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**2007 Minority Women's Health Summit
Women of Color: Addressing Disparities, Affirming
Resilience, and Developing Strategies for Success
Luncheon Presentation: Overcoming Challenges through
Education and Commitment
Department of Health and Human Services Office
on Women's Health
August 24, 2007**

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[START RECORDING]

FRANCIS ASHE-GOINS, R.N., M.P.H.: I would like to thank you for showing up. I would like to thank our sponsors. I need to acknowledge our sponsors. Our sponsors are, in case you didn't see it: Verizon, The United Health Group, Baylor College of Medicine and The Intercultural Cancer Counsel and your beautiful bags were donated by The Lupus Foundation of America. Please give them a round of applause.

[Applause]

Thank you. Now our federal contributors that gave us some money, so we could do this. HRSA, Office on Women's Health. Oh, Health Resources and Services Administration, I have to break it down. SAMHSA, Substance Abuse and Mental Health Services Administration, Office on Minority Health and Administration on Aging, let's give them a big hand. Thank you.

[Applause]

And in your book is a long list of outreach collaborators that spread the word out across the nation and told you about this wonderful conference and you had to be here. I'd like to thank my outreach collaborating organizations.

[Applause]

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As with any conference, planning is pivotal. You saw yesterday, they talked about me. But I need to acknowledge my cochairs and present them with an official Cheryl Washington designed certificate of appreciation. This said, Department of Health and Human Services Office of Women's Health, Certificate of Appreciation is presented to Adrienne Smith to acknowledge your outstanding commitment to the 2007 Minority Women's Health Planning Committee. Thank you.

[Applause]

Alright. Now, a lot of people have heard this name. The Department of Health and Human Services Office on Women's Health, Certificate of Appreciation is presented to Aleisha Langhorne.

[Applause]

To acknowledge your outstanding commitment to the 2007 Minority Women's Health Summit Planning Committee.

[Applause]

ALEISHA LANHORNE: Thanks.

FRANCIS ASHE-GOINS, R.N., M.P.H.: You're welcome.

Thank you so much. And now I turn the program over to your moderator Sharon Barrett. I want to say that there are a lot of other people that worked. I think I acknowledged the planning committee before. They will also get Certificates of Appreciation. But I wanted to definitely acknowledge the

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cochairs. Thank you very much. Oh, I never introduced myself. I'm Francis Ashe-Goins, the Deputy Director for the Office on Women's Health. Thank you.

[Applause]

SHARON BARRETT, M.S.: Hello. Good afternoon, is everybody enjoying your lunch? Yes? Well, what I'm going to ask you to do is to eat quietly.

[Laughter]

I know you want to network and have conversations with your friends that you may not have seen in the last five minutes. But I would ask that if we can keep things down quiet, it would really be helpful because, we're going to have the clanging of the dishes. As Francis said, I am Sharon Barrett. And I am a member of the Minority Women's Panel of Health Experts. And I'm also the cochair for the program and agenda committee for the conference. And so on behalf of the rest of the committee, I'd like to welcome you to the luncheon.

I've been given tasks to do before we can actually get started. And so I'd like to take care of those things and get that out of the way. The first thing I'd like to do is have Sabrina Matoff-Stepp come up. Okay. She's going to say a few words on behalf of Ed Brandt. Some of you may know him, others may not. But I'll turn it over to you. Sabrina?

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SABRINA MATOFF-STEPP, MA: Thank you very much, Sharon, and I want to thank Sharon and Fran for allowing me a few minutes. This is not on the agenda. But I really feel sometimes you just have to take advantage of an opportunity and run with it. And I'm kind of putting myself out here and going on a limb and hopefully you'll indulge me for a few minutes here.

Again, my name is Sabrina Matoff-Stepp and I'm the Director of the Health Resources and Services Administration Office on Women's Health. Some of you may know Dr. Ed Brandt. He was the Assistant Surgeon General between 1981 and 1984. He has been at the University of Oklahoma for the last several years. And the reason I'm mentioning him today is because number one, he has really been a pioneer for women's health. He's been a long time member of the NIH advisory committee on women's health.

Some of his accolades, I'm going to just briefly go over. But the reason I'm mentioning is, right now, Dr. Brandt is dying. And I think it's an opportunity for us to just for a moment acknowledge someone who has spent a career acknowledging his contributions both to the nation and to women's health. And to just reflect on someone who, I think, has done a huge service to all of us. So if you can just listen for a moment, I'm just going to say a little bit about him. Dr. Brandt

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received his Bachelor of Science degree in Mathematics in 1954. He began his career in the Department of Biostatistics and Epidemiology at Oklahoma State University. He was the Associate Dean of the College of Medicine and Associate Director of the Oklahoma University Medical Center.

He was the Dean of Graduate Studies at the University of Texas Medical Branch. He was the President of the University of Maryland at Baltimore and the Vice Chancellor for Health Affairs at the University of Texas System. And again, perhaps he's most known for being the Assistant Secretary for Health in the Department of Health and Human Services between 1981 and 1984.

He also was a representative to the World Health Organization and he really was a pioneer in bringing to light a lot of the awareness and promotion around the HIV/AIDS epidemic during those early years of the 1980s, and has been acknowledged for those contributions as well. He's been at the University of Oklahoma, as I said and been a mentor to many, many students.

One of his students, Dr. Amanda Cash, who's a Fellow in my office right now. And she is literally at his bedside. Think of a modern day, *Tuesdays with Maury*. Here is a man who, I think has taught many, many people and I think is continuing to teach. And his legacy is going to live on.

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But I thought it would be really timely for this conference, it's a women's health conference and to acknowledge Dr. Brandt, who may not be with us much longer, to just think of him. Keep him in your prayers. And thank you very much for this moment.

