



Día de la Mujer Latina

Día de la Mujer Latina, Inc.
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Biosketch-Venus Ginés

On a routine flight to Los Angeles, Flight Attendant Venus Ginés slipped and fell on the airplane prompting an immediate need for medical attention. At the ER, the doctor casually asked if she had her mammogram yet. Upon hearing a ‘No, I’m Latina, we Latinas don’t get breast cancer” he explained that cancer did not discriminate and offered to do a clinical breast exam. To her shock, he found a lump. After being diagnosed with breast cancer in 1992, Venus decided to focus her graduate research on cancer in Latinas. She discovered both a paucity of statistical data as well as limited ethnic-specific cancer health education material. In 1996, Venus developed a culturally specific video/picture book on breast cancer (*Una Nueva Esperanza*) and later (*Hombre Sin Limite*) on prostate cancer for American Cancer Society (ACS). A health *fiesta* was the only way to determine if the picture books adequately addressed some of the fears and barriers of this population-at-risk. *Día de la Mujer Latina* became a reality when Venus together with ACS & the Mexican Consulate's office, assessed, planned, coordinated, collaborated and implemented the first non-traditional culturally relevant Latino family health fiesta. This process involved a community-wide collaboration of Latino clubs, private and non-profit organizations, state and county health departments, community merchants, media, volunteers and other healthcare providers to provide early detection and screening for breast/cervical/prostate cancer, HIV, Diabetes, and cardiovascular diseases.

Since May 10, 1997, more than 27,000 Latinas have registered at our 1-day health *fiesta* w/over 3020 receiving medical care. Venus also teaches cultural competence to medical and nursing students. This ethnic specific project is currently recognized as a national “best practice” and being replicated in 22 cities, 7 counties in Georgia, as well as Puerto Rico. **Día de la Mujer Latina, Inc.** is a non-profit (501©3) organization in the state of Ga.

Ms. Ginés earned a **B.A.** from **California State University** and a **M.A.** from **Georgia State University (WMSI)**, focusing on the cultural and system barriers faced by Latinas with breast cancer. Venus presented at a Congressional Panel for the recognition of the term “**Latino**” as a proper category term for the new population from Latin America. Now, all federal programs must include both terms. **Nationally**, she serves on the Steering Committee for the NCI-funded *Redes en Accion*, the nationally recognized **Intercultural Cancer Council (ICC)** and charter member of the **Susan G. Komen National Hispanic/Latina Advisory Council** and NCI’s **Director’s Consumer Liaison Group**. Venus represented the state of Georgia at the **President’s Cancer Panel** and served on the **Board of Trustees** of the **Georgia Cancer Coalition**. Venus received the **Compañeros Award** at the **Latino Summit** in ATL; the **Vision of Hope Award** in the Breast Cancer Conference in San Antonio, as well as the **National Latina Activist Award** in Chicago. Venus was appointed to the Blue Ribbon Panel of **National Cancer Health Disparities Progress Review Group** in Washington, DC and **Chaired the Trans HHS Cultural Competence in Education & Training Roundtable**. **Georgia’s Governor Perdue** appointed Venus to the **Latino Commission** and **currently serves in the State’s Cancer Plan** and the **Health Strategies Council**. She’s a Leadership Atlanta, Class of 2004 alumni, a Research Associate at Kennesaw State University & Adjunct Instructor at Morehouse School of Medicine. Venus served on the Board of Visitors for Grady Hospital, WellStar Health System and Emory Healthcare and a board member of the YMCA Metro Atlanta. She founded the Intercultural Center for Health & Wellness in 2004, (1st Latino Health Resource Center in Atlanta) and concluded the Community Voices Video on women from 12 Latin American countries speaking on disparities. Venus is currently Faculty at Baylor College of Medicine; Chronic Disease and Prevention Center.

Venus Ginés, MA

Abstract

Understanding the Issue of Mistrust in Latinas and Clinical Trials

In order to understand the cultural dimensions that play a role in the lack of Latina participation in clinical trials, it is vital to document the many underlying reasons for their fear and mistrust.

Many people think of the Tuskegee experiment when we mention unethical trials, but there were others, including one impacting my own family and community – the sterilization campaign against Latinas on welfare in Spanish Harlem in the 1950s. This led to a pervasive mistrust of doctors and the medical system in Latinas to the point that I only sought treatment for pre-natal care and in emergencies. A literature review on medical abuse among poor and disadvantaged women of color highlighted the sterilization campaign against Puerto Rican and Mexican women from the 1940s through the 1970s. Sterilized at 28 and dead by 56, my mother instilled my mistrust at an early age. My breast cancer was discovered by accident – literally, while receiving care for an on-the-job injury. Among many of the factors that hinder Latinas from access, preventive screening and clinical trials, mistrust continues to be one of the leading reasons noted in the survey forms from the last 5 years of DML. However, there has been no specific study addressing how to overcome this mistrust.

More than 300 public health officials, medical researchers, and patient advocates worked over several years as the EDICT (Eliminating Disparities in Clinical Trials) team, in designing a series of practical policy solutions to clinical trials disparities at the federal, state and institutional levels in the public, private and non-profit sectors. These recommendations address the issue of mistrust, with the implementation of participant navigation and fostering community involvement from the designing of research protocols to the reporting of findings. This bottom-up approach led to various ideas of how advocates can help with education, recruitment and retention of clinical trial participants – as well as fostering safeguards and a positive return for the community in the form of better information and knowledge about – in my case – breast cancer and Latinas.

