

Department of Health and Human Services

Office on Women's Health

2004 Minority Women's Health Summit

“Women of Color, Taking Action for a  
Healthier Life: Progress, Partnerships and  
Possibilities

Conference Report

The 2004 Minority Women's Health Summit was held on August 12-15, 2004 at the JW Marriott Hotel in Washington, DC. This conference was co-sponsored by the Department of Health and Human Services' (DHHS) Office on Women's Health (OWH), the National Hispanic Medical Association (NHMA) and the National Medical Association (NMA). Federal government partners included the Health Resources and Services Administration (HRSA), Substance Abuse and Mental Health Services Administration (SAMHSA), Food and Drug Administration's (FDA) Office of Women's Health (OWH), Office of Minority Health (OMH), Centers for Disease Control and Prevention (CDC), National Institutes of Health's (NIH) Office of Research on Women's Health (ORWH), and the Agency for Healthcare Research and Quality (AHRQ). More than 550 individuals attended and participated in the three-day conference. Participants attended four plenary sessions, two luncheon presentations, thirty-nine workshop sessions and two poster presentation sessions. Participants also had an opportunity to visit the exhibit room and wellness center to learn more about minority women's health programs and tools for self/family health promotion. The purpose of this report is to provide a brief synopsis of the sessions held at the conference.

The conference participants were also engaged in physical activity during the conference. Proceeding each plenary session there was a 20-minute workout session that was stimulating to all participants.

Evaluations for each plenary and workshop session as well as an overall conference evaluation form were completed by participants. The results of these evaluations are included at the end of this report.

## **Thursday, August 12, 2004**

### Opening Plenary Session I

#### Panel: Exploring Accomplishments in Minority Women's Health

The conference opened with welcoming remarks from Cristina V. Beato, M.D., Acting Assistant Secretary for Health, DHHS; Wanda K. Jones, Dr.P.H., Deputy Assistant Secretary for Health (Women's Health), DHHS; Elena Rios, M.D., President & CEO, National Hispanic Medical Association and James Christian, Sr., Esq., General Counsel - Director of Health Policy, Government Relations, & Regional Coordination, National Medical Association. The minority women's health overview plenary panel consisted of three dynamic speakers including Vivian Pinn, M.D., Director of the Office of Research on Women's Health, National Institutes of Health; Antonia Novello, M.D., Commissioner, New York State Department of Health, and Mary Chung Hayashi, Founder, National Asian Women's Health Organization. They presented new information and explored accomplishments in minority women's health that have taken place in the past seven years. They also reflected on current issues that need additional emphasis in order to improve health outcomes for minority women and their families.

**Friday, August 13, 2004**

Plenary Session II

Panel: Heart Disease – The Number One Killer of Minority Women

Barbara Yawn, M.D., Director of Research, Olmsted Medical Group; Elizabeth Odilile Ofili, M.D., Professor of Medicine, Chief, Section of Cardiology, Director, Clinical Research Center, Morehouse School of Medicine; Nanette Wenger, M.D., Professor of Medicine (Cardiology), Chief of Cardiology, Grady Memorial Hospital and Vivian Berryhill, Founder & President, National Coalition of Pastors' Spouses discussed heart disease with the audience. Dr. Wenger provided the audience with many compelling statistics regarding minority women and cardiovascular disease, risk factors, and some possible solutions to reduce CVD among minority women. Dr. Yawn described her current cardiovascular disease research in Olmsted County, Minnesota. Dr. Ofili emphasized the need to recognize the spectrum of differences in CVD diagnosis among women, and to empower them with knowledge. Some healthcare providers are not adequately prepared to make a true diagnosis, and women must advocate for themselves to improve the health care experience. Ms. Berryhill stated that the African-American church remains the primary vehicle in the Black community to rally people, launch movements, and influence the masses, and churches are prime sites for preventive cardiovascular disease programs.

Luncheon/Presentation I

Panel: Diabetes – What You Don't Know, Can Kill You

Lillian Tom-Orme, Ph.D., MPH, RN, FAAN, Research Assistant Professor, Health Research Center and Rovenia Brock, Ph.D., Author, *Dr. Ro's Ten Secrets to Livin' Healthy*, President, Dr. Ro Gear, Inc. spoke to the audience about diabetes. The theme for this panel was "What You Don't Know Can Kill You." Dr. Tom-Orme indicated that the theme for this session would be inappropriate and perhaps frightening for American-Indian Alaska Native populations. She added that a more appropriate theme would be "There are Dangerous Obstacles on Your Journey". American-Indian Alaska Native people believe life is a journey, and speak in terms of being on a journey. Traditional cultural practices and beliefs are very important. These practices have been modified over the years, often resulting in less healthy lifestyles. There is inadequate minority representation among public health professionals, clinicians, and researchers. This is especially true in native populations. Other significant challenges for American-Indian Alaska Native populations are diabetes, and increased tobacco use among women.

Rovenia Brock discussed making small, incremental changes to lead a healthier life and prevent diseases related to diet, obesity and overweight (e.g. diabetes and heart disease). She emphasized that these conditions are not a natural part of the aging process, but are often perceived as such.

## **Workshop Session A**

### Cardiovascular Disease

Corliss McKeever, M.S.W. and Kathleen C. Ashton, Ph.D., APRN, BC gave two presentations and conducted a question and answer session about cardiovascular disease.

Corliss McKeever discussed her program focused on African Americans in Portland, OR entitled, "Lookin' Tight Livin' Right." This is a "train the trainer" program utilizing existing relationships between beauty/barbershop operators and their clients to gain access to the target population. Its overall goal is to reduce cardiovascular disease (CVD) among African Americans in Oregon. The objectives of this program are to promote physical activity, smoking cessation, nutrition education, and use of preventive clinical services. Data showed that the program was reaching African Americans at risk for CVD. Delivering preventive health education messages through beauty and barbershop operators was shown to be an effective method in this community.

Kathleen Ashton discussed a program being implemented in New Jersey entitled, "WHF Teen Esteem Fitness and Nutrition Program". This program is for sophomore girls at Trenton Central High School. This program addressed the link between metabolic syndrome and minority women's risk of heart disease. The program is a school-based, girls-only intervention that replaces the health and physical education class. It was offered to 10<sup>th</sup> grade girls in an inner city high school beginning in September of 2004. The program consists of an aerobic fitness routine (30-minutes, 3 times per week), regular health education curriculum, nutrition and meal planning, special guests, activities and assignments.

### Diabetes

Carolyn N. Oguda, M.B.A., HCA; Ellen Boneparth, Ph.D.; Ann G. Pauli, M.A.O.M., C.P.A. and Helen A. White, M.B.A. discussed diabetes with the audience.

Carolyn N. Oguda discussed a program entitled, "Change for Life/Cambia Tu Vida." This program is being tested by the New Hampshire REACH 2010 Initiative. It is a community-based, behavior change program for African descendents (in English) and Latinos (in Spanish). The program uses the Transtheoretical Behavior Change Model to help participants change risky behaviors related to diabetes including diet, physical activity, overweight/obesity, smoking, excessive alcohol use, and poor stress management. The goal of the program is to make knowledge of healthy behaviors and the process of behavior change a common topic of conversation. An evaluation of the pilot program suggests that it has been effective in stimulating behavior change and has resulted in weight loss and improvement in participants' quality of life scores.

Ellen Boneparth shared the three typical segments of diabetes prevention messages: dimensions of the problem, warning signs and risk factors, treatment and/or prevention strategies. When discussing dimensions of the problem, simple, dramatic and personal statistics are often used. When discussing warning signs and risk factors, it is important to encourage women to look introspectively for warning signs in their lives. Common

messages that incorporate prevention strategies include linking diabetes to obesity, linking diabetes to other diseases, complications related to diabetes, and lifestyle modifications including diet and exercise. Existing messages are typically negative, blaming and overwhelming. It is important to change the message and change the messenger. Characteristics of a good message include being positive, supportive, repeating and reinforcing. Characteristics of good messengers include having a shared background with the audience and being able to provide group support and follow-up activities.

Ann G. Pauli discussed the Paso del Norte Health Foundation. The mission of this foundation is to effect long-term improvements in the health status of the population through health promotion and disease prevention initiatives, partnerships and educational campaigns in the Paso del Norte region of the U.S.