[Applause]

SHARON BARRETT, M.S.: Thank you Sabrina. Okay, task number two. For those of you who will be attending any of the workshops that were marked Yorktown Room there will be no sessions held in the Yorktown Room. They're going to be held, hopefully in the Capitol Room A. So wherever on your agenda you see Yorktown, it's now changed to the Capitol Room A. The other piece is that this session which is entitled "Overcoming Challenges Through Education and Commitment" is also being evaluated and you will get CEUs for it. And so this is just a reminder that it's been approved for Continuing Education. So please see your program book for information on how to get your Continuing Education Credits. If you have any further questions about this, you can write them down and then turn it in at the registration desk. Okay?

Okay, I've done all the tasks that I have to do. And now I get to the fun part. I have the distinct honor of being able to introduce two women who have had outstanding careers,

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in different directions, but both very outstanding women in their own right.

And I think that after you hear them speak today, you'll also feel the same way. Our first speaker is Graciela Alarcon, who is currently at the University of Alabama. And she is currently the Jean Knight Lowe Chair of Medicine in Rheumatology. And she joined the Division of Clinical Immunology and Rheumatology in 1980 as a research fellow under the sponsorship of the American College of Physicians.

In addition to that, she has spent her whole academic career studying the impact of rheumatic diseases and its effect on patients afflicted by the Rheumatology and has worked to try to eliminate the impact of it. She's also worked on reducing toxicity from methotrexate. And she along with her other colleagues, Dr. Kramer [misspelled?], Weinblatt and Hoffmeister, were given an award in 1997. It was the Virginia Engalitcheff Award for improving the quality of patients living with arthritis. It was in 1993 when her career path shifted and she began studying and looking at the issue of Lupus. And she's currently a member of the SLIC [misspelled?] group which is an international organization looking at Lupus. And she's conducting large scale Lupus studies especially as it affects minority populations. She's published over 300 clinical and research papers throughout her whole academic career at the

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University of Alabama. And she is a Senior Scientist at the University of Alabama in Arthritis and Musculoskeletal Diseases and at the Minority Health Research Center. So what I'd like to do is turn it over to her. Dr. Alarcon.

[Applause]

GRACIELA ALARCON, M.D.: Will there be any time for questions?

FEMALE SPEAKER: Yes.

GRACIELA ALARCON, M.D.: Okay. Well, thank you so much for the introduction. I must add just that as important as the professional life is, I'm also the mother of three children and the grandmother of two beautiful grandchildren. So with that said, let me just get to the topic of this presentation.

I was asked by the Lupus Foundation if I could talk in this session about Lupus. And it's very hard to actually put a talk in which the all the audience is going to be very heterogeneous. So for those of you in which a presentation is above, I'm sorry, I apologize for that. And if this is really below your knowledge, I'm also sorry. But it is very hard to put a talk for everybody.

So I'm going to divide the talk in four parts. The first one is going to be an introduction. The second, I want to present a little bit of data about our own LUMINA Cohort and I will explain to what is that. Then I will touch on the issue

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of this session, which is empowerment and bring some conclusions.

So what is really Lupus? Lupus is a multi systemic autoimmune disease. That means that it can affect, really, any part of the body. And autoimmune really means that the body is attacking itself. The cause of the disease is unknown, but we know now, at least, that there is a biological component to it. In other words the person may be predisposed to it and then there are environmental factors that really may be playing a role in precipitating the disease, for example, exposure to the sun or sunlight.

The disease is not very frequent. The incidence is about one in eight per 100,000 individuals. The prevalence varies depending on the population study. But over all the important point is that this disease is more common among minority populations and among women.

So it's nine to ten times more frequent in women versus men. And that suggests in itself that the female hormones play a role in really triggering the disease onset because, the peak instance of the disease is really during the reproductive age years of the woman.

However, the disease also may affect infants, children and now as the population gets older, we are seeing Lupus

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patients or patients with new onset disease even very late in life.

It is much serious in younger individuals. However, if the disease occurs in older individuals, because they already have a number of other problems, medical problems, then the tremendous consequence of the disease may be actually greater than in much younger patients. Because they already have heart disease, hypertension, diabetes, you name it. So the consequence may be a lot more.

So if we want to make a diagram or a cartoon about what are the factors of that influence the course of the disease or the onset of the diseases, and I put in this, at the center of it, ethnicity. And ethnicity, not only is it biological concept really, but really very, very much broader one which includes the genetic factor—being those that come from the ancestors other genes.

But those are the nongenetic factors which are going to include the culture. Which are going to include the environment per se, the behaviors, the socioeconomic stats, et cetera. And that you're going to have a disease that may be different from person to person. And as time goes on, the person is going to have variable degrees of disease activity, is going to suffer the consequence of having the disease, but

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also of the treatments used for the disease and eventually may succumb to this disease.

Now, as I explained already, it's a disease more common in women, but it can happen in men, like shown in this. And this is kind of the reason if you remember the first slide I put, I put a butterfly. And the reason for the butterfly is of this rash that you can see in all these patients of different ethnic background. This is the classic butterfly rash. So in this particular young man, he went to Alaska, stopped his medicines and was exposed to the sun mercilessly during the summer and came back to Alabama looking like this, unfortunately.

So, as already said, it can be very valuable in explaining the presentation, course and outcome. And there's not really a single test that can allow you to tell that the patient has Lupus. Initially, back many years ago, before many of you were born, the disease was only diagnosed in its very latest stages when a person would die.

Then in the early 1950s to '60, there appears some test that may help in the diagnosis. And therefore, it was possible to diagnose the disease in much earlier times. And finally, in the 1970s, the American College of Rheumatology came up with criteria to make a diagnosis. And the reason we have criteria is because we don't have a cause. It's not like saying you

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have Strep Throat because your throat has been infected with the Strep. It's not the same thing.

The very first time in medicine that a concept of survival was applied was to Lupus. This is the expected survival of patients with Lupus in the 1940s. The paper was published in 1950s. And you can see that at four years, 50 percent of the patients have already died. Now, this is quite different today. And one of the reasons is because this test was discovered, so right at the time in the late 1940s, early 1950s, two things really changed-

FEMALE SPEAKER: Talk into the mic.

GRACIELA ALARCON, M.D.: [Inaudible] okay so I'll take this and-

FEMALE SPEAKER: Use the other microphone.

