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Living with LUPUS

HOUSTON, TEXAS — Dia de la Mujer Latina, in partnership with The American College of Rheumatology have joined forces to raise awareness about Lupus with a mission to eliminate lupus related health disparities among racial and ethnic minority populations disproportionately affected by Lupus.

According to Venus Ginés, President and Founder of Dia de la Mujer Latina® (DML), “I found out I had Lupus around the same time that I was told I had breast cancer. Although college educated, I had no idea what Lupus was and suffered from health literacy on the topic of breast cancer. I was told by the breast surgeon that I need to undergo a double mastectomy and the rheumatologist raised concern on how this aggressive surgery might impact my immune system. I was ready to just give up and die.”

Lupus is a chronic autoimmune disease that can be very unpredictable, inflicting havoc on some organs, such as heart, kidneys, lungs, blood, skin and joints. It affects more African Americans and Latinos than Caucasians, however, Lupus is an equal opportunity oppressor. According to research, there are an estimated 1.5 million Americans suffering from this disease with over 5 million people worldwide. Yet, many are living with symptoms but not identifying the disease making it difficult to diagnose and treat. Although there is still no cure for Lupus, it can be managed. Venus has learned to thrive with the occasional Lupus Flare ups and is committed to raising awareness globally.

This partnership is focused on increasing awareness and understanding of Lupus among minorities, especially Latinos by first educating Promotores (Community Health Workers) on the signs and symptoms of Lupus in order to add Lupus to their knowledge based health topics. Promotores/CHWs, are trusted members of their community and play an important role in promoting community-based health education and prevention in a manner that is culturally and linguistically appropriate, particularly in communities and for populations that have been historically underserved and uninsured. Venus developed a bilingual training curriculum on a variety of diseases and core competencies for Promotores (Community Health Workers) and plans to launch the Lupus Awareness training in Texas, California and Georgia.

Dia de la Mujer Latina y Su Familia® Fiesta de Salud is DML’s signature program, along with its Promotores/CHW Training Program, developed in 1997 as a community specific grassroots program, serving more than 104,000 folks in 40 major cities, Puerto Rico, Dominican Republic and soon Mexico, in an effort to motivate inform, navigate and educate our vulnerable populations in a culturally and linguistically proficient manner via its dynamic team of Promotores/Community Health Workers. DML, has trained and certified over 1400 Promotores (Community Health Workers).

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