight again. How do you want to deal with that? Do you want to unlist your phone number? Do you want to get e-mail addresses? So we talked about every range of what it meant to be written about, as much as I could. I also felt like it was important to be constantly reminding them that I was a reporter, particularly Deborah because our relationship was...we spent a lot of time together. We did things that traditionally journalists and subjects don't often do together like traveling and the ways that we did. I always had my notebook out. I always had my tape recorder out. In the book she calls me her reporter. This is one of her nicknames for me. I think that was because I was constantly reminding her that I was a reporter and that this was a piece of ethnography, essentially a journalistic piece. I did think about it constantly and it really didn't change much throughout the process. I approached the scientists in the same way. I had the same conversations with them.

[Chancellor Martin:] A number of students, or community members, asked a question about the long history of racial and economic injustice that you documented. I guess there are a number of questions related to that. One is was it your goal to expose it or to suggest particular remedies, not just in this case but overall? Maybe I would add to that since you're talking in such an interesting way about the impact of what you were doing on Deborah and the family. I would love to know what impact it had on your view of these issues.

[Rebecca Skloot:] Yeah. When I started working on the book, I knew about this history of mistrust between African Americans and science and the reasons why it existed. I think some of that actually came from when I was very young, my father's side of the family was Jewish. I grew up hearing stories about the Holocaust. I think, now that I look back on it, it may be a little odd that when I was 10 my favorite book was *The Painted Bird* by Jerzy Kosinski and *Night* by Elie Wiesel. I was sort of really consumed, everything I could, about the Holocaust.

One of the things that I couldn't get enough of was reading these stories about the research that scientists did on Jews in the concentration camps, which led me to learn about eugenics in the United States, you know, which was in some ways our version of that. It was sort of gave Hitler some of his ideas. Which, of course, led me to learn about the research done on slaves without their consent. So from a very young age, I was interested in this and reading books about the history of research on African Americans and other people in the United States. So, I knew going in about that history. And I think informed, obviously, some of my questions. One of my big questions was so this is another Tuskegee, which is a question I often hear. So the Tuskegee syphilis studies, as probably a lot of you know, have often been held up as some of the most unethical research done in this country where hundreds of African American men with syphilis were essentially studied to watch how syphilis kills you from infection to death without being offered treatment. This is only one of many stories like it in the history of African Americans, but it's the most famous one.

So, one of my questions was, is this another Tuskegee? I did want to uncover that but not; my goal was to really find out what role did race actually play in this story? Not so much to put it out and say this is another Tuskegee, this is another one of these stories but to just really find out. Initially when I first started reading about the HeLa cells, a lot of the stories that I was reading sort of framed it as this racist white scientist who'd stole these cells from this black woman because he knew they would be valuable and maybe didn't treat her cancer in order for the cells to grow. None of that is actually true. A lot of my goal was to actually find out, ok what role did race play in this and what role didn't it play in this. What can we learn about building trust between minorities and the scientific research institution through telling stories like this?

And I do think, I end up talking about this a lot. I travel all the time and I talk about the book and a lot of what ends up coming up is this is still an enormous problem in this country and really all over the world, this mistrust. Scientists know this. They know we really need to bridge this gap of trust because it's very dangerous for everyone you know for the minorities and the people who have very good reasons to not trust doctors. They don't want to go to the doctor and they will not participate in research. They are under-represented in studies and this is a big problem for them health-wise. Scientists are over here saying, "Ok, We have to figure out how to get them to come over here and be part of medicine." What they don't often understand is why that gap exists. There have obviously been other books that have documented the entire history. There is a great book called *Medical Apartheid* that is about the history of research on African Americans. Most scientists actually don't really know that history.

I recently had a woman who is an AIDS researcher stand up at one of my events and say, "This is something I deal with all the time. My patients, if I have black patients, they will not participate in the research. They won't let me do anything to them because they're convinced I'm trying to inject them with AIDS." She said, "I always thought they were crazy, that this was a conspiracy theory. Like, I

now understand where that comes from. I can now say to them, I understand where that comes from and we can talk about that and I can say this is how what I'm doing is different from this other stuff." I think one of my goals was actually bridge that gap a little bit and to help hopefully move the discussion beyond just another case of mistrust but to say what do we do about that?

