Good morning, everyone. Thank you all so much for being here this early morning. I am Carson Pattillo and I’m the Vice President of National Education Programs for The Leukemia & Lymphoma Society. And it is my pleasure to welcome you to this continuing education symposium entitled Cancer Clinical Trials and the Underserved: Community-based Strategies.

I would like to thank our esteemed speakers, Bertie Ford and Mary Jackson Scroggins, for being with us today.

I would like to note that this program is supported through a cooperative agreement with the Centers for Disease Control and Prevention. And no commercial support funds were used for this activity.

Our program today will address many important topics, including the causes and impact of cancer health disparities, the importance of early intervention and access to care, the challenges of recruitment and retention of underserved populations into cancer clinical trials as well as strategies to enhance treatment access and trial participation, education support services for underserved cancer patients as well as community-based participatory research as a partnership intervention.
Our first speaker today will be Bertie Ford. And Ms. Ford is a clinical oncology specialist for Genentech BioOncology in the field of targeted therapies, health disparities and minority recruitment for clinical trials. She was co-chair of the Participant Navigation Team of the Eliminating Disparities in Clinical Trials Project, EDICT, and currently serves on the board of directors for ONS and director-at-large. She also serves as the ONS liaison to Sisters Network, a national organization for African American women with breast cancer. Ms. Ford is editor and co-author of the second edition of the Manual for Clinical Trials Nursing. She will be talking to us this morning about disparities in clinical trials. I’d now like to turn the podium over to Bertie and please help me welcome her.

Slide 2

Disparities in Clinical Trials

Ford:

Good morning.

Slide 3

Declaration of Independence

“We hold these truths to be self-evident. That all men are created equal, that they are endowed by their Creator with certain unalienable rights. That among these are life, liberty and the pursuit of happiness.” [sung]

A couple of weeks ago I had the awesome opportunity to attend the ICC [Intercultural Cancer Council] Biennial Symposium on minorities in cancer care. This slide came up. I’m sure many of you have not heard the Declaration of Independence being sung before and you probably never will. But it brought back memories that in choir. I do not sing and my son can attest to that. But I saw this slide and it brought back memories. In our choir we sang this song. We sang the whole Declaration of Independence. So I thought I would kind of wake you up this morning. I won’t be on American Idol, I promise you.

But I thought this was very poignant. We’re here in Philadelphia, the birthplace of our Declaration of Independence and the birthplace of democracy. We talk about the right to life.
And when we say that, we want people to have the right to a lengthy, healthy life. But unfortunately, for many Americans, that is not an option for them due to a multitude of causes and this is just not the case. So that’s what we’re going to talk about today.

**Slide 4**

**Advances in Medical Science**

“Profound advances in medical science have contributed to increased longevity and improved quality of life for many Americans.” Many of you know Dr. Harold Freeman, who I was able to talk with at the symposium a couple of weeks ago. Dr. Freeman to me is truly a phenomenal man who has really tried to bring health disparities to the forefront and this is one of his quotes.

**Slide 5**

**Despite These Advances . . .**

Despite these advances, some Americans have not fully benefitted from this progress, particularly the poor and underserved, and as evidenced by their higher cancer incidence and lower survival.

So a few statistics. Many of you have heard these statistics before. African Americans have a 33% higher mortality rate for all cancers combined, compared to Caucasians. Without sufficient minority enrollment in clinic trials, it’ll be very difficult to address these disparities, looking at whether it’s due to socioeconomic status or there are some particular characteristics of the race and response to treatment outcomes.

Use of new drugs or treatment is based on the results of well-designed, well-controlled clinical trials that are void of bias. They need to represent the full gamut of patients and the full gamut of people who are likely to benefit from these drugs. If we do not have adequate representation, we don’t know if all populations will benefit from these drugs.

Many of you do know that I work for Genentech. And many of you do know that the agent that I work with, Tarceva®, has shown significant improvement in most populations, but in particular people of Asian descent. So unfortunately, there are a very low number of African Americans
who were on the trial for Tarceva. So one of the institutions that I actually cover has a trial specifically to recruit African Americans to clinical trials with Tarceva. So of course, we have the overall benefit for populations, but we want to make sure that that benefit is for everyone.