Helen A. White discussed the incidence, etiology, diagnosis and treatment of Type I and Type II diabetes in women at various stages of life. She also discussed socio-economic factors facing women with diabetes, sources and types of health coverage, lifestyle changes essential to achieving and maintaining optimum health, the role of women in families, and breaking the chain of diabetes in families.

#### Coordinating Committee on Women's Health

PonJola Coney, M.D. and William Catherino, M.D., Ph.D. discussed benign gynecologic conditions including fibroids, polycystic ovarian syndrome (PCOS) and endometriosis with the audience.

Endometriosis affects at least 5 million reproductive-aged women in the United States. Characteristic symptoms include pelvic pain, pain during sexual intercourse, and infertility. During menses, pelvic pain is worse but it can also occur in the abdomen or chest. The pain is caused by uterine tissue that has spread, through an unknown mechanism, to other parts of the body where it remains responsive to monthly hormonal cycles. Recent research has shown that women with endometriosis have abnormalities in natural immunity; the disseminated uterine tissue provokes an autoimmune response, but that response is ineffective in clearing the tissue from the body. Instead, it continues to grow and spread. This is a very active area of research, and it may provide new approaches to treatment. Endometriosis tends to improve or resolve entirely at menopause.

Polycystic Ovarian Syndrome, or PCOS, affects an estimated 3 million women in the United States, including 3%-5% of African American and Caucasian women. One study has estimated a prevalence of 21% among Pima Indian women. Women with PCOS may show few symptoms until the condition is well developed. Symptoms include infrequent periods, acne, and growth of body hair that reflects an excess of male hormones. Infertility and miscarriage are more common among women with PCOS. Insulin resistance is a hallmark characteristic of PCOS, and it amplifies the male hormonal activity. Many women with PCOS are obese and carry increased risk of heart disease and endometrial cancer. Current research seeks to reduce insulin resistance with a variety of

drugs and other therapies, including lifestyle changes. Menopause can have minimal effect on PCOS, as the male hormones continue to circulate.

Uterine Leiomyoma, or Fibroids, may occur in almost all women, although most will have no symptoms. For unknown reasons, African American women are three times more likely to develop symptomatic fibroids than Caucasian women. Symptoms include one or more palpable masses in the uterus or pelvis, irregular and heavy menstrual periods, infertility, miscarriage, preterm labor, chronic pelvic pain, and urinary incontinence. The heavy menstrual bleeding can cause anemia, sometimes requiring blood transfusion. Recent research suggests a disruption in cellular signaling pathways, with circulating reproductive hormones stimulating growth of fibroid tissue. Molecular studies have identified a growth mechanism shared by fibroids and keloids, but more research is needed. This relationship may explain the increased risk of symptomatic fibroids among African American women, who also are more prone to keloid formation. Fibroids tend to shrink and become much less bothersome after menopause.

#### Nutrition

Kim-Phuc Nguyen, M.S.; Linda S. Boeckner, Ph.D., R.D.; Yolanda Gale Pearson, M.S., R.D., CDE and Soundrea Hickman, Ph.D. discussed several aspects of nutrition with the audience.

Kim-Phuc Nguyen discussed cancer prevention through nutrition education among Vietnamese communities in California. The goal of this project was to develop and evaluate a culturally sensitive and relevant nutrition education program for low-income Vietnamese immigrants to reduce their risk of developing cancer. The results showed that the mean cancer prevention knowledge score and dietary quality score were significantly higher for the intervention group, and that a significant increase in exercising occurred among intervention participants.

Linda S. Boeckner's presentation focused on rural Hispanic women. Her project examined differences in eating and physical activity behaviors, selected health conditions, and behavioral determinants for eating and physical activity across three weight categories among rural Hispanic women. The results showed that 25.7% of participants reported having diabetes, with significant differences in the presence of diabetes demonstrated across weight categories. Significant differences in blood pressure were shown in obese women compared with normal weight women. Time limitations and pervasiveness of unhealthy food were the predominant perceived barriers to physical activity and healthy eating. Educational interventions for Hispanic women should include assessment of risk factors and behaviors related to exercise and physical activity.

Yolanda Gale Pearson discussed the program, 'Habits Not Diets, Six-Week Weight Control Program' with the workshop audience. Week one involves a discussion of habits that lead to weight gain and appetite triggers. In week two, participants discuss the reduction of risk factors. Week three consists of a discussion on meal planning, menu makeovers, meal ideas and developing a new meal plan. Week four topics include shopping and cooking smart, using the food label to your advantage, and using healthy

convenience items. Week five discussions center on a healthy approach to fitness, setting up a fitness program, motivation tips, and making wise choices when dining out. The focus of week six is overcoming barriers and maintaining lifelong habits.

Soundrea Hickman has studied the impact stress has on our bodies and health. She analyzed existing research to determine what methods can be utilized to gain mastery over the stressors in our lives. The objective was to teach quick fix strategies as well as life long strategies to reduce vulnerability to stress, better prepare for stressful periods, and recover from stress. She found that stress diminishes effectiveness, and too much stress over a long period of time can be harmful and even debilitating. The seminar provided participants with a collection of invaluable stress management tools.

#### Centers for Disease Control and Prevention

Linda Teplin, Ph.D., Mary Muse, R.N., M.S.N., CCHP and Veronica Sanders discussed health and mental health issues among incarcerated women with the workshop audience. The number of women arrested, jailed, and imprisoned in the United States continues to increase. From 1995 to 2002, the average annual rate of growth of the female inmate population was 5.2%, higher than the 3.5% increase in the male inmate population. By year-end 2002, women accounted for 6.8% of all prisoners, up from 6.1% in 1995. This meant there were 97,491 women in State and Federal prisons. Women entering jails and prisons have higher incidences of chronic physical and mental illnesses and often have significant histories of early childhood sexual abuse, substance abuse, and addictions. A recent CDC study estimated the rate of early syphilis cases among women in correctional facilities in 30 counties was 11.8 percent. The Bureau of Justice Statistics estimates that 2.9 percent of all women in state prisons are known to be HIV-positive, with nine states reporting rates of greater than 5 percent. A significant percentage of women enter jails and prisons for committing crimes involving violence. These women have often experienced dysfunctional family relationships or substance abuse problems. A continued focus on the challenges of addressing chronic and infectious diseases, mental illnesses and the issues of transition back into the community for these women is critical.

#### Health Education

Zoraida Ettrick, B.S., Ellen Eidem, M.S. and Judy Ann Bigby, M.D. discussed health education with the workshop audience.

Zoraida Ettrick discussed a program entitled, 'Women Together for Health'. This program addresses the health risks of cardiovascular disease and cancer by focusing on physical activity and basic nutrition principals. The mission of empowering women for a healthier tomorrow guides the curriculum and activities. A twelve-hour (8 or 12-week) behavior change intervention is offered in English and Spanish at schools, community centers, and worksites. It targets women with limited incomes and education. Preliminary data from the program (as measured by pre- and post-surveys), revealed positive trends in dietary quality, awareness of weight and health risk, increased physical activity, reduction in stress, and improved stress management skills among the participants.

Ellen Eidem discussed the Women's Health Mobile Clinic Outreach Program. This program started in May of 2002 as an all-volunteer effort. More than two thousand women have been screened at over 100 sites. The target population of this program includes 'at risk' women in Los Angeles County, uninsured, <200% FPL, specific ethnic groups – Latina, African American, Armenian, Korean, Chinese, and Filipina women, recent immigrants, and those in underserved areas of Los Angeles, CA. The goals of the program were to improve the health of 'at risk' women in Los Angeles County, to provide preventive health screenings, improve access to care, and increase awareness about health risk factors.