[Chancellor Martin:] Interesting. You opened the book with a quote from Elie Wiesel about the importance of not treating any human being only as an abstraction. And I had some undergraduate students at my home the other night to talk about the book. A couple of them are pre-med and they asked the following question, though they certainly agree that treating any human being as an abstraction is wrong and horrifying or leads to horrifying things. The ability to distance one's self as a scientist or a physician from what you tell as a set of human stories is also important, or they at least raise the question how they are meant to manage those dual necessities. I wonder what commentary you would offer them.

[Rebecca Skloot:] Yeah, it's an important issue. The Elie Wiesel quote is "We must not see any person as an abstraction. Instead we must see in every person a universe with its own secrets, with its own treasures, with its own source of anguish and with some measure of triumph." My goal with this book was to essentially put a face on human biological materials, right. So much of the future of medicine depends on research on these tissues that are in laboratories that nobody really thinks about where they came from. There is actually a person behind every single one. I think it's actually very important to realize that and to think about that. At the same time, for me this quote was actually just as much about the scientists because scientists are often seen as these, especially for people who don't know science, they're just these people out there doing these things that are sometimes scary. I felt like it was very important to put a human face on them and to show their anguish, their triumph and to show the ways in that they were just human beings doing this work.

Part of why we get to this point of abstraction is because it is actually essential for scientists, in a sense, to be able to distance themselves. Doctors; you do not want a doctor who is totally invested in you and your life doing surgery on you because if you start to crash on the table, that doctor is going to panic. Suddenly there would be all these emotions and obviously the doctor is going to panic either way but this is why doctors people don't do surgery on their family members or people who they know who are close to them. It really does require some sort of distance from your subjects. But that distance can go too far. And so, part of what this book I think is about is looking at that distance and getting people to think about, "Do we really need to be that distanced from those cells to point where we don't actually remember that they're from a person and we don't really think about them as being attached to a family or anything?"

Often I get the question of, "Ok, what do we do about this?" I actually think that just hearing the stories, what I hear from medical students and various scientists is just hearing the stories and starting to think about cells in a slightly different way, that actually, that goes a long way. It's just being reminded that you can't distance yourself too far, that part of the job of being a scientist is actually finding a balance of being sort of you know distanced enough so you can do your work but not so much that you forget who you're working on.

[Chancellor Martin:] Interesting. On a different set of questions, here's one from another group of students. Do you think citizens are going to assume a larger role in how human tissue is used in the lab and in the marketplace? What is your prediction about tissue ownership?

[Rebecca Skloot:] Yeah, that's a good question. It's funny. Where we are now in terms of the ethics of all this stuff, what was done with the Lacks family in the 70's, science coming to them and taking samples just for research with their names attached to them, that would be illegal today. That would violate federal law. That federal law sort of already existed in the 70's when this happened to the family. That you can't do anymore without consent.

Where it gets trickier is if your samples are taken for other reasons; biopsies, routine blood work. As long as your name is removed from them, those are often stored and used for research. And that doesn't require consent. So there is a lot of discussion right now about that. Ok, what do we do? This is sort of inconsistency essentially in tissue research. This has been a debate that has been going on for a long time, especially now when we're at a time when the idea of taking a person's name off of a sample and that making it anonymous and no longer attached to the person doesn't really hold up. Because your DNA is in there. There have been plenty of cases where people have been tracked down using their cells. The anonymization doesn't really hold that much water now. Fifty years from now, what is that going to mean? So there is a lot of discussion saying we probably should be getting consent for research on all human tissues. I don't actually hear much resistance to that. I talk to these groups of people all the time; bioethicists and lawyers and scientists. Everyone seems to agree that it's pretty clear, people want to know the stuff that's going on. How do you do that without inhibiting science is the big question? What is this going to look like? How are we going to do this? The question of whether people will have more of a role, I actually don't think they really want one. It's interesting. People want to know. There have been lawsuits, many lawsuits, over tissues used without people's consent. I've talked to people involved in all the cases. The Lacks family says this, "If they had just asked us, we would have said yes." Really people know it is important to donate for science and this research does need to be done. They just don't want to find out after the fact, particularly when money is involved. I actually think there is this big daunting from various groups saying, "If we start to acquire consent for all tissue research, science is going to come to a screeching halt because people are going to start demanding money and people are going to want to say exactly how they want their tissues used. But that is probably not actually the case. Most people don't really want to have that kind of a role. They just want to be asked.