I’m going to talk a little bit about health disparities. Then I’m going to talk a little bit about the hematologic malignancies. We all hear a lot about prostate, breast, colorectal and the differences in incidence and mortality. We don’t hear a lot of that with the hematologic malignancies, and since this is sponsored by The Leukemia & Lymphoma Society, I wanted to share some current data with you about that. Then I’m going to talk about some of the strategies and programs that are available, that many of you are familiar with, that it’s not a one recipe job to try to eliminate these disparities.

Slide 6
What is a Health Disparity?
So what is a health disparity? Well, there are three different definitions on this slide. Gaps in the quality of health and healthcare across racial, ethnic and socioeconomic groups. Population-specific difference in the presence of disease. Health outcomes or access to health. And then the NCI [National Cancer Institute] definition, adverse differences in cancer incidence, cancer prevalence, cancer death, cancer survivorship and the burden of cancer-related health conditions that belong to specific population groups.

There’s also biological variations. So variations in possession of poor prognostic indicators. Many of you’ve heard that African American women, though the incidence of breast cancer is low, the higher mortality may be due to the triple negative breast cancer.

There are coincident disparities. That means that the proportion of incidence is significant. For example, African American men have the highest incidence of prostate cancer. And then there are other coincident disparities related to the ability to have a health lifestyle. And a lot of us take that for granted. I take it for granted that it’s 1.5 miles from my house to the gym, because I know because I’ve jogged it, but there are people who can’t even leave their house and feel safe.
You know, we talk about children and obesity. Children can’t just go outside to play on the playground if they’re in an unsafe neighborhood.

We also talk about oh, you should just eat healthier. Well, if the closest store to you does not have any fresh fruit that looks tasty to you or fresh vegetables, that’s not going to be an option for you.
So those are kind of coincidental disparities.

Slide 7
Disparities Associated With Race, Ethnicity, Gender
Disparities are often associated with race, ethnicity, gender. When we think about women, there’s a greater risk for disparities among women. Income level. Sexual orientation. And I never really thought about that until I was at the ICC meeting and thought about well, what could be the difference there? But there are differences in lifestyles, differences in behaviors that can lead to an increased risk of cancer. Geographic locations. I’ll share a little bit about that later. And of course, age. Unfortunately, as we age, our incidence, of course, increases. Especially after the age of 65.

Slide 8
Institute of Medicine Report
Many of you have seen the report from the Institute of Medicine, Unequal Treatment Confronting Racial and Ethnic Disparities, and this report proved that unequal treatment is often provided. However, the title may lead one to think that it refers to minority groups. Institutions and investigators conducting cancer clinical trials many times don’t think it’s their responsibility to engender public trust, and public trust is one of the issues with recruitment of the underserved and minorities to clinical trials.

There’s a significant gap in life expectancy. We hear that life expectancy is increasing. Well, it is increasing for Caucasians, but for many that gap is either the same or even lower, so that – not gap, but that baseline is decreased or even lower, so that gap is actually increasing. And we hear that for the first time possibly children may have a lower life expectancy than their current
parents or grandparents. This is kind of like our financial situation. Our children may not have the same financial benefits that we experience because after all, the goal for our parents was that we did better. But with the current financial situation, our children may not do better.

Recently I read in *The New York Times* about a government-sponsored study that showed declines in life expectancy, especially for women in the Deep South, in Appalachia, along the Mississippi River and southern plains Texas. So this is pretty significant.

**Slide 9**  
**Insurance Coverage**

Just wanted to show this slide. I think everybody knows now that there are 45 million uninsured. We’ve heard that. I don’t know if any of you attended a special session, but that is truly the case, and we can only see that increasing with the state of our economic – our economy today. And under-insurance, or no insurance at all, is truly a deterrent to people entering on to clinical trials.

I know when I was a research nurse, I hated to even think about the financial aspect. My goal was to see this patient, see if he was eligible for the trial, hope that he consented to enter the trial and not have to worry about that financial part. Unfortunately, we can’t do that now. But definitely no insurance or being under-insured is truly a deterrent to patients entering trials.

**Slide 10**  
**Cancer Disparities Examples**

Let’s talk about the leukemias. Leukemia patients are one of my favorite types of patients to take care of and probably was because especially acute leukemias, when they came into the hospital, when I first was in nursing, it’s not so much the case now, they were with you for weeks, months even. So you got to know them very well, so you’d better like them. But I just want to talk a little bit about the different hematologic malignancies and some of the disparities there.

