

Title: Standing on the Shoulders of our Ancestors: Surviving and Thriving Beyond Cancer
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Flashback: During NACR's 2001 American Indian / Alaska Native (AI/AN) Survivorship Conference, the AI/AN survivors shared their personal cancer stories. Tina Aguilar (Wasco / Warm Springs) spontaneously wrote a poem as she was listening to participants share their

stories. While attending the Spirit of EAGLES conference held in partnership with Seneca Nation in Buffalo, NY, I was reminded of Tina's powerful poem and reflected, "then" and "now". So, 16 years later, how are our AI/AN survivors faring? Overall, the majority of our people are winning the battle Tina refers to and most are transitioning from being a "patient" to a "survivor" to a "thrifer". Part of this transition is letting go of the anger, frustration, fear, etc., from the cancer experience ... to allow yourself to begin to be "free"

"Sharing Hearts of Survivors"

Tina Aguilar

Sitting and listening to stories being told,
Women and men from all tribes young and old
Each has a story of cancer to share with all others.
Listen what is said by each sister and brother.
This dreaded disease that's claimed many lives,
Is still trying its best to break up husbands and wives
It doesn't care of age, race, and gender
Only that it can find a body to enter
God has placed compassion on many hearts here
One day there will be a cure for those we hold dear.
Do not give up – there's too much at stake
With God's help, we will win this fight—Piece of cake!

(again) and to accept that cancer does not identify you; that there is hope and happiness and to rejoice each day for the gifts the Creator grants us all.

By what right do I dare make such statements? Because NACR has the largest AI/AN cancer survivorship support program (>1,000) and data based on patients who have taken the time and effort to complete a very long survey about their quality of life (QOL). We started doing this work

in 1996. The name of this program is "Native American Cancer Education for Survivors" or "NACES" for short (<http://natamcancer.org/naces.html>). NACES started as a research grant, evolved into support, informational program. It is a web-based, quality of life survivorship education program that originally was designed for breast cancer patients. However, so many of our

people have cancers other than cancer, our team supported or expanded much, but not all (such as the side bar on "story-tellers" is limited to breast only) of the information to multiple



The NACES Team

(people who created information on the branches and leaves and/or supported NACES):

Linda U. Krebs, Lisa Harjo, Mark Dignan, Kate Jones, Judith S. Kaur, DeeAnn DeRoin, Jennie Joe, Caren Trujillo, Maxine Brings Him Back
Janis and Daniel Petereit

types of cancer that affect both men and women. The website is free. There also is a toll-free number (1-800-537-8295) to talk with one of NACES Survivorship Navigators (also called, "Native Sisters"). NACES is supported by volunteers (which is why it may be a few days before you receive a call-back and why some information needs to be updated).



The NACES web pages average 800 visitors daily and 941 AI/AN survivors and 244 family members of survivors have completed the NACES QOL survey (n=1,185). Of these, most are female and almost half

(46.0%) have high school or less education. The majority of survivors live in the Northern and Southern Plains and the Southwest. More than half of the survivors were diagnosed and treated for cancer five or more years ago (with 10%



diagnosed more than 20 years ago!).



About 1/3 (37.1%) live in the urban area and 1/3 (33.6% live on a Reservation) and 18.5% live in a rural community, but not a Reservation, and 10.9% move back and forth between the city/rural/Reservation. Slightly more than half (53.4%) are full bloods.

Access to cancer care remains a challenge. Also, half (48.7%) travel more than 100 miles ONE WAY to access care and because of the quality of our highways, this travel takes more than two hours of driving time. Unfortunately, only 12% were able to access care through Indian Health Services (Purchased Referred Care, formerly called "Contract Health Services"). Most have obtained cancer care services through Medicaid (because about half of our patients are younger than 50 years old when diagnosed with cancer), Medicare, the Veterans Administration or Indigent Care programs. When asked to rate their QOL, the majority of our survivors answered "excellent, good or okay":

Physical QOL = 82.6%

Social QOL = 85.0%

Emotional QOL = 81.1%

Spiritual QOL = 92.1%

So, what do these data mean for our people? Treatments are improving significantly and most, but not all of our survivors are living beyond the cancer experience. We need more people

helping newly diagnosed patients get into quality care as soon as is feasible. Many of our survivors continue to have late or long-term side effects from the cancer or cancer treatments and need help to reduce their symptoms and to improve their QOL. And, we need more survivorship support programs and efforts in our local communities. Our team has had the honor of working with AI/AN survivors for more than 21 years and there is no work that we have done that is as rewarding as educating, caring for and supporting these people and their families. Join the efforts!