Judy Ann Bigby discussed a program designed to develop and evaluate a model curriculum to improve faculty ability to address and teach about the needs of minority and other underserved women. Faculty assessed curricula, identified objectives, developed a multi-session curriculum, and designed and implemented a two-day training for thirteen Center of Excellence faculty representatives. The training included didactic sessions, experiential learning, group exercises, and problem solving. The curriculum was evaluated through self-assessment questionnaires, session evaluation forms and telephone interviews. Learners attended a training session to review the curriculum and strategize implementation. They rated the training as excellent, and rated the historical context of minority women's health, working with interpreters and case discussion as the most valuable sessions. Learners' assessment of their cultural competency skills increased post-training. The most growth occurred in their ability to locate resources, train others to obtain culturally competent medical histories, and apply cultural information as hypotheses. Learners planned to incorporate the curriculum at their home institutions. The results suggest that institutions can successfully collaborate to develop curricula, and that learners desired more emphasis on implementation strategies.

### Pregnancy

David E. Berry, Dr.P.H., Frances Walker, M.S. and Silvia Henriquez, M.A. discussed the topic of pregnancy with the workshop audience.

David E. Berry described a case study of hospital utilization among Hispanic women with gestational diabetes in the Texas-Mexico border area. The results showed that utilization of inpatient hospital services by border women is significantly less than the rest of Texas, and all pregnant Hispanic women in Texas. Explanations may include the impact of low insurance coverage, high Medicaid coverage, other access barriers to local organized health services, restrictive public policy and a harsh economic environment. Evidence-based, accessible diabetes services are needed to assure appropriate care at the border.

Frances Walker discussed the 'Target Outreach for Pregnant Women Act' (TOPWA), which was established in 1999. Its goals are to find and provide services to pregnant women at risk for delivering an HIV-infected or substance-exposed infant, who are not receiving adequate prenatal care. The objective of the program was to reduce perinatal HIV transmission in Florida by helping at-risk pregnant women access the health and



social service system. Close to 13,000 pregnant women have been enrolled in the program, and TOPWA has conducted over 9,000 HIV tests.

Silvia Henriquez substituted for Destiny Lopez during this session. She discussed Latinas and reproductive health. Lack of health insurance, cultural and linguistic differences, poverty, discrimination and lack of awareness all contribute to poorer reproductive health outcomes for Latinas. This presentation identified the most pressing reproductive health care issues faced by Latinas living in the U.S. They examined factors that contribute to poor reproductive health outcomes, and the goal to work with advocates developing action-oriented strategies to communicate with Latinas about accessing reproductive health care services.

Agency for Healthcare Research and Quality (AHRQ): Advancing Patient Centered Care  
Cindy Brach, M.P.P.; Rosaly Correa-de-Araujo, M.D., M.Sc., Ph.D.; Harvey Schwartz, Ph.D. and Anne Beal, M.D. discussed many issues around advancing patient centered care with the workshop audience. Research has shown that the way in which patients and health care providers communicate with each other can have an impact on patient satisfaction, quality of care, and patient outcomes. Good communication is essential to achieving patient-centered care and is better achieved through health care providers who are culturally competent and patients with certain level of health literacy. This session addressed health literacy, cultural competence and how they affect health outcomes and the relationship between health care professionals and patients. The presentations focused whenever possible on gender differences across racial and ethnic and age groups and on strategies to overcome barriers toward improvement of cultural competence/health literacy. A consumer perspective was also discussed, making the session very useful for all types of audience. The session was well attended and the speakers received a great deal of positive feedback, with numerous relevant questions raised at the end, which resulted in a dynamic discussion and exchange of information. In addition, the session brought together a diverse group of practitioners and researchers interested in advancing patient care in diverse populations.

#### Minority Women's Health Panel of Experts Session

Nancy Atmospera-Walch, R.N., M.P.H., NHA, CDE, CHES led a group discussion focusing on the issue of health literacy. The discussant assessed the experience, knowledge of the discussion group and discussed what they wanted to learn about health care literacy. The majority of the group did not have previously knowledge of health literacy issues. The group also watched a video developed by the American Medical Association on Health Care Literacy. The video included several cases that illustrated health care literacy issues. After each case, the group had a discussion about the case. Ms. Atmospera-Walch also shared with the group an actual experience she has had dealing with low literate patients and what strategies she has used to deal with this issue.

### **Workshop Session B**

#### Cardiovascular Disease

Repeated from Workshop Session A

Diabetes

Repeated from Workshop Session A

Coordinating Committee on Women's Health

Repeated from Workshop Session A

Substance Abuse and Mental Health Services Administration (SAMHSA)

Jackie McKinney, Imani Walker and Dalimarie Perez, M.P.A., C.A.S.A.C. discussed substance abuse and mental health across the lifespan of women. Dalimarie Perez discussed issues related to Hispanic girls. Her presentation focused on the need to gain understanding of diversity issues faced by Hispanic girls, to identify trends and at-risk behaviors facing Latino youth, and to identify effective prevention materials and programs targeted to Hispanic girls.

Breastfeeding

Nicole Prudent, M.D., M.P.H.; Sherry Payne, B.S.N., R.N.; Charlene Burnett, B.S.N., R.N., IBCLC; Ursuline Singleton, M.P.H., R.D. and Rebecca F. Sze, F.N.P., M.S.N., M.P.A. discussed breastfeeding with the workshop audience.

Nicole Prudent's presentation explored cultural and systemic barriers to breastfeeding among African American women in the U.S. She reviewed the implementation of the 'Baby-Friendly Initiative' in an urban setting. The results of the initiative showed increased rates of breastfeeding in a hospital serving a multi-ethnic population.

Sherry Payne and Charlene Burnett discussed the Community Demonstration Project, which is designed primarily to promote breastfeeding among Healthy Start participants. The participants were "at-risk" families residing in Kansas and Missouri. The goal of the Community Demonstration Project is promotion of breastfeeding among women of color, with a focus on illness prevention. Breastfeeding rates among project participants increased by twenty percent, and improvement in perinatal outcomes was also noted.

Ursuline Singleton provided information on "Fathers Supporting Breastfeeding", a breastfeeding promotion project in the Special Supplemental Nutrition Program for Women, Infants and Children (WIC). This was one of several initiatives designed as part of a continual effort to increase breastfeeding initiation and duration in the WIC program. This project focused on educating fathers about the benefits of breastfeeding so that they can have a positive impact on their partner's decision to breastfeed. The goal was to provide breastfeeding education and awareness to fathers, and highlight the important supportive role they have in making breastfeeding successful. The primary target audience for this project was African American males.

Rebecca F. Sze discussed breastfeeding among Asian American Women in New York City. An initiative was launched to raise awareness of the benefits of breastfeeding in the Asian American community, and to increase the rate of breastfeeding among Asian

American women visiting the Women's Health Department at the Charles B. Wang Community Health Center (CBWCHC). The initiative was launched utilizing workshops, the Chinese language media, and breastfeeding doulas. Focus groups were conducted to obtain feedback on the breastfeeding program. The results indicated that the percentage of postpartum women visiting CBWCHC that continued breastfeeding at three months increased by fourteen percent.

#### Sudden Infant Death Syndrome (SIDS)

Andrea C. Furia, Stacy Scott and Julia B. Anderson discussed Sudden Infant Death Syndrome with the workshop audience. SIDS rates have fallen markedly in all U.S. populations since scientists found that putting infants to sleep on their back reduces the risk of SIDS. However, SIDS rates among African American infants remains double that of Caucasians. The National Institute of Child Health and Human Development formed a strategic alliance with three national women's leadership organizations focused on reducing the risk of SIDS in African American infants. The alliance organized three regional summit meetings that attracted over 1,200 members. Those who attended the summit meetings now serve as catalysts for SIDS risk reduction activities in their communities. These strategic alliances form effective community infrastructures to reduce health disparities.

#### Access to Care

LaVonne M. Moore, R.N., MA, C.N.P., M.S.; Mercedes Moore, B.S.; Victoria D. Ojeda, Ph.D., M.P.H. and Susan Staskowski, B.S.W. discussed access to healthcare issues with the workshop audience.

LaVonne M. Moore discussed utilizing community-based collaborative action research at the NorthPoint Health & Wellness Center in Hennepin County, Minnesota.

Mercedes Moore discussed the Latino Health Initiative of the Montgomery County Department of Health and Human Services in Maryland, which has recruited and trained lay health *promotoras*. The *promotoras* (primarily Latina) reach out to their neighbors to facilitate enrollment in the Maryland Child Health Program. They also deliver information about available health services and healthy lifestyle practices that can reduce health disparities. The *promotoras* navigate language and cultural barriers, help hundreds of Latino families obtain health insurance and services, and teach healthy behaviors. In turn, the *promotoras* gain increased self-confidence and leadership skills.