There are 1,500 new cases of all leukemias among Hispanic-Latino men. There were 1,100 deaths in 2007. 1,800 deaths in African Americans in 2007. And the five-year survival rate for African American blacks with all leukemias is 10% lower than for non-Hispanic-Latino whites. I
think we’ve done a very good job of educating – not a very good job, but we’re kind of high on the scale of educating people about colon cancer, prostate cancer, breast cancer, lung cancer and the signs and symptoms, and recommendations for screening. But of course, there are really no recommendations for screening for the hematologic malignancies.

I don’t know about you, but I really don’t want to start thinking about screening bone marrow biopsies. I think I would like to avoid those.

So of course, if you had a CBC [complete blood count] today, it may look a whole lot different with the diagnosis in two months.

So we do need to educate people more about the signs and symptoms of hematologic malignancy, especially just a reminder about bruising, fevers, unexplained night sweats, bone pain and weight loss. I don’t know about you, but if I started having weight loss I would certainly know that something was wrong.

One of the things about treatments and especially with certain types of malignancies, one of the things that I believe adds to the disparities is that people aren’t able to get – even though they start on treatment – people are not able to get their treatment as recommended. I know that many of you know about the importance of planned dose on time. That if your chemotherapy is supposed to be given every three weeks, every four weeks, as based upon the clinical trials, that’s when you need to get it. So if you have some things going on at home, you have transportation issues, you have other priorities that you think, “Oh, let me let my chemo wait a week” or “I don’t feel like taking it this week,” that is not doing the patient any good. We know that it’s very important for patients to stay on their treatment schedule.

Slide 11

AML Facts

I don’t know if any of you saw in The Wall Street Journal, it was April of 2008, about a woman who – and I won’t say the name of the institution – but a woman who was 52 years old, who was transferred from her hospital because they didn’t have a specialist who treated her type of
leukemia, she had AML [acute myelogenous leukemia], and she went to a larger center. But before she could be treated, she had to come up with $105,000 in cash. Did anybody see that article? And for those of you who have taken care of patients with AML, you know you don’t have a lot of time to think about where should I get treatment, when should I start treatment. No, they wanted $105,000 in cash from this woman. She had quit her job to take care of her mom, so she had not adequate insurance. They were able to mobilize some funds, so they came up with $75,000. I don’t know how many of us in this room could easily come up with $75,000. So they let her start her treatment with that. But just to know that this is possibly a trend.

A lot of hospitals have lost money on patients who don’t have insurance, but I can’t imagine going to somebody and telling them that they have to have cash up front to get their treatment. But this is what’s occurring. So this again can impact the health of our patients.

**Slide 12**

**ALL Facts**

ALL facts. Acute lymphocytic leukemia. Given equal access, we know that ALL is more common in children, but all children have similar benefit. Hispanic-Latinos have a higher incidence and mortality rate for ALL. Obesity in Hispanic-Latino children increases risk for relapse and obese children with ALL are more likely to experience the side effects of treatment, including hyperglycemia and risk of infection, relapse and mortality.

So for those of you who take care of patients with ALL, we know that the treatment is at least two, two and a half years. So there’s a lot of risk for noncompliance. I can tell you, I remember taking care of young – and of course, a lot of them were young – I remember this young man who was going on a date and he asked for his treatment to be delayed because he had an Ommaya reservoir and so his physician agreed. But that probably wasn’t helpful to him to get his treatment delayed. So there’s lots of room for noncompliance, not taking that methotrexate, not taking the steroids as you should and not coming in for your required treatment. So that can lead to poor outcomes.

**Slide 13**
CML/CLL Facts
CML [chronic myelogenous leukemia], CLL [chronic lymphocytic leukemia]. There’s a lower incidence in minorities. Survival rate is similar across all minority groups. But obesity again increases risk in Hispanic-Latino, white, African American black men.

We all realize that obesity is a risk for many malignancies, but I didn’t realize the impact that it had on our hematologic malignancies.

Slide 14
Hodgkin Lymphoma Facts
Hodgkin’s lymphoma. African American black children have lower event-free survival than non-Hispanic-Latino, white children. They have the same overall survival. Severe obesity, which is a BMI [body mass index] of greater than 35 kilograms, is associated with a higher risk of acquiring Hodgkin’s lymphoma. And African American blacks overall have a lower incidence.

Slide 15
NHL Facts
Another obesity correlation with non-Hodgkin’s lymphoma, 10% of cancer-related deaths among Hispanics and Latinos. Six percent of new cancer cases among African American blacks, though there is a lower five-year survival in African American blacks, non-Hispanic-Latino whites.

