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From the Media: Interview with Sally Squires February 19, 2008

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JACKIE JUDD: Sally Squires thanks for joining me.

SALLY SQUIRES: Thank you for having me.

JACKIE JUDD: This project was over a decade in the making, what got you started?

SALLY SQUIRES: Well in 1989, Dr. Koop, the former Surgeon General, invited me to come down to Carville, Louisiana to interview people who had Hansen's disease, and many of the scientists that were working on Hansen's disease at the time.

JACKIE JUDD: Which is leprosy.

SALLY SQUIRES: Leprosy we know it better as, right. And what was really interesting to me is that the way they were able to help spare the hands and the feet of people with leprosy, was applicable to diabetes. And of course, we have something like 20 million people with diabetes; we didn't have quite that number then. So in other words, what the treatments that they were finding for leprosy were being applied elsewhere, and he wanted to tell that story.

JACKIE JUDD: Had you even known the story of Carville before that?

SALLY SQUIRES: I did not. And I went down, and I was thinking that at the time, I had a 2 year old, and I was a little concerned, like, could I bring anything home? I wasn't worried about me, but could I spread anything to my family. And that's one of the things that we try to dispel. There are

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so many myths surrounding this particular disease, which is really one of the most ancient and one of the most feared in the world's history. Leprosy, I mean you say that and people cringe.

And there are so many worse diseases and people have suffered so much, who have this disease, in terms of being stigmatized and really cast out.

JACKIE JUDD: Well for the younger people in our audience who may not even be aware of what it is, what is Hansen's disease?

SALLY SQUIRES: Right, well Hansen's disease or leprosy as we know it really throughout the world, is an infectious disease; it's slightly infectious. It looks like 95-percent of us are immune to it, and 5-percent could be potentially susceptible. It is found worldwide, the rates are still just as common as they ever were. The reason that you don't hear about it is because of the treatments that were developed at Carville. And that's the wonderful story.

It's a mycobacterium; it's related to tuberculosis. And we still don't know how it's spread. So it's kind of out there.

JACKIE JUDD: And it was so horrifying to the public, because of the great disfigurement it caused.

SALLY SQUIRES: Exactly. Without treatment, what happened, it wasn't like in BenHur and all of these horrible

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little movies, and different things that are out there. You see people who supposedly their fingers drop off, their noses drop off, that's not what happens. The damage is very similar to what happens in diabetes. So the mycobacterium actually hides in nerves, and it likes cooler parts of the body. So when it does that, and it stays dormant for a very long period of time it appears, when it does that, then you slowly lose those nerve endings.

And you injure yourself and you don't realize it, and so you start to have some of your fingers will be kind of crooked, or they'll start to look a little odd. And this gradually occurs, but it's not that anything drops off.

JACKIE JUDD: And it migrates to the face.

SALLY SQUIRES: It can migrate. The nose and the earlobes are the cooler parts of our bodies. So that's where it likes to hide.

JACKIE JUDD: So set the stage then, for Carville. Tell me about it.

SALLY SQUIRES: Yes. It's a fantastic place. It's really an important place in our nation's medical history, and in its history itself. It's 300 acres, a former cotton plantation on the banks of the Mississippi, so it's beautiful. And the house was designed by a very famous architect of the era. It is tranquil; it's on what amounts to almost an island in the Mississippi, because it's on a point of land.

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When I first arrived there, I came down a road, it was a sunny day. I was going to an event at the facility. I was a little nervous; you know you always are when you go to a new place. I passed a road gang on the highway, working in the culvert, that was kind of interesting.

I arrived to Cajun music. And I met Dr. Koop and some of the other staff members. The place is huge, and it's hard to describe, our film tried to capture that with an aerial view. But it's also very intimate, because the people of the community are really wonderful. This was both a refuge, and in some ways a jail for people who had this disease. It was a refuge from society, and also a jail because most of them had to go there in the early days. They didn't have a choice.

