



# Native American Cancer Research (NACR) Corporation: “Native American Cancer Education for Survivors” (NACES) Fact Sheet



- 🍵 How is your quality of life (QOL)?
- 🍵 NACES research shows Natives who live 5+ years after their diagnosis have good quality of life (feel healthy, spiritually strong, good family / friend support, clear minds, hopeful).
- 🍵 You can talk with your provider about ways to improve your health
- 🍵 Now you know. Now you can.

## What is the Purpose of NACES?

Improve the QUALITY OF LIFE for  
Native American cancer survivors by:

- 🍵 Developing and testing culturally specific cancer education materials
- 🍵 Making the materials easily available through the internet
- 🍵 Helping survivors find resources to help them with their cancer issues
- 🍵 Giving information that may help improve the patient's quality of life.



## What is NACES?

- 🍵 Web-based
- 🍵 FREE!!
- 🍵 Quality of life survivorship education
- 🍵 Designed for breast cancer patients
- 🍵 But has information relevant to patients who have other types of cancer
- 🍵 Includes both genders
- 🍵 Tailored to the individual
- 🍵 Resource for those needing information
- 🍵 Research study
- 🍵 Culturally specific
- 🍵 Inter-tribal
- 🍵 Uses the Medicine Wheel and Circle of Life

## Definition of “quality of life”

- 🍵 How well you are able to do everything you want to do: physically, mentally, emotionally, and spiritually



## In addition to Patients, NACES is used by



- 🍵 Native Patient Advocates
- 🍵 Family and others who care about them.



This Fact Sheet is dedicated to Mary P. Lovato (Santo Domingo Pueblo), Rosanne Wyman (Mohawk), Walter Woods (Cheyenne River Sioux), and Gloria Suazo (Taos Pueblo)



## Code Name and Online Survey

 **Native American Cancer Research**  
Quality of Life Survey 

Please create a username and password for your surveys.  
**IMPORTANT:** You must put something in every menu or text box.

Create your username by using the two pulldown menus, and enter a number from 1 to 999:  
Color:  Symbol:  A number from 1-999:   
(NOTE: An example username might be Red-Bear-3)

Enter your desired password:

In case you forget your password, select a question that you can answer so that you can retrieve your password:

## What percent of the 600+ Native cancer survivors ...?

- ☞ Were very hopeful about their prognosis?
- ☞ Were diabetic?
- ☞ Were obese or overweight?
- ☞ Had difficulty concentrating more than a few times each week?
- ☞ Said they had no social support or not enough social support?
- ☞ Traveled more than 300 miles one way for their cancer care?
- ☞ Had difficulty getting cancer treatment?
- ☞ Took part in spiritual activities 2+ times daily?
- ☞ Received help from Indian Health Service?

### Index for QOL Limbs

- Spirituality
- Communication
- Treatment
- Clinical Trials
- Health Information
- Side Effects
- More Health Problems
- Help and Support

12%  
43%  
50%  
92%  
02%  
50%  
22%  
43%  
17%

SNV



## The Surveys are on the “trunk” of the NACES QOL Tree

## More than 600 Native Survivors Completed Parts or all of Survey

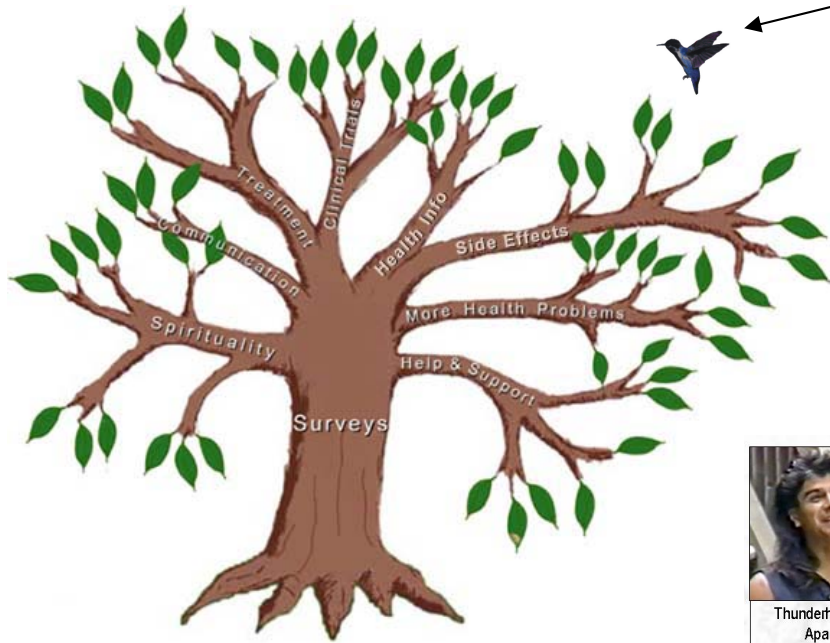
- ☞ Almost half live in the Southwest (also where the largest tribal Nations are located)
- ☞ Almost half live on Reservations
- ☞ Almost 1/4 live in urban areas
- ☞ ~2/3 diagnosed more than 5 years ago
- ☞ >50% are “full bloods”
- ☞ 17% GLBT
- ☞ >50% = Less than High School / GED Education
- ☞ >50% work for pay
- ☞ 1/3 had private health insurance (note: Indian Health Service is NOT insurance)