Slide 16
Multiple Myeloma Facts
I think we are all pretty aware that multiple myeloma is very significant in the African American population, especially among African American men. Hispanic-Latinos have a higher incidence rate compared to non-Hispanic-Latino, whites, and survival again is poorest among African American blacks.

Slide 17
Disparities in Clinical Trials
So clinical trials, which is why we’re here. The FDA [US Food and Drug Administration] did a review from 1995 to 1999 and basically minorities represent less than 10% of those enrolled in clinical trials. Again, this rate is correlated with income, socioeconomic status, education, insurance coverage.

I think if I were to look at a root cause, and we think about education, and we’re telling our children and telling everybody how important education is, so if you have access to a good education,— primary education — which will then allow you to go on to secondary education, pretty much you would hope that you would have an increased income level, have increased access to insurance and benefits. But if you don’t have that bottom good primary education, your benefits decrease without that education.

**Slide 18**

**Coalition for Cancer Cooperative Groups**

The Coalition for Cancer Cooperative Groups did a review from January of ‘03 to ‘05 and they found that in their trials 88.6% of the participants were Caucasian, 8% were African American, 2.8% were Asian-Pacific Islander, 5.6% were Hispanic-Latino and 0.5% were Native Americans. This was a study that was also in conjunction with the Patient Advocacy Foundation and Global Access Project.

**Slide 19**

**Enrollment by Race and Ethnicity**

This next slide gives you a pictorial about that.

And I have to say, The Leukemia & Lymphoma Society did a good job of that slide for me because I was trying to use SnagIt® and move it around and it was a challenge. Thank you.

**Slide 20**

**Who are Underrepresented?**

There are also other people who are underrepresented. The elderly. Of course, that’s when our incidence of cancer does increase, but two thirds of cancers occur in elderly, but only one third
of the elderly are on clinical trials. Again you look at access. Do they have adequate transportation? Do they have adequate resources?

Women are definitely not under-represented in breast cancer trials, but they are definitely under-represented in colorectal cancer and lung trials.

We know that children have the highest enrollment on clinical trials. Sixty percent of all children are on clinical trials. But once they reach the age of 15, only 10% of the adolescents are on clinical trials. And being the mother of a teenager, I can see why that would occur. Whereas your parents are letting you know that this is what you need to do, adolescents have a whole other idea of what they want to do and whether to enter on a clinical trial.

So actually when you think about ALL, we know that ALL is pretty treatable in children, but as you get into the teenage years and young adult years, even though you’re treating ALL kind of similarly to children, the outcomes are not the same. So they are looking at clinical trials with ALL that actually allow people to enroll until their 30s because they want to address this difference in outcomes in adults versus children being treated.

People with low income, regardless of their ethnicity, are under-represented in trials, as well as those in rural areas.

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**Slide 21**

**Patient Barriers**

So we know that many of you have heard about the various barriers. Just to review what the patient barriers may be. Cost and insurance and, unfortunately, that’s really at the forefront of whether people can participate in trials. Luckily, Medicare is covering clinical trials. And standard and Phase III trials, probably still not Phase I, but at least many of the things on Phase I trials are covered.

There are still cultural qualms related to research. There’s lack of awareness of clinical trials. I remember Mary was at a meeting presenting at the ICC and she talked about lack of invitation
and she’ll probably go into more of that, but that is very true, that many people are not invited to participate in clinical trials.

I remember I have a physician who’s a minority physician and he believed in clinical trials, but he would be the judge of whether he was going to present that trial to the patient, based upon whether he thinks whether they could actually comply with the trial.

I have to say that my son, who you’ll see a little bit later in this presentation, has been on two clinical trials. One of them was looking at adolescents and the impact of puberty on blood pressure and glucose. And most recently, which is a trial which I said – well, let’s just say he doesn’t have a choice, I just make him do it – but it was a trial comparing Southern boys with Midwestern boys and their future goals and their ideas about sex. So I had to sign the consent form and I said you sign and you put your information and put this in this envelope and seal it and I will not look at it. I don’t think I wanted to look at it really. But he’s been on two trials. But that’s because clinical trials are important to me. So you think if that happens to every family and they see a little clinical trial, they may want their member to participate. I’ve tried to participate on trials, but I have usually something that disqualifies me.