Victoria D. Ojeda described the health status of women in California ages 65 and older. She described the diverse racial/ethnic groups, demographic and socioeconomic characteristics, health insurance coverage and use of health services among these women. Almost sixty percent of California's 3.4 million adults aged 65 and older are women. The majority of older women are white. Latinas are the next largest group, followed by Asian American and Pacific Islanders, African Americans, American Indian/Alaska Natives and all other groups. About forty percent of Latina, AAPI, and African American women report a fair/poor health status compared to twenty-five percent of non-Latino white women. Women's ability to perform moderate activities declines with age

and is related to poorer health status. Higher rates of poverty among racial/ethnic women increase their likelihood of being dually eligible for Medicaid and Medicare. In contrast, white women are more likely to have Medicare and other forms of insurance. These study findings are relevant for healthcare providers, public health practitioners, and policy makers. The changing population of older adults is likely to have diverse healthcare needs due to socioeconomic and demographic factors.

Susan Staskowski discussed the Women's Self Employment Project (WSEP). This project involved client surveys to investigate health insurance coverage and price of services. Results showed that clients could not afford the cost of health insurance or health care services. A literature review was conducted to find non-traditional options.

### Lupus

Kelli Carrington, M.A.; Mara T. Adams, A.B., V.P.; Carmen C. Ferlan, M.P.H., M.I.S. and Trina Evans-Williams discussed lupus with the workshop audience.

Kelli Carrington discussed the Health Partnership Program (HPP), which is a community-based medical research program operating as a collaborative effort between NIAMS and Washington, DC area community leaders and representatives. The project utilizes biomedical and behavioral research with underrepresented patients affected by arthritis and other rheumatic diseases. The program aims to enhance understanding of health disparities and their causes, and provide direction for improving the health status and health outcomes of the minority communities affected.

Mara T. Adams discussed the ways nonprofit health advocacy organizations have successfully reached out to minority populations. She described a coordinated national effort to raise awareness and education and increase research funding for lupus.

Carmen Ferlan discussed the Lupus Awareness Project. This is a culturally relevant lupus intervention using lay health workers (promotoras) to encourage patient-self-management. The objectives are to provide basic information about lupus, teach health behaviors that may reduce organ damage and other complications, suggest ways for the family to foster positive health behaviors, support and teach the person with lupus and depression to maintain a normal lifestyle.

Trina Evans-Williams discussed the Louisiana Lupus Awareness and Education Project. The purpose of this project is to increase the awareness of Systemic Lupus Erythematosus (SLE) throughout the target area by providing informational seminars to public health staff and other health care workers, by increasing the capacity of community-based and faith-based organizations to address SLE as part of their health outreach work, and by providing information and education opportunities to women. The Louisiana Lupus Awareness and Education Project organized six information seminars in the spring 2004. A total of one hundred and twenty nine individuals participated in the project. Post-seminar surveys indicated that 94.1% of project participants were more informed about SLE after attending the seminars.

Organ and Tissue Donation

Mary Ganikos, Gloria Brooks, Erma Jean Lawson, R.N., Ph.D. and LaFrancis Rodgers-Rose, Ph.D. discussed organ and tissue donation with the workshop audience. Mary Ganikos described the Health Resources and Service Administration organ and tissue donation programs. Gloria Brooks is an organ recipient who shared her personal story of survival. Erma Jean Lawson and LaFrancis Rodgers-Rose discussed psychosocial dimensions of heart transplant. Their experience has included both rural and urban African American women. LaFrancis Rodgers-Rose is a heart transplant recipient.

Minority Women's Health Panel of Experts Session

Mary Harper, Ph.D., R.N., FAAN, LLD, DSc; Evaon Wong-Kim, LCSW, M.P.H., Ph.D. and Ming-der Chang, Ph.D. led a group discussion focused on partnerships between communities and research institutions such as universities. Although community agencies need the expertise of research institutes and can offer research subjects, universities often do not see the benefits of involving community agencies. Some participants suggested that involving local community agencies was perceived as a waste of time by the university. Also, the tenure process for many junior faculty members incorporates minimal emphasis on community activities. The structure of the university and its tenure review process should be revised so that work with the communities is encouraged and recognized. The government can provide funding for research that insists on community participatory research in order to ensure true partnership between these entities.

**Saturday, August 14, 2004**

Plenary Session III

Panel: HIV/AIDS – Take the Power to Prevent It

Jane Fowler, Founder/Director, HIV Wisdom for Older Women; Barbara Aranda-Naranjo, Ph.D., R.N., FAAN; Hydeia Broadbent, Hydeia Broadbent Foundation and Yvonne Davis, M.P.H., Independent Consultant – HIV/AIDS and Women discussed HIV/AIDS with the audience.

Jane Fowler stressed the importance of dispelling the myth that seniors do not engage in sexual activity and are therefore not at risk for sexually transmitted diseases. Many seniors are sexually active, but may not realize that unprotected sex is unsafe unless the relationship is mutually monogamous and neither partner is STD-infected. Jane Fowler's personal commitment and passion is to reach older women (who comprise a larger proportion of the single senior population) with a message that could save their lives. HIV does not discriminate...it is not how old you are, but knowledge and behavior that impact transmission. Senior citizens currently account for between thirteen and seventeen percent of the AIDS cases in America, and nearly eighteen percent of the female AIDS cases are in women over fifty (the majority in women of color). Many older individuals with HIV are invisible, isolated, and ignored. Older women must understand today's risks and be aware of steps to protect themselves.

Barbara Aranda-Naranjo discussed how the context of our lives shapes what we think, what we feel, and what decisions we make. Our cultural beliefs shape our perception of that context, our social support, families, friends, and colleagues in our community. What happens when our experience is negative, and the people that can help us appear alien and removed from our cultural beliefs and way of life? She shared several stories about women she has served and the lessons they have taught her about living with HIV and feeling disconnected within the health care system. She asked the audience of women and fellow providers what we could do to make changes in our communities. She believes the standard of care for women is insufficient. The holistic approach of including psychosocial, cultural, and spiritual components of a person's life must be considered. If these issues are not addressed at every visit, especially the first encounter, women will not return. She believes our health system is fragmented, and we as providers and community members need to "stand in the gap" for women and for all family members. The gap represents the lack of quality of care provided to women, especially minority HIV-infected women. Many of our health departments and clinics are experiencing serious economic problems. She encouraged volunteering at least three to five hours a month to ensure that our community clinics and agencies are maintaining the standard of care we would like for ourselves.

Hydeia Broadbent provided a personal statement about being HIV positive. She was born in 1984 to an intravenous drug user. Hydeia's mother became infected with HIV and passed it on to Hydeia at birth. Hydeia was adopted when she was an infant and diagnosed with HIV at three. The healthcare professionals said that she would not live to be five years old. Hydeia started speaking out because kids were not as open as she was about her status. She would tell somebody in a heartbeat, "I have AIDS." She did not know that there was something wrong with having AIDS. She did not know that she was supposed to be ashamed. She did not know that supposedly, she did not have a future. Hydeia told the audience about her life now. She has graduated from high school, and will be a freshman at North Carolina Central University in January 2005. She is 20 years old. She has had boyfriends. She has best friends. She has one mother and one father. She has appeared on "Oprah," "20/20," "Maury," and "BET" numerous times, sharing the message of how important it is to get tested for HIV and know your status. She didn't fit the criteria of what people expected her to be, and she's proud because now her sister is able to say that she has HIV without anybody in their community fearing her. She's proud because other kids that go to her school now can say that they have HIV and not worry about being kicked out. She ended with: "So what I'm saying today is that, that's me."

Yvonne Davis gave the audience an example of what American Indian and Alaska Native women are facing in the fight against HIV/AIDS, and risk factors they experience that compound the problem. She explored some prevention strategies that work. However, there are only limited numbers of strategies that have been proven effective in the American Indian, Alaska Native, and Native Hawaiian communities. She identified a strategic process in working with this community and described dialog with indigenous leaders. She discussed how you can address current HIV and AIDS health issues for

indigenous women and then recommended action-oriented strategies. More strategy development targeted to this population is needed.