GRACIELA ALARCON, M.D.: Is this any better? Okay, I'm sorry. I was given the other. But anyway, so I already showed you the graph with at very stiff mortality coming from the 1940s, early 50s. But then at that time there were two events that were tremendously important. They changed the disease.

One was the discovery of this cell in the blood of patients with Lupus. So for the first time, patients could be tested to see if they could have the disease. And the second event that was perhaps equally or more important is, the discovery of cortisone. Cortisone and all those derivatives

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that we know today is the most potent anti-inflammatory. So for the first time, the disease could be treated in a more or less aggressive manner and being controlled.

As a result of that and all the advances in the medical care, then we have— This is the same institution, Hopkins, published in 2006 is data from 1987 to 2004. And we see that at 5 years, more or less the same, the majority of the patients are alive. So yes, it has an increased mortality, a decreased survival, but nothing like was seen in the very early or middle years of the last century.

So how do we measure the impact of the disease? Well, obviously, we can measure mortality. But if the disease is not so bad anymore, that doesn't produce significant mortality we have to measure other things such as disease activity. That means how bad the disease is at a given point in time. The damage caused by the disease or the treatments and how the patient is functioning. So this is just to give you an idea of the relationship between activity and damage.

When the person starts having Lupus, there is no damage done to the organs. A person may have damage for other reasons, but in terms of Lupus, not. Then they're coming—the flares of the disease that tend to be less and less as time goes on, and finally, as time goes, damage starts to accrue.

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And I'll give you some examples that are graphic examples to actually demonstrate this.

For example, very typically patients with Lupus as the faces that I show you before, will present with rashes like shown in these two upper figures. Now, the big percent with arthritis, they may present with an acute pericardium effusion, I mean, this very enlarged heart is due to the fact that there is fluid in the pericardial sac. In contrast, damage is what happens to a patient after many, many flares of the disease or unfortunately many treatments received for the disease.

And for example, we have, this is a person with Lupus that has had rashes, eventually loosing her hair. And that may not be serious except it is very cosmetically unacceptable for women with Lupus, or for men for that matter. This patient is loosing a finger. This is the fundi of the eye, so that's what we see when we put ophthalmoscope and we see this lesion over here. This person is loosing their vision due to a medication used for the disease. And this person has asymmetry of the face due to neuropathy. So this is damage. These are irreversible things that are happening to the patient.

Now we already talked about how mortality has improved. However, I just want to show you that in Lupus, mortality has not improved for everybody. And we can see here that for African American women, actually over the years '78 to '98,

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which is the last date that we have, we've actually seen an increase. And that's particularly true for the middle aged women. And as compared to that, we have here the data for Caucasians, are really very, very much stable. So the question is why is this happening?

There is no data in this—the CDC for the Hispanic population. But I suspect that may be comparable to the African Americans. And lastly in the introduction about functioning, the little triangles here represent for the normal population function. And I want you to pay attention to any, I mean, you can look at any one and you can see that the Lupus patient is functioning, all these scales well below what the normal population is. This is not really the normal population. This is the general population, which includes people that might have other chronic diseases as well, although the majority are going to be healthy.

So we can see that this is a disease that affects significantly the quality of life of the people affected. So it's a potentially fatal disease, yes, it is. We know survival is better than decades ago. But there are still disparities in terms of the frequency of the disease, the disease manifestations and the outcomes of the disease.

So a little bit about LUMINA, which is a cohort of patients with Lupus. Dr. Barrett mentioned that I switched

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gears back in 1993. There was the opportunity to study Lupus in minority populations. And I guess the reason why we were granted the funds to do the study was because in addition to study the African American population, we decided also to include Hispanics in our cohort. Now this is the only cohort of Lupus patients that include the three major ethnic groups in the U.S.

So the study is being conducted in Alabama, in the island of Puerto Rico, and in Texas. So, it's not representative of the whole U.S.A. but is actually is best as we can get, the only cohort that includes all groups.

So we include patients that met criteria that have relatively short disease duration, had a defined ethnic group, meaning they clearly were either or, and belonged to the geographical area. Of course, we had an informed consent, and this is work to be conducted on a yearly basis.

And just to point to you, some of the features of these patients, they are middle—the majority, as you can see, are women. But just want to pay attention to some of the features. For example, the Hispanic Texas and the African Americans are the ones less educated, the ones that have more people below the poverty line. And the ones that are less likely to have health insurance.

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So right there, you can see there are discrepancies between the ethnic groups in this Lupus population. Now, in terms of the disease per se, we are also going to see that they are different. For example, the Hispanics from Texas, the majority of Mexican descent and the African Americans, are very comparable. They have more acute disease onset. They also have the kidneys more frequently involved. And they have more active disease. And they develop more damage as the disease goes on. So the interesting thing is that when we—initially we only were going to study the Hispanics in Texas. And then a little bit on the political side, the Hispanics from Puerto Rican descent they said, we are also Hispanics and we are being excluded. So we tried to actually contemporize and we got a supplement to study the Puerto Rican cohort.

And interestingly, the Puerto Rican do not behave like the Hispanics from Texas in any of the aspects. So then we have not increased the Hispanic population, we have to actually have two subsets of patients. Just one table with data actually of one of the analysis, this is early data in which we tried to see what variables may affect the accrual of damage among these patients.

And in this analysis, Hispanics ethnicity from Texas, all their age, the more criteria, the use of this medication,

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and the activity at diagnosis were predisposing to a poor outcome, meaning the accrual of damage in general.

And this is a survival curve in our patients. This is just univariable. That means that is only taken into account ethnic group. And we can see, the Hispanics from Texas and the African Americans are the ones that have a much steeper drop in the survival curve as compared to the Caucasians and the Puerto Ricans.

And you can see that the Puerto Ricans have not been followed as long because they only started in the cohort years later. However, this is an adjusted, just like the CDC data that shows the increase on the mortality of women. When you adjust for socioeconomic and other clinical factors, what happened is ethnicity disappears and poverty comes. So this suggests really that, it's not just a biological component of ethnicity but also the nonbiological component which is operating to bring this poor outcome.

