A Sacred Journey: A Wonderful Story of Caregiving

August 25, 2014 By Rae Lewis-Thornton

I attended a screening of the documentary *A Sacred Journey* sponsored by Clorox CareConcepts. It was a heart wrenching and heart filled story of one film maker, Ernesto Quintero brother's journey with ALS and his families role as caregivers.

This was perfect timing in the back drop of the recent ice bucket challenge among celebrities to support ALS. For me I was able to learn more about this devastating disease, but equally important is the conversation about caregiving. After the screening there was a very thoughtful and honest dialogue about caregiving with a panel of experts, including the film director Ernesto.

The documentary begins when Ernesto's brother Juan is diagnosed with ALS. This film touched the very core of me. It is one man's courage to fight against the odds. The film highlighted Juan's desire to give something back to the community. He decided that he wanted to leave a legacy by painting a mural for his former elementary school. Juan rallied his close knit family and they all rose to the occasion to make his dream come true.

I was overwhelmed by this story of courage and perseverance. As ALS ravaged his body, Juan held onto his spirit. It made me think about my own 31 year journey of living with HIV and AIDS for 22. Right now, I'm at a junction in my life where I'm incredibility tired. Tired of medications, tried of sickness, tired of trying to make it happen, just simply tired.

This documentary helped me to put things into perspective. ALS is an horrible degenerative disease. As I watched the documentary I could do nothing but think, at least I can walk and use my limbs. Now be clear, I never compare illnesses because I believe each persons journey should stand on its on merit. Pain is pain and should never be measured. What one person can withstand, my devastate another and vice-versa. But this film made me at least acknowledge that even living with AIDS, I am blessed on so many levels.

I was struck by the strong family support and solidarity surrounding Juan. The father knocked me off my feet when he said, "God is the doctor of all doctors." This is one strong family in the face of one tough illness.

The family have risen to the occasion of caring for Juan. Caregiving is not easy. I remember those days when I took care of my mother during her battle with cancer of the mouth. It was a long 2 1/2 years. The commuting her back and fourth to the hospital for chemotherapy. The midnight calls and runs to the hospital. Even preparing her to come home from the hospital was not easy. Just trying to decide how I should clean her apartment and what to use that was safe for the both of us took work.

This documentary definitely stuck a cord. I know first hard that there are very little resources for caregiving. I was impressed with this family as they provide around the clock care for Juan.

I was also impressed with Clorox's innovative project Care Concepts When Care Comes Homes. Clorox has created a full line of cleaning and personal products for caregivers. As a person living with a chronic illness, these products will be helpful for me and truly, any basic personal care needs for a family.

The most impressive part is that Clorox took this concept a step beyond making products. When Care Comes Home is an important on-line resource guide for caregivers. There is a caregivers guide from day to day caregiving with steps along the way. It is especially refreshing to see the partnership with the council of experts on the various topics of caregiving.

There are 66 millions Caregivers in the United States and very little conversation. Caregiving and Caregivers are important but yet forgotten. I think Clorox's When Care Comes Home is a great project. Parenting with Ernesto to create dialogue around caregiving is wonderful. Overall it was a great evening combining the arts and healthcare eduction. Oh yeah and lots of popcorn.

There will be two more screening of this documentary with a panel discussion that will also include Ernesto. One in **Los Angeles on Oct 1, at the CineFamily Silent Theater** where Juan and his family lives and another on **November 13, 2014 in Washington, D. C. at the West End Cinema.** You should consider attending.

Of course, the evening was not complete until Ernesto did the ice bucket challenge for his brother Juan.

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