### Luncheon/Presentation II

#### Panel: Cancer – How to Reduce Your Risk

Linda Burhansstipanov, M.D., President/Executive Director, Native American Cancer Research, Corp. (NACR), Native American Cancer Initiative, Inc. (NACI); Amelie Ramirez, Dr.P.H., Associate Professor, Dept. of Medicine, Baylor College of Medicine, Center for Cancer Control Research and Alexine Clement Jackson, Chair, Intercultural Cancer Council presented information about the many aspects of cancer.

Linda Burhansstipanov indicated that little money is allocated for cancer in Indian country. However, breast cancer rates in the Southwest are increasing every year among Navajo, Hopi, Apache, and many of the Pueblo tribes. Even though rates are low, they are increasing, and the data does not reflect that. Another example is cervical cancer. The rates of cervical cancer among the northern plains of the U.S. are quite high. The factors involved in these rates are lifestyle, environment, and heredity. Lifestyle is the most significant risk factor for cancer among this population. Overall health is important for cancer prevention. Linda Burhansstipanov posed several questions: "What do I need to do spiritually to be a strong woman? How do I walk the path of wellness and good being, and how do I become a model to my children, my godchildren, my little nieces, my nephews?" Most American Indian communities are not interested in disease-specific prevention, but how to achieve overall health and well-being.

Amelie Ramirez discussed cancer among Hispanic/Latina women. The primary challenges of breast cancer educational outreach (particularly among racial/ethnic communities) are barriers posed by myths and misconceptions about the disease. These perceptions often result in under-utilization of cancer prevention strategies, such as mammography and participation in breast cancer research. Although breast cancer is less common among Latina women than among Caucasians and African Americans, it is also the leading cause of cancer death among Latina women, and their five-year survival rates remain lower than those in other ethnic groups. These troubling statistics may be due in part to insufficient access to health care and lack of insurance. However, many health educators attribute poor outcome in Hispanic and Latina women to certain cultural beliefs that create obstacles to early detection and discourage open and proactive management of breast cancer. She discussed common attitudes and beliefs among Latina women that health care providers and minority community leaders should be aware of as they plan programs to promote breast cancer early detection. Greater participation by Latinos in clinical trials is vital in order to better understand risk factors and the impact of cancer among Latino populations. This presentation was based on focus group data and survey results of *Redes En Acción*. This national media campaign aimed to raise awareness of cancer research and increase participation in cancer clinical trials among Latinos. Additional data came from a research study entitled 'Clinical Trials Outreach for

Hispanics', whose goal was to determine the most effective and efficient outreach strategies for increasing clinical trials awareness among Latinos and other groups.

Alexine Clement Jackson believes we have the opportunity to save our lives by examining risk factors we can avoid to prevent disease. She described the STEP strategy. The S is to stop risky behavior. The T is to take charge. The E is to educate yourself and your family about cancer risks. The P is to participate (in clinical trials, public education, collaboration, activities that allow you to tell the story or to give the message, and in advocacy). She encouraged lobbying, writing letters, working to change health policies that deal with access to care, and increasing funding for research.

### **Workshop Session C**

#### HIV/AIDS Prevention

Danielle Laborde, B.S., M.P.H., Ph.D.; Mr. Steven Diaz; Shani Harris Peterson, Ph.D. and Janet Cleveland, M.S. discussed HIV/AIDS prevention with the workshop audience.

Danielle Laborde presented information on an HIV peer-led education program using a Historically Black College and University minigrant process. The goal was to pilot test the development and implementation of HIV/AIDS/STD prevention education for women attending Historically Black Colleges and Universities. The objectives were to 1) engage students in developing culturally-sensitive approaches to HIV education focusing on abstinence, being faithful and condom use, 2) assist students in implementation and evaluation, and 3) identify barriers to establishing or expanding campus HIV prevention activities.

Mr. Steven Diaz provided information on the *Lideres Campesinos por la Salud*. This program was started in 1999 by the Farmworker Justice Fund, Inc. as a means of reaching migrant workers in the United States. Promotoras de Salud (lay health educators), seek to educate, provide HIV testing, and social/medical services. The promotoras participate in HIV Prevention Community Planning Councils and provide migrants a voice within their communities.

Shani Harris Peterson discussed the importance of targeting adolescent sexual risk taking as a point of intervention in reducing HIV among African American women. She discussed a study that extends the current literature by exploring the relationship between contextual factors (both structural and process) and sexual risk taking among an economically diverse sample of late adolescent girls. Based on the findings, it was recommended that researchers investigate the role of residential and non-residential fathers in girls' sexual development.

Janet Cleveland discussed CDC's new Advancing HIV Prevention initiative, referred to as AHP. AHP is aimed at reducing barriers to early diagnosis of HIV infection and increasing access to quality medical care, treatment, and use of ongoing prevention services for people living with HIV. The goal is to decrease the number of new HIV infections in this country. AHP is one component of an overall HIV prevention portfolio.



AHP emphasizes the use of proven public health approaches to reduce the incidence and spread of disease. The initiative involves four priority strategies: 1) make voluntary testing a routine part of medical care, 2) implement new models for diagnosing HIV infections outside medical settings, 3) prevent new infections by working with persons diagnosed with HIV, and 4) further decrease perinatal HIV transmission.

#### HIV/AIDS Clinical Trials

Maria Luisa Zuniga, Ph.D.; Monica Gandhi, M.D., M.P.H.; A. Toni Young and Imogen Fua presented information to the workshop audience on HIV/AIDS and clinical trials.

Maria Luisa Zuniga explored HIV/AIDS clinical trials knowledge and experiences in a cohort of Latina women living with HIV. HIV positive Latina women were recruited from community and university-based clinics in San Diego, CA. Perceived barriers to participation in clinical trials included lack of information and denial of illness. This pilot research suggests that the broad and complex categories of fear, lack of information, denial of illness, and culture may serve as useful constructs for future studies of barriers in HIV positive Latina populations.

Monica Gandhi discussed the Women's Interagency HIV Study, a multi-center, prospective cohort study. The objective of this study was to investigate the natural history, pathogenesis, clinical, laboratory, and social/behavioral aspects of HIV infection in an observational cohort setting.

A. Toni Young discussed the "Equal Access" study being conducted by the Community Education Group to determine barriers and facilitators to participation of African Americans in preventive HIV vaccine trials. This research is being conducted at the community level by female African American researchers.

Imogen Fua discussed The Global Campaign for Microbicides, which is a broad-based, grassroots effort to mobilize public demand for microbicides and other female-controlled prevention options. Because of this advocacy effort, the federal investment in microbicide research and development almost tripled to \$91 million in 2003. Through grassroots mobilization, constituents can effectively demand the development of prevention tools to meet their real needs. Women of color can and should take action to ensure that microbicides will be available by the end of the decade.

#### Cancer

Evaon Wong-Kim, M.S.W., M.P.H., Ph.D.; Tracy Mack, M.S.W.; Armando Valdez, Ph.D.; Janice A. Allen Chilton, B.A., M.A., M.P.H., Dr.P.H. and Janice S. Emerson, M.S. presented information to the workshop audience on cancer.

Evaon Wong-Kim discussed a qualitative study conducted to understand the relationship between cultural beliefs and quality of life. The subjects were Chinese American and Chinese immigrant women living in San Francisco, who had been diagnosed with cancer within the past two years. The results showed that the factors important in determining

quality of life among Chinese American women, were not as important for Chinese immigrant women.

Tracy Mack discussed a partnership between the National Cancer Institute Cancer Information Service (CIS) and the South Carolina Department of Health and Environmental Control (DHEC) to place a CIS Partnership Coordinator within the South Carolina DHEC. This partnership provides culturally appropriate educational and screening opportunities to reach Native Americans in South Carolina, builds capacity for cancer education within tribes, and enhances the quality and quantity of collaborations between Native Americans and health care agencies. This project demonstrated that building partnerships between tribes and state/federal/private agencies can increase native women's access to education and services. Collaborating partners who speak with one voice to native communities can increase trust and participation in screening programs.