So going back to our initial graph, we can see that it's not only the genetics; it's also the nongenetic factors which are very important in determining the outcome of the disease.

So how can we actually empower women to better deal with this disease so that their long term outcomes will be better? That means how do you strive for positive help? Not

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the lack of disease but being healthy. And this concept was brought about by a Jewish Sociologist, Antonovsky, back in the 1960s, I believe and he call it Salutogenesis, so trying to strive for being healthy.

So if we apply that to health is the belief that you can participate in all healthcare decisions by switching from a traditional modeling, which the doctor tells you what to do, to really a proactive model in which you really take part of your health. So to do that, Antonovsky brought two concepts.

One is the use of the generalized resistant resources and the second the sense of coherence. So what are these resources? It's kind of common sense. Are those available to the individual to resist the daily stresses of life? And he actually developed this concept because he was impressed that people have immigrated to Israel that have been in concentration camps, for example, were able to deal with the stressors such as changing from being fertile to being in menopause without really any problems. And he said how come these women that have suffered so much can actually cope with all this without really any problems? And that is how he developed that.

So the resistant resources are the socioeconomic status, the knowledge, the ability to cope with a problem, the presence of social support or the lack of it and the cultural

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beliefs. In other words, the person utilizing all these elements to actually promote health, okay.

So if you utilize those resources in a very positive way, that's what sense of coherence is all about it. So can these apply at all levels? Yes, it can be applied at the societal level to try to change the economic structure, the socioeconomic structure of the country. At the community level, advocacy groups are the best example of that, and the individual level because, as health providers, we have the obligation to provide knowledge to our patients.

But the patients on the other hand can improve the way they cope with illness, the social support can be strengthened at the family level. That's important particularly of women that tend to be dependant on their husband or their family members. And they need to utilize their cultural beliefs in a very positive manner.

So in Lupus specifically, there are modifications that may really have a positive impact on the outcome of the disease. We know smoking is very detrimental and actually takes away some of the effect of the medications. Improved physical activity, for example, drinking, and more over, the important thing is the physician patient interaction to change from a passive mode to really active mode. So the patient can be the proactive person of this equation.

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So in conclusion, Lupus as a disease affects disproportionately women and minorities. The intermediate and long term outcomes of the disease are worse in minority population. But it's not just due to their genes, but very importantly to the unfavorable socioeconomic status and empowering women to use their generalized resistance resources. So that they can actually achieve health rather than disease is tremendously important.

In terms of the studies, we have the support of NIH, our own institutions and private foundations and I want to thank you again for your attention and the invitation to be part of this symposium.

[Applause]

SHARON BARRETT, M.S.: We could take one question or two questions if there is a burning question? Vicky?

VICKY: Thank you for a very interesting presentation. If you go to your first slide where you had the different pieces, you didn't talk much about the ad. Could you say something about the importance of that or if there's certain patterns of that mixture that or if there are certain patterns of that mixture that would put you more at risk?

GRACIELA ALARCON, M.D.: Well, that is a talk in itself. But just to give you an understanding, we are all cut along according with the U.S. Census as belonging to one or

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other racial or ethnic group. In reality, we are a mixed population. We all have genes that are coming from our ancestors. Either being those European, African, or Asian. In the U.S., the majority of African Americans have about 80-percent African genes versus about 20-percent. That's in general, okay? There are people that have a lot more and a lot less. And the same is true of the Caucasian population.

So when we try to study a disease about minorities or about ethnic groups, a more precise way to study it would be using the concept of mixture. Those genes though are very important. Those are our ancestral genes. But other genes are not linked to the ancestral genes that may be also important in Lupus.

FEMALE SPEAKER: I have a brief question as well. You talked about the role of resistance to stressors as being relevant to the issue of Lupus. And I don't know whether Lupus has been included in the work of the Adverse Childhood Experiences study. Or if you're aware of the ACE study, that was sponsored by CDC that shows a very strong dose, response relationship between early trauma and all sorts of negative health outcomes 50 or 60 years later? It's easy to find at acestudy.org.

But we've just completed a symposium on trauma and I'd be very interested on whether there's a literature on the

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relationship between early trauma and Lupus in your patient population?

GRACIELA ALARCON, M.D.: No, as far as I know. I have not found a study dealing with that. Perhaps we've been too busy trying to understand the disease itself or trying to understand the relationship between spouses, for example, because the majority are women, or adolescents and their parents. But to my knowledge there is no study in which the events of early childhood have been studied to determine whether or not that influences the outcome of the disease.

FEMALE SPEAKER: Do you know if it was included in the ACE Study?

GRACIELA ALARCON, M.D.: What?

FEMALE SPEAKER: Do you know if Lupus was included in the A-C-E Study?

GRACIELA ALARCON, M.D.: No. I don't know.

FEMALE SPEAKER: Okay. Thank you

FEMALE SPEAKER: I was wondering how you can account for the fact that there are no Native Americans or Asians or Pacific Islanders with the disease?

GRACIELA ALARCON, M.D.: In my study or— The reason we didn't include them in our study is because the population of Native Americans and Asians in the areas where we actually are studying Lupus are not really that big. Now there are many

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studies done, particularly in California, where the Asian population is actually a higher proportion. And those studies have included Asians. There are also studies in Canada, particularly in Western part of Canada where the Asian population is large and include Asians.

In general, and there are studies coming from Hong Kong, China, Singapore et cetera that show the disease has in intermediate outcome. It's not as bad as in African American's, for example, but not as good as in Caucasians.

Now as to the Native American population, there also are studies that have included Native Americans but the population in our state, Texas and the island of Puerto Rico is not large enough to justify including them.

SHARON BARRETT, M.S.: Thank you Dr. Alarcon. I think it's important that we hear about Lupus. It's a disease that some people know about but a lot don't know about it. And I think we ought to thank Francis for keeping Lupus on everybody's screen. It's because of her efforts that we have had town hall meetings on Lupus and now we have the luncheon presentation. So hopefully, it has expanded your knowledge base a little bit more. So thank you.