Language and linguistic differences are definitely an issue. In our town of Columbus, Ohio, we have definitely an influx of people from Somalia, so trying to communicate and have literature that’s specific to them, as well as Hispanic. But one thing that we have found is that just because – we should not assume that people can even understand and really read in their own language. That’s what we’re discovering. We have a liaison relationship with the community and we have found that people can’t even read in their own language. So we’re so happy to get things in the Spanish language. But they can’t even read that.

There’s still mistrust. And that’s why it’s very important to have a relationship with the community.

There’s practical obstacles, such as transportation, childcare, work.
Study design and eligibility criteria: we know that again many minorities have comorbidities. So if you’re on a trial, say Avastin®, and if you have uncontrolled hypertension, that is not a drug that you can receive. If you have other comorbidities such as hepatitis or a history of IV [intravenous] drug use and have some liver dysfunction, you probably won’t be able to enter on to a clinical trial. Or if you have uncontrolled diabetes, you may not be able to enter on to a clinical trial.

And again, disease stage. Sometimes, depending on where you are, maybe there are not trials for stage 1 or maybe there are not trials for stage 4, so even though people want to participate, they might not have the appropriate stage.

And of course, there’s lack of primary care awareness of clinical trials.

Slide 22
Physician/Investigator Barriers
There are physician barriers. So unless you have a good infrastructure, you may not be able to participate in clinical trials. There are definitely a lack of minority investigators. I know that the academic institution that I used to work with, right now though we have two, one in the GU [genitourinary] division and one in the community division, but that’s two African American investigators of all the hem-onc investigators.

Lack of physician referral. Again, lack of awareness. A bias about trials. So they may think oh, this is the better treatment, so I want you to get that treatment and not go on this trial.

We need to really make people understand that cancer clinical trials are something that are part of the standard of providing quality cancer care, so that people actually demand to be on a clinical trial if they’re eligible, not look at a clinical trial like it’s a scary thing.

In looking at applied clinical trials in January of ‘08, they documented that 9.3% of Caucasian physicians participate in clinical trials. Which I was shocked about that low number. And only
3.7% minority physicians participate in clinical trials. Many minority physicians are younger and they don’t actually have that infrastructure yet to participate in trials.

**Slide 23**

**Physician Benefits**

We have to remind the physicians of the benefits to participate in trials. The community visibility, the community relationships, the ability to network, the ability to participate in significant research and to make a difference earlier in the clinical trial projectory. Because as you know, it takes ten to fifteen years for a drug to be approved, so the more people who can participate and enroll patients in a trial, the better it is.

**Slide 24**

**Strategies**

So what are some of the strategies? The National Cancer Institute has a special populations branch that was started twenty years ago and they actually have then gone on to develop the Center to Reduce Health Disparities. There’s the website [on the slide]. So that’s an excellent resource for us.

**Slide 25**

**Promoters**

What other things can we do to promote clinical trials? Developing trust is truly a significant thing. So you don’t want to go to the community and say oh, we’d like you to participate in this trial, without ever having a relationship with them.

We need to understand patient fears. We need to do a lot of education about trials. I don’t know about you, I’ve done a lot of education. The NCI, the Oncology Nursing Society and many other organizations have done a lot of education related to trials, but we still need to do a lot more. We need to learn about patients’ concerns about trials, discuss cost, involve their families and ensure that you have a staff that’s committed to minority participation in trials. And I know we sometimes think how could people not be committed or you think how can people not be
committed to cultural competency or learning about health disparities. Well, I know this group is committed, but not everybody we work with is committed.

Slide 26

Promoters (Continued)

We need to make sure that we have a diverse staff. The staff are educated about trials. I was in the Clinical Trial Nurse SIG [Special Interest Group] meeting and many of us who work in research institutions, we have research titles, but there are staff who actually are giving the treatment, but they may not consider themselves research staff, so they have to be educated about the importance of clinical trials.

We need to have relationships in the community, form partnerships, eliminate those practice obstacles, if we can, such as transportation, parking. And instill the perceptions that clinical trials are truly a benefit for all.

Slide 27

Other Programs

Other programs. The NCI has community cancer programs, the CCOPs [community clinical oncology programs] and the DCOPs [Dayton Clinical Oncology Programs]. They have the Community Networks Program. We have the Minority-based Community Clinical Oncology Program that was instituted by the NCI, which is going strong, Cancer Disparities Research Partnerships, Patient Navigation Research Program, which I believe has nine institutions.