Armando Valdez discussed a study that examined whether an education intervention using innovative technology could effectively overcome known breast cancer screening barriers for low-income Latinas. The results showed that the intervention was very effective in overcoming knowledge and attitudinal barriers to breast cancer screening. Intent to obtain a mammogram increased significantly among women that never had a mammogram, as well as those who were previously screened. The study demonstrated that low-income, low literacy Latinas are receptive to interactive, multimedia technology, and this innovative approach can effectively increase their breast cancer screening rates.

Janice A. Allen-Chilton discussed a qualitative study conducted to explore perceptions about breast cancer and the concept of prevention among West-African women. This study investigated the concept of cancer prevention, as well as general perceptions and attitudes about cancer and breast screening exams. Also assessed were information levels regarding appropriate health care seeking behavior and cancer knowledge. Preliminary findings suggest that cancer is not well understood among West-African women. The women reported interest in finding out more about cancer and would participate in screening, if available. Fear of the disease did not equate with avoidance of information or seeking appropriate health care.

Janice S. Emerson discussed the effect of depression on an educational program to increase mammography rates. Subjects were African American females attending churches in Nashville and west Tennessee rural communities. The program consisted of viewing two videos and a group discussion about the importance of screening in breast cancer prevention. The results showed that the rates of mammography were lower for depressed women as compared to non-depressed in both geographical areas. The findings highlight the need to incorporate psychosocial factors in programs to improve preventive health behaviors in the faith community.

#### Domestic Violence

Martha E. Banks, Ph.D.; Trina Jackson; Judith M. Leconte, M.S.W., LCSW and Shelby Ortega, M.A. presented information to the workshop audience on domestic violence.

Martha E. Banks discussed head injury assessment for women of color who have been victims of intimate partner violence. At least 1.8 million women are severely beaten by their intimate partners every year in the U.S. Injuries sustained by women of color tend to be more severe than those sustained by white women. It is estimated that fifty percent of women will sustain mild traumatic brain injury across the life span. Given the extent of intimate partner violence and head injuries, it is likely that shelter professionals and other health care providers will encounter clients who have sustained such injuries. Professionals need to be equipped to treat and/or appropriately refer victims who have sustained head injuries.

Trina Jackson's presentation focused on her experience as a Violence Prevention Educator working with African American students at Tufts University. She discussed perceptions of relationships between black women and black men at the university. They perceived the university setting as a hostile campus environment. Over the course of three years, they developed strategies to empower black students to navigate these challenges, confront dangerous myths about intimate partner violence, and to self-advocate for a campus that is more responsive to their social and academic needs.

Judith M. Leconte discussed a three year collaboration between the Washington State Department of Health and the International Community Health Service on an MCHB grant to address the question: "What processes are required to adapt mainstream practices to increase the rates of culturally relevant domestic violence screening and intervention in a community clinic serving an Asian Pacific Islander population?" She described the six challenges (trust, language, confidentiality, safety, layers of culture, and beliefs about domestic violence) faced by this project. She provided processes for addressing the six challenges, and introduced a technical assistance guide that included a pilot assessment tool and targeted plan. She suggested activities and sample materials, and described the lessons learned during implementation with protocols, tools, training, referral, documentation and community education. There was a facilitated discussion on cultural relevance and domestic violence identification in community clinic settings.

Shelby Ortega discussed the impact of acculturation and Latino values within intimate relationships, and described a culturally appropriate model for Latina victims of intimate partner violence. The researchers are exploring how Latinas' cultural values and roles inform their understanding of violence within intimate relationships. They are also exploring Latina definitions of healthy relationships, and the barriers encountered in seeking support and/or relief from violent relationships.

#### Physical Activity

Mary Z. Dunn, R.N., Ph.D., A.P.R.N., B.C.; Diane M. Bennett; Ruby S. DeLaGarza, B.S. and Ebony Hughes, R.N. presented information to the workshop audience on physical activity.

Mary Z. Dunn presented "Physical Function of Older Latinas". The objectives of her study are: 1) to test the plausibility of a causal model of quality of life variables predicting functional outcomes in older Latinas, and 2) to derive future studies of quality

of life that would test interventions to improve cognitive and physical function. This project is important because the aging population will increase 20% by 2025, with greater increases in groups designated as Hispanic.

Diane M. Bennett spoke about a program that maximizes exercise possibilities of in-cell housing areas in a correctional environment. This program demonstrated the feasibility of developing an in-place exercise video to promote health of the female prison population.

Ruby S. DeLaGarza discussed a wellness initiative designed to assess faculty and staff needs and interests with regard to personal wellness and health promotion programs at the University of Texas-Pan American (UTPA). The Provost's Initiative on Campus Wellness was created as a step towards improving the physical fitness of university employees. The results show that the average weight of women at UTPA was higher than it should be according to the National Health & Nutrition Examination Survey. A campaign was started to encourage walking around campus. A monthly lecture series was also scheduled to cover a variety of topics on health including nutrition, physical fitness and stress.

Ebony Hughes discussed Families in Motion, a neighborhood-walking program. An initiative of the African-American Womancare Committee of Magee-Women's Hospital at the University of Pittsburgh Medical Center, this is an intergenerational project designed to promote fitness, health, family and community togetherness. Utilizing their own neighborhood, participants gather together to walk weekly. Healthy refreshments and health education materials are provided. This program is designed to be easily replicated and tailored to diverse communities.

#### Food and Drug Administration (FDA)

Veronica Jean Scott, Calvin O. Matthews and Taylor R. McGlawn, M.S.W. spoke during an FDA sponsored workshop. All three speakers are "Take Time to Care Scholars". They addressed chronic illness and medication use.

Veronica Jean Scott discussed the GRECC-FDA Scholars Program. The goals of this program were to develop, implement and evaluate a train-the-trainer model of the FDA 'Take Time to Care' program. 'Take Time to Care' was designed to reduce health disparities in rural and urban underserved populations, especially African American female populations. The program's effectiveness will be evaluated. The program had five objectives: 1) to measure the effectiveness of the model in achieving program goals, 2) to develop, implement and evaluate a GRECC-FDA Scholars Program competency-based core curriculum, 3) to measure the effectiveness of the trainers in developing functioning community coalitions and/or partnerships that conduct community-based participatory education research programs, 4) to measure the effectiveness of the coalitions and/or partnerships in conducting programs that reduce health disparities in the targeted communities, and 5) to evaluate the likelihood that the model can and will be replicated. The outcomes include the selection of scholars, and implementation of several community-based education research projects.

Calvin O. Matthews discussed a community-based participatory prevention research study of complementary and alternative medicine (CAM) use in older adults in rural and urban Alabama assisted living facilities. This study has added to the body of knowledge about CAM use in-older African-Americans in southern communities. The results can be used to design educational interventions effective in promoting appropriate and safe CAM use in older adult community-based populations.

Taylor R. McGlawn participated in the development of a community-academic partnership to study disparities in breast cancer rates among African-American women living in three rural Mississippi counties.

### Gynecologic Issues

Ivy M. Alexander, Ph.D., C-ANP; Sabrina Dudley Johnson, and Jo Jean Elenes presented information on various gynecologic issues, including menopause and chronic pain management.

Ivy M. Alexander described a study that investigated perceptions and experiences of urban black women in the transition to menopause. Topics of interest included symptoms experienced, symptoms perceived as most bothersome, perceived midlife health risks, and self-management strategies. Conclusions included the following: 1) menopause is seen as a normal life transition, 2) there are many common symptoms, some not well recognized, 3) participants accurately identified midlife health risks, and 4) participants indicated preference for alternate methods of symptom management. These conclusions have implications for improving quality of care. It is important to address the symptoms black women experience as bothersome, to educate about management options, and to support self-management of symptoms.

Sabrina Dudley Johnson is a member of The Fibromyalgia Association Created for Education and Self-help (FACES). The topic of her presentation was fibromyalgia, pain management disparities, and the adverse effects of fibromyalgia on gynecological issues. She highlighted various community partnerships that FACES maintains. She issued a call to action for national, state and local health officials to partner with nonprofit organizations advocating fibromyalgia awareness, and to establish fibromyalgia, CFS and chronic pain management disparities as priority health topics.