And it comes back to this issue of trust. Really everybody wants that in a sense, I think. When cases come up, when people find out oh this tissue was taken; just a couple weeks ago a family in New York found out that their son's brain was taken without their consent and used in all sorts of research. When those things hit the press, it freaks people out. It makes this problem of trust worse. It does seem like we're heading in a place where uniform consent is probably going to be required for tissue research. And that some people will say no, but not very many. There have been studies that have looked at if we tell everyone we're going to take your tissues, we're going to store them, we may sell them but you're not going to get any money, will you say yes? There is something like 4% of people said they would say no. Usually that's for religious reasons. There are definitely religions out there that say you need all your parts intact when you go into the afterlife. If some of you is living on afterwards, you're stuck in this sort of in between place.

I do think that is actually where we're going. I think the concern of how people are going to respond to that is a little over blown. I don't think people care that much, they just want to know.

[Laughter]

[Chancellor Martin:] There was one question that wanted to focus on your view of informed consent and whether it changed over the course of your research and the writing of the book? What did it mean to you when you started and what does informed consent mean to you now?

[Rebecca Skloot:] I don't think it did really did change that much. I think the question of what does it mean to get informed consent for research on tissues, that's a very hard one to answer, in part because we don't know what tissue research is going to look like in 50 years. You take a sample and you put it in a bio bank and you get permission to do something. What does it mean for someone to be informed when maybe 50 years from now we're going to be able to learn something that that person might not have wanted. I think you can actually tell people that, they get that. People who aren't comfortable with that uncertainty will say so. But I think it made me appreciate how complex informed actually is, the informed part of the consent and particularly the role that education plays in that and various other issues. One of the things that very few people talk about is if you're deaf or hard of hearing and you're going to the doctor and they don't realize it; I mean that is another level of lack of access that they had. Not only did they not have the education to really understand the science. They couldn't hear a lot of what was going on.

I don't think it changed my idea of what my understanding of informed consent as much as it made me think a lot about where education, access to education, plays a role in it. If you go to the doctor and you don't speak English, you speak Spanish or French, you're going to get a translator in the room. Someone is going to get you the translator. If you don't speak science, they're not going to get the science translator because that person doesn't exist. I think when you talk about informed consent for any research, you probably need to be talking about that.

[Chancellor Martin:] Here's an interesting question. Was the promise of cell culture overblown and does the trumpeting of new discoveries extend to other medical breakthroughs like stem cells, monoclonal antibodies and gene therapy?

[Rebecca Skloot:] Yeah the promise of cell culture, especially when people were first starting to try and grow cells, was way overblown. Not only was it going to change the world and cure all diseases, it was actually going to make it so people could live forever. The overblownness of that, there is a whole chapter essentially in the book that talks about that. And you know, it does happen with a lot of advances. I honestly think that is an issue with the media more than anything else. You know, this is something that we talk about a lot as science writers. How do you write about scientific advances in a way that actually conveys the realistic hope? It's like conveying some of the hope without being "Whoa! This is like Our Savior has arrived!" Which sometimes tends to happen. I do think that happens a lot with science.

[Chancellor Martin:] But there are no specific claims right now that you're particularly worried about?

[Rebecca Skloot:] No. No. It's...

[Chancellor Martin:] You're an optimist, I can tell.

[Laughter]

Alright.

[Rebecca Skloot:] Yeah, I'm an optimist. There are good science writers out there. This is one of the things that I think is pretty amazing about blogging now. In the time when cell culture first started and all these incredible reports were coming out and they're going to make you live forever and all this stuff, there was no other voice out there saying, "Whoa. This is overblown." People this is a little like...It actually scared people, some of the reports about cell culture. Now if a story gets published where somebody did the equivalent of what was done with cell culture, you would have science bloggers from all over the world being like "Whoa! Whoa!" It would create such an enormous stir on-line that that actually helps, I think, to keep some of this in check, is that you now have scientists out there commenting on the media in a way that you didn't before.