[Applause]

SHARON BARRETT, M.S.: And now I get to introduce someone who's very dear to me. I have worked for and with Dr.

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Gaston for the last 13 years. So she's no stranger to me by any means. But every time I look at her bio, I get moved by the things that this woman has been able to accomplish. And I hate reading her bio and so I'll just kind of paraphrase it a little bit. But she has dedicated her life to improving the health status and minority families in our nation and abroad.

And she is the first African American woman to direct a public health service bureau, and only the second African American woman to achieve position of Assistant Surgeon General and rank of Rear Admiral in the U.S. Public Health Service. She was the direct-

[Applause]

But let her tell it, she hasn't really done much. As the Director of the Bureau of Primary Health Care in the Health Resources and Services Administration, she directed a bureau and was responsible for a budget that reached \$5 billion, serving 12 million poor, underserved and disadvantaged people in the nation. She was the architect of the 100-percent access and zero disparities. And that's taken on a number of different kinds of terminology these days, but it was her effort that made us begin to look at one community at a time to try and reduce the disparities that existed within that community. And it was with her foresight and her staff that she was able to accomplish a lot in this area.

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Now, before she was a Bureau Director, she didn't want me to mention this, but she also was at NIH. And she was responsible—she changed the management of children and Sickle Cell Disease that resulted in significantly reducing morbidity and mortality in young children and around the world for which she is internationally recognized.

Her awards are numerous and they include every award that you can possibly get within the public health service, okay. There are two cities, Cincinnati and Lincoln Heights in Ohio. In Cincinnati, there is a Buford-Gaston Building that's been named in her honor. She's a member of the prestigious Institute of Medicine. She has also received three honorary Doctorial Degrees from the University of Pennsylvania, Dartmouth University and the University of Medicine and Dentistry of New Jersey.

She's received both the National Medical Association award and an AMA award. She's also, at the University of Cincinnati in the College of Medicine, had a scholarship named in her honor. And each year, two underprivileged students are given a full scholarship to attend four years of medical school and they're called the Gaston Scholars.

[Applause]

But let her tell it, she hasn't done very much. She's been featured in the national Library of Medicines Exhibit, an

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exhibit that's called "Changing the Face of Medicine in Women Physicians." And in addition to that, she's been on "The Larry King Show," "Larry King Live" and also on "BET."

And after she retired from the Federal Service, she began another career. And for the last six years, she's been working to improve the health status of African American women. She and Dr. Gayle Porter have coauthored a book, many of you know, the book called Prime Time, the African American Woman's Complete Guide to Midlife Health and Wellness. Both she—Dr. Porter, would you like to stand up for a second?

[Laughter]

[Applause]

As a result of their book, they have now gone across the country and started Prime Time Sister Circles. And the last achievement, and she and Dr. Porter have just won a prize called the Purpose Prize from Civic Ventures, is that right Civic Ventures? And you may have seen them written up in the Washington Post. And she might tell you a little bit about that either here or during her workshop that's coming up.

The last thing she asked me to mention was that her biggest accomplishment, the one that she's most proud of are her two children. Who are now very fine young adults who are out in the world following, not after her—after their mothers footsteps, but they're now adults and very, very proud of all

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they accomplished, and she's great. So I'm going to turn it over to her now.

[Music playing]

MARYLYN HUGHES GASTON, M.D.: Turn up the music so we can hear it. Can you hear the music, we need a revolution? [Inaudible] I don't think, I- Could anybody hear, were you playing "We Need a Revolution?"

FEMALE SPEAKER: Yes.

MARYLYN HUGHES GASTON, M.D.: Okay, great. Yes, yes. Webster defines revolution as a radical change in a situation. And there's no question, we need to radically change the situation of our health in our communities of color, our women of color and their families and their healthcare system.

[Applause]

Good afternoon everybody. Well, I'm delighted to be here. And I want to join the chorus of thanks to Dr. Wanda Jones and Francis Ashe-Goins for having this wonderful conference. We need a conference like this that just focuses on us as minority women. And certainly now a conference that's looking at the solutions, not just the problem, but the solutions, the strategies, the best practices so that we can take them back and replicate them.

Needless to say, we face multiple challenges to overcome through education and commitment. But I think our

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bottom line challenge is in the disparity of our health outcome, specifically our death rates.

As an African American woman, let me tell you, I continue to be upset with these statistics. I've seen them year, after year, after year, after year. I started seeing them when I entered the Public—I saw them before I even entered the Public Health Service. The fact that we as African American women are dying at rates that are greater than any other group of women is outrageous. But I want you to look at all of the women.

Here we are. The red bar is African American women, yellow bar Caucasian women, gray are Native American, blue are Asian American and green are Hispanic women. Dying from heart disease, cancer and stroke and diabetes is the number four cause of death for African American women, Native American women and Hispanic women, mainly.

I hope you notice that our Asian women are doing very well. Some of our Asian women are doing quite well. And in fact, they need to be the benchmark for all the rest of us, okay? Yes. [Applause]

And I want you to know, that most of these deaths are preventable. Most of the deaths are preventable. Turn to somebody and say this, tell them most of the deaths are preventable. And I want this message, if there's a message you

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take out and spread as revolutionaries, I want you—that's the message you spread. And you tell everybody in your family, you tell—when you go to those beauty parlors, tell a beautician. You tell a beautician, you will have told 500 heads. [Laughter]

And my outrage grows even greater when I look at the statistics from the National Center for Health Statistics in terms of our global life expectancy. Do you know that we as women, in this country, are 26th in the world? Twenty-sixth in the world in terms of our life expectancy, our minority women are even higher than that.