Jo Jean Elenes discussed the “El Cambio de Vida: lo que es bueno saber sobre la Menopausia” project. The purpose of this project was to collaboratively develop educational tools on menopause that are culturally and linguistically relevant to Hispanic women of Mexican descent. The educational curriculum includes lay health worker manuals, visual aids for each session, and a participant manual.

### Kidney Disease

Coralease C. Ruff, D.N.Sc., R.N. and Shaun Hill presented information to the workshop audience on various aspects of kidney disease.

Coralease Ruff's presentation focused on urinary incontinence in African American women. She conducted a study to determine the effectiveness of a behavioral therapy management program in reducing the severity of urinary incontinence and improving quality of life for African American women. The specific aims of the study were to compare the effectiveness of Kegel exercise and biofeedback in reducing the severity of urinary incontinence, and to examine the impact of pelvic muscle therapy on quality of life in women. Almost all participants reported improvement when they performed exercises. Discussion of urinary incontinence led to increased awareness and consequently to improvement in accidental urine loss. Exercises appear to be effective with and without biofeedback when practiced regularly and properly.

Shaun Hill discussed chronic kidney disease and the National Kidney Foundation (NKF). The mission of NKF is to prevent kidney disease and urinary tract diseases, improve the health and well-being of individuals and families affected by these diseases, and increase the availability of all organs for transplantation. The National Kidney Foundation provides public education, screenings, advocacy, research, professional education, programs and services.

#### Office of Minority Health (OMH) Session

“Environmental Health: Environmental and Occupational Exposure for Minority Women  
Stephanie Miles-Richardson, D.V.M., Ph.D., CDR and Lisa Pham, B.S., M.S. discussed environmental health with the workshop audience. The presentation focused on environmental and occupational exposures for minority women.

Lisa Pham discussed the Nail Salon Project. This project was started to improve the quality of life for Asian Americans and Pacific Islanders. It was funded by the Environmental Protection Agency (EPA) Region 6 in Dallas, Texas, the EPA's Design for the Environment Program, and the EPA's White House Initiative on Asian American and Pacific Islanders. The project involved extensive literature research, recruiting and visiting pilot shops, and developing outreach materials.

#### Minority Women's Health Panel of Experts Session

Nicole Prudent, M.D., M.P.H.; Margaret Equopi Bate', M.S. and Luz Alvarez Martinez led a group discussion on special minority groups including African immigrant women, Caribbean women, Asian immigrants and refugees, and Latina immigrants and undocumented workers. The group discussed immigrant women's health (including refugees) while in the US. Topics included barriers concerning access to healthcare, difficulties during acculturation (including depression), being a refugee/having a displaced family and communication. Excerpts were read from an article about an African woman describing her strength and mental attitude. One of the group members talked about her lesbian experience. Other individuals shared their experience with immigrant women in their communities. Members felt there was an open dialogue, which increased their understanding of issues faced by immigrant women.

Luz Alvarez Martinez believes women of color must focus on the impact of racism on our health. She emphasized the enduring impact of colonization and its influence on indigenous ways. She noted the resurgence of interest in Aztec dancing in recent years, and its potential to counteract this impact. She stressed the need to re-achieve the mind, body, and spirit balance, offset by the racism of our oppressors.

Margaret Equopi Bate pointed out that most African immigrants to the US (both male and female) have completed high school by the time they arrive. In fact, many come to this country to further their education. She continued to say that the most commonly known health information about African women relates to the practice of female genital circumcision/mutilation. Emotional issues exist for many African immigrant women even after they are settled in US.

Nicole Prudent discussed the strength and resilience of Caribbean and other immigrant women. They are familiar with hardships, and work to secure a better future for themselves and their families. However, the vestige of a hard past and poverty often leaves them with complications that are difficult to overcome. For example, children who are born with low birth weight tend to become obese and develop metabolic syndrome in the future. Therefore, children who are born to women who are nutritionally deprived are at higher risk for obesity and its cardiovascular complications. Studies document the increasing prevalence of obesity among immigrant populations. Many families strive to come to the US, unaware of the effect of "food abundance" on their previously deprived system. They expect to get healthier and instead, become sicker. We must work to educate and support our immigrant sisters (particularly those from poor countries), to help prevent obesity and complications associated with living in an industrialized country.

### **Workshop Session D**

#### HIV Testing/Disclosure

Kama Brockmann, Ph.D., LCSW; Yvette Macedon and Carla Dillard Smith, M.P.A. presented information on HIV testing and disclosure issues to the workshop audience.

Kama Brockmann's presentation focused on African American women's experiences of disclosure and non-disclosure of their HIV/AIDS status in various life domains including family, children, intimate partners, friends, religious settings and substance abuse treatment settings. In general, women did not feel their religious leaders and fellow congregants stigmatized people with HIV.

Yvette Macedon presented information on ACT Now! This is an outreach and early intervention program that identifies HIV positive women of color and connects them with resources. The objective of the program is to engage high-risk women of color in HIV counseling, testing and referral, and link them to care and support. The results indicate that groups previously resistant to HIV/AIDS issues are now actively involved in advocating, educating and supporting infected and affected members. More high-risk people of color are accessing counseling, testing and referral services. Many HIV positive

individuals have been linked to primary care, case management and other support services.

Carla Dillard Smith discussed the California Prevention and Education Project's Hot Zone Project. Hot Zone provides a comprehensive approach to HIV prevention services for African Americans living in Alameda County, California. The benefits of this project include the ability to provide health services to disenfranchised communities, increase client awareness of their own risk factors and HIV/STD status, and intent to change risky behaviors.

#### HIV Care

Marcia E. Jackson, B.A., M.A., Ed.D. and Deborah Parham-Hopson, Ph.D. presented information to the workshop audience on care for women living with HIV/AIDS.

Marcia E. Jackson presented information on Positive Perspectives. This program was designed to determine whether skills building groups and individual counseling sessions could prevent or delay adverse health outcomes among African American women with HIV/AIDS. The goals of the program were to alleviate maladaptive coping and psychological distress; encourage cessation of high-risk behaviors; reduce the progression of HIV disease; increase access to care by providing family-centered case management; and decrease the risk for re-infection.

Deborah Parham-Hopson discussed care for women with HIV/AIDS. She shared several statistics and proceeded to ask the question "how do we care for these women who are living with HIV and AIDS?" She stressed the efficacy of prevention and emphasized that HIV is 100% preventable. Women need improved integration of prevention and treatment services, (to include other STDs and substance abuse), access to antiretroviral therapy, and increased emphasis on services for young women and women of color. Knowledge about preventive behaviors and the need to practice them is critical for each generation of young women. Prevention programs should be comprehensive, and include participation by parents as well as the educational system. Community-based programs must reach out-of-school youth in settings such as youth detention centers and shelters for runaways. Funding through the Ryan White CARE Act can assist in these efforts. Dr. Parham-Hopson also discussed characteristics of successful programs and initiatives for women living with HIV/AIDS. These include offering a continuum of care; provision of co-located services that are easy to negotiate; making a women feel at home; creating a sense of community; providing an atmosphere of acceptance and empowerment; welcoming family and support network; and having a staff that is flexible and responsive.

#### Cancer

Repeated from Workshop Session C

#### Sexual Assault

Lori S. Robinson, Joyce Lukima, Alma Golden, M.D. and Mehru Master presented information on sexual assault to the workshop participants. Lori S. Robinson discussed sexual violence in the African American community. Joyce Lukima discussed rape and



sexual assault within the United States. Alma Golden discussed adolescent sexual assault and statutory rape. Lastly, Mehru Master discussed trafficking issues.

### Mental Health

Andrea Ault, B.B.A., M.P.A.; Geraldine M. Disnard, M.S.N., M.P.H., R.N.-B.C., P.M.H.N.P; Tiffany G. Townsend, Ph.D. and Martha E. Banks, Ph.D. presented information on mental health to the workshop audience.

Andrea Ault presented findings from the Homeless Family Study in Westchester County, NY. The objective of this research was to explore factors that influence a mother's decision to seek and use mental health services.

