

**Chagas Disease in the Americas:
Improving Access and Tools for Patient Diagnosis and Treatment**

**Friday, October 2, 2009, 9:00 AM – 5:30 PM
Los Angeles, California, USA
October 2, 2009**

Remarks by Maira Gutierrez, Chagas patient

Good morning,

My name is Maira Gutierrez. I am a 36 year old native of El Salvador, and I've been living in the United States for almost 30 years. I have Chagas disease, and I wanted to share a brief history of my experience since my diagnosis, because I think it helps illustrate the "neglected" nature of this disease, and the difficulties Chagas patients face.

I was diagnosed in 1997, after donating blood to the Red Cross. A letter was sent to me about 3 weeks after I donated blood, explaining that because of the results of the blood screening test, my blood donation could not be used. The letter asked me to call a 1 800 number for more information. I called the next day. A representative called me back about 3 days later. Her first questions to me were "Are you alone? If you are not, can you go to a place where you are?" My heart sank at that moment, I thought I was dying. She explained that I had Chagas disease, and asked if I had been out of the country in the last 10 years. She also stated that she didn't have any further information, but a booklet would be sent to me explaining exactly what Chagas disease is. I received the booklet about 3 days later. The information was very vague. The booklet stated that there was no treatment for the disease, and that I had a 60% chance of my disease becoming active. I scheduled an appointment to see my physician right away. When I told her I had Chagas disease, her response was "the only time I've heard of that was in medical school." She had no idea what to do with me or how to treat me. She referred me to an Infectious Disease specialist. He sent me back to my physician to get some lab work done. It took the lab technicians about an hour to figure out what test to do for Chagas disease. I tested positive again, and when I asked if there was treatment, I was told "no." I later went in for a brief check up but was told that nothing could be done. I kept calling my doctor's office to see if he had heard anything new from the CDC or the infectious disease specialist, but after a while it felt like I was bothering him, so I stopped calling.

Eleven years after being diagnosed with Chagas disease, I received a frantic call from my sister to turn on the TV. There was a special report on Chagas disease on the local news, stating that a new clinic was opening in the Los Angeles area. Unfortunately by the time I turned on the TV, the report had ended. However, my sister did get the name and phone number of the hospital. I called the next day, and they made an appointment for me. A few days later I met with Dr. Meymandi at the Olive View – UCLA Medical Center, who you will hear from later tonight during the panel discussion. This is when my new journey to treatment began. I completed a three-month course of the drug called Nifurtimox in June of 2008, and I continue to be monitored annually. I've had heart

palpitations for a few years now, but hope they will eventually disappear. The treatment is supposed to reduce my chances of developing more serious symptoms – like heart disease. To this day, I don't know if I am cured, or if I will ever be cured. I don't know if – or when – I will develop more serious symptoms.

What's clear to me from my experience is that there is little awareness of this disease in the general healthcare community here. I don't think the Latino community here knows much about this disease either. Before I was diagnosed, I didn't know anything about the disease, and my primary healthcare provider wasn't able to help me get more information or get treatment. The fact that I was even diagnosed was kind of by chance; I later found out that the US blood banks didn't routinely start screening for Chagas disease until 2007 – just two years ago. I was diagnosed much earlier – in 1997 – only because I happened to give blood when the Red Cross was doing some exploratory screening for Chagas disease. So I would have to assume there are many others like me who have never been diagnosed.

I'm here today to share my experience in the hopes that events like this will help to raise awareness about the disease, and will help Chagas patients have a better treatment experience in the future.

I'll be participating in the panel discussion later today and would be happy to answer any questions that you have at that time.

Thank you.