Slide 28

Other Programs (Continued)

We all have had access to what patient navigators are and do. There was a session yesterday. But they want to make sure that there’s some data that supports patient navigations, that the patients who are navigated have better outcomes. There’s the Network for Cancer Control Research among American Indian, Alaskan native populations. There’s ENACT, which is a website on your screen, Education Network to Advance Clinical Trials. The Community Physician Network, which I’ll share a little bit, and the NSABP [National Surgical Adjuvant Breast and Bowel
Project]. I was very lucky to be involved with NSABP and one of the NSABP diversity strategic planning work group people are here. That committee has been going on I think for eight or nine years and it is truly their role to increase recruitment of minorities to NSABP clinical trials. So it’s great, the NSABP, and I’m sure some other cooperative groups – I think CALGB [Cancer and Leukemia Group B] has a group that is starting. SWOG [Southwest Oncology Group] has had that in the past, that they have a committee devoted to developing strategies to increase minority recruitment to the trials.

Morehouse Clinical Research Center actually has developed its community physician network and they have over 165 practices that are involved. They started out with educating minority physicians about clinical trials and participation. Right now they’re actually in the process of getting low level clinical trials offered. So if you have a physician who’s interested in a clinical trial, it’s not like you can say oh, I just want to be in clinical trials, so you have to have that infrastructure. So start off with some low-level trials, participate as an affiliate with an academic institution or a larger community institution, and then go on to industry trials. Because industry wants to see that you’ve been able to complete and do adequate and appropriate and concise clinical trials from other institutions or other areas before participating in those. So this just started in 2006. Hopefully, we can see some good results from that group.

Slide 29

Patient Navigator Services
I don’t want to go too much in-depth into this slide, but patient navigator services are definitely an option for patients who are on clinical trials or are not on clinical trials, to help them get through that process and get them to the right place.

Slide 30

Intercultural Cancer Council
Some other resources are the Intercultural Cancer Council, which is a collaboration that started almost twenty years ago. They have a collaboration with the Baylor College of Medicine. Then they host this biennial symposium every two years, which was this amazing group of people,
who are all truly passionate about eliminating disparities. Not just in clinical trials, but eliminating healthcare disparities.

I was actually able to go to this biennial symposium because on behalf of ONS, as director-at-large, you get assignments as needed, and I was asked two or three years ago to attend EDICT, or Eliminating Disparities in Clinical Trials. So I was planning on going there and reporting what happened at EDICT. Well, it was really kind of a working meeting and people gave suggestions and strategies and ideas for looking at policy that might impact enrollment into clinical trials. So the next thing I know, they asked me to be on a committee. I’m like, okay, the next thing I know I’m co-chair of the committee and I’m like, how did that happen? But my committee was patient navigation. They developed nine opportunity teams and Mary will probably tell you about her team. We rolled out our recommendations at the biennial symposium. So EDICT has developed policy that will target insurance companies, that targets the legislatures, which hopefully will help to eliminate disparities in clinical trials. So it’s a pretty exciting opportunity.

Slide 31
A Nurse’s Role
As oncology nurses, we definitely need to educate ourselves about whatever disease process we have and about any strategies that are out there related to minority recruitment. We need to understand that disparities exist and why they exist. We need to practice culturally and linguistically competent health services and understand how respect is demonstrated in our patients.

One of the booklets that is actually produced by ICC, it’s called Cultural Competence in Cancer Care, I think this is a phenomenal book. I think it costs $6 and you can actually call ICC to order this. I think everybody should have this in their pocket. It’s excellent, it goes over Latino-Hispanics, it goes over Appalachians and rural Americans. It’s a nice little pocket guide.

Slide 32
A Nurse’s Role (Continued)
We need to address our environmental issues. We need to know that many times people who are underserved, who do not have adequate insurance, do not live in the most environmentally safe places. So understand how environment can promote their disparity. And accept that we have biases that may, if we’re not aware, interfere with our care.

**Slide 33**

**CCONS Community Outreach**

This is one of my colleagues, who’s actually sitting up here. Many of you know that I work as a clinical oncology specialist with Genentech. That is actually another name for a sales position. That’s what I’ve been doing for a year. I am blessed to be able to travel down into West Virginia and Portsmouth, Ohio. I love that job. But that job doesn’t give me a lot of time to really address my passion for addressing health disparities. Yeah, we have Tarceva and I help patients get that, but that doesn’t do it. So I say that’s the job that keeps the lights on in my house, but it’s working with my ONS chapter and the things that we do to try to improve care for the people in our community that keeps my heart light on. We have a community outreach committee that started in 1994. When I became president I remember – one of the few things I remember – is doing a presentation about cultural diversity. I said that one of the things I really wanted to do was have a community outreach committee, but you can’t do it on your own. But I had lots of colleagues who thought that was very important and we went from a committee of five to I think we have a committee of eighteen or twenty. So we’ve really been able to do a lot of things in our community.