JACKIE JUDD: Why did it even begin as a place for people?

SALLY SQUIRES: It turned out that we had leprosy throughout the country. But Louisiana had a lot of it, and particularly in the late 19th century. So there were people in Louisiana, a muck raking reporter, which I love [laughter], and he came in at 16 with the New Orleans Times Picayune, and it was called the Daily Picayune, and he wrote stories about a pest house in New Orleans. And the pest house was about to eject its patients. I mean this sounds very similar to today. You know, what do you do with people who have a fear disease? They were gonna be out on the street, and he thought what

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should we do to help them? And he got a dermatologist in New Orleans, to help him, and he wrote stories, and used this dermatologist as his source, and they decided that they should use an abandoned plantation as a place of refuge for these patients, and so that's what happened.

JACKIE JUDD: And what year was that?

SALLY SQUIRES: That was in 1894, when they first arrived, and nobody wanted these patients in their backyard, so they had to be whisked out of New Orleans under darkness. It was a November night, they put them on a coal barge, and the crew of the tug that took the coal barge, let out the line as far as they could, because they were afraid that they might get the disease.

And they took these six patients up to this abandoned plantation, and they let them out, and they were met on horseback by a Civil War veteran who had actually been a confederate Civil War veteran. He had a friend who was a patient, and he wanted a place for this man to live. So he met them, and they had very minimal medical care.

And from that, in 1896, the Daughter's of Charity, a Roman Catholic order, came to take care of them because they needed help. Two came from Emmittsburg, Maryland, two from New Orleans. And they basically thought they were going to their deaths, because they thought being with these patients, they would probably never see their families again.

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JACKIE JUDD: But it turned into a very different kind of experience.

SALLY SQUIRES: It turned into a very different kind of experience, and actually, one of the Nuns did die, but she died of typhoid, not of leprosy. And in fact, in one-hundred years at this facility, as far as we can tell, no staff member, no Daughter, ever got the disease from the patients. That's how difficult it is to get it.

And yes, it turned into an oasis, and by 1921, the federal government came in and again, basically because of a wonderful man named John Early, who was one of the first patient advocates in the United States, and he figured out that nobody would pay attention to leprosy unless he somehow exposed the upper echelons of society.

So he took a trip from the West Coast, he was under guard, and he absconded, he saved his money, and he absconded, and he took a first class train trip all across the country, and didn't tell anyone who he was. He then came to the Willard Hotel, here in Washington, right across from the White House; it was then the home to the Vice President, and also to members of Congress. He stayed there for three days, and then he called a press conference. And he announced to these kind of worried reporters that he not only was here, but he had leprosy, and that he had been living among the leaders of Congress. And he said he didn't think he was really going to

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infect anyone, but he wanted the country to pay attention to this disease. And he wanted a place where people with leprosy could be safe and have treatment. And so from there, Congress took up the case of a national leprosarium, and that occurred in 1921. Louisiana stepped up to the plate and said, we'll take it, because lots of places thought about it, but they weren't all so sure that they wanted it. And Louisiana, and it's really Louisiana's gift to the nation, and said we'll do it.

JACKIE JUDD: One of the other things that made me chuckle in the documentary, in terms of drawing attention to this, was the use of celebrity. Tallulah Bankhead.

SALLY SQUIRES: Yes Tallulah Bankhead. He was a wonderful man. What we've found is in each generation of this 100-year facility, there was someone who came to the forefront as really a spokesperson for people with leprosy.

And you're talking about Stanley Stein, who was a Texan, who ended up in Manhattan with a real love of theater, and discovered he had leprosy, and he had to go to Carville. He arrived at Carville, which is a hot southern place, and he arrived in a 3-piece wool, Brooks Brothers' suit, with a New York Times, and a New York Review of books, tucked underneath his arm. He was Jewish, mostly a Roman Catholic population, although there were lots of different religions. And he really

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seemed to be a fish out of water, but he started the first patient newspaper called the Star.