[Chancellor Martin:] So science blogging is good for us?

[Rebecca Skloot:] Yes. I think science blogging is very good for us. I think it's very good for scientists too because part of where we are is we are at a point where there is this huge shift in the idea of what scientists' role in communicating science should be. Historically in the 50's, 60's and even 70's and 80's wasn't necessarily, you know, scientists talking to the media, scientists writing on a blog. Scientists writing for the general public was considered not academic. You were actually looked down on if you were a scientist and you wrote a book that was published for the general public as opposed to being published for academics. I think more and more people are actually realizing it's actually very important for science and for the general public that scientists be able to communicate to the public. In a lot of ways that is one of the things this book is about, is what happens when scientists can't communicate with people? I think science blogging is important, both in terms of this role in media but also in terms of everyday people being able to read what scientists are writing but also scientists being forced to articulate in a general public sort of way what they're doing. Which I think that helps them get better at talking to the media, which helps the media from overblowing things. I think it's part of the big cycle.

[Chancellor Martin:] So speaking of the media, we have a great School of Journalism here and also Department of Communication Arts. And we had questions from students who wanted advice from you given the difficulty of identifying journalism and media coverage that has integrity. They asked what advice you would have for aspiring journalists.

[Rebecca Skloot:] What advice I have for aspiring journalists? You know the one thing I often tell students who are interested in journalism is that there are a lot of people out there who can string sentences together. Now with blogging, actually, this is a big issue for journalists. They are like, everybody is a journalist, right? You're here; you're local. Something happens, you can go write it on your blog. This is becoming an issue in some ways for journalists; it is officially becoming.

So there are a lot of people who can write sentences. There are a lot of people who can go out and report something but the one thing that I think really good writers have and writers who succeed is ideas. That's not something that's actually very easy to do, to cultivate your own curiosity and to start thinking about what ideas actually are. Because so much of journalism is actually about that, finding stories and recognizing stories. For me so much of that is just about following your curiosity, when something grabs you. I have these things that I call what moments. Moments when I hear something out in the world that makes me stop and go "What?" This was one of them. There are these cells that have been growing for decades after this woman died, she was a black woman. That made me stop and go "What?" and then spend years going after it.

Aside from this, one of my most widely read stories is actually about goldfish surgery. There is a whole world in veterinary medicine of people who will spend hundreds of dollars to do surgery on their goldfish for cancers, to get tumors removed, x-rays, CT scans. I met a guy who had a fish chiropractor because one of his fish had broken its back. It's a whole incredible world. I learned about that just because I was at the vet with my dog and the doctor came out from the back and took his gloves off and the person behind the counter said, "How did it go?" He said, "Great. Patient is up, swimming around." I went "What?"

I stood up with my dog and my receipt and I said, "Excuse me. What did you do surgery on and who pays to have an old goldfish operated on? How do you anesthetize a goldfish?" This story it ended up I did it for TV, I did it for radio. This was one of my most widely circulated stories. But I think it's a good case study essentially in where that is actually the ability to be curious and to follow your curiosity is I think it's one of the things that you will find in any good writer and also the ability to see connections between things that seem very desperate and to actually stare at things long enough and think about things long enough until you start to see those connections. I think that's all important.

My other advice is embrace the web. There are a lot of young journalism students who resist that and that's not a good idea.

[Chancellor Martin:] Those are great answers. One aspiring journalist asked about spending 10 years researching and writing one book, whether you ever got discouraged and considered giving up.

[Rebecca Skloot:] I never considered giving up. I definitely got discouraged. I definitely thought I might be working on it until I was 90.

[Chancellor Martin:] You don't seem to be that old.

[Rebecca Skloot:] No, I'm not that old. No, fortunately...maybe yes. No I didn't ever consider giving up. I think part of that, I think there were a few reasons. Part of that is I'm really hard-headed. This is something my parents have been watching all the responses to the book. I get that question every once in awhile. They just think it's sort of hilarious because they say the side of you that wouldn't give up on this was such a pain when you were a kid. I was just like I'm going to do what I want to do. There was some of that; it was just me and I was determined to do this thing.