And Ilene back here, who is our current president, was a truly phenomenal chair of our committee.

**Slide 34**

**Teaching Interpreters Breast Self-Examination**

Many of you know Jaci Holland, and there she is. One of the most exciting things that we’ve done recently is attend the Asian American festival. I’ve always said I wanted to go, but it’s Memorial Day weekend, so it’s coming up. But it was an amazing opportunity that we had. And we educated, my colleagues educated interpreters to then educate their constituents about breast
self-exam. And they had this education. We were in a nice little tent. And then the women went on to have mammograms. It was an amazing situation. We have ideas about people and one idea is Asian women are pretty proper, they’re not going to be – they’re going to be quiet and maybe not ask questions. See this woman there? Women were actually doing the breast self-exam on themselves. So it was a wonderful experience for us to interact and they didn’t care that some of us – what race we were. We were educating them about breast self-exam.

**Slide 35**

**Connie Gilbert Teaching BSE to Chinese Women**

Connie Gilbert, who’s one of our ONS chapter members, has done a phenomenal job this year educating a lot of women about breast self-exam and breast care and working – and she speaks Cantonese and Mandarin. I think she speaks a couple of languages, so she’s really been able to do a lot of outreach.

**Slide 36**

**Additional Solutions**

Some of the things that we can do, if they’re not available in your institutions, are to attend disparity lectures and conferences, participate in cultural awareness programs, and definitely communicate with each other. I think a lot of us in here are very open and just to be open to whatever experiences that we can have.

**Slide 37**

**Establish Programs and Departments**

Jaci Holland, who’s now a consultant for the Diversity Enhancement Program, she used to be a program manager, but has retired – don’t say retired to Jaci because I think she’s working sixty hours a week. But the Arthur G. James Cancer Hospital has a Diversity Enhancement Program and they do a lot of outreach in the community, do a lot of education to help establish that relationship, to help increase patients – to come to the James and then be on clinical trials.

And then again our ONS community outreach committee, we’ve received several grants from ONS that are available for cervical cancer education, breast cancer education, and I know that
ONS truly wants to increase the amounts of the grants that are for public education, and diversity and inclusion are truly a thread that ONS wants to continue and promote.

Slide 38
Sisters Network
One of the things the community outreach committee has also been able to do is to start a Sisters Network. Well, I would say we’ve been able to support a Sisters Network chapter in Columbus, Ohio. I don’t know if many of you know what Sisters Network is. It’s a national organization of African American breast cancer survivors that was started in Houston in 1999. So the core members are in pink and the rest of us are on the committee. But we’ve been able to partner with them with educational fashion shows. We had a welcome reception for them. So that’s another avenue for us, to get the word out about clinical trials.

Slide 39
Presentation by Sylvia Mand
A couple of weeks ago one of our members, Sylvia Mand, did an excellent presentation on cultural competence. We had a brunch on a Saturday, offered CEs, and she did an amazing job. So these are some of the things that your chapter can do to help increase your knowledge and your comfort with cultural competency.

Access to cancer clinical trials will speed up the drug development process and most likely will improve treatment or find an earlier cure for many cancers. There’s just not one issue, and Mary will talk about many other issues, and there’s just not one solution. We definitely need to work together to develop a positive outcome for generations to come.

Slide 40
Homecoming Photo
And this is my future generation. This is his homecoming picture. But tonight I’m going to be missing out, it’s his prom. He’s a junior, so he’s got one more year for me to pull out a lot of money for him to go to the prom. As long as I leave cash and gift cards, he’s good.
Slide 41

Closing Quote

I just want to close with this quote and the author is unknown. It’s fitting and how I feel about addressing disparities and making sure that there’s equal health [care] for all Americans.

“My life shall touch a dozen lives before this day is done, leave countless marks for good or ill ere sets the evening sun. This is the wish I always wish, the prayer I always pray. Lord, may my life help other lives it touches by the way.”

Thank you for your attention.

Pattillo:

Thank you very much, Bertie.