


# “Native American Cancer Education for Survivors” (NACES)

## Indigenous Peoples Cancer Survivorship Across the World

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## This workshop is dedicated to Eduard Gamito, dear friend and colleague

Born 1962  
Passed January 22, 2008  
Dear Ed, we miss you and we honor you



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## “Native American Cancer Education for Survivors” (NACES)

## Objective: By the end of this segment, the workshop participant will be able to:

1. Describe how the NACES (Native American Cancer Education for Survivors), a web based public health education cancer survivors quality of life, particularly in those populations who are underserved or live with disparities.

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## What is NACES?

quality of life – how well you are able to do everything you want to do: physically, mentally, emotionally, and spiritually

- Web-based
- 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
- FREE!!

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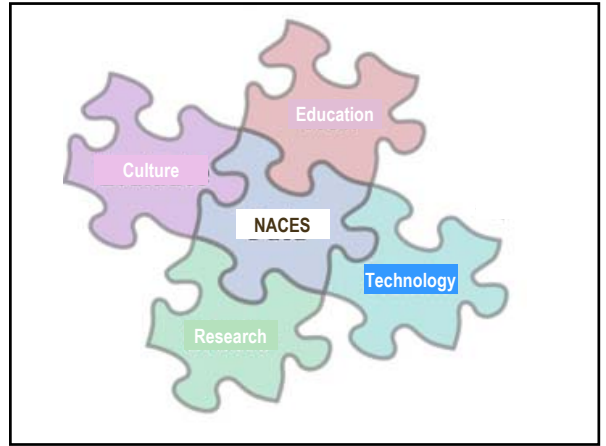
# “Native American Cancer Education for Survivors” (NACES)

## What is “Native American Cancer Education for Survivors”?

- Resource for those needing information
- Research study
- Culturally specific
- Inter-tribal
- Uses the Medicine Wheel and Circle of Life

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## Research Question

- Does a culturally relevant cancer intervention that can be adapted by the individual Native American cancer patient to address personal needs, increase access to and utilization of resources that improve the Native American survivor’s quality of life (QOL)?

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## Purpose of NACES

Improve the QUALITY OF LIFE for American Indian, Alaska Native, North American Indian (AI/AN/NAI) women and men who are breast cancer survivors by:

1. Developing and testing culturally specific cancer education materials
2. Making the materials easily available through the internet
3. Helping survivors find resources to help them with their cancer issues

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## NACES is designed:

- Originally for
  - Native American breast cancer patients, Advocates and families
  - To give information that may help improve the patient’s quality of life.
- Expanded in 2007 to include:
  - Indigenous peoples from all Nations
  - Information that may be useful for those with other types of cancer

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## Layout of the Quality of Life Tree Information



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## NACES Native Survivors' Advisory Committee

<b>Dorcas Bloom</b> Siberian Yupik Dx breast cancer 1998	<b>Dennis Whiterock</b> Navajo Dx 2001 Multiple Myeloma	<b>Rosanne Wynan</b> Mohawk Diagnosed 1997 uterine / cervical cancer	<b>Michael T. George, Sr.</b> Coeur d'Alene Dx 2001 Throat Cancer
<b>CeCa Whitewolf</b> Confederated Tribes of Umatilla Dx 1998 Breast	<b>Frankie White Dress</b> Oglala Lakota Dx 2001 Breast	<b>DeAnna Finifrock</b> Fond du Lac Dx 1998 Breast	<b>Arlene Wahwasuck</b> Prairie Band Potawatomi Dx 2002 Breast

## Native Patient Advocates

Available by toll free phone (1-800-537-8295) 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)

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## NACES Data

- 318 surveys (taken offline June 2<sup>nd</sup> for updates/refinements until July 1<sup>st</sup>)
- Most implemented with a “Native Advocate”
- Question:** How much of an impact does the Native Advocate have on data collection?
  - Most of the surveys are from OK and AZ = two dynamic Advocates

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## Overall, do you feel you are \_\_\_\_\_ able to do everything you want to do on a daily basis?