For example, we as African American women are 33rd in the world in terms of our life expectancy. And I hope all of you remember in this context, we spend \$1.9 trillion every year on health, more than any other nation in the world to get these kinds of outcomes. I don't know why we're not marching in the streets. [Applause]

And less than three-percent of that 1.9 trillion goes to prevention, you do know that. Dr. Elders used to always say, and I love it, we have not a healthcare system but a sick care system. My sisters, we need a revolution. But our physical health is not our only major challenge but also our mental and emotional health. [Applause]

I'm reading from our book, Prime Time. You know I had to read from the book. "Did you ever wonder why so many

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sisters look so angry? Why we walk like we've bricks in our bags and will slash and curse you at the drop of a hat? It's because stress is hemmed into our dresses, pressed into our hair, mixed into our perfume and painted on our fingernails. Stress from deferred dreams, for dreams not voiced. Stress from the broken promises. The blatant lies, stress from always being at the bottom, from never being thought beautiful, from always being taken for granted, taken advantage of. Stress from being a black women in white America." This is by Opal Palmer Adisa and we start our chapter called stress can be managed with this poem.

But you know, as I travel around the country, and both Dr Porter and I do a lot of traveling, we're talking to many groups of women, minority women, and they all say, that's not just black women, that poem could be for us. Okay? So we're very sensitive to that as an issue. But let's look at the data. Here, this is from CDC and they looked at severe psychological distress in women. And that was defined as stress, feeling anxious, feeling overwhelmed, being mildly depressed. And you can see in the early years, okay, the early years, 18-44, African American women are the most distressed, and as we get older, the Latino women are the most distressed, although African American women are still more distressed than our white sisters.

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The data available for Native and Asian women, we were told by CDC was just too small to include in the data. Now, you know, that's something we really need to fight about. We need to be on the case when it comes to including everybody in the data even, okay? [Applause]

Absolutely. And we need to be on the case, in terms of looking at all the groups inside the Asian group, inside the Hispanic women, the Puerto Rican, the Cubans, well, you know what I'm talking about. Okay. And why is all this so important? Don't forget our mind body connection.

You know, we talk about holistic health but, you know, we don't practice it here in the nation. We really don't. We have our physical health program over here, our mental health program over here, our church back here. Can I get an amen from somebody? [Applause]

But look at this. Stress, depression and anxiety are major risk factors for hypertension, heart disease, diabetes, lung cancer; look at this, premature aging even. So our stress is not just distressing us, it is killing us. So those big killers I showed you, that mind body connection is playing a major role. And I want to drive this point home because you've got a lot of work to do in your communities when you go back, in terms of this whole issue of integrating better mental

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health and physical health in our healthcare system. And in all of our programs, that needs to be done better.

And look at this, these data are very compelling. These data are data from Hopkins but they've been reproduced in other universities. This is showing, okay, look over here, what Hopkins did was look at cardiac patients. They wanted to look at depression and the incidence of cardiac mortality, especially heart attacks. They looked at a group of cardiac patients, and what they saw was the yellow bar, or orange, is minor depression. So in a group of cardiac patients, if they had a minor depression that wasn't treated, wasn't treated, their risk of dying from a heart attack went up 1.5 times, okay.

If they had a major depression, the blue one that wasn't treated, it went up three times. But I want you to look at this group, because this is what got Dr. Porter and I when we saw this. That the noncardiac patients, people without a history of a heart problem, et cetera, if they had a minor depression that wasn't treated, their risk of dying from a heart attack was the same as the cardiac patients. And if they had a major depression that wasn't treated—I got excited—if they had a major depression that wasn't treated it went up four fold.

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We were so concerned about this that that's what prompted a book, a holistic book, Dr. Porter's a Clinical Psychologist, I'm a physician and so we wrote Prime Time, this holistic book. Which is a book to really give women, not only motivation but strategies and skills to begin to take better of them health, their health in a holistic way, okay.

But you know these challenges all too well because most of you have put your training and your commitment where your mouth is. And you've been out in these communities working away, very hard I know it, 24/7, working, educating, and putting your commitment to work.

You've already created revolutions. You've initiated and developed change in your communities and in your systems of care. You already have established some programs addressing aspects of disparities. Programs focusing on cultural competence, health, literacy and language barriers, all three we have to deal with if we're going to deal with these disparities, we have to deal with it in a major way.

Some of you are even helping to change the curricula of the medical schools in your community to really begin to train students and give them skills regarding cultural competence and health literacy. And I've been impressed that even the mass media is on board. I mean you can't look at the evening news

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without some kind of health segment, right? Every night there's something on there.

And I tell you as I go through the communities, women are listening very closely. They are listening very closely and trying their best to make these lifestyle changes. In fact, as you know, so many women don't even make a healthcare change unless Oprah recommends it, is that the truth?

[Laughter]

And thank God for the healthcare system, now focusing more on quality and patient centered care. Yes, we have a revolution going on and have had some movement, but we still have major challenges. So my challenge to you for this meeting is learn as much as you can because, you're really going to have to go back and continue to do the educating. Learn all these wonderful strategies, these models and practices and what you need to do to replicate them.

Network with as many women as you can that are in here. Network with all of them because they're doing the same kind of work and they can help you replicate it.

When you go back to your communities, well, even on your way back, when you're on those airplanes and those trains, don't just sleep or read a newspaper, before you forget, because you know, we in—especially those of you that are in mid-life, you know— A woman said to me not too long ago, she

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said, you know, I used to have a photographic memory, but for the past five years it hasn't had any film in it. [Laughter]

That's the way it feels, that's the way it feels. So you younger women get ready, okay. So even on the way back though, make some plans to move into action because, if you don't take this information and do something with it, you have wasted your time.

Knowledge is power, but it really becomes powerful when you act on it and make a difference. Make plans to reconnect with the people that you've met here and have them involved with your replicating. Make plans to mobilize your community around it.

I want you to leave here committed to work on four levels and I'm going to give you the four levels. I want to start with a level that's very, very important and end with the level that's most important, okay?

The very important level is the women you serve. First of all, you must continue, all of you must continue in your communities to work for equal access to care. You absolutely have to continue to do that, for everybody regardless of race, ethnicity and socioeconomic status.

There are still problems, not only just in poor people accessing, there are still problems in terms of attitudes in the way poor people, poor women are treated. And I hope you

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know that poverty is a major determinant of health. Gandhi said that the worst form of violence is poverty. And when you know the poor communities and poor people, he was right on the money.