And through his theatrical connections in New York, he became a very public spokesperson for leprosy. One of the things Stanley would always write to people, he saw articles or broadcasts, if they used the L-word, which is like the N-word for African Americans, people with leprosy hate to be called the word leper. It is akin to the worse thing you could do to them, and that's one of the things that we hope that this film will show, that people should not be described by their illness. They are people first, and these are people with either leprosy or Hansen's disease, they are not that L-word. And that was Stanley Stein's passion.

And so in the film we have this wonderful picture of Tallulah Bankhead, not only sitting next to him, but planting a kiss on his cheek. Which was like what Princess Diana did with Mother Teresa in India, with leprosy patients, and with AIDS patients; saying look these people are okay, they are part of our society, we have to embrace them just like we do people who are healthy.

JACKIE JUDD: Also at Carville, there were great medical breakthroughs.

SALLY SQUIRES: Very great medical breakthroughs.

JACKIE JUDD: Effectively a cure.

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SALLY SQUIRES: Effectively a cure and Carville was for decades, the place with thalidomide, which of course is a very scary drug, but has proved to be extremely useful against many illnesses, from cancer to AIDS. And it's particularly useful in a very extreme form of leprosy. And we wouldn't know that if the people at Carville hadn't kept thalidomide as a repository and used it very carefully. And they were able to continue research on it when it was forbidden in this country. So it was a very good thing.

We've also learned how there is a fifty-cent device that has been developed at Carville, that helps people that have diabetic neuropathy. That means your nerves in your hands and feet are starting to have problems because of your diabetes. And it's a little filament, it costs fifty cents, and you can touch it, and depending on how well you can feel that touch, that's when they know if what they're doing is good or bad for you, or how they need to adjust treatment, and that all came out of Carville. So it's really fantastic.

JACKIE JUDD: Sally when you got into this project, did you expect that the lessons of Carville could be so well applied, not only in terms of the medical applications that you've described, but issues of stigma and discrimination involving other illness, HIV/AIDS for example. Did you expect all of that to flow for Carville?

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SALLY SQUIRES: Actually I didn't expect it at my first trip, but once I got there and I saw that this was a disease that had taken away these people's lives, their children were taken away from them, it's the only disease in our nation's history where people were denied the right to vote. Their families often abandoned them. Most of them took false names. Many of them are still buried under names that are not their own. And I realized it was a metaphor for illness. And also a metaphor and a lesson in how do we treat people in the public health realm? How do we treat people who when Carville started there was concern that this disease would be quite contagious. We know that's not true, but how do you protect the public health as well as patient rights?

And so once I got there, I realized there was something very special that could perhaps teach us a lot of lessons in how we treat all kinds of people with disease. And let's face it, whether we get cancer or heart disease, or we just get old age and die from that, we're all going to be ill at some point. So how do we treat people who are failing because of health reasons? And how do we help them, and keep them active members of society?

JACKIE JUDD: And a final question. Describe Carville today, what it is, what it is used for?

SALLY SQUIRES: It's very different today. We really feel like we got in just as the window was closing. The

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facility was turned back from the federal government to the state because really, Carville became a victim of its own success. With the treatments that were developed there, this multi cocktail treatment, that helps people worldwide to avoid the complications of leprosy. The facility wasn't needed. People didn't need to be sequestered, so the research part of it moved in to Louisiana State University in Baton Rouge. And most of the really elderly patients in there, just a couple of dozen left at most, are living in Baton Rouge as well,

And so now, Carville trains at risk youths to be helpful members of society. There's a Job Corp training there. And there's National Guard training. So in many ways, it's kind of come full circle. It's come from this place that was a place where people had to hide from society, to a place where people can kind of go and renew themselves and come back into society as productive members.

JACKIE JUDD: Well that's a fascinating story. Thank you.

SALLY SQUIRES: Thank you.

JACKIE JUDD: Thanks for coming in. Sally Squires.

[END RECORDING]