- ☞ Stories, What is it, Spiritual Beliefs, Examples, Traditional Healing, Natural & Alternative Healing
- ☞ Introduction, Poor Communication, Passive, Aggressive, Assertive, I-Messages, Helpful Hints, The ? Icon
- ☞ Stories, Before Treatment, Ceremony, Surgery, Radiation, Chemotherapy, Other Preparation, After Treatment, Palliative Care
- ☞ Stories, Introduction, Importance, Native Issues, Types, Benefits & Drawbacks, Barriers, CT Phases, Information collected, Informed Consent, Trial Options
- ☞ Basic Nutrition, Culture & Food, Foods During Treatment, Survivorship and Foods, Foods and Cancer Prevention, Traditional Foods
- ☞ Cancer Pain, Fatigue, Hair Loss, Lymphedema, Chemotherapy, Sexuality / Intimacy
- ☞ Diabetes and Cancer: Stories, Introduction, diabetes, Pre-Diabetes, Types, Type 2 Risk Factors, Symptoms, Diagnosis, Treatment, Management, Management II, complications, Sick Day Self Care, Chronic Illness, Emotions, Breast Cancer and Diabetes
- ☞ Resources (financial, travel, medications), Starting Support Circles, Medicine Wheels and Finding Help



## Layout of the Quality of Life Tree Information



The hummingbird appears next to the current leaf being viewed

- You may move back and forth among the limbs or among the content areas (leaves on the limbs) as desired
- For those without Internet access, please call the Native Patient Advocates for help



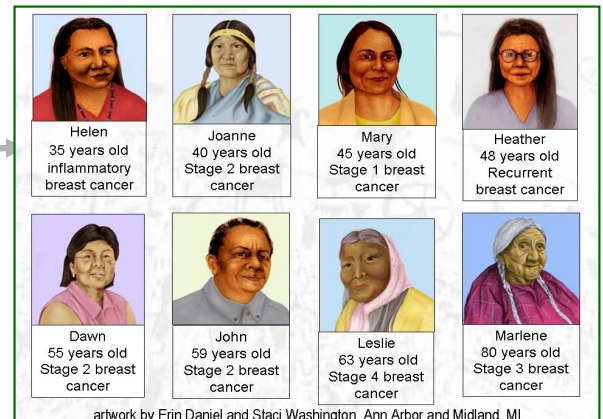
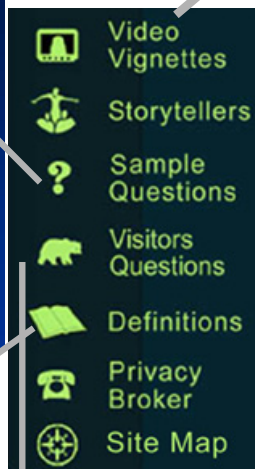
Thunderhand Joe  
Apache  
Diagnosed:  
1990 pancreas cancer

Well, I went through my chemotherapy and I had to tell the guys in the band that now I am going to lose my hair. ... Okay, now I was bald and I don't know, I thought it was okay. It wasn't as bad as I thought. But, anyway, so I cut all my hair off. I got it short about as short as Dawn's. Because I did not want to lose it from this. So I told cancer you can have my hair. That's all your getting. No more. Take my hair.

### Examples of Patient Questions for Healthcare Providers specific to Clinical Trials

- If I take part in this study, am I letting myself be treated like a guinea pig?
- How do I know I'm really getting medicine?
- If IHS / Tribal / Urban clinic does not have the medicine, how can your study pay for it so that I can get it?
- How can your study help me get to and from the clinic and my home?
- How can your study allow my children to travel with me so that I can take part in it?
- How can your study support my hotel costs if I have to be near the clinic for a few days?

### Side Bar



artwork by Erin Daniel and Staci Washington, Ann Arbor and Midland, MI

### Example of Definitions

**“Survivor”:** Begins at the time of diagnosis (biopsy) and extends throughout life

**Visitors’ Questions** NACES receives many unsolicited comments from visitors to our web site. We encourage you to talk with your doctor or nurse about any medical questions you may have. The following is an example of a question & answer  
**Question:** If chemotherapy is not helpful, what's next?

**Answer:** There are many different drugs and drug combinations to try. When one does not work, another may. Another possibility may be enrollment in a clinical trial. Your healthcare provider may also consider a combination of therapies. Unfortunately, sometimes there are no effective treatments and comfort care through hospice can be considered. Please talk with your healthcare provider about all possible options. LUK & AB Posted: 3-22-2008

- Some survivors do not want to be identified as a survivor (e.g., ostracized by the tribal community).
- Storytellers are caricatures that are based on real survivors' stories, but they include more than one survivors' experiences to avoid the real person from being identified.





## Trained Native Patient Advocates are Available to Help (from Denver, CO)

## Trained Native Patient Advocates are Available to Help from other Regions



- 📦 Volunteers (i.e., not available for immediate needs) to help patients obtain the information on the web site (e.g., uncomfortable or don't know how to use the web, prefer to talk with live person)

## Take Home Message about “Issues”

- 📦 Need assertive strategies to access timely access to quality cancer care
- 📦 Need help (e.g., Native Patient Advocates)
- 📦 Transportation continues to be an issue
- 📦 AIAN cancer patients continue to be younger than other racial groups at the time of diagnosis
- 📦 About 2/3 are at advanced stages (3 and 4) of cancer at the time of diagnosis
- 📦 Most do not have private health insurance
- 📦 Most have significant co-morbidity conditions that can contribute to their QOL.

## Fact Sheet & Info Partially Supported by:



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National Cancer Institute [PI: Burhansstipanov, NCI R25 CA 101938]

Susan G. Komen for the Cure® [PI: Burhansstipanov POP0503920 and POP0202135]



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