You must continue to fight on every level for universal health insurance. But I also want to remind you, well first of all, let me remind you, yes, that the IOM has taught us that the fifth, the number five cause of death, in the nation, is being uninsured. So for our minority women, number one is heart disease, cancer two, stroke three, diabetes four, five being uninsured. We have to make some changes.

And let me just say, there are communities across the nation that are really—some communities have 95-percent of people into care, but that's another lecture. You have to fight for equal access. But equal access does not only involve health insurance, it's also about language access. It's about equal access to information. I feel the gap widening more and more in terms of this information age that our minority and poor women are not participating.

Equal access to affordable pharmaceuticals, all of this is, when you think of access, you have to think of all these. Equal access to equal treatment, do you know that if our women, all of our women had access to equal treatment, we could eliminate two-thirds of the disparity and death from breast

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cancer. Two-thirds, it's been documented, okay. This is something we absolutely have to focus on. And there are models out there doing it.

There's a wonderful model in Contra Costa, Californian where the whole county decided they were going to change the late diagnosis of breast cancer in all their women in their county. And it's a wonderful model and they did it. They really did it. And it's a model we talk about frequently.

They also need access to policy decisions. The women you serve need help in moving from the illness focus to wellness focus. You know, as I said, I speak all around the country and I can tell you, women are really struggling with their health.

They are not living lives of prevention. And they don't know their risk factors or how to decrease them. They need a lot of education and a lot of support and help to act on what they know. There's this huge gap, as usual, we have it too, but we know we're not, it doesn't translate into action. Just think about those New Years resolutions all of you make and three years later, I mean three months later, nothing's happening. You can't even remember what the resolution was.

[Laughter]

I know. Like some woman said, your walking in my shoes Dr. Gaston, I know it because I've been there too. They need

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help in getting motivated to make these difficult lifestyle changes; to eliminate habits of disease and adopt habits of health.

The reason that's so important is CDC has shown us that of the major determinants of health, heredity, environment, medical care of course lifestyle is the most important. So go back and educate, motivate and agitate, okay. Go back and educate and motivate and support your young minority sisters in your community. And help them to know they have to start now. They're not focused on their health. They're not focused on the choices they're making and the chances they're taking with their health. You've got to focus on the young. When you look at their data, they're worse off than the midlife women in many ways, okay. And I want you to also go back and focus on the older women to help them know, yes, that it is never too late. It is never too late for them to make these changes. That's the first level.

Second level is working when you go back at the level of your staff in your organizations. As you know, many of the women in your workplace are stressed to the hilt, just like all of you are. They may be even stressed more. Because see, you get to come to these conferences. And you renew and you reinvigorate and they're back there doing the work. They're stressed to the hilt.

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How many of the women in your workplace are overweight? Probably two-thirds of them based on the national average, how many are pre-diabetic and will have full blown diabetes in the next five or ten years? But it can be prevented if somehow they get some help right now.

Are you fighting to make sure your agency is providing and defraying some costs for smoking cessation programs, for exercise, for weight loss, for some stress management training? All of these things, look at your workplace, there are a lot of things that need to be improved right there in terms of minority women's health.

How often are you're employees encouraged to take off, to take vacations. I hear people say I haven't had a vacation in three years. How is that possible? You know, that should be mandated almost. You know, European countries mandate that many of them, okay? Does your cafeteria need help in improving the health foods that they're providing?

The third level is that of you family. Are you having discussion with your family about your family's health? Are you doing it in a proactive way and not just reacting when a problem comes up? Does everybody have the chart? Know, I mean really do that just like you do the genealogy? Many of us have the genealogy but we don't know about the illnesses or the deaths. And you know this, as summer's ending, there've been a

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lot of family reunions this summer, a lot of them. I hope many of you took advantage of having all that family together to talk about and document your health.

Are you all reading food labels together? Probably not because they're members of my family, they don't know what's the most important thing on the food label, salt, fat, sugar? The serving size, that's why it's first, because that tells you how much salt, how much fat, how much sugar is in that serving size. You can pick up a bag of potato chips and you say oh, this isn't too bad, you know, the total fat is three grams. The salt is only 100mg. Well, they're talking about five potato chips. That's what they're talking about. [Laughter]

[Applause]

You have to read these labels. Let me tell you one of my favorite stories. And this is a true story. And we're going to talk about our Prime Time Sister Circles in greater detail during the workshop. But anyway, in one circle, we had a grandmother who was in charge of her—who had the care of her nine-year-old grandson because the mother had died from HIV, from AIDS. And so as part of the circle that we have them do is go back and talk to their families about, you know, they're entering this to really change they're lifestyle and let families know what's going to happen. So she told her little grandson, she said, you know, I'm in this program and we're

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going to have to change how we eat and we're going to have to start exercising, blah, blah, blah. And she said, and because, and this is a good thing too because we always have them have a goal, a goal of what they want to do and why. And she said because my goal, sweetie is to live long enough to see your grandchildren and your grandson.

So one day, they had a sale on Doritos and she loved Doritos. So she went to the supermarket and got all these Doritos, got the salsa, put it all in there. And he was running around the store, you know, as little nine-year-olds do, doing whatever. And finally when she was checking out, he came and he saw all these things on there and she said, he picked up the Doritos bag, he read the label, he said, "Nana, did you see all this salt in here and all this fat? What are you doing? We can't eat that." He told the cashier, "My nana's not buying these. We're going to put these back because she's going to live long enough to see my grandson."

[Applause]

I know, well, [inaudible]. Okay, I'm on the way. And my last level, but certainly not the least is the most important. And that is how healthy are you? How healthy are you? Are you living daily lives of disease prevention and health promotion? Do you know your risk factors for the big killers and are you working every day to eliminate them? Are

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you prioritizing yourself, yourself and your health first? I know you're so busy taking care of Lottie Dottie and everybody that you're not on your to do list. Or if you are on the to do list, you're at the bottom. See, I've been there. I know exactly what you're going through. Thank God, I retired and I'm not going through that any more. But the fact of the matter is I even started making changes before I retired.