Also some of it was Deborah. She was oddly my biggest road block and my biggest obstacle at all times, but she was also the thing that made me feel like I could keep going. Because whenever she would have

some sort of reaction to me and she would start mistrusting me and pushing me away, she would very quickly turn around and say, “Ok, sorry. That’s not actually about you. This is part of the story of what happened to me. This is me not trusting anyone, not just you.” She was incredibly resilient and was very self aware in those moments and wanted so badly to learn. She would carry this basic dictionary around with her. It was very inspiring to be with somebody who was so desperate. She was like no one is going to stop me from learning. And that helped too.

The other thing which you often don’t hear from writers is I talked about it a lot as I was working on it. You know, you’d go to dinner parties or whatever and meet people. They would say what do you do? I’m a writer. What are you working on? I would tell the story. Every time their jaws would drop and they’d go, “My God! Tell me more.” They would ask questions. Inevitably they would often say, “Why are you out of your house? Go home and finish this because I want to write the book.” That was very stressful for me but that was actually really helpful. It was good to hear from people, right this is actually important and people really do want to hear it. I’m actually the only person who is like HeLa, HeLa, HeLa; I’m so tired of HeLa. That was just me.

[Chancellor Martin:] Not like being a goldfish surgeon.

[Laughter]

You know several students asked, or community members, I don’t know which, whether you think any members of the Lacks family ever regretted working with you on this book or regretted any of the portrayals of them in the book.

[Rebecca Skloot:] That’s a good question. They have been really involved since the book came out. It’s interesting because in the book, Deborah is really the main person in the family who is invested in the story and really wanting to do the book. Her brothers, they were like ok you guys are doing it. Every once in awhile they would get annoyed that it was happening, just because they were like “You’re still here?” But they just really weren’t that involved. But then when the book actually came out, well before it came out, I sent a big box of manuscripts to the family, like 30 of them. And they read it. I felt like it was important for them. I did the same thing with the scientist. Basically anybody who was alive who is in the book read it before it came out.

One of the things that happened was that the younger generations who had not been involved in this really at all, grandkids and great-grandkids, read the book and were just blown away by the cells. They knew these cells existed. They had been hearing stories about them but they didn’t really know what they had done. They knew their parents were mad at something but they didn’t know why. So they read the book and they were like “Henrietta is a rock star!” She helped with all this incredible science. They were really proud of that. They were proud that she was a black woman and she had done that. I think for the older generations watching the younger generations not just embrace the story but really get excited by it. A lot of them were like “I want to go to school and be a doctor and I’m going to study this stuff.” The other thing that happened was the younger generations read the book out loud to the older ones, because they don’t really read, and that gave, I think, the family a chance to talk about some of the stuff in the book, both in terms of the cells but I think more in terms of what the family went through because they just never talked about it. They were horribly abused as kids and their kids never knew

that. It opened up a dialogue in their family. They have all really come together over the book. They're very involved.

If I'm on the East Coast, my schedule of my events is on my calendar and they watch it. Periodically ten of them will show up at one of my events. Usually like now towards the end, they're always late for everything, this is just a Lacks thing. We will be sitting here talking and winding down and then ten of them would walk in the room. The room would just go nuts with cheering and standing up. Scientists would stand up and say this is what I did with your mother's cells and this is why it was important and thank you and I'm sorry if this is hard for you and will you sign my book? I've done readings where I've had rows of Lacks sitting next me all signing books.

No, I don't think they regret it. There are certainly distant relatives who don't like the fact that there is personal information in there, that Henrietta's parents were cousins. But they are minority really. The interesting thing is that for the immediate family, they felt that was really important to include. People ask about the fact that they were cousins and the sexually transmitted diseases. Her kids are like, she died from a sexually transmitted disease. Of course, you have to have that in there. Her kids were deaf, perhaps in part because their parents were cousins. You have to have that in there. For the family that was all important. I only really heard from a couple very distant relatives. Usually the immediate family was like, "It doesn't affect you." I don't hear from them too much about that.