Geraldine M. Disnard discussed various models of mental health/mental illness in Hispanic *Promotoras de Salud* in Texas. Qualitative data suggested mental illness is not viewed as a discrete illness that is treated separately. It was further hypothesized that three explanatory models inform promotoras current concepts of mental health/mental illness: biomedical, naturalistic and personalistic systems.

Tiffany G. Townsend discussed a community collaboration to reduce stress among African American women. Preliminary empirical validation was provided for a stress reduction program designed to address the distinct experience of stress among African American women. Significant reductions in reported stress, anxiety and depression were noted at post-test.

Martha E. Banks' presentation outlined issues faced by women of color with disabilities, and described innovative, culturally relevant approaches to psychotherapy and research for those women.

### Research

Hattye F. Board, M.P.H., R.D., L.D.N.; Carol Parsons, J. Rogers and Leatrice Shacks, M.Sc., M.P.A. presented information on issues involving research. Hattye F. Board's presentation focused on minority recruitment in a randomized trial of older adults. Leatrice Shacks' presentation focused on research participation and African American women.

### DHHS-Office on Disability – Women and Disability

Madeline L. Darden, M.S.W.; Claudia Gordon, Esq. and Sharman Word Dennis, M.Ed. presented information to the workshop audience on issues involving women and disabilities.

The purpose of this workshop was to provide a forum to discuss challenges and opportunities associated with women of color who have disabilities, including cognitive, physical, psychiatric, developmental, sensory, substance abuse and chronic disabilities. This workshop was unique in that it focused solely on women of color who have disabilities. Research findings and information on the translation of national advocacy efforts into practical programs and activities was provided to conference participants.

Attendees learned how to promote change in their communities and work towards parity for women of color with disabilities in the United States.

#### Substance Abuse

Aimee C. Maychack, CCDCI; Denise Wolf, R.N., M.P.H.; Sonya Miller Reese and Tamika Gilreath presented information to the workshop audience on issues involving substance abuse.

Aimee C. Maychack demonstrated the process the Ohio Women's Coalition Smoking Cessation and Prevention Initiative has taken to make agencies tobacco free. She presented preliminary data on the initiative and its success. Minorities are a target market in advertising campaigns by the tobacco industry. The discussion included smoking mortality statistics, information regarding the association between tobacco and cancer, information on nicotine dependency, and steps to achieve a tobacco-free agency.

Denise Wolf discussed a community-initiated substance abuse prevention program with Native American women. The women are from a southwest Tribe that enacts promotion of healthy behaviors through giving voice to experience, valuing all women as experts, and breaking social isolation. By placing substance abuse within the context of women's lives, and including all women regardless of level of risk, stigmatization was prevented and empowered change was validated. By highlighting the impact of intergenerational trauma, an opportunity to connect with origins of emotional pain and harmful coping was provided.

Sonya Miller Reese discussed "Women with Voices: Recovery in Action." This is a recovery support network in Miami, Florida. The recovery network is a viable tool in preventing relapse and promoting long-term recovery. Peer-to-peer recovery support services have been an effective means of extending and enhancing the treatment continuum and sustaining recovery from substance abuse.

Tamika Gilreath discussed cigarette smoking among African American women. Using data from the National Health Interview Surveys, her study assessed the influence of sociodemographic variables on recent smoking behavior and cessation patterns of African American women twenty years and older. Results indicated statistically significant variations in smoking behavior by region, income and education. The results of the study provided useful information about smoking differences among African American women by region of the country. The findings may be valuable in identifying and targeting subgroups of African American women for prevention and/or cessation programs.

#### Minority Women's Health Panel of Experts Session

Barbara Yee, Ph.D. and Mary Harper Ph.D., R.N., F.A.A.N., L.L.D., D.Sc., facilitated a group discussion on "Federal Contract/Grant Writing Review and Funding" and "Future Directions for Research in Minority Women; Research Risks for Minority Women; Recruitment and Retention in Minority Women in Clinical Trials." Miriam F. Kelty, Ph.D. (DHHS/National Institute on Aging) and Angela Bates (DHHS/NIH Office of

Research on Women's Health provided an overview of the grants process and opportunities in acquisition of federal contract and grants. Darlene Yee-Melichar discussed research risks for minority women and clinical trials. Information on resource materials for research on women's health is available online as follows:

- **ORWH Fact Sheet**  
<http://www4.od.nih.gov/orwh/decade-2.pdf>
- **Women of Color Health Data Book** (English version)  
<http://www4.od.nih.gov/orwh/wocEnglish2002.pdf>
- **Agenda for Research on Women's Health for the 21<sup>st</sup> Century, Volume 7** (This is a brief summary of an 8 volume set. Vol. 8 is available in Spanish)  
<http://www4.od.nih.gov/orwh/agenda-vol7.pdf>
- **NIH Publications on Women's Health Issues** (Contains women's health publications and contact information for each NIH Institute or Center)  
<http://www4.od.nih.gov/orwh/NIHPubs.pdf>
- **2004 Comprehensive Report: Tracking of Human Subjects Research Reported in FY2002 and FY2003** (NIH aggregate report on participation in NIH funded clinical research. It includes the current policy and extramural and intramural data sorted by race/ethnicity and sex/gender, background information, contacts and references. NARRATIVE [http://www4.od.nih.gov/orwh/Updated\\_2002-2003.pdf](http://www4.od.nih.gov/orwh/Updated_2002-2003.pdf)  
DATA TABLES [http://www4.od.nih.gov/orwh/DataTables\\_FY2002-2003.pdf](http://www4.od.nih.gov/orwh/DataTables_FY2002-2003.pdf)
- **Science Meets Reality: Recruitment and Retention of Women in Clinical Studies, and the Critical Role of Relevance** (Proceedings from a national meeting held in 2003 looking at lessons learned, continuing challenges and ethical and policy issues in recruiting and retaining clinical research participants).  
[http://www4.od.nih.gov/orwh/SMR\\_Final.pdf](http://www4.od.nih.gov/orwh/SMR_Final.pdf)

#### Cardiovascular Disease

Jennifer B. Campbell, Dr.P.H. MHSA, CHES and Chantay Walker, Ph.D. discussed spirituality and faith-based initiatives in regards to African American women and cardiovascular disease. *Generations* is an effective faith-based cardiovascular disease prevention program that encourages African American women of all ages to adopt heart healthy lifestyles and reduce their risk of cardiovascular disease. It is the first national cardiovascular disease prevention program for African American women implemented in faith-based organizations.

Sunday, August 15, 2004

#### Closing Plenary Session IV

Panel: Where Do We Go From Here? Setting a Plan for Action to Reduce Health Disparities in Minority Women

Nancy Atmospera-Walch, B.S.N., R.N., M.P.H.; Elena Rios, M.D. and Jetta Vance-Turner participated in the Closing Plenary Session entitled, "Where Do We Go from Here? Setting a Plan for Action to Reduce Health Disparities in Minority Women."

Nancy Atmospera-Walch discussed Asian, Pacific Islander and Native Hawaiian women with the audience. She described the clients, major health concerns, income levels, main languages spoken, and services offered at the Kalihi-Palama Health Center, Kokua Kalihi Valley – CCoE, Papa Ola Lokahi, Waianae Coast Comprehensive Health Center and the Waimanalo Health Center.

Elena Rios described three levels of focus she believes are necessary to improve minority women's health. These levels are individual, program, and community. There are many ways to collaborate with DHHS OWH. Potential avenues of collaboration include local, state, regional and national governmental entities, National Centers of Excellence and Community Centers of Excellence, National Women's Health Information Center and the Minority Women's Health Panel of Experts. There are many ways to improve minority women's health on the individual, programmatic and community levels. Suggested actions included networking and mentoring; increasing education efforts for minority women; developing community collaborations; collaborating with the media and health professionals; and identifying spokespersons in your community.

Jetta Vance-Turner discussed women and disability issues with the audience. Women generally experience health disparities, misdiagnosis and discrimination at much higher rates than men. This is an even greater hurdle for women with disabilities. In the general population, women have a higher rate of disability than men (due primarily to women's higher average longevity). Twenty-eight million women in the U.S. are living with disabilities. She discussed some of the challenges faced by women with disabilities. She encouraged women to lobby, educate, empower, form alliances and create partnerships.

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