We remind women, the fact of the matter is, you can't take care of Lottie Dottie and everybody unless you're first taking care of yourself. And you first are fit. And people can—women can relate to that. And certainly when we remind then when they get on these airplanes what they say, when the mask comes down, what? Put yours on first. Before your child, okay. Because you'd be unconscious if it's on the baby, your unconscious, the baby is sitting there what happened to mama? [Laughter]

And you're no good to anybody. Turn to somebody and say, I'm putting my mask on first. Absolutely, we're not going to have any questions.

FEMALE SPEAKER: Okay.

MARYLYN HUGHES GASTON, M.D.: Okay. And don't feel guilty. Don't feel guilty. This is self care. This is—don't feel selfish. See, that's the problem we've had in the past. No, you change that paradigm. Because you know you can take

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better care of someone if you're in good shape yourself. And if you don't do this, you're going to burn out. Because the jobs all of you are doing, leads to burnout. So you have to really focus on protecting that.

If you're not fit, you won't be able to serve your community. You cannot support your staff, the women in your workplace, and you certainly can't role model for the family. And for those of you that are Christians, remember what Jesus taught us, what? Love others as what? We love ourselves.

I bet you're also too busy to exercise. That's the most frequent barrier that we hear women talk about. And I know that's your issue too. Let me tell you, I used to use that. That old tired excuse when I was working. And then one day I had an epiphany. First of all, I looked at my calendar. Those of you that live by your calendar, look at it. Everybody's on it but you, everybody. And this is your life. This is your life.

So I had an epiphany. I said now wait a minute, I'm trying to find— At that point I was trying just to find 30 minutes, you know, the minimum amount, I'm trying to find 30 minutes. I said, well, in a 24 hour day, there are 48, 30 minutes. And I can't find one out of 48? I said, oh, I got to run and get me a time management course. But think about that.

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Stop using that as an excuse. You find time for everything else, okay.

Do you have a daily stress management plan in place? Deep breathing, we know that deep breathing throughout the day, not just when you're feeling stressed, but what you're trying to do is reverse. See right now, the sympathetic nervous system is taking over because you're chronically stressed. And it's in charge. Your blood pressure's up, your pulse is up, insulin is up, epinephrine, corticoid steroids, all those toxic hormones. You want your parasympathetic to be in charge to bring all that down. All those hormones et cetera, okay. Deep breathing, over time chronically will help you do that.

I want you to go home and get some post-its and put on there breathe. Breathe. Put it on your computer, put it in your car, put it on your refrigerator, on you mirror in the morning, okay? Have positive self statements in the morning when you wake up. Stop saying, oh, this is a bad hair day. My nose is too big. I've gained so much weight. I'm a child of God. I'm loved, I'm loving, those positive statements.

[Applause]

Those positive statements help to decrease your stress. A good friend of ours, Dr. Reverend Renita Weems, I hope many of you know her, yes, Renita, if you ever see that name within a 50 mile radius on something, go see her, okay. She says you

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have to get yourself ready in the morning to go out. Because when you go out, the Babylonians are waiting on you. And one time we said that and a woman stood up in the back and she said you know what I have to get myself ready in the bathroom to go to the kitchen table because I live with some Babylonians.

[Laughter] [Applause]

And I want all of you to start looking at your relationships. Have friendships with healthy positive people. You know, Dr. Porter, is right. All these people you have to stress you, Dr Porter reminds us, you know, some of us were born to people that stress us. Some of us gave birth to people that stress us. Some are partnered and live with people that stress us. And then we go out and find a whole bunch of other people and bring them into our lives and they stress us. Look at the toxic people around you and you can start with looking at the people that are in your house.

I know, she keeps telling me time is up, I told her we just can't have any questions. Because I want you to hear this story because this will really get you.

These are two women entering heaven okay? And one, the first one says to the other one, how did you die? And she says I froze to death. And the other woman said that must have been horrible, that was a horrible death. She said at the beginning it was, but you know, after I began to freeze, see at the

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beginning I was hiding. But when I began to freeze I began to calm down and I really had a calm death. So she said what did you die from? So she said, well you know, I knew that my husband was having an affair, so I left work early and went home because I just knew she was probably in the house at that time. So I walked in there and he was reading the newspaper. And of course I asked where she was and he said she wasn't here, he didn't know where she was. But I knew she was in that house. I ran up to the attic, I looked all in the attic. I went to the bedrooms looked under the bed, in the closets. I went in the basement, looked everywhere.

And said, I was so angry and I was running up and down the steps and I was so out of shape that I had a heart attack and died over my husband. The other woman looked at her and said, well, you know it's too bad when you were in the basement you didn't open that freezer, you could have saved both our lives. [Laughter] [Applause]

I am. See, I hope I've relieved a lot of stress, everybody laugh more. [Laughter]

And finally, and finally, I've talked mainly about physical and emotional health but our spiritual health is real important. Data out of Hopkins and Duke and San Francisco are documenting the power of prayer. As a matter of fact, women that pray every day, have one third less risk from dying from

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all causes than women that are not praying. But anyway, look at the data.

I want to end the way we end the book. The last chapter of the book is called "Reaching the North Star." And it's a poem by Becky Bertha called "Poem for Flight." We end the book and I'm ending this, in fact, every talk we give we end it with this because, we think it's so significant. And the intent of this poem, we hope, will really provide even more motivation for you to make these changes and also you can remember this for the women.

There will come a day, and it's not far off now, when you wake in the morning and know that you were meant to be happy and healthy. And that you want it more than you want things or memories or any concrete place called home. More than all the strings of the past that fasten you, more than you want justice or pride or even your old clay image of yourself or the faint chance that all that has gone wrong may still change. It is you. It is you. It is you who hold the power to change. And whatever it is that holds you, whatever it is you think you cannot live without, the time has come to open your hands and let it go. Run, flee, disappear, break loose, take wing, fly by night, move like a meteor. Be gone. If you fear it will never be possible, think of Harriet Tubman who traveled alone the first time, who finally freed 300 slaves but

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first she had to free herself. There's a Harriet in all of
you, now's the time to finally free her. Thank you.

[Applause]

[Music playing]

[END RECORDING]