	Phys	Spirit	Soc	Ment
I am never able to do everything I want to do	7.7%	4.1%	4.3%	Ext poor 2.2%
I'm not able to do most things I want to do	27.5%	8.2%	21.5%	Poor 7.5%
I am able to do most things I want to do	41.8%	38.4%	34.4%	Okay 43%
I am able to do everything I want to do	23.1%	49.3%	39.8%	Good 36.6%
				Excellent 10.8%

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## Characteristics

- Diagnosed with breast cancer
  - 34% - not diagnosed (family members)
  - 6.4% - diagnosed with last year
  - 14.9% - diagnosed between 1-4 years ago
  - 44.7% diagnosed more than 5 years ago

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## Characteristics

- Age
  - 1910-1919 = 2.2%
  - 1920-1929 = 1.1%
  - 1930-1939 = 9.8%
  - 1940-1949 = 32.6%
  - 1950-1959 = 41.3%
  - 1960-1969 = 8.7%
  - 1970-1979 = 1.1%
  - 1980-1989 = 3.3%

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## Characteristics

- Blood Quantum
  - Full blood = 44.4%
  - 75-99% = 12.2%
  - 50-75% = 17.8%
  - 25-49% = 11.1%
  - Less than 25%=14.4%

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## Characteristics

- Education
  - No education / schooling = 9.7%
  - Grade school / elementary = 7.5%
  - Middle / Junior high = 9.7%
  - High School / GED = 24.7%
  - Technical / Apprentice = 7.5%
  - Some college = 24.7%
  - College AA degree = 2.2%
  - College BA, BS degree = 10.8%
  - Masters, Doctorate or more= 3.2%

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## Characteristics

- Told by Health Provider You have Problem:
  - High blood pressure = 45.6%
  - Diabetes =45.6%
  - Arthritis / Rheumatism = 30%
  - Obesity = 33.3%
  - Thyroid = 21.1%
  - Habitual Tobacco Use = 26.2% (not to be confused with ceremonial use)

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## Characteristics

- Close blood relative (parent, sibling, children) diagnosed with cancer = 81.6%
- How many close blood relative(s) have / had cancer:
  - 1 relative =32.1%
  - 2 relatives = 21.4%
  - 3 relatives = 16.7%
  - 4 relatives= 7.1%
  - 5 or more relatives = 9.5%

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## Characteristics

- Of these blood relatives with cancer
  - 42.4% of the relatives had BREAST cancer
  - 70% diagnosed younger than age 50

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## Characteristics

- How far from your home (one way) did you travel for cancer treatment
  - 0-25 miles = 16.7%
  - 26-50 miles = 11.7%
  - 51-75 miles = 8.3%
  - 76-100 miles =16.7%
  - 101-200 miles = 20%
  - 201-300 miles = 15%
  - 301-400 miles = 11.7%

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## Characteristics

- Where do you live?
  - On the reservation = 38.9%
  - In a rural setting, but not on reservation = 18.9%
  - In a city, town, village = 26.3%
  - move back & forth among city, rez, rural = 15.8%

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## New Symptoms since Diagnosis

Symptoms	Fatigue	Pain	Memory Problems	Insomnia
Yes	32.6	26.1	16.3	14.1
No	67.4	73.9	87.7	85.9

Body aches = 35.9%  
Changes in concentration = 6.6% (4.4% of overall total – unable to concentrate at all)  
Feeling Moody = 22.8%  
Feeling depressed = 21.7%

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## Symptoms Today

Symptoms	Fatigue	Pain	Concentration	Neuropathy
Not a problem	25.3	52.8	5.5	56.5
Few days a month	30.8	19.1	13.2	27.7
Once a week	11.0	5.6	24.2	5/4
Few days a week	17.6	10.1	49.9	5.4
Every day	15.4	12.4	14.3	12.0

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## To what degree do you feel non-Native providers control your cancer?

Level of Control	Overall %
Not at all	18.2
Little	8
Fair	18.2
Good	35.2
Completely	18.9

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## How useful do you feel?

	Overall%
Not at all	14.3
A little useful	19.8
useful	24.2
Very useful	24.2
Extremely useful	17.6

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## Positive Changes from Having Cancer

	Overall%
Not at all	2.3
A few good changes	6.8
Good changes	21.6
A lot of good changes	33.0
A great deal of positive changes	36.4

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Feeling Isolated Since Diagnosis	
	Overall%
Very isolated/alone	7.8
Occasionally isolated/alone	18.9
Rarely isolated/alone	15.6
Feel okay (not isolated/alone)	35.6
Feel well supported and not isolated /alone	22.2

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To Join the Study, go to  
<http://www.NatAmCancer.org>  
and click on tree



- Code Name
- Survey
- Side Effects Limb
- Side bar:
  - Videovignettes
  - Story Tellers
  - Visitors' Questions