They are also really involved in the movie. They are very excited about that. They're going to be consultants on the film, so they're actually helping eventually with the screen development of the actual movie and they'll be involved in that, which is exciting.

[Chancellor Martin:] When will the film come out...

[Rebecca Skloot:] Not sure exactly but we're finding screen writers now and having that fun and speculative who is going to play who game all the time.

[Chancellor Martin:] Who is going to play whom?

[Rebecca Skloot:] We don't know. There are serious rumors that Oprah might play Deborah which would be pretty amazing. That is totally not verified by anyone. The family is certainly interested.

[Chancellor Martin:] You heard it here!

[Laughter]

[Rebecca Skloot:] We haven't quite gotten to that yet. The movie will probably be like 2 or 3 years.

[Chancellor Martin:] Why did you... Just a couple more questions. Do you have enough energy for a couple more? One person wanted to know why you decided to set-up the foundation to support college scholarships. Why college scholarships for the family?

[Rebecca Skloot:] Yeah. Well initially my thinking was that it was just going to be for college scholarships. It turns out it's not just for college scholarships. For me, this story is very much about

access to education. Deborah also got to a point where she really believed that if she had just had the most basic fundamental education and if her family had, that a lot of it wouldn't have been so scary for them and that maybe some of the things that were very traumatizing for them wouldn't have even happened because they would have been able to ask questions and they wouldn't have been so afraid of really the science. She really felt like so much of the story was about the fact that they didn't get to go to school.

When I talked about the foundation and I said I wanted to do an education fund, she felt that was appropriate too. But then, of course, once the book was out and I was setting up the foundation I started thinking more about, once I actually realized it was going to happen. I mean it always seemed like a bit of a pipe dream because I didn't even know if the thing was going to get published, let alone actually anyone was going to buy it. Once it was actually clear that it was happening, I realized that I really wanted it to be broader than that because, of course, Henrietta's kids are not going to be going to school any time soon. Their big struggle is with access to health care. So we helped them with that in a few cases so far. We're hopefully going to be able to keep doing it.

[Chancellor Martin:] Good. Then perhaps a final question would be, based on what you said about curiosity and the importance of ideas, what's got your attention right now?

[Rebecca Skloot:] You're looking at it. I really am still spending all my time talking about this book. I travel. I'm at different schools all the time. I feel like that's part of the job of this book, the story, is to keep talking about it. Also I'm working on a young adult version for 10 to 14 year olds. It's been really widely adopted in high schools. I've done some events with high school students and often their siblings come. They're like, "We want to read the book too but my mom won't let us." Middle school teachers will come and say, "I really want to teach this in the class." I actually got an e-mail from a 13 year old yesterday who read it and loved it. But I think for your general 10 to that age range is a little advanced.

One of the things that I started seeing when I was doing these events with the high school students and the younger ones is that they were just getting so excited about science, particularly young girls and young black girls but really just any girls. One of my favorite moments in a school was when a girl came up to me and said "You're not a dork! I thought all scientists were dorks!" She really genuinely thought you just had to be a geek and she didn't want to be a geek. She was like "I didn't want to be a scientist because I didn't want to be geek, but I like science." I realized one of the things this book is doing is it's actually a story about women in science. It's a story about that. I got excited about the idea of introducing not just girls but I think there's really something important there to show young girls that look what women in science can do. We'll see how that goes.

[Chancellor Martin:] That's a great thing. I told you that one of the undergraduates who came to my home the other night to discuss the book made a beautiful point which I won't be able to reproduce. We were talking about the degree to which the book is about loss and what it means to lose a mother at an age when you would never have known her and then to hold onto the cells as something semi-tangible. One of the students said what's amazing about your book and about the entire story is the use of the cell line to develop storylines, the legacy of Henrietta for her children, grandchildren, great-grandchildren are storylines that are based on cell lines. I thought it was...I haven't captured all the nuance of the point

but I thought it was a really nice one. You have certainly done that and we thank you and thank you for being here.

[Rebecca Skloot:] Thank you. Thank you for your questions. Thank you.

[Applause